

Exploring the contextualisation of methods in research synthesis: three studies in dementia and communication

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Abstract

This thesis constitutes a programme of research to adapt and test three review methodologies. The methodologies include: a Scoping Review, a Meta Study and a Narrative Synthesis. The objective of methodological development was to create systematised processes for identifying suitable forms of communication for participants from contextualised research evidence and synthesis. Communication (data collection) methods are pivotal in understanding lived experience and representing views. The empirical focus of the thesis surrounds forms of alternative communication methods in the context of people with dementia. These alternative research methods are particularly important for participants who may not use verbal forms of communication as their primary method of interaction. The thesis proposes the introduction of a new review genre called ‘methods contextualisation’ which could assist reviewers in critiquing data collection methods and interpreting voices in research.

The thesis is structured in three phases: development, implementation, and conceptualisation of the methodologies. Outcomes of the thesis produced both methodological and empirical findings. The adapted methodologies are presented as a typology, offering different forms of critical understanding about communication methods to influence future *choice* and *use* of those methods. Findings identify and synthesise relevant forms of knowledge. The thesis proposes methods contextualisation processes could be embedded into dementia theory, research and practice.

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Author Declaration

I declare that this thesis is a presentation of original work and I am the sole author. This work has not previously been presented for an award at this, or any other, University. All sources are acknowledged as references.

Chapter 1: Introducing the thesis approach and rationale

1.1 A methodological exploration

This thesis represents a methodological and empirical *exploration* of research. My approach to exploration guides the structure of the thesis. The emphasis I place on exploration represents the precedence placed on the *journey* as well as the *destination* of the research. Exploration may be imagined as travel into unfamiliar regions of research, which are unexplored or under-developed thus far. Exploration has been distilled into three phases within this thesis. These include: the development of a methodological approach (chapters one, two, three and four); implementation of the approach (through three empirical studies in chapters five, six and seven), and conceptualisation of the contribution of the research approach (chapters eight and nine).

The thesis proposes the introduction of new genre in systematic approaches to the literature called ‘methods contextualisation’ (the ‘destination’ of my thesis). Methods contextualisation is sub-divided into three approaches in the thesis, but it can be described broadly as review processes for identifying suitable forms of data collection methods to employ with research participants using contextualised research evidence and synthesis. As such, this genre can provide guidance to primary researchers for interpreting the choice and use of available data collection methods. This genre was developed by modifying existing literature reviewing methodologies originally designed for alternative interpretive purposes. Three studies provide the testing-ground for exploration of the revised methodological templates in dementia and Augmentative and Alternative Communication (AAC) methods research. Methods Contextualisation is of paramount importance to this topic, as AAC represents a range of alternatives to conventional interview-based research methods in order to facilitate greater participation in research and real-world settings.

If the methodological contribution of this thesis is viewed as the destination, the first step is to explain why the journey was undertaken at all. The three rationales identified below are the main foci of chapters one, two and three. Chapter one also presents the research questions for the thesis and the structure of the thesis. Background information to describe key principles and practices such as: methods contextualisation, systematic reviewing or synthesis, review methodologies and features of the chosen research topic, are embedded within chapters. These are introduced incrementally to explain the thesis rationales. The

structure, therefore, is designed first and foremost to tell the methodological story of the research.

The first of three rationales for a methodological exploration I have called the '**extension of the methodological horizon**'. This describes my aim to extend an aspect of reviewing methodology. An example of this type of rationale is Realist Synthesis, created by Pawson (2002). (The specific features of the methodology are not relevant at this stage; instead, I refer to it in order to exemplify a similar rationale that provided a new methodological avenue for reviewing). Pawson (2002) proposed a new purpose for synthesis of evaluation research studies. Primarily, he proposed this type of reviewing should be able to 'take a long view' about policy interventions because individual evaluations could not hope to keep up with the policy cycle. A new methodology was required to capture the successfulness of the major intervention approaches to policy in a given area. Therefore, Realist Synthesis reviewing would also represent a move toward the creation of a systematic evidence base that could adopt a progressive understanding about 'what works' in social interventions for policy-makers (p.158), in other words, extending the research horizon.

In this thesis, the extension of the methodology horizon relates to the way researchers *choose* and *use* data gathering research methods that form the basis of participant communication (usually in the context of primary qualitative research). A subsequent section (1.3) explains there is currently no transparent or systematic approach within, or outside of, reviewing and synthesis for choosing and using data collection methods. This issue is fundamental to the representativeness and trustworthiness of the data and the voices it represents. This rationale is explored in-depth during the course of sections 1.2, 1.3 and 1.4.

I have summarised the second rationale for methodological exploration of **the inadequacy of current methods** for the desired purpose for the synthesis. An example of this kind of explanation is given by Dixon-Woods et al (2006b). In their pursuit of methodologies to critically analyse a complex body of literature, they found current methods insufficient. In particular, they refer to specific requirements, such as the production of mid-range theory. In the case of this thesis, current methods were found to be insufficient in synthesising material surrounding research methods and their context. This rationale forms the basis of chapter two.

The third rationale for methodological exploration could be summarised as **the influence of the characteristics of the topic**. Dixon-Woods et al (2006b) also mentioned the qualities of the literature being investigated. They described access to healthcare by vulnerable groups as a scattered and an inconsistently defined topic. These characteristics contributed to the way methodological exploration was developed. In the case of this thesis, the topic highlighted the importance of being able to contextualise research methods. This is the focus of the third chapter in the thesis. The topic choice is justified in chapter three also, demonstrating how it may be viewed as a good fit for the methodology.

The three rationales help to articulate the methodological exploration I have undertaken. They explain my approach and also provide a level of transparency for the reader in determining the legitimacy of the foundations on which my contribution is based. The next section in this chapter expands on my first rationale (extending the research horizon) in terms of influencing practice related to data collection methods choice and use, culminating in the concept of method contextualisation. I also present my research questions and thesis structure.

1.2 Rationale one: Extending the research horizon

This section provides a background to how the thesis intends to extend the methodological horizon (the first rationale for my methodological exploration). I present an overview of the spectrum of synthesis methodologies. I define synthesis and types of reviewing. I explain what synthesis *is* and what it *does* and how it could be used to extend the research horizon in terms of systematising the choice and use of research methods. I also provide a background section to the historical development of systematic reviews. I refer to three types of reviews, drawing on examples of methods-centred reviewing. This section lays the foundations for section 1.3 which explains the absence of processes or methodologies with this intent. My exploration of this field eventually evolved into the concept of methods contextualisation (explained in section 1.4). This chapter closes with explanation of the thesis research questions (section 1.5) and structure of the thesis (section 1.6).

Forms of reviewing and synthesis

First, I will describe what synthesis is. The term synthesis describes the process of gathering together several forms of evidence to produce new meaning. Synthesis is a form of secondary data analysis, combining several processes to understand what is currently

‘known’ about a topic to produce new understandings. Typically, this kind of research identifies effects or patterns across a pool of primary research results. The role of synthesis is therefore synonymous with broader interpretation across research which can reduce flaws, biases, misinterpretations or context-dependent aspects inherent in the analysis of single studies (Wilson and Petticrew, 2008, p.722). Theoretically, the collective interpretation of research results can produce more accurate and trustworthy interpretations. Thus, syntheses are considered an important addition to health and social research. Hence, syntheses of existing research make a valuable contribution to knowledge (Grant and Booth, 2009). The vantage point of synthesis has advantages over single primary studies of phenomena. By extension, *systematic reviews* (a form of syntheses) can help researchers and policy-makers to deal with the “*explosion*” of information available for synthesis (Petticrew, 2006, p.7). Systematic reviews are the focus of the methodological exploration in this thesis.

There is a wide and varied landscape of systematic reviews which can provide a number of functions beyond calculation of intervention effects or impact (the most frequent form and function of synthesis). Typically, “*systematic reviews have the explicit aim of avoiding the drawing of wrong or misleading conclusions either from biases in the review or from biases in the studies contained in the review*” (Harden and Thomas, 2005, p. 259). They also “*analyse their data and produce new knowledge by bringing the results of many studies together*” (op cit). It is this new knowledge which holds the key to the potential for reviews to contribute most significantly to research. Synthesis contains processes, or apparatus, to carry out functions such as: creation of new theory or hypothesis, categorisation, identification of research gaps, process interpretation and critical appraisal. The more interpretive types of synthesis may be suited to changing perspectives or research practices towards data collection choice and use.

The characteristics of systematic reviews differ from unsystematised literature reviews. The latter is a generic term for a synopsis of current literature (Grant and Booth, 2009, p.97). In contrast, systematic reviews and reviews follow systematised processes. First, the reviewer defines a question and then carries out a comprehensive search. The search results are screened against inclusion criteria of desired characteristics appropriate to answer the research question. The process typically involves a critical appraisal and synthesis (including an assessment of heterogeneity) and, finally, review results are disseminated (process described in Petticrew, 2006, p.27, box 2.1).

Systematic approaches to the literature (Booth, Papaioannou & Sutton, 2011) (or ‘reviews’) describe a methodology which is not technically a systematic review, nor is it an unsystematised process. This is partly because *systematic reviews* are indicative of a more stringent methodological process than *reviews* in general, usually including more emphasis on exhaustive searching techniques. A systematic review characteristically “*seeks to systematically search for, appraise and synthesise research evidence, often adhering to guidelines on the conduct of a review*” (Grant and Booth, 2009, p.95 table 1).

Next, I will try to describe what the review landscape looks like. Fourteen reviews are presented in Grant and Booth’s typology (2009). Many of these types contain sub-sets of methodologies. The typologies are based on *review* or *systematic review* status. *Reviews* include: critical reviews, literature reviews, mapping reviews, overviews, rapid reviews, scoping reviews, state of the art reviews and umbrella reviews. *Systematic review* approaches include: meta-analysis, mixed studies reviews, qualitative systematic reviews, systematic reviews, systematised reviews, systematic search and reviews. There are overlaps amongst these types, many have similar intentions and therefore fall short of ‘mutual exclusivity’ (Grant and Booth, 2009, p.106).

Of these sub-categories of systematic reviews, meta analytic approaches are the most well-known form. Meta Analysis is, “*a technique that statistically combines the results of quantitative studies to provide a more precise effect of the results*” (Grant and Booth, 2009, p.94, table 1). However, this type of the review represents effect-based, aggregative techniques. (Other statistical types include: Hierarchical models, Bayesian methods, Bias-adjustment, Causal diagram-based analysis (Petticrew et al, 2013b, p.1237-8, table 2). They extract study outcomes to determine effectiveness and test hypotheses. Yet, reviews and systematic reviews can also provide the answers to the *why* and *how* questions inherent to understanding the use of data collection methods. Such a purpose is typified by reviews with *interpretive* elements. Amongst the systematic approaches to the literature, those offering interpretive approaches are: scoping reviews, mapping reviews, qualitative systematic reviews and mixed study reviews. (Individual review types may receive more than one of these labels due to the lack of standardisation in this field).

Interpretive review types contain functions relevant to understanding the choice and use of primary research methods through secondary analysis. Preliminary or preparatory reviews outside of the systematic review family, can also examine methods. Scoping and mapping

reviews are itemised within review types presented in Grant and Booth's typology (2009). Scoping reviews are: "*A preliminary assessment of the potential size and scope of the available research literature. [These reviews] aim to identify the nature and extent of research evidence (usually including ongoing research)*" (Grant and Booth, 2009, p.95, table 1). Alternatively, mapping reviews "*map out and categorize existing literature from which to commission further reviews and/or primary research by identifying gaps in research literature.*" (Grant and Booth, 2009, p.94, table 1). (There is a more detailed section about definitions and functions of these review types in section 2.4). These reviews may be useful in identifying research gaps and understanding the nature of current choices and use of research methods. In other words, through scoping and mapping I could infer a summary of trends in research practice decision-making.

Qualitative review types (including a sub-set of methodologies such as: Meta Ethnography, Meta Study and Critical Interpretive Synthesis) can provide researchers with themes or constructs or conceptual models to guide principles of research (Grant and Booth, 2009, p.94, table 1). This type of reviewing is capable of equipping researchers with different perspectives on choosing and using research methods. In contrast, mixed study reviews (for example, Realist Synthesis, Framework Synthesis and Narrative Synthesis) typically combine qualitative and quantitative data and, in doing so, synthesise both the outcome and processes of phenomena (Grant and Booth, 2009, p. 94, table 1). These reviews may assist in understanding the use, in particular the implementation, of methods. As a review type, mixed reviews incorporate a wide variety of evidence- a necessary component of compiling a comprehensive resource for researchers.

The historical development of methods-centred reviews

The thesis extends the potential for reviews to interpret the data surrounding data collection methods selection and application. This discussion now positions the thesis in the historical development of reviewing, especially how reviews engage with methods identified in primary research reporting. I will demonstrate how the concept of engaging with the interpretation of methods already exists to some degree in reviewing. There are three main review types I draw on. The first is the classification and interpretation of primary research methods in mapping reviews. The second is the emergence of conceptually-focused reviews that may interpret the methods used in a topic or disciplinary field or fields. Thirdly, I consider reviews that can offer a meta-level understanding of the

role of methods (including: Meta study (reviews of reviews), quantitative meta synthesis of methods factors and meta syntheses of relevant methods factors).

Primary research methods and methodological approaches have been analysed through mapping techniques to understand the strengths and weaknesses of the evidence base (Gough and Thomas, 2012, p.45). The EPPI Centre, for instance, has been developing mapping reviews since the 1990s (examples include Gough et al., 2003; Peersman, 1996). The body of methods-centred maps has featured as a part of this approach. A paper by Mialke-Lye et al (2016) recently provided an overview of the nature and contribution of mapping reviews. They looked at the role of maps in reviewing, including their methods and products. They identified several mapping reviews which focused on synthesis of research methods as opposed to findings (Althuis, et al., 2013; Berger et al., 2014; Vallario et al., 2015 and Curran et al., 2004). Studies in the same review engaged with topics such as the interpretation of primary study designs (exploration of the extent of heterogeneity (Althuis et al., 2014). It is also possible to map the influence of research methods attributes to raise broader questions about validity (Lévesque et al (2012) explored the attributes of validated study instruments).

Mapping and scoping reviews commonly omit systematic quality appraisal and synthesis stages (Bragge et al., 2011). This is how they are generally differentiated from systematic reviews. There is a recent precedent for methods-oriented reviews to map study quality (Althuis et al., 2014; Vallario et al., 2015). However, development of this aspect of reviewing is generally confined to health intervention research (Mialke-Lye et al., 2016). Therefore, methods-centred mapping tends to contribute to understanding about the apparatus of research designs or components only. Nevertheless, it is possible to envisage a broader role for methods-centred mapping, perhaps to interpret study components or methods attributes to a greater degree.

Conceptual reviews have also contributed to the evolution of the methods-centred agenda in reviewing. They typically apply one of two approaches: i) to compare primary research perspectives and paradigms as a feature (and sometimes a focus) of research; ii) to provide review of concepts. Conceptual reviews *problematise* literature (Barnett-Page and Thomas, 2009). Problematism involves the examination of the context in which knowledge is produced. In other words, how the literature constructs problems which become the subject of subsequent research. This inherently involves engagement with

methods on a given topic or discipline. Conceptual review methodologies which problematise the literature are: Critical Interpretive Synthesis, Meta Narrative and Meta Theory (Barnett-Page and Thomas, 2009).

Meta Study describes and de-constructs theories. This methodology also assesses study quality, whereas Meta Narrative reviews compile the social and historical contexts to explain the heterogeneity of conclusions about a topic. This methodology assesses research perspectives as a feature of this study context. Similarly, Critical Interpretive Synthesis aims to articulate broader narratives that operate across broad bodies of evidence. The methodology seeks to identify the study method in order to build understanding to extract wider messages emerging from research (Barnett-Page and Thomas, 2009). However, there are relatively few published examples of these three methodologies in comparison to other forms of general narrative syntheses (Dixon-Woods et al., 2006b; Greenhalgh et al., 2005). This may explain the recent creation of reporting standards (e.g. 'RAMESES' for Meta Narrative reviews by Wong et al., 2013).

The role of conceptual reviews could be expanded in methods-oriented synthesis. Conceptual reviews synthesise a broader range of study types and methods, making them suitable for the critique of primary methods. Conceptual review data is typically heterogeneous, their types of reviews focus more narrowly- Meta Ethnography often utilises purely ethnographic studies; and Thematic Analysis tends to use study approaches to analyse interview-based and qualitative data (Barnett-Page and Thomas, 2009). However, there are challenges to developing this area. It can be argued the analysis of methodological characteristics in conceptual reviews (such as data gathering techniques) is often marginalised, possibly because researchers pursue high theoretical relevance in studies (Gough and Thomas, 2012, p.44). Perhaps, this is an inevitable consequence of efforts to diminish the emphasis of qualitative principles on study *quality*. (The impact of the dual heritage of interpretive reviewing is discussed in 2.3). Therefore, future methods-focused conceptual reviews could embrace methodological characteristics as an acceptable focus. Therefore, reviewers may have to tackle the secondary status of methodological characteristics in methods-centred conceptual reviews; overturning any assumption that the interpretation of methods apparatus has no place in rich conceptual or contextual discussion.

A second type of conceptual reviews has thrived in intervention-led research. It offers a specialist tool for identifying and interpreting theory, potentially in the context of the methods. Conceptual reviews generate conceptual models (Kopeck et al., 2010) and review conceptual models as ways of explaining research theoretically (e.g. Raina et al., 2004- compare the models for caregiver processes and burden that have been produced in research). Both approaches incorporate methods components (usually in interventions) to explain how processes work or how they can be optimised. They produce visual and theoretical summaries of how a range of practical, psychological, environmental or clinical factors may interact. Both approaches use a narrower focus toward methods. Consequently, they do not encounter many of the paradigmatic-driven challenges of the conceptual reviews designed to problematise the literature.

Meta reviews are the third category to be included in this discussion. There are different types of meta reviews now in use in research. Meta reviewing (or meta epidemiology) refers to a review of reviews. Different forms of data are synthesised to answer a broad research question (Gough and Thomas, 2012, p.50), such as a comparison of methods (e.g. Warren et al., 2012). This approach requires a substantial body of primary data and secondary synthesis of material to create a meta-level review. This review type is, therefore, not necessarily available to a reviewer working within unsynthesised fields where there are no existing reviews. Meta reviews can be a way of describing a number of sub-reviews to draw broader conclusions, which can include methods.

By comparison, Meta analyses typically aggregate study results (or method-based components) that relate to the study outcomes. Meta analysis (the most widely known statistical method) determines study effectiveness; they measure how methods variables influence study findings, especially in intervention and clinical research (e.g. Benbassat and Tarragin, 2013). Lastly, there are a number of examples of meta syntheses (or meta reviews) which are commonly used to describe methods-based factors (quantitatively or qualitatively). In these cases, meta synthesis represents a more general term aimed at bringing interpretations across studies together. (Recent examples include: Egan et al., 2009; Sword et al., 2009; Barley et al., 2011). Therefore, the different types of methods-centred meta reviews configure extracted methods characteristics across studies or reviews of studies. The reviewer gains a meta-level perspective about how the implementation and operationalisation of methods can influence findings and conclusions about a given topic,

particularly outcomes. Arguably, the specialist role of meta reviews could be employed for gaining a ‘top-down’ perspective about methods.

Summary

From an early stage of exploration I believed the scoping, qualitative and mixed-methods reviews had the potential for facilitating the extension of the research horizon. The historical development of reviews has led to many different approaches to the interpretation of research methods. Methods-based mapping approaches describe and collate many types of methods apparatus from primary data studies. By contrast, conceptual reviewing interacts with methods and methods perspectives as a result of synthesis across broad fields of study. Meta reviewing is a broad category which generally engages with methods apparatus and perspectives in quantitative or narrative forms of synthesis, often viewing methods in relation to the impact on study outcomes. There is scope to build on all of these approaches. Mapping reviews could start to interpret methods apparatus data to a greater degree; conceptual reviews could engage more with methods characteristics; and meta reviews could expand specialist methods-based syntheses across reviews or studies. However, in these cases reviewers may need to envisage a greater and more dynamic role for methods data in order to unlock this potential.

There is currently no methodological review genre which combines the collection of methods characteristics with either a conceptual critique or an in-depth evaluation of the role of the methods processes (and their application). I argue, researchers can more effectively justify study design research including data collection once research method choice and use can be synthesised comprehensively. Methods contextualisation was created to describe how perspectives about the choice and uses of research methods were formulated. The concept is explained in the next section.

1.3 Common practice in identifying research methods

This discussion explains current practices of choosing primary data collection methods in research in more detail. This also explains why advancing the practices of choice and use of methods is important. Three current practices are described. None of these are standardised in research, nor are they always made explicit in research reporting. This

section precedes the presentation of methods contextualisation as a possible solution (section 1.4).

Currently, there is no standardised way researchers who conduct qualitative primary research approach the application of research methods across different contexts and different participant groups (in systematic reviews or by any other means). There was no singular framework or theory to explain primary research methods choice and use. Literature which theorises how research methodology approaches are framed could be considered relevant (Hammersley, 2011). Hammersley (2011) identifies three methodology genres within social research: **methodology-as-technique**, **methodology-as-philosophy** and **methodology-as-autobiography** (p. 20).

The first genre (**methodology-as-technique**) was associated with hypotheses testing (pp.20-22). It was argued methodology provided the knowledge and skills necessary for practising social research. However, Hammersley argues the approach favours positivist, proceduralist techniques (pp.21; 33). The second **method-as-philosophy** genre was formed from post-structuralist qualitative research methodologies which criticised the positivistic stance that had preceded it (p.23). Researchers built a platform with increasing emphasis on research philosophy, as qualitative methodologies sought to differentiate themselves from quantitative methodologies. According to this viewpoint, different (incommensurable) paradigms cannot be separated from social science. The genre emphasised the variety of different assumptions within those qualitative perspectives (underpinned by Kuhn's (1965) conceptualisation of distinctive research paradigms that shaped corresponding research) (pp.23-24). The third genre was **method-as-autobiography**, represented the growth in interest in reflective, ethnographic or autobiographical accounts. Hammersley (2011) argued the method-as philosophy approach demonstrated some awareness of its own limitations, insofar as it did not sufficiently guide researchers on *how* to carry out research (p.26). This approach constituted a realistic perspective, describing how aspects of research actually were, such as the construction of social relations in the field (p.27).

I argue there may be several genres within the literature which help me to theorise the selection and use of data gathering *methods* specifically. The first, is related to traditions in research paradigms (typified by early landmark qualitative methodology guidance: Guba, 1990; Guba and Lincoln, 1988; Lincoln and Guba 1985; Denzin and Lincoln 1994a;

2000). This approach shares similarities with Hammersley's (2011) method-as-philosophy genre. The stance argues that paradigms (a 'net' covering ontology, epistemology and methodology (Guba, 1990, p.17 cited in Denzin and Lincoln, 1994b, p.13)) guide researcher beliefs; "*these beliefs shape how the qualitative researcher sees the world and acts in it*" (Denzin and Lincoln 1994b, p.13). "*A researcher describes a flexible set of guidelines that connects theoretical paradigms to strategies of inquiry and specific methods for collecting and analysing empirical materials*" (Denzin and Lincoln, 1994b, p.14). In other words, paradigms are anchored in specific methodological practices (op cit). Research designs are driven by flexibility, consistency and coherence within the methodology (Holloway and Tores, 2003); therefore, data collection methods decisions can be viewed as "*paradigm-driven*" (Wolgemuth et al., 2015, p. 352). Thus, this genre is influenced primarily by theoretical considerations.

The second genre I have identified is more pragmatic. Data collection choices are driven by certain expectations for a narrow range of conventional methods. Researcher perspectives have rarely been examined on this matter. Brown (2010) interviewed applied researchers on this topic. The justification for a pragmatic approach was that clients, and by extension, policymakers have expectations for conventional types of data collection methods (Hendrick et al., 1993 cited in Brown, 2010, p.230). The study found that applied researchers rejected epistemological and ontological considerations as a foundation for building research designs (including how data would be gathered) (p. 240). This insight into the way research 'works' in real world settings may be significant in the exploration of the role of methods contextualisation. Transparent and robust processes for examining methods options could make a range of methods more accessible. This genre is influenced by pragmatic practice considerations.

The final genre I identified is a 'participant needs' genre, which commonly appears in relation to a particular range of qualitative methods (usually reserved for research with vulnerable or marginalised groups). This approach is both theoretically and practice-oriented because of its emphasis on a certain range of methodologies with user groups with certain characteristics. Therefore, evidence of this genre can only be found in a particular niche of research. Aldridge (2014) argued for selection of methods through "*creative, individualistic 'bottom-up' approaches to working with vulnerable groups*" (p.125). This often involves *adaptations* to methods, *inclusive* approaches and *individualised* approaches (p.112-4). Research with vulnerable groups requires a more complex range of designs,

methods and ethics procedures, without which researchers risk a lack of researcher engagement with vulnerable groups (p.114).

Arguably, creative, individualistic and bottom-up approaches in the participant needs genre of research most successfully engage with qualitative principles of *authenticity* and *credibility* in guiding data collection selection choices. Furthermore, these two concepts can be viewed as the foundations for eliciting participant *voice* (James and Busher, 2006). (Authenticity and credibility were originally incorporated into qualitative research from grounded theory principles (Glaser and Strauss, 1967). Therefore, it is possible to demonstrate there is an association between adapted or alternative methods selection in primary research and marginalised groups, such as people with dementia. In addition, voice emerged as a relevant concept in relation to contextualising methods because of its link to credible and authentic data. The topic of voice in dementia research is discussed in chapter 3.2.

In summary, a researcher's decision to adapt methods, or use more inclusive research methods, is often dictated by several factors, some more formally contingent on methodological theory than others. Method selection is an important issue in research, yet practices are little understood. Genres I have identified exist on a theoretical sphere (based on the influence of paradigms); a real-world practice sphere (based on pragmatic choice) unlikely to be articulated in research reporting, and, a specialised research topic (based on participant needs). Research methods selection could lead to naïve application of methods that are poorly understood. Alternatively, conventional primary research methods selection could lead to exclusionary practice. I therefore consider clarification of methods choice and use important. Equally, I view it as an under-researched area, which deserves to be the focus of review methodologies. Currently, the role of systematic reviews has not been considered within the genres identified. This was the first step in understanding the need to extend the methodological horizon in reviews.

1.4 Methods contextualisation as a feature of synthesis

I believe methods contextualisation could be a way of formalising research methods choice and use. This section considers definitions of the concepts for context, contextualisation, and, (the newly created) methods contextualisation. I argue the latter rests on the idea of an inseparability of methods and context. This chapter also explores two parallel examples of synthesis methodologies also focused on the inseparability of context with other

important aspects of reviews (Realist Synthesis and Complex Intervention reviews). Based on the evidence, I propose methods contextualisation could become a new genre in reviewing. I suggest EPPI Centre reviews; interpretive reviews and realist reviews (which share interpretive elements and elements of contextualisation) broadly match the features capable of extending the horizons of research.

Context may be regarded as additional information about different aspects of a study. The term is regarded as a description of the research phenomena, including information gleaned about the mechanics of an intervention process such as population, location and the wider environment (CRD, 2009, p.169). In reviewing, study context is most commonly associated with the interventions, specifically the appropriateness of an intervention. This is because reviews (in particular those focused on effectiveness) aim to summarise the results of several studies (about a single intervention) carried out in different settings and with different populations (CRD, 2009, p.169-70). Where the effects of studies vary according to setting, population or intervention or other characteristics, the overall picture of context is useful in determining in which circumstances the evidence is applicable (CRD, 2009, p.170). Hence, context is often associated with the concept of applicability of findings.

Contextualisation is the term for the activity or process of building up a picture of context, perhaps beyond quality appraisal techniques. Broadly, the term refers to the interpretation of findings within the study or review and in relation to the wider literature base. The Centre for Reviews and Dissemination's guidance (2009) describes contextualisation processes in relation to reviews of literature; the guidance urges reviewers to contextualise both the nature of the research *and* the findings within the existing evidence base (based on Wilson and Petticrew, 2008 cited in CRD, 2009, p.81).

I define Methods contextualisation (MC) as: ***a concept to describe review processes for identifying suitable forms of communication (data collection methods) to employ with research participants from contextualised research evidence and synthesis.***

As a concept, this term conveys the sense of a methods-centred review, combined with the process of contextualisation to assess and interpret methods. Methods contextualisation processes embody a specialist approach (or genre) to reviewing literature. Any review-based variant of methods contextualisation focuses on synthesis of the *choice* and (or) *use*

of methods to inform future research decisions. The source for this information is based on the narrative descriptions embedded in study reporting and other study information.

The focus of methods contextualisation arises from the implication that methods chosen and the ways in which methods are used dramatically alter the way research is viewed and interpreted. Participant communication determines the facilitation of researcher insights into lived experiences or points of view. This concept (and associated methodologies) may help to maintain trust in the authenticity and representativeness of views in research. They also assist researchers in maximising future participant engagement. Methods contextualisation offers a way to centralise participant needs in identifying forms of communication in research; other unsystematised processes may depend on researcher preference. This may be especially important amongst participant groups that require a range of alternative communication methods to articulate their voices. Therefore, this genre of methodologies (variants of which are adapted from existing reviews) holds the potential to provide a systematised and evidence-based option for justification of data collection choice and use.

My definition is based on the assumption of the inseparability of methods and context. The concept of the inseparability of context from aspects of research or reviews can be found in two existing examples.

Firstly, Pawson (2002; 2006) identified the dynamic between context, mechanisms and outcomes as inseparable in Realist Synthesis. Context refers to the study setting, such as the characteristics of the setting and the programme locality (Gough and Thomas, 2012, p.43). The essence of the conceptualisation of context is that it is futile to understand only which interventions work, it is crucial to understand the different contexts in which the mechanisms continue to operate (op cit). The theory-based philosophy of realist synthesis emerges from a need to produce clear policy guidance on which social interventions were successful in which contexts. By collecting and synthesising contextual information about interventions, the reviewer can differentiate between 'soft targets' and genuinely effective interventions (p.167). This methodology prioritises the relationship between contexts and mechanisms as features of a study and outcomes. Identification of unique factors, that may act as mechanisms in particular contexts, is a helpful idea. However, this methodology is focused on outcomes to understand what works in which circumstances, methods contextualisation seeks to explore methods use and choice.

The second example is complex intervention reviews (Petticrew et al., 2013a; Noyes et al., 2013). This genre of reviewing is a parallel example of the inseparability of complexity and intervention outcomes. Complexity of context emerged as a dimension of this type of reviewing (Noyes, et al., p. 1264). What makes an intervention complex can be summarised by a number of factors; such as: if it has numerous interactional components; if it is directed at many target groups or organisational levels; or if implementation processes could be flexible or adaptive (Petticrew et al., 2013a, p. 1210). Ultimately, these factors represent a number of causal pathways affecting the intervention outcome. These multiple causal pathways derive from complex relationships between components and the myriad of contextual factors on which the intervention is based (op cit). The focus of future research in this area is framed around asking better questions that take account of intervention complexity and its implications for synthesis (Noyes, et al., 2013 p. 1263). The emphasis on complexity is relevant to methods contextualisation, particularly as populations and implementation processes may be varied.

The final part of this section presents what I believe to be features of methods contextualisation in existing review methodologies. These are located in reviews with interpretive elements (already identified as potentially significant in section 1.2).

I argue, there are three existing systematic approaches to the literature that already possess features of the process of contextualisation (these are: the Evidence for Policy and Practice and Co-ordinating (EPPI) Centre approach - including Systematic Mapping; Realist Synthesis; and reviews from traditions of qualitative enquiry (identified in Gough and Thomas (2012, pp.43-44)). However, methods contextualisation is currently not the central priority in the methodologies. A systematic review methodology text by Gough and Thomas (2012) refers to contextualisation in existing review methodologies. The three approaches first identified from this source remained central to this thesis; these formed a crucial part of the first stage of methodology selection (section 2.4).

Firstly, Gough and Thomas (2012, pp.41-44) highlighted what I view as *methods contextualisation* characteristics in relation to the (EPPI) Centre reviews (pp. 42-44). (Scoping studies formed a part of the EPPI Centre reviews (p.42); as did systematic mapping (p.45)). This methodology determined the “*breadth, purpose and extent of research activity in any given area*” (p.45). Reviewers wishing to use the EPPI Centre methodology were encouraged to configure findings in order to *locate* them in appropriate

socio-cultural contexts (Gough and Thomas 2012, p.42). This meant understanding the socially-constructed world and the context in which findings are based, including the perspectives of the authors of primary studies. The approach emphasises that, however objective the methodology the findings are a reflection of assumptions of the perspectives of the primary study author (and reviewer). Therefore, the EPPI Centre review approach used different forms of context (including literature context or theoretical context) to examine interpretations of findings. The different forms could be described as the nuances of the methods-context relationship.

Another approach referred to by Gough and Thomas to utilise contextualisation were reviews from the '*distinctive tradition of qualitative enquiry*' (2012, p.43). A range of methodologies fit this description; employing textual approaches to data and qualitative principles of research in theory generation. Critical Interpretive Synthesis (CIS) (Dixon-Woods et al 2006b) was referred to by Gough and Thomas (2012) as one example. Qualitative principles at the heart of this methodology influenced inductive searching and the gradual development of the research question as part of the process. Gough and Thomas (2012) comment CIS "*contextualised findings within an analysis of the research traditions or theoretical assumptions of the studies included*" (p.44). I believe interpretation of perspectives using inductive approaches to generate theory about methods would be valuable to methods contextualisation. However, I realised I would need to make some changes to the way the methodologies were conceptualised. For instance, Gough and Thomas (2012) argued that in assessing quality of studies creators of CIS chose between critical analysis of theoretical research perspectives, and the analysis of methodological characteristics (p.44). I consider this distinction unnecessary, unhelpful even. The contextualisation of methods considers methods characteristics bound to these perspectives. It is these perspectives which I feel shape the contextual landscape from which methods choice and use can be analysed.

Finally, Gough and Thomas linked Realist Synthesis to contextualisation (p.43); created by Pawson (2006). The reviews emerged from Realist Evaluations (Pawson, 1997). The process linked outcomes (the phenomena the intervention tries to effect) with underlying mechanisms (key characteristics that facilitate change on which the intervention is based) and context (the setting or population etc.).

Realist synthesis contextualises findings by hypothesising, testing and refining Context-Mechanism-Outcome (CMO) configurations. As such, Realist Synthesis is a member of the theory-based school of evaluation. Gough and Thomas' (2012) commentary states "*Realist Synthesis asserts that much systematic review activity simply starts from the wrong place; the issue is not which interventions work, but which mechanisms work in which context.*" (p.43). For instance, a Realist Synthesis was conducted to test potential opposition (or threats) to the legislative ban on smoking on cars which carry children (Wong et al., 2011). The methodology enabled authors to understand and explain the nature of each threat and to infer the most likely outcome if the legislation were to be proposed. Therefore, this form of synthesis could offer the opportunity to evaluate theories about methods contextualisation by breaking down the processes of methods choice or use into constituent parts. In doing so, I could theorise about principles about future choice and use of methods.

Therefore, I characterised contextualisation in terms of either: i). locating findings in socio-cultural contexts to enhance the ability of the reviewer to understand them; ii). a critical process to understand research traditions or theoretical assumptions and iii). To provide context as component of theory to determine the way the phenomenon works, involving mechanisms and outcomes, contextualisation as the process of arriving at this understanding of significant areas of context. I also characterised methods contextualisation in three different ways: **to 'locate' methods in contexts; to examine research perspectives;** and finally, **to provide a broader theorisation of contexts.**

1.5 Broad research questions

The thesis introduction sets out the three rationales for the methodological exploration undertaken, these were: extension of the methodology horizon; inadequacies of current methodologies and, the influence of the research topic. The first rationale has been explained within the first chapter. The other two will be explained in chapters two and three. At this juncture, I consider it important to convert the discussion about methodological exploration within the thesis into broad research questions.

The broad research questions within of the thesis are listed below.

- How can methods contextualisation be developed in reviewing?

- What were the strengths and weaknesses of the methodologies chosen?
- What is the contribution of methods contextualisation in the field of Augmentative and Alternative and Communication (AAC) methods with people with dementia?

The thesis is considered to be methodological exploration, and the research questions reflect this aim. The first two questions will guide the development, implementation and conceptualisation phases of the review. The first question addresses how methodologies that support methods contextualisation could be developed by adapting or modifying existing review methodologies. Secondly, the thesis also aimed to determine the perceived strengths and weaknesses of the methodologies implemented, perhaps leading to ways to more accurately conceptualise methods contextualisation. The third aim articulates the necessity to present empirical outcomes from the studies undertaken. This question reflects the contribution to topic knowledge the thesis will make.

1.6 Structure of the thesis

Chapter two addresses my second rationale- the inadequacies of current review methods. Outcomes from this chapter shaped the (structured) approach to methodology selection I used in adapting current methodology templates to make them ‘fit for purpose’. This structured approach to methods contextualisation development is presented, consisting of three approaches. These approaches are: to ‘locate’ methods in contexts; to examine research perspectives; and finally, to provide a broader theorisation of contexts (initially identified in chapter 1.4). I justify the selection of individual methodologies for the three approaches (i.e. forms of methods contextualisation) in sections 2.4 and 2.5 which depict the stages of methodology selection. Each methodology is selected according to criterion.

Chapter three explains the influence of the *topic* on the methodological exploration. This is the third rationale. As a secondary function, the chapter also justifies the selection of dementia research and the associated Augmentative and Alternative Communication (AAC) methods as a topic. Chapter four presents the three modified methodological templates from existing methodologies. The chapter explains the processes of each review, including adaptations I made for methods contextualisation. I also describe other methodologies that could have been chosen.

Chapters five, six and seven explain the implementation of the methods contextualisation reviews. These chapters present empirical findings from three different approaches

created. The presentation of the syntheses methods and results follow the standard reporting traditions. Chapter five is a scoping review design combined with a Systematic Mapping approach to interpret research attributes and concepts. Chapter six is a Meta Study (Paterson et al., 2001) designed to provide a rich case analysis of AAC interpretive frameworks. This synthesis incorporates a Cluster technique to identify evidence (Booth et al., 2013b). The third synthesis (chapter seven) is a Narrative Synthesis (Popay et al., 2006) designed to provide synthesis about implementation issues surrounding the research methods.

The final two chapters describe the way the methodological journey was eventually conceptualised. The penultimate chapter (eight) discusses the development of the methods contextualisation approach. I discuss the aim and the purpose of methods contextualisation and what has been achieved. I reflect on the suitability of the dimensions of the methodologies chosen, and their strengths and weaknesses. Finally, I consider the impact of the sequence of the reviews. The chapter proposes a model to conceptualise the three approaches to method contextualisation as an emerging perspective. The final chapter explores the overall contribution of the thesis to methodology and to new knowledge more widely; including why the methods contextualisation purpose is of benefit. I reflect on the thesis approach and identify avenues for future research.

Chapter 2: Rationale two: Inadequacies of current methodologies and strategies for adaptation

2.1 Introduction

Chapter one outlined three different rationales for justifying the thesis as a methodological exploration. This chapter discusses the second rationale, the inadequacies of current methodologies for methods contextualisation. I envisaged methods contextualisation as the term to describe review processes for identifying suitable forms of data collection methods to employ with research participants using contextualised research evidence and synthesis. Thus, this genre of reviewing engages with the interpretation of choice and use of research methods.

This chapter will show review methodologies are currently inadequate for methods contextualisation, but they could be modified. Three examples of contextualisation have already been discussed in chapter one (1.4). (These were: EPPI Centre reviewing, interpretive reviews from the tradition of qualitative enquiry and, reviews from the realist theory-based school of evaluation). Methods contextualisation approaches were summarised as: to 'locate' methods in contexts; to examine research perspectives; and finally, to provide a broader theorisation of contexts. These avenues of research are pursued in greater depth in this chapter in order to identify suitable methodologies from systematic review types that would be targeted for adaptation.

The chapter begins by reiterating the suitability of interpretive reviews, in particular their configurative characteristics. This is the basis for the next step, that is, to outline inadequacies in the features of interpretive reviews for methods contextualisation (either as inadequacies of design or implementation). The discussion draws on legacies from review heritage to explain the origins of some short-comings. I explain why this legacy has potentially obstructed the development of methods contextualisation. I describe the two stages of my *methodology selection*. The first narrowed possible methodology options and the second used sets of selection criteria. Three specific methodologies were selected from these criteria to be adapted and implemented. (Adaptations are presented in chapter four).

2.2 Conceptualising the characteristics of interpretive reviewing

First, I will explain my interest in interpretive review methodologies for methods contextualisation. Methods contextualisation is envisaged as a way of interpreting the

choice and use of research methods. There are a number of review types which possess contextualising and interpretive elements (EPPI Centre reviewing and mapping, interpretive reviews from the tradition of qualitative enquiry and, reviews from the realist theory-based school of evaluation (introduced in chapter 1.4). Overall, this section conceptualises this characteristics of *interpretive reviewing* in order to explain next step in my methodological exploration.

The term *interpretive reviewing* describes a wide umbrella of review types and methodologies. Broadly, these methodologies incorporate inductive and interpretive techniques in analysis. These techniques are based on the principle that synthesis output, ‘the whole’, is greater than the sum of the parts (Kastner et al., 2012). When first conceptualising interpretive reviewing, theorists began to consider *how* reviews handled data, and if the synthesis used *interpretive* or *integrative* material, or both. Noblitt and Hare first used these descriptors (1988), followed by Dixon-Woods et al (2005, p.46). Thus, conceptualisations moved away from less helpful ‘qualitative’ and ‘quantitative’ descriptions. Other helpful terms for describing reviews are *aggregation* and *configuration* (Voils et al., 2008, p.6; p.14). *Configuration* organises data into patterns to be interpreted, and *aggregation* ‘adds up’ or integrates reoccurring aspects of findings. Interpretive reviews apply configurative techniques, although mixed reviews may apply both. Therefore, interpretive approaches produce new knowledge from synthesis, and identify patterns in data which would be useful to understanding complex contexts in which data collection methods are chosen and used.

This section discusses the principles and characteristics of interpretive/configurative approaches in more detail. I argue that many characteristics *are* suitable for methods contextualisation in comparison to aggregative approaches. It is essential for me to convey these principles and characteristics in order to later explain the ways in which I feel that interpretive reviews are also inadequate. The general tenets of interpretive synthesis can be described as: the generation of theory; integration of data (‘thick’ description); the role of the reviewer in interpretation; and commonality between studies (Cooke et al., 2012, p.1435-6). Typically, configurative reviews interpret theory *during* the review to build meaning whilst aggregative reviews use theory *before and after* the review to frame the question and make use of findings (Gough and Thomas, 2012, p.52). Interpretive reviews are also suited to answering complex questions such as: the meaning of a specific phenomenon, the process of an action or event, the attributes of an activity or the

appropriateness of an intervention (Hansen and Trifkovic, 2013, p.31, table 5). This approach aims to “*interpret, describe, summarize and present data, events and observations*” (op cit).

The characteristics of interpretive reviews govern processes that could potentially provide a wealth of information for methods contextualisation. The characteristics of interpretive reviews are combined in different ways for different purposes. The characteristics are: **epistemological position** (ranging from idealist to realist), **iteration**, **‘problematism’ of the literature**, **interpretation** (ability to ‘go beyond’ primary studies), **creation of a synthetic product**, and, **heterogeneity or homogeneous data** (adapted from Barnett-Page and Thomas, 2009, appendix figure 1 ‘*Dimensions of difference*’). The mixes of characteristics underpin different interpretive methodologies and, therefore, different outcomes for methods contextualisation. Each characteristic is described in more detail below.

Epistemological positions in reviews can be located on an idealist and realist spectrum. The various interpretive epistemologies are listed below:

- Subjective idealism- there is no shared reality that is separate from or independent of multiple alternative human constructions
- Objective idealism- there is a world of collectively shared understandings
- Critical realism- our knowledge of reality is mediated by our perceptions and beliefs
- Scientific realism- it is possible for our knowledge to approximate closely to an external reality
- Naïve realism- reality exists independent of human constructions and can be known directly (adapted from Spencer 2003, cited in Barnett-Page and Thomas, 2009, Appendix figure 1).

Iteration refers to the level of refinement in the process, typically a process of back-and-forth adjustments to the parameters of the review question. Generally, the more idealist the review approach is, the greater the levels of iteration in the review. This flexibility could be helpful to contextualisation of methods. **Problematism** of the literature is linked to the epistemological position of the reviewer. Reviews which problematise the literature

most are less likely to accept the assumptions held by the primary study authors. A review that problematises the literature does not automatically transfer understandings and concepts without considering the context of the knowledge base. Such a concept is particularly relevant to the focus of methods contextualisation in this thesis.

Interpretation is a term used to describe the spectrum Barnett-Page and Thomas, call “*going beyond primary studies*” (Barnett-Page and Thomas, 2009, appendix figure 1). This refers to the way the review configures data. Interpretive analyses typically translate or transform data. Translation of data involves the identification of patterns and common themes; whereas, transformation of data involves processes to add levels of analytical understanding, such as the generation of theory. Both approaches are viable for methods contextualisation- this characteristic would depend on the idealist or realist position of the methodology. The **synthetic product** describes the outcome of the review, more specifically, whether the format of the outcome is suited to making direct policy recommendations. Highly conceptual interpretive reviews typically make less direct policy recommendations. I considered this characteristic in methodology selection. Finally, heterogeneity of data is an expression of whether the data synthesised is **homogeneous** or **heterogeneous**, or somewhere in between. This is another important consideration for methods contextualisation. Heterogeneous reviews may analyse different study types and data types. However, greater homogeneity may facilitate in-depth comparison of data gathering methods.

This section suggests interpretive reviews possess relevant features and characteristics that would be considered useful to this methodological agenda. However, the next section describes other ways in which interpretive reviewing could be modified in order to maximise the potential for methods contextualisation, relating to flaws in characteristics of design, implementation or reporting.

2.3 Inadequacies in interpretive reviewing

The previous section indicates the existence of many useful characteristics in interpretive reviewing for methods contextualisation; however, I consider this form of reviewing inadequate in a number of ways. Firstly, there is limited precedent for ‘qualitizing’ data. Secondly, quality appraisal is considered inadequate as a screening device. Thirdly, there is a narrow range of tools to guide synthesis results reporting and insufficient methodological reporting. Fourthly, syntheses can be misinterpreted- implementation can

lack sufficient depth. Fifthly, there is an overemphasis on generalisability (probably a result of aggregative review heritage). Finally, key aspects of synthesis lack consensus, such as the issue of synthesis across interpretive paradigms. These points are explained in more detail in the following section.

The first aspect I will address is the breadth of application of interpretive syntheses across a range of study perspectives, study types, and data types. Capturing the data collection narrative is vital to the way I envisage methods contextualisation. This can be limited in interpretive reviewing, owing to the focus of synthesis commonly employed. The focus of interpretive reviews tends to surround the synthesis of themes from findings in qualitative studies (such as Qualitative Evidence Synthesis (Booth, (2013a), p.8-9). Methods contextualisation would require the interpretive synthesis of data from a range of studies. ‘Data’ would be made up of narrative commentary in methods sections and relevant implementation sections of primary studies.

Therefore, I believed interpretive reviewing for methods contextualisation might require ‘qualitizing’ techniques embedded in the synthesis. Sandelowski et al (2006) used this expression for mixed synthesis reviews; they “*qualitized*” (or “*quantitized*”) review findings in a way that departed from the original study approach. It is crucial that methodologies designed for methods contextualisation can synthesise a diverse range of evidence types that do not fit neatly into either quasi-experimental intervention research or narrative qualitative research. Qualitizing material is a way of transforming materials into data in a common form for synthesis (Sandelowski et al., 2006). Without qualitizing techniques for a range of data, I risked creating a bias towards qualitatively-framed studies. The methodologies needed to be able to synthesise the maximum volume of research and resources available. This includes methodology papers or other reflexive pieces which do not fit easily into conventional reporting formats.

The second aspect of discussion in this section surrounds the inadequacy of quality appraisal (QA) as a screening device in interpretive reviewing for methods contextualisation. This is because, as a screening device, quality appraisals tend to prioritise rigour over relevancy. I envisaged relevancy of the data collection methods would be as important as the rigor of the overall study components. However, some aspects of quality appraisal procedures possess similar objectives to the methods contextualisation reviews. For example, an example of a QA procedure asks whether

studies used appropriate methods to help people to express their views (Barnett-Page and Thomas, 2009). However, robust QA procedures are not widespread across methods. Barnett-Page and Thomas (2009) commented on the presence of robust quality appraisal in just three review methodologies (Framework Synthesis, Narrative Synthesis and Thematic Synthesis). Therefore, in the absence of robust procedures, I realised I may need to exercise caution when applying QA techniques for methods contextualisation, particularly if important data may be disregarded as a consequence of measuring study rigour.

The third inadequacy I identified in interpretive reviewing is the narrow range of tools to guide synthesis results reporting, including insufficient methodological reporting. Hannes and Macaitis (2012) describe the issue of reporting synthesis in the following way: “*The description of the synthesis was a weak issue in many reviews. There appears to be a black box between what people claim to use as synthesis approach and what is actually done in practice...*” (p.434). Therefore, the relevancy of the available reporting guidance options needs to be considered for the development of the methods contextualisation genre. Tong et al (2012) commented that while there are reporting guidelines for qualitative research (COREQ *Consolidated Criteria for Reporting Qualitative Research* Tong et al., 2007); there were no reporting guidelines for *reporting* the synthesis of qualitative research. Consequently, a range of tools are emerging. For instance, STARLITE (a mnemonic for: *sampling strategy, types of study, approaches, range of years, limits, inclusions and exclusions, terms used, electronic searches*) is a reporting tool for literature searches (Booth, 2006) SALSA (Search, appraisal, synthesis and analysis) tool (Booth, Papaioannou & Sutton, 2011) and CerQual (Lewin et al., 2013). Although aspects of these tools offer a certain level of transparency, they do not specifically enhance contextualisation of research methods. I will attempt to avoid these pitfalls and make reporting as transparent as possible. Methodological reflection was a significant consideration in the thesis.

Although implementation of methodologies is the responsibility of the reviewer, I suggest that the complexity of the analytical task in interpretive reviewing is perhaps more prone to misinterpretation where methodological guidance is sparse. Sometimes, it is unclear how reviewers should put methodological theory into practice. This is a weakness of interpretive reviewing due to the fact methodological guidance is not simply a ‘recipe’ for success. The methods contextualisation reviews address issues of misinterpretation through the creation of modified methodological templates that fully explain processes

undertaken. Finfgeld-Connett (2014) examined the development of interpretive synthesis through published metasyntheses (or interpretive syntheses) and found that findings were not necessarily reaching their full potential. Research questions were unambitious, usually focusing on a single broad abstraction. Reviewers also made assumptions that study samples were too small and often data analysis or synthesis was incomplete. Finfgeld-Connett (2014) argued models were under-used; there was often insufficient analysis across studies, and refutational analysis was not fully realised (pp. 1587-1589). I anticipated analytical depth would be crucial for many aspects of methods contextualisation, especially the conceptual analysis of study perspectives and implementation factors. It is crucial that methodologies can convey how to achieve this.

Finally, I argue key aspects of interpretive synthesis lack consensus, which can disrupt the implementation of the review. This inadequacy potentially stems from the legacy of positivistic, effect-driven reviews as one element of the heritage of interpretive reviews. Booth (2009) describes this as a “*dual heritage*” for Qualitative Evidence Synthesis, such methodologies use interpretative methods. Sandelowski and Barroso (2007) summarised the predicament “*While qualitative research synthesis is being pulled hard on the one side toward the generalizing imperatives of evidence-based practice, it is also being pulled hard on the other side toward the anti-generalizing impulses of postmodern inquiry*” (p.9). This extract is indicative of the conflicting impulses of reviews using interpretive approaches, potentially limiting in-depth methods contextualisation and placing undue emphasis on assigning levels of quality.

In the following discussion I provide a brief synopsis of the legacy of theoretical tensions in interpretive reviewing in order to explain the origins of the emphasis on rigour (quality) over relevancy. In aggregative research, there is a preoccupation with minimising bias and elimination of ‘error’ by increasing statistical strength. The origins of aggregative reviewing are anchored in the integration of study effects through Randomised Controlled Trials (RCTs) dating back as far as the 18th Century. James Lind conducted the first recorded RCT and he was also the first to record a systematic review method. He wrote: “*as it is no easy matter to root out prejudices ... it became requisite to exhibit a full and impartial view of what had hitherto been published on the scurvy ... by which the sources of these mistakes may be detected. Indeed, before the subject could be set in a clear and proper light, it was necessary to remove a great deal of rubbish.*” (Lind (1753) cited in Grant and Booth, 2012, p.92). The synthesis of research evidence continued during the

20th Century, eventually influential bodies such as the Cochrane Collaboration (founded 1992) or the Centre for Reviews and Dissemination (University of York) emerged to become centres of excellence for reviewing and review methodology for health care research. Reviews proved useful in determining the efficacy of treatments and interventions which require high quality studies to generate statistically strong results. Since the dawn of the Evidence-Based Medicine (EBM) movement in the 1990s, diversification of approaches and methodologies has occurred and systematic reviewing is now a rich tapestry of aggregative and configurative methodologies and perspectives. One of the main criticisms of EBM and EBP (Evidence-Based Practice) has been the over-reliance on statistical methods (often associated with pharmaceutical interventions) which result in “*reductionist*” and “*standardised models*” (Dixon-Woods et al., 2006a, p.30). The influence of these models may mean that the review methodologies which developed were shaped by reductionist principles also. Thus, reviews fail to acknowledge individual variability, or the influence of *context* that are central to many methods (op cit).

Gradually, interest in qualitative methods evolved into international centres such as the EPPI Centre, Joanna Briggs Institute, the Cochrane Qualitative Methods Group and the Campbell Collaboration. These centres developed alternative perspectives on good quality review evidence; such as: rigour, trustworthiness, plausibility and credibility (Eisner 1991; Guba and Lincoln (1989) and Lincoln and Guba (1985), cited in Hannes et al., 2010 p.1736). Ideas of quality were, therefore, adjusted to interpretive paradigms; however, they continued to re-enforce the rigour over relevancy agenda.

The synthesis of multiple qualitative paradigms is debated. Such issues are interpreted differently according to the paradigm perspectives now in existence. For instance, some scholars argue that dialoguing with texts under a single hermeneutic approach is possible as long as philosophical assumptions are taken into consideration (Zimmer, 2006). (An hermeneutic process requires the reviewer to present accurate representations of data from the individual constructions he or she identifies (Baszanger & Dodier, 1998; Reeder 1988 cited in Paterson et al, 2001, p.60)). Interpretive reviewing formed a new spectrum of perspectives with their own entrenched positions. Progress in methodological development is not easily achieved because there is no singular perspective to re-imagine interpretive reviewing (as is the case for positivistic reviews).

Other aspects of interpretive reviewing lack consensus, such as restrictive protocol structures that limit iterative search cycles and may narrow questions (Finfgeld-Connett and Johnson, 2013). Another sphere which is evolving is the increasing role of lateral and iterative approaches (Flemming and Briggs, 2006). Partially, this is driven by practical issues. Scholars, such as Cooke et al (2012), comment on the need to improve the indexing of qualitative articles in databases (p.1439). The appropriateness of the apparatus of interpretive reviews has been called into question. These include: precisely formulated review questions; exhaustive searches; structured approaches to quality assessment and transparency and replicability of the synthesis that have become synonymous with quality across all reviews (Dixon-Woods et al., 2006a p.31). However, this accepted practice derived from aggregative reviews, is being questioned.

In summary, in order to develop a methods contextualisation approach I needed to assess the need to modify inadequate aspects of interpretive reviewing. Some of these aspects hinge on theoretical perspectives, such as, what can be included as data, or, whether research paradigms are incommensurable within a qualitzing approach. However, other inadequacies I have identified may be a result of methodological ambiguity, or reviewer reporting error. Speaking broadly, I considered interpretive reviews suitable but I thought they lacked the necessary methodological emphasis on interpreting research methods contexts. The next section discusses which types of reviews with interpretive features I decided to engage with in the thesis.

2.4 First stage of methodology selection

The stages of methodology selection identified review methodologies which exhibited the features I considered most conducive to methods contextualisation. I suspected there might be different ways to contextualise research methods data, just as there are different ways to contextualise findings in existing reviews (see section 1.4). I recognised the operationalisation of methods contextualisation might require different approaches to facilitate different objectives associated with the concept.

I required a strategy for developing both the concept of methods contextualisation (in its possible forms), and a way of matching methodologies to iterations of this concept. One option would have been to simply select forms of contextualisation. However, this assumed that methodologies were the best choice, without exploration of the different options. Also, the process of selection helped me to more accurately define the concept of

methods contextualisation and its objectives. Review types associated with contextualisation represented the beginning of my exploration of features suited to methods contextualisation.

Criteria for multiple approaches were based on contextualising review types (identified in Gough and Thomas, 2012 p.41-44 discussed in section 1.4). I developed the methods contextualisation concept prior to the creation of the criteria. The discussion below conveys the two stages of selection. In the first stage, I identified methods contextualisation objectives. These were linked to the specific review types which specialised in that objective. This created a smaller pool of possibilities. In the second stage I conducted a criteria-based exercise on the previously defined methodology options. Therefore, I did not judge a full range of methodologies against criteria (see table 2.1). This gave me the opportunity to create specialist sets of criteria based on particular review types or functions (which were based on methods contextualisation objectives). However, as a result of this strategy, I potentially eliminated suitable methodologies based on my perception of the suitability of review types to methods contextualisation objectives (explained in greater detail in this section).

I will begin with background information about different methodologies (figure 2.1 and scoping and mapping definitions). I then tabulated a variety of review and systematic review choices and categories (table 2.1) in order to provide a reference point for the narrative explanation of decisions made in stage one of the selection process. Finally, I explain the first stage of the selection process and summarise associated characteristics of the narrow pool of possible methodologies- tabulated in 2.2.

I have included Figure 2.1 to help explain further origin and objectives of the possible methodologies as a point of reference.

Subjective idealist review approaches

Critical Interpretive Synthesis- This is a multi-disciplinary, multi-method technique developed by Dixon-Woods (2006). Critical Interpretive Synthesis uses meta ethnographic and grounded theory methods, applied across a large body of qualitative and quantitative data. The whole process is built around the idea of being critical of the literature and contextualising findings. Synthetic constructs constitute the main outputs of the research to generate theory.

Meta Narrative- Greenhalgh et al's (2005) approach was influenced by the need to create synthesis that could assist in providing answers for complex areas of policy. The work was influenced by Kuhn's work *The structure of scientific Revolutions* (1962) which argues that the pursuit of knowledge, and the form of knowledge sought, is influenced by paradigms and epistemological positions. Paradigms dictate the value ascribed to knowledge through underlying assumptions embedded within the particular viewpoint. The methodology tries to understand the unfolding storyline of the research over time (acknowledging that there is no single story, and viewpoints may be incommensurable). Their work led them to map out the various meta narrative traditions in a given research terrain.

Meta study- Paterson et al (2001) developed Meta Study, a multi-faceted and multi-layered approach to synthesis. Pre-synthesis phases include meta method, meta theory and meta-analysis (of findings) (Zhao, 1999). It uses a subjective idealist approach to question the constructions of qualitative research and the secondary constructions of knowledge. The method recognises that research is produced from a sociological, historical and ideological context. Ultimately, underlying assumptions of research are constructed

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Critical realist review approaches

Thematic Synthesis- Thomas and Harden (2008) developed this approach to combine Meta ethnography and Grounded theory to create a thematic synthetic product. Adapted to consider effectiveness and appropriateness of intervention, uses a barriers and facilitators framework. Line by line coding is applied. Free codes are grouped to make descriptive themes which are used to build analytic themes.

Framework Synthesis- Brinton et al (2006) and Oliver et al (2008) created Framework synthesis which draws on the framework approach for primary research developed by Pope, Ziebland and Mays (2000) that draws upon the work of Ritchie and Spencer (1993) and Miles and Huberman (1984). It offers a structure in which to analyse volumes of data, involving coding and usually a priori indexes. The synthetic product is a diagrammatic representation of each of the key dimensions identified in the themes.

Textual Narrative Synthesis- This methodology organises methods into a more homogeneous group. Typically, this method collects data on characteristics, quality, context, findings. Can be used to demonstrate heterogeneity between studies. Developed as Narrative synthesis by Popay et al (2006).

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Other review methodologies

Meta ethnography- textual method to build comparative understanding. Synthesis achieved through translation of studies into one another (reciprocal translation), Refutational synthesis and Lines of Argument synthesis to build an overall picture of data (Noblitt and Hare, 1988).

Objective idealist epistemology.

Grounded Theory- Based on grounded theory method (Glaser and Strauss 1967 and Strauss and Corbin 1990, 1998) underpinned by principles of using an inductive approach to achieve synthesis. Processes involve simultaneous phases of data collection and analysis, theoretical sampling, constant comparison, theoretical saturation and the generation of new theory. Synthesis methods developed by Kearny (2001) Eaves (2001) Finfgeld (1999). Synthesis conducted using grounded theory studies. Objective idealist epistemology.

Ecological triangulation- Methodology draws on Web et al's (1966) and Denzin's (1978) concept of triangulation to accumulate a body of knowledge from various vantage points. The principle rests on identification of relationships between behaviour, persons and environments. Formulaic ecological sentences are created to explain data. Scientific realist epistemology

(All adapted from descriptions in Barnett-Page and Thomas, 2009)

Figure 2.1 Description of most common systematic review methodologies

Figure 2.1 describes the central interpretive syntheses methods. The range of interpretive reviews is described according to epistemological position. It does not include non-systematic reviews which are described in the section below.

Scoping and mapping definitions

Mapping and scoping reviews can fulfil interpretive functions to locate studies in a literature landscape. I initially summarised scoping and mapping in section 1.2, I expand on these review types here. There is a lack of consensus on what scoping and mapping reviews are. In this section I explore the definitions and provide my own position. The scoping term is described in various ways (it is often used interchangeably with the term 'mapping'). However, scoping may be regarded as a rapid (and possibly unsystematic) examination of an area of literature and its different characteristics (Gough et al., 2012). It is commonly associated with a subsequent review on a topic. Examples of methodological scoping frameworks include: Arksey and O'Malley (2005) and Levac et al., 2010).

Findings are collated and summarised, but unlike systematic reviews, there is no synthesis

phase (Levac, 2010). Therefore, when applying a scoping framework, mapping and scoping are difficult to tell apart (Miake-Lye et al (2016).

Evidence mapping methods differ in that they may involve: stakeholder consultation, rigorous search strategies, and the production of a visual or searchable database.

Mapping reviews have a specialist purpose to go beyond an account of a research field; they “*more explicitly identify aspects of studies that help to describe the research field in some detail; the focus and extent of such description varying with the aims of the map*” (Gough et al., 2012). They may be a singular exercise, or form part of a broader process (to identify a sub-set of papers to synthesise, for instance). A map may, therefore, form an initial stage in a series of syntheses or mixed method reviews, in order to inform further review processes. In addition to the functions above, mapping has a third role to interpret findings of a synthesis (Peersman, 1996 cited as an example in Gough et al., 2012). In this example, Peersman employs a Systematic Mapping exercise to help locate included health promotion studies in the wider literature.

Bragge et al (2011) used similar distinctions in a mapping initiative study. They defined scoping as an overview of the types of evidence available to examine the extent range and nature of research activity (based on Arksey and O’Malley, 2005, table 1), and they defined mapping as the systematic organisation of a broad field of research evidence (based on Katz et al., 2003 cited in Bragge et al., 2011, table 1). They appeared to differentiate between the two methods on the basis that the scoping has less ability to synthesise results and has no quality appraisal procedures to produce in-depth appraisal and synthesis, whilst mapping provides study context in study descriptions.

In summary, I conclude that to define the difference between the two approaches, it is helpful to think of the literature base as a landscape, or territory. Scoping would assess the dimensions of the literature landscape, as if a person were describing that landscape at first glance. Dimensions of the literature landscape are more important than the sense of how the aspects of the landscape relate to one another. Understanding the way pieces of literature relate to each other is a greater concern for mapping reviews. Mapping provides many of the functions of a geographical map of the literature landscape; it provides commentary on how the landscape is organised once it has been scoped or surveyed. There is an emphasis on context and categorising the terrain and sparse gaps in knowledge, and relaying what is relevant (or irrelevant) for readers. However, distinctions between

scoping and mapping have not been formalised. Due to the lack of reporting guidelines, academics acknowledge it is difficult to identify distinguish between them (Bragge et al., 2011).

Table 2.1 below provides an overview of the broader review types from which groups of methodologies were selected. Table 2.1 summarises the initial range of methodologies I explored for relevant methods contextualisation features. It also provides some insight into alternative ways of grouping the reviews according to characteristics such as interpretive stance or epistemology. The * symbols in the second and third rows indicate which methods were selected from the first stage of my methodology selection based on particular features I decided were suitable for methods contextualisation (discussed below).

Table 2.1 Overview of broad review types

Category of review (type or epistemological label)	Review methods
Interpretive reviews (Barnett-Page and Thomas, 2009, appendix 1)	-Meta Narrative, Critical Interpretive Synthesis, Meta Study, Meta Ethnography, Grounded Theory, Thematic Synthesis, Textual Narrative Synthesis, Framework Synthesis, Ecological Triangulation
Reviews (Grant and Booth (2009) typology) (Non-systematic reviews) *Preliminary reviews I have identified as focused on locating studies	-Critical Reviews -Literature reviews -State of the art reviews -Overviews -Rapid review -Umbrella reviews -*Scoping reviews -*Mapping reviews
Conceptual reviews (problematizing literature and literature perspectives*) (Barnett-Page and Thomas, 2009, appendix 1-	-Meta Ethnography -Grounded Theory -Thematic synthesis -*Critical Interpretive Synthesis,

problematizing the literature table)	-*Meta Narrative, -*Meta Theory
Theory-Based Evaluation reviews that create a broader theorisation of context.	-Realist Synthesis -Textual Narrative Synthesis
Subjective idealist epistemology (of interpretive review type) (Barnett-Page and Thomas, 2009, appendix 1)	-Meta Study -Critical Interpretive Synthesis -Meta Narrative
Critical realist epistemology (of interpretive review type) (Barnett-Page and Thomas, 2009, appendix 1)	-Textual Narrative Synthesis -Thematic Synthesis -Framework Synthesis

Stage 1 Identifying compatible and incompatible studies: narrowing the field

I researched the forms of contextualisation in reviewing (first introduced in section 1.4 Gough and Thomas, 2012, pp.41-44). These forms were associated with EEPI Centre reviewing, Critical Interpretive Synthesis and Realist Synthesis. I developed a sense of what might be a broad objective for methods contextualisation (and subsequently, suitable methodology types) by building on the descriptions accompanying contextualisation.

A). Summary of contextualisation descriptions (Gough and Thomas, 2012, pp.41-44):

- i). **Locating findings in socio-cultural contexts** to enhance the ability of the reviewer to understand them
- ii). Part of a **critical process to understand research traditions** or theoretical assumptions

iii). **Context as component of theory** to determine the way the phenomenon works, involving mechanisms and outcomes, contextualisation as the process of arriving at this understanding of significant areas of context

B). Summary of perceived methods contextualisation objectives:

- i). A way to sketch out the landscape of *choice* of methods through the **location of methods** and relevant contexts, and relationships between the two (requires examination of methods-context relationship)
- ii). A way of **examining perspectives** governing the methodological processes and the development of research methods (focus on perspectives that shape the contextual landscape)
- iii). A specific form of contextualisation that determines the **broader theorisation of context**

C). Identifying a type of review/systematic review:

- i). Emphasis on locating studies and their methods attributes - a **preparatory review type** would show what the attributes of the methods context were, and retain an emphasis on locating (or mapping) studies
- ii). Concentration on **examination of theoretical perspectives** because it would help to expose assumptions, particularly surrounding method choice and use
- iii). **Theory-based evaluations** to assess studies in terms of the characteristics of methods and their contexts, (including implementation if possible)

D). Shortlist of possibilities (ranges) checked against criteria:

- i). **Scoping and mapping reviews**
- ii). **Critical Interpretive Synthesis, Meta Narrative, Meta Study reviews**
- iii). **Realist Synthesis, (Textual) Narrative Synthesis evaluation reviews**

I will now provide an overview of these phases in stage one according to each of the three approaches, with reference to additional material that helped to direct my decision-making. Firstly, I unpacked features of contextualisation (stage 1A). These can be described as surrounding locating studies (EPPI Centre review), creating a critical understanding of

research traditions (Critical Interpretive Synthesis) and the role of context as a component of (causation) theory (Realist Synthesis).

Next, exploration of contextualisation helped me to decide what could become the objectives for methods contextualisation (stage 1B). These could be summarised as: locating methods in the literature landscape; interpretation of wider research perspectives, and determining the broader theorisation of context. (I eventually prioritised theorisation of *implementation* in the criteria stage because of connections between intervention implementation and data collection phases, and the way the research is carried out).

With the objectives in mind, I returned to the guidance on question focus to try to narrow down options further (stage 1C). These included preliminary review types that: located studies, reviews based on examination of theoretical perspectives, and theory-based evaluations. Thus, under the first approach, I moved away from EPPI Centre systematic reviews to specialist preliminary review for *locating* studies and defining the literature landscape. I hoped these methodologies would examine the size and scope of the literature base and map its dimensions (Grant and Booth, 2009, p.94, table 1). I have provided definitions of these two methods above. Below, I describe why I rejected other forms of reviews (see table 2.1).

All other types of non-systematic reviews were rejected on the basis that they did not specialise in locating the included literature (listed in table 2.1). For instance, ‘Critical’ reviews did not place an emphasis on locating studies or providing a critique of contributions in field (Grant and Booth 2009, p.94, table 1). ‘Overview’ reviews included surveys of literature, but this usually refers to drawing broad conclusions about medical contexts (op cit). Finally, rapid reviews included systematic review elements to perform critical appraisal but there was no specific emphasis on location of included studies or defining the literature base. The method typically analysed overall quality of literature (op cit).

I then identified possible groups of methods and noted their specific characteristics to inform the direction of each review (stage 1D). Table 2.2 is a summary of the pool of methodologies and their characteristics. Figure 2.2 depicts the source of one of the characteristics- question focus. Both are displayed below. According to the first methods contextualisation approach, appropriate review methods were: are scoping and mapping reviews (see definitions above and table 2.2). Under the second approach, I narrowed the

selection to Critical Interpretive Synthesis, Meta Narrative, Meta Study reviews. My choices for the third approach were between Realist Synthesis and Narrative Synthesis.

Associated characteristics of the first approach

Associated characteristics of scoping and mapping are displayed in table 2.2 below. Non-systematic reviews did not feature in the interpretive epistemology spectrum, nor did they appear in the 'question focus' review typology. I considered epistemological stances consistent with interpretive approaches (e.g EPPI Centre reviews had an implicit social constructionist stance according to Gough and Thomas, 2012, p. 42). Scoping and mapping did not feature in Hansen and Trifkovic's (2013) table of systematic review classification types and commonly asked questions (p.30-31, table 5). I felt descriptive features of the mapping and scoping had similarities to the interpretive hermeneutic review type. This type recommended analysis of study *attributes*. An extract of this source is displayed below- figure 2.2.

Associated characteristics of the second approach

I identified a group of reviews which problematised the literature: Critical Interpretive Synthesis, Meta Narrative and Meta Study reviews (Barnett-Page and Thomas, 2009). Associated methodological characteristics included epistemological position (see table 2.2). This was a more straight-forward exercise than the first approach. All reviews were subjective idealist. All three methodologies were also Complex Interpretive Hermeneutic reviews (figure 2.2). The type of commonly asked question for conceptual reviews was specified as questions surrounding *processes* (figure 2.2).

Associated characteristics of the third approach

This approach led me to the identification of methods contextualisation as the broader theorisation of context and, subsequently, the identification of Theory-Based Evaluation reviews as my priority. My choices were between Realist Synthesis and Narrative Synthesis. In associated characteristics, both conformed to a critical realist approach, but they differed quite dramatically in other ways. There were differences in key characteristics. Narrative Synthesis was not specified in the classification table (Hansen and Trifkovic, 2013, p.30-31, table 5). I thought it shared qualities with multi-component mixed reviews on the basis of realist epistemology and mixed-method analysis techniques (figure 2.2). Narrative Synthesis is designed for answering complex interpretive questions about intervention implementation (or effectiveness). Whereas, Realist Synthesis types

were explicitly labelled as ‘Focused Effect-driven, Impact’ reviews (Hansen and Trifkovic, 2013, p.30, table 5). Therefore, methods contextualisation appeared to suit a question surrounding *appropriateness* of intervention given the preference for interpretation of implementation. This was the Narrative synthesis approach, whereas Realist Syntheses typically focused on efficacy.

Table 2.2 below summarises the definable features of methods contextualisation and review types linked to associated methods contextualisation approach. I provide the possible groups of review the subsequent criteria reviewed. I also provide the details of associated approaches which featured in the criteria.

Table 2.2 Overview of methodological options and associated characteristics

<i>Stage one: defining features suitable to methods contextualisation</i>		
Methods Contextualisation approach	Review types associated with methods contextualisation approach	Compatible methodology options & associated characteristics*
		*Associated characteristics based on: Epistemological stance (Barnett-Page and Thomas, 2009, appendix item 1); Broad systematic review type (Hansen and Trifkovic 2013, p.30-31, table 5); Suitability for which commonly asked research questions (Hansen and Trifkovic 2013, p.30-31, table 5).
Location of methods (and examination of methods-context relationships)	Preliminary reviews specialised in mapping (Grant and Booth, 2009)	Outcome: Scoping/ Mapping <ul style="list-style-type: none"> • <i>Epistemological stance</i> : Often implicit e.g. scoping component in EPPI Centre Review (Social Constructionist) (implicit- source: Gough and Thomas, 2012, p.42) • <i>Broad systematic review type</i>: Not specified in systematic review classification table (Review type-“review” Grant and Booth, 2009, p.94, table 1) • <i>Focus of commonly asked research questions</i>: Not specified in classification table (Analysis of attributes on the basis of similarities to complex <i>descriptive</i> systematic reviews)
Examination of research perspectives	Reviews that provide an examination of theoretical perspective i.e.	Outcome: Critical Interpretive Synthesis, Meta Narrative, Meta Study <ul style="list-style-type: none"> • <i>Epistemological stance</i>: Subjective Idealist • <i>Broad systematic review type</i>: Complex Interpretive Hermeneutic systematic Review • Analysis of processes

	Conceptual reviews (problematise the literature and literature perspectives (Barnett-Page, 2009))	
Create a broader theorisation of context	Theory-Based Evaluation (Pawson, 2006) review approaches	Outcome: Narrative Synthesis, Realist Synthesis <ul style="list-style-type: none"> • <i>Epistemological stance:</i> Critical Realist • <i>Broad systematic review type:</i> Narrative Synthesis not specified/ Realist Synthesis-Focused Effect-driven Impact Review • <i>Focus of commonly asked research questions:</i> Narrative Synthesis- Not specified in classification table (Assessment of appropriateness on basis of similarities to multi-component mixed methods review)/ Realist Synthesis- Efficacy

I have referred to the contents of this figure 2.2 (below) in the discussion in this section. It shows the linkages between classification of review types and commonly asked questions in those types of reviews (Hansen and Trifkovic (2013)). This demonstrates how multiple approaches to methods contextualisation require multiple methodological designs and approaches. Finally, figure 2.2 shows how interpretivism had the potential to become a common thread across the reviews despite significant differences in design and implementation.

	Classification of questions and systematic review type	Characteristic questions	Examples of possible synthesis methods
Complex Reviews	<p>Hermeneutic (interpretive and/or descriptive)</p> <ul style="list-style-type: none"> - Questions aiming to interpret, describe, summarise and present data, events and observations 	<p>What are the attributes of this specific intervention or activity?</p> <p>What is the meaning of a specific phenomenon?</p> <p>What is the process of a specific phenomenon or event?</p> <p>Is this complex intervention appropriate?</p>	<p>Framework synthesis framed by dimensions explicitly linked to particular perspectives</p> <p>Critical interpretive synthesis of ethnographic studies</p> <p>Conceptual synthesis such as meta ethnography</p> <p>Multi-component mixed-methods reviews</p>

Figure 2.2 Interpretive, Complex Hermeneutic characteristics

Extract from “*Classification types and questions commonly addressed by systematic reviews*” table (rows arranged in a slightly different order) (Source: Authors’ elaboration and Gough et al. (2012) in Hansen and Trifkovic, 2013, p.30-31, table 5).

In this section, I have provided an in-depth description of review and systematic review methods, a description of the first stage of selection, and a summary of the characteristics of those potential methodologies. The three approaches helped to provide a transparent process of narrowing possible methods to pairs or groups of three of methodologies. The process was based on features I believed would be suitable to methods contextualisation. As a result of the process, I clarified methods contextualisation objectives, suitable features and potential methodologies. An overview of the methodological characteristics reveals synergy between many aspects of the potential methodologies, with the exception of the third approach where there were distinctive difference between the epistemology; review

type and question focus in Realist Synthesis and Narrative Synthesis. The next section depicts the section stage of methodology selection.

2.5 Second stage of methodology selection

The second stage of methodology selection involved the application of three lists of criteria to help to differentiate between the studies; specifically, features that may contribute most to methods contextualisation processes. There were no pre-existing indicators or pre-requisites for methodological characteristics due to the fact methods contextualisation was an emerging concept. I created the criteria from aspects I considered significant to the objectives of methods contextualisation identified in the previous development stage. (Where relevant, I traced the explanation for each criterion to evidence, such as the explanation of contextualisation (Gough and Thomas, 2012, pp. 41-44)) The criteria are explained below addressing each of the three approaches in turn.

Approach one (locating methods using a preparatory review):

1. *Ability to analyse the methods-context relationship*: methods-context relationships create meaning in this form of methods contextualisation so that the reviewer can eventually contextualise the findings in the most appropriate ‘socio-cultural contexts’ (Gough and Thomas, 2012, p.42), or in this case, the research context.
2. *Capacity to map methodological attributes*: Attributes describes the methods-context components, methods contextualisation will analyse these relationships. Mapping and locating studies is an important aspect.
3. *Ability to locate findings within a broader literature*: This criterion emphasises the centrality of location as a feature of methods contextualisation. It is derived from the concept of configuration of findings in an EPPI review in order to ‘locate’ those findings (Gough and Thomas, 2012, p.42).
4. *Rigorous methodological structure*: I considered it an important part of methods contextualisation to be able to explicitly encourage a rigorous methodological structure to facilitate comprehensive study location processes.
5. *Elements of descriptive and interpretive analysis*: this criterion was designed to ensure an in-depth approach to analysis.

6. *To identify gaps in the literature*: I considered this another facet of locating studies i.e. to identify where studies are not located, as well as where they are located in the literature landscape.

Approach two (interpreting perspectives using a conceptual review):

1. *Capacity to explore the context of perspectives behind methods*: This criterion was derived from the explanation of contextualisation amongst Qualitative Traditions of Enquiry (Gough and Thomas, 2012, p.43). The analysis of perspectives facilitated a critical stance towards the literature.
2. *Subjective idealist methodology*: Synonymous with the Traditions of Qualitative Enquiry and the influence of research perspectives on subjectivity.
3. *Ability to analyse interpretation processes relating to multiple methods*: Gough and Thomas (2012, p.43) suggest that Critical Interpretive Synthesis was created as a response to Meta Ethnographic approaches. It resembled a solution to how to synthesise diverse bodies of literature with multiple disciplinary perspectives and methods. Methods contextualisation would also need to contend with a diverse range of approaches in alternative methods and methodologies.

Approach three (broader theorisation of context using a Theory Based Evaluation method):

1. *Capacity to determine appropriateness of implementation of methods*: During the process of developing the review criteria, I strengthened my position on the significance of implementation in methods contextualisation. I identified implementation as a key part of the process in explaining the broader explanation for how and why interventions work in a Theory Based Evaluation (TBE) approach.
2. *To contain methodological features to distinguish between context-specific and more general aspects of findings*: Understanding the contexts attached to specific methods (phenomena) would allow the methods contextualisation reviewer to understand which methods are appropriate and when. I thought this criterion could also facilitate the creation of theoretical models to evaluate methods.

3. *Techniques to analyse a number of study approaches:* The Theory Based Evaluation framework had to be flexible to deal with several methods and study approaches, especially since intervention designs might be relatively rare in alternative methods.

The next section describes the outcomes of stage two. I discuss each in relation to the criteria.

I will now describe which ranges of methodologies were chosen, how and why. I provide a detailed explanation of how each methodology met the requirements of each criteria and a summary of the outcome of the process according to the methods contextualisation approach.

The pool of possible methodologies I assessed against the three sets of criteria were:

- First approach: Scoping review, mapping review
- Second approach: Critical Interpretive Synthesis, Meta Narrative, Meta Study
- Third approach: Realist Synthesis, Textual Narrative Synthesis

A basic description of each methodology can be found in section 2.4 (see figure 2.1 and description in text for scoping and mapping).

Below, I address each criterion in turn to discuss to what extent the characteristics of the methodology meet the criterion. A description of each criterion has been provided in section 2.4.

Outcomes:

First approach

Criterion 1: The first criterion involved the analysis of methods-context relationships within studies. Both **scoping and mapping** had the potential to aggregate and configure understand surrounding methodological attributes (and methods-context relationships abetween attributes).

Criterion 2: Mapping methodological attributes onto the literature landscape was viewed as a primary function of a **mapping review** (or mapping exercise).

Criterion 3: Locating findings in the broader literature. This is a function of **mapping** (particularly types of mapping such as Systematic Mapping), which analyses the characteristics of included and excluded studies following results of study identification.

Criterion 4: The fourth criterion specified a robust methodological structure. **Scoping** frameworks such as Levac (2010) offered the most detailed step-by-step template, translating the methodological intention of each stage into guidance for practice.

Criterion 5: Both **scoping and mapping** reviews enabled the reviewer to compile descriptive and interpretive analysis. Although, each typically concentrated on collecting and analysing slightly different range of data attributes.

Criterion 6: The identification of gaps in the literature is particularly associated with mapping and, to a lesser degree, scoping (Arksey and O'Malley, 2005). Both **scoping and mapping** approaches provide reviewers with confidence they have not missed relevant areas of research. Scoping conveys the dimensions of the literature, whilst mapping defines the strengths and weaknesses in relation to the literature landscape.

Outcome

Scoping and mapping provided a good way to accentuate the 'location' function of reviewing. Both methodologies had the potential contributions to make to methods contextualisation. I decided on a *combination* of the two approaches that could enhance my ability to understand methods, contexts, and relationships between the two. At one level, the body of literature could be scoped to identify the included studies, and at another level, mapping could generate a map of the included studies in relation to those excluded (following the initial identification of studies).

Second approach

Criterion 1: The first criterion stipulated the methodology would explore the context of the perspectives behind the methods. This was explicitly mentioned in relation to **all three methodologies** (see the description in figure 2.1 in section 2.4). Critical Interpretive Synthesis (Dixon-Woods et al., 2006) viewed contextualisation of findings to particular research traditions (or perspectives) as a central part of a critical approach. Meta Narrative (Greenhalgh et al., 2005) has a similar philosophy. It attributed differences between studies to differences in underlying research traditions; for instance, by incorporating the 'tools' that define the process of enquiry (i.e. research methods) into the concept of building understanding of research perspectives. (It also linked findings to the time period of the development of that perspective). Meta Study (Paterson, 2001) defined elements of the perspective through sociological, historical and ideological heritage. Identification of

underlying assumptions in perspectives formed a central part of this methodology, and could help to explain why fields of research developed.

Criterion 2: The second criterion requested a subjective idealist epistemological stance. **All three** methodologies assumed this position (i.e. there is no single shared reality that is independent of multiple human constructions (Gough and Thomas, 2012, p.43)). Therefore, all had the potential to synthesise the various interpretations of reality to create theory.

Criterion 3: The final criterion called for analysis of interpretation processes across multiple methods. **All three methodologies** synthesised a diversity of research study approaches and perspectives, often across paradigmatic divides. Critical Interpretive Synthesis navigated between different perspectives and methods in order to gain a critical understanding of the literature base; however, methodological characteristics were not seen as a priority in comparison to theoretical contributions. Meta Narrative specifically compared differences between specific communities of literature using different methodological and philosophical approaches to reach common understandings. In this way, the reviewer could ask questions about the unfolding ‘storyline’ of research over time using perspectives as a framework. The approach investigated methods as the tools that define the processes of enquiry. However, adaptation for methods contextualisation would be limited in its capacity to analyse multiple methods characteristics at the individual study level.

In contrast, Meta Study not only analysed different research perspectives but also contained apparatus for interpreting methodological characteristics as a part of methodology (the ‘meta method’ phase). This could yield conceptual data as well as data on methods characteristic; therefore, reviewers could reach conclusions about how research is undertaken. This approach constituted a systematic strategy for the analysis of methods and the perspectives that govern their design and interpretation.

Outcome

Meta Study was considered the strongest chance of establishing methods contextualisation. It was selected on the basis of provision of higher-level theoretical insights asking fundamental questions about the impact of perspectives. This approach also had the ability to target more specific features of methods and the context of choices and uses of those methods. *“The meta method component is the study of rigour and epistemological*

soundness of the research methods used in the research studies” (Paterson et al., 2001, p.10). The Meta Method component required the reviewer to elaborate on how methodological characteristics have impacted on research findings (p.11). Therefore, the methodology had a ready-made strategy for connecting methods analysis to the paradigmatic underpinnings.

Third approach:

Criterion 1: The first criterion surrounded the methodologies’ capacity to determine appropriateness of implementation of methods. During the process of developing the criteria in the second stage of methodology selection, I realised it was difficult to define the role of data collection within Theory-Based Evaluation structures. In order to achieve a broader theorisation of contexts featuring methods, I would need to define the influence of methods in as much detail as possible. I chose to focus on the *implementation* phase instead of the focus on the outcomes of research. This provided an opportunity to specialise in a deeper understanding of context and mechanisms relating to data collection methods. Hence, the criterion automatically increased suitability of Narrative Synthesis because of its ability to specialise in factors shaping implementation (Popay et al., 2007, p.25). Realist Synthesis synthetic products produced theory of contexts, mechanisms and outcomes.

Criterion 2: The second criterion stated the review had to contain methodological features to distinguish between context-specific and more general aspects of findings. The advantage of the Narrative Synthesis methodology was I could identify various underlying mechanisms or contexts specifically affecting the implementation of methods. The methodological structure aimed to consider any factors that might explain any differences in facilitators or barriers to successful implementation across the study (Popay et al., 2007, p.12, fig. 2). By comparison, Realist Synthesis attempted to understand which mechanisms operated when. However, the results of the evaluation concentrated on overall outcomes, without specifically forming a judgement on the implementation of methods.

Criterion 3: The final criterion promoted the methodologies’ ability to analyse interpretation processes relating to multiple methods. In this regard, Narrative Synthesis was good at facilitating diversity of study designs. The methodology encompassed a plethora of analysis and interpretation techniques that could be customised to facilitate the

analysis of multiple methods. In contrast, Realist Synthesis configured data from different study approaches and contexts, yet it was reliant on intervention designs from which programme mechanisms, context variables and outcomes that were identified and measured.

Outcome

Narrative Synthesis was the more obvious choice due to its emphasis on implementation and study type flexibility (a variety of types were likely to be present in (non-intervention) studies that applied an array of alternative communication methods). The basis of this methodology was textual interpretation. I believed this was likely to suit narrative methods commentary (derived from study reporting) which would be crucial to understanding methods processes.

Therefore, all three approaches I selected contained interpretive elements. I considered them suitable for methods contextualisation. The first phase of selection helped me to deconstruct the main objectives of methods contextualisation and identify these in methodological groups, and to map out the characteristics in possible methodologies. The second phase was the criteria development phase. This helped me to choose the most suitable options from a (narrower) group of methodologies I already considered potentially compatible with methods contextualisation. The criteria revealed a combination of methods for the first approach (scoping and mapping), a more marginal preference for the second (Meta Study), and a definitive choice for the third approach (Narrative Synthesis). (I did not require complete compatibility offrom the methodology with every aspect of the criteria because methodological I felt adaptations could be undertaken- see chapter 4.2). The chosen methodologies shared similar characteristics, such as compatibility with complex hermeneutic review research questions or epistemological stance (see table 2.2 in section 2.4). Chapter four (4.2) expands on the reasons for adaptations and the nature of those adaptations to create templates.

Having established the different methodologies to adapt for methods contextualisation, I turned to the review sequencing. Figure 2.3 displays the relationship between the sequencing of the reviews. The studies were all completed separately in the order presented. The scoping review had a positive impact on both subsequent reviews, and the Meta Study informed the Narrative Synthesis. Sequencing success was considered largely was serendipitous, and was not designed for a directly comparative purpose. In terms of

sequence, my only consideration was to implement the scoping first to increase familiarisation with the literature. Reviews were not arranged and re-arranged into an optimal configuration (I reflect on this in 8.4).

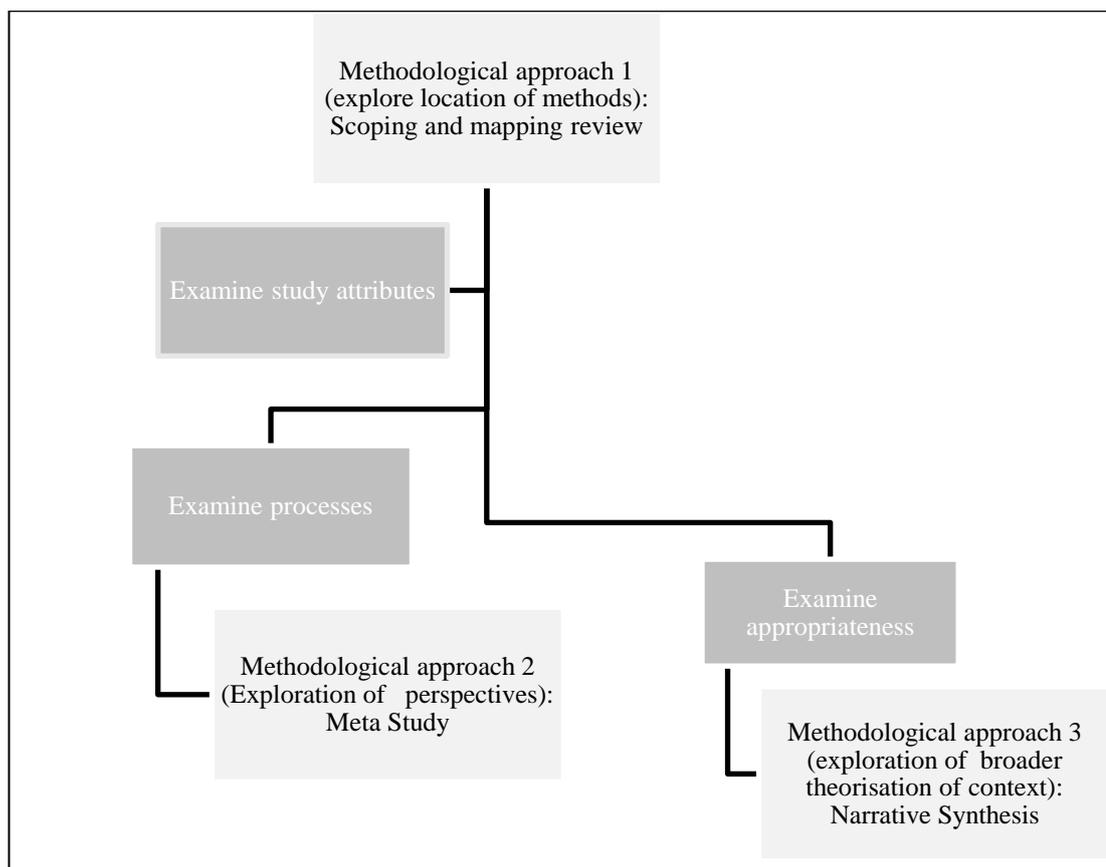


Figure 2.3 Schematic of reviews within the thesis

2.6 Summary

This chapter began by exploring the characteristics of interpretive reviews, identifying them as suitable for methods contextualisation. Secondly, the chapter explored the inadequacies of interpretive reviews. I alluded to theoretical tensions, inappropriate review apparatus, and inadequacies in the ways reviews are conducted and reported. Finally, the chapter looked at the parameters for review methodology selection. I applied a structured approach to methodology section using features of methods contextualisation linked to review types. Secondly, I applied a criteria stage to identify the most suitable methodologies. The outcomes of this process provided justification for the modification of templates for: a scoping and mapping combined review, a Meta Study, and a Narrative

Synthesis. The templates adapted from these existing methodologies are presented in chapter four.

Chapter 3: Rationale three: The influence of the topic and basis for its selection

3.1 Introduction

This chapter discusses the influence of the topic of Augmentative and Alternative Communication (AAC) on the development of methods contextualisation. The chapter also justifies the selection of this topic. Together, both strands explain the way the topic fits the development of this genre of methodology (developed by modifying existing approaches) and, conversely, how the methodology fits the development of the topic.

The synthesis of data collection methods choice and use presented different challenges for available interpretive systematic approaches to the literature. I recognise how methods contextualisation was *influenced by* the topic selection as a result of two factors, these were: the marginalisation of the social science perspective in dementia (emphasising the need for contextualisation); and, the exclusion of the alternative communication research perspective from dementia research (signalling the lack of synthesis of communication alternatives and the potential role for methods contextualisation in promoting alternative (or augmenting) data collection methods).

The justification for the selection of AAC use in dementia research is threefold. The first justification relates to way methods contextualisation in alternative methods can support participant voice (section 3.3). In other words, the synthesis of data collection choices and uses can have a significant effect on the representation of marginalised groups, whose voices may be challenging to hear. The second justification is the suitability of the data as potentially complex and rich to facilitate interpretation (section 3.4). Thirdly, the review topic can be justified because it is a viable focus for synthesis techniques, representing a unsynthesised field (section 3.5).

The chapter provides a backdrop to these reasons for selecting topic. In describing definitions, policy relevance, concepts and perspectives the chapter highlights the different facets of the topic rationale presented above.

3.2 The influence of the topic on the methodology: definitions and initial impressions

The topic selected for synthesis was Augmentative Alternative Communication (AAC) methods used in dementia research. In this section I show how features of this topic

influenced the methodological agenda of this thesis. (Sections 3.3, 3.4 and 3.5 justify the choice of the topic for carrying out the methodological agenda). The definitions of both aspects of this topic are provided below, alongside other background information. In the initial stages of this methodological exploration, features of this topic influenced the direction I took, ultimately prioritising *contextualisation* and data collection *methods*.

The first influential feature of the topic was the domination of medicalised perspectives in dementia research. For instance, the term dementia is an umbrella term that is classified as a Major Neurocognitive Disorder (DSM V, 2013). Medically, dementia is:

“A syndrome in which multiple domains of cognitive impairment, generally including memory impairment, is sufficiently severe to affect everyday function”
(Camicioli, 2013, p.1).

Dominant perspectives, such as these, have an influence on the way topics are conceptualised. This brings issues of contextualisation to the fore, highlighting particular biomedical perspectives.

The medicalised conceptualisation of dementia tends to categorise the population according to the various different sub-types of dementia. A typical explanation will explain that the main types of dementia are: Alzheimer’s disease (62%), vascular dementia (17%), mixed-dementia (10%), dementia with Lewy Bodies (4%), Frontotemporal dementia (2%), Parkinson’s dementia (2%), and other dementias (2%) (Alzheimer’s Society Report, 2014, p.52-53 (% represents the proportion of sub-type cases)). Typically, people are diagnosed as having mild, moderate or severe dementia. (In addition, Mild Cognitive Impairment (MCI) (Gosht et al., 2013) can precede dementia, but this is not always the case). Whilst it is important to highlight the prevalence of individual sub-groups, this type of conceptualisation can have the effect of homogenising people with dementia as a group, emphasising their diagnostic categories as opposed to unique experiences.

Cure and treatment are clearly important priorities in research, yet biological and medical explanations are limited as explanations of the experience of dementia. From a bio-medical perspective dementia is interpreted in a certain way. For instance, there is a spectrum of diseases that cause dementia (Holmes, 2008, p.103). Established aetiological risk factors for Alzheimer’s disease include: age, family history and Down’s Syndrome and

other genetic factors (Thomas, 2008, p.432). Biologically, the neurodegenerative diseases that lead to dementia are often characterised by processes that result in the “*aberrant polymerisation of proteins*”, examples are forms of protein ‘tangles’ or ‘plaques’ (Holmes, 2008, p.103). This research focuses on causation, cure and diagnosis rather than experience of the disease. However, research about improving experiences in the immediate term is vital in the absence of a cure. Social science research hopes to understand and improve the experience of people with dementia; this is paramount to improving lives whilst there is not cure available.

Communication difficulties are one of the main ways that difficulties can surface. Communication difficulties are interconnected with many symptoms. Each dementia subtype has diagnostic criteria (Camicoli, 2013, p.8, fig 1.1), yet symptoms across the types of dementia can be grouped broadly into cognitive problems (affecting: memory, orientation, attention, executive function (to perform complex cognitive processes), language, praxis (motor planning i.e. ability to interact successfully with the environment), visuospatial ability) and neuropsychiatric problems (affecting: behaviour, personality or causing hallucinations). These two groups of symptoms can cause impairments in functional ability, such as performing activities of daily living (based on differential diagnosis explanations in Camicoli, 2013, p.5). In this way, the topic influenced the issue of data collection methods as a factor in social sciences research because of the links between dementia and communication and communication enhancement methods. An umbrella term for a group of communication enhancement (or ‘alternative’ or ‘augmenting’ methods) is Augmentative and Alternative Communication (AAC). These offer an alternative to conventional interview-based research. AAC is defined below.

The simplest way of describing AAC is:

“AAC includes any method of communicating that supplements (augments) or replaces (provides an alternative to) the usual methods of speech and/or writing where these are impaired or insufficient to meet the individual’s needs.”(Murray and Goldbart, 2009, p. 464).

Alternatively, the American Speech and Language and Hearing Association (2015) provided the following definition:

“Augmentative and alternative communication (AAC) includes all forms of communication (other than oral speech) that are used to express thoughts, needs, wants, and ideas. We all use AAC when we make facial expressions or gestures, use symbols or pictures, or write.” (American Speech and Language and Hearing Association, 2015)

Therefore, although, it is rather a specialist term (not regularly heard in dementia research), AAC has a broad remit. Definitions convey the social role of communication, the multiple channels for expressive or receptive communication, and the verbal and nonverbal content. There is also a sense of communication with and without additional equipment or systems in these definitions from the inclusion of symbols and writing. There is even a sense of diversity in types of communication in different settings such as art-based methods such as pictures, or more traditional speech enhancing interactions (supplementation of speech). In theory, interactions can happen with more than one facilitator, or more than one communicator, with different forms of AAC potentially happening simultaneously.

In relation to research, it is clear that AAC could be both the data collection method(s), and an augmenting method to the main data collection method. It can be a straightforward data collection method (such as a word board which involves pointing to symbols on a physical board). Alternatively, AAC could influence methodological approach to the whole study approach and analysis (such as the interpretation of gesture or body language or arts-based methodologies. These would lend themselves to particular paradigm approaches, and alternative processes of transcription, interpretation or analysis). Further examples of AAC in a dementia research context are provided in section 3.3.3; and further theorisation of the ways to categorise and conceptualise AAC are provided in section 3.4.

The presence and prominence of AAC in dementia was unknown at the outset of this thesis. Prior to the first study, I realised ‘AAC’ was not commonly referred to as a specialist area in the dementia research landscape; in fact AAC and dementia appeared to co-exist relatively separately from one another. Dementia and AAC have their own distinct identities in biomedical or communication arenas. Overlaps in the choice and use of methods, could be significant and so the background research I conducted attempted to understand if dementia researchers used AAC but called it something else; or, if they under-used alternative methods (relying on interview-based forms of research). There had been no systematic reviews conducted across the entire AAC and dementia field

previously. The lack of interest in alternative methods reviews is explored in section 3.3.3, and a rare example of a review of a subsection of AAC (arts-based methods) conducted by Beard (2012) is discussed. The topic, therefore, provided the opportunity to combine the idea of particular data collection methods with contextualisation.

3.3 The justification of the topic: Supporting voice

I now move on to my justification for the topic selection. The first reason is the topic supports participant *voice* (addressed in sections 3.3.1, 3.3.2, and 3.3.3) (two additional reasons are provided in sections 3.4 and 3.5). I have previously explained the most well developed genre of research about data collection methods choice and use is the ‘participant needs’ genre of research with marginalised or vulnerable groups (section 1.3). A topic chosen from within this perspective could offer an array of examples of adapted, inclusive or individualised data collection methods narratives for interpretation in synthesis (characteristics identified by Aldridge, 2014, p.112-114). I therefore, decided that suitable topics would focus on vulnerable or marginalised groups, or research which explored concepts of authenticity or credibility (and the associated concept of voice in section 1.3). A topic associated with these concepts could most clearly demonstrate the important role of methods contextualisation, linking it directly to the principles of good quality primary research. I believe data collection methods which offer alternatives or ways to augment existing communication of participants are one of the most profound examples of supporting voice in existence.

I have addressed evidence for how the topic supports voice in three steps. First, this section will describe how policy has increasingly emphasised the issue of dementia and the rights of people with dementia, such as the Mental Capacity Act (DH2005a). However, I discuss how advocacy is relatively underdeveloped in comparison to a field such as AAC (3.3.1). Secondly, this section will explain the definition of voice in research more widely and what it could mean for dementia research and methods contextualisation synthesis. Thirdly, the discussion will explore the existing traditions of voice research in dementia (because voice is a hallmark of the Participant Needs genre which I have identified as an area of research which engages with methods contextualisation concepts and considerations for marginalised groups in section 3.3.2). I will also highlight the relative lack of consideration of alternative methods in dementia research (3.3.3).

3.3.1 Dementia policy and advocacy

The numbers of diagnosed and undiagnosed people living with dementia highlights the need for those with the condition to be considered as a significant group in society. Taking the UK as an example, currently, approximately 850,000 people are living with dementia. This is estimated to rise to one million by 2025 (Alzheimer's Society Report, 2014, p.43). Figures could rise significantly if diagnoses increase. Proportions of undiagnosed cases remain high. The Government Report 'A State of the Nation' revealed only 48% of people in the UK with dementia had a diagnosis (DH, 2013, p.14). It is estimated around 69% of people in institutionalised care in the UK have a form of dementia (Alzheimer's Society Report, 2014, p.30). Underdiagnoses have implications for marginalisation of people with dementia. Nevertheless, people with a diagnosis represent a significant section of society.

Despite being a relatively large group, there are signs that marginalisation is common. Recent global policies have emphasised the deconstruction of negative stereotypes of dementia (and aging). Policy has emphasised societal acceptance and meaningful lives. The World Health Organisation has recognised dementia as a global issue. The WHO model of steps towards acceptance of dementia raises awareness of dementia and also attempts to provide a pathway for monitoring shifts in attitudes towards the disease (WHO, 2012, p.88, figure 6.1). The six steps represent the issues involved in making dementia a public health priority. The steps are summarised as: ignoring the problem; some awareness in the media; building dementia infrastructure; more established advocacy efforts (including publication of data and development of professional guidelines); policies or dementia strategies and, finally, normalisation and acceptance of dementia as a disability. The WHO (2012) guidance argues stigmatisation is particularly common in lower and middle income countries (p.82, table 6.1). Therefore, social policy solutions have tried to find ways to promote social acceptance and inclusion for people with dementia.

Policy and legislation has only recently established rights for people with dementia. To refer again to the UK as an example, the National Dementia Strategy (2009) was the first dementia-specific strategy the Government had produced. Speaking broadly, the strategy prioritised care needs and service delivery. The strategy pushed communication issues to the forefront because it encouraged discussion about communication barriers in everyday care. In addition, the strategy recognised the need for increased patient feedback and including in this evaluation of services. In some ways, the strategy further operationalised

concepts which were enshrined in the Mental Capacity Act (DH, 2005a). In brief, this Act protected those who lacked capacity, but more importantly, it provided the right of individuals to make decisions about their care if they had capacity. The Act had an impact in social research because researchers could utilise the option to take ‘consent in the moment’ (where appropriate) to hear the voices of people with dementia. Thus, in theory, levels of capacity or cognition could no longer be used as the basis for marginalising or excluding people from decision-making or expressing their needs or wishes.

Patient advocacy movements have developed in dementia, illustrating there have been steps forward in combating marginalisation in health and social care arenas. The patient involvement agenda called for the democratisation of services through service user input. For example, the legacy of the Research Governance Framework for Health and Social Care (2005b), in the UK in 2005, made PPI (Public and Patient Involvement) compulsory. The independent body INVOLVE was instrumental in creating the structure for public involvement. CLRNs (Clinical Local Research Networks) were tasked with PPI. These were sub-divided into clinical groups, which included dementia in DenDRoN (dementia and neurodegenerative diseases) (Iliffe, 2011). Yet, this advocacy and policy which supports the rights and voices of people with dementia is relatively embryonic compared to other fields such as AAC.

In contrast, Augmentative and Alternative Communication advocacy policy has been established for several decades. Hourcade (2004) traced the emergence of AAC as a discipline from 1971 to 1980. This field developed as part of the US Government response to the pressure from the education sector to provide services for children with speech and language impairments. This manifested itself in the Education for all Handicapped Children Act (1975). This act arguably provided a legal precedent for the existence of interventions to assist groups with AAC. The 1980s brought forth an enormous growth in the number and variety of communication devices and their technological capabilities (Hourcade, 2004, p.236). From this platform, AAC research has increased and expanded across user groups and breadth of research and interventions. Therefore, this accelerated development may be valuable to dementia research.

When I began exploring the background of the topic, there were limited signs of overlap between the two fields. People living with dementia featured as one of the long term or permanent users of AAC (Beukelman, 2007). However, the extent of AAC use in

dementia research and practice, or everyday communication was unknown. I therefore regarded synthesis as a potentially valuable undertaking, particularly as there was a history of advocacy for marginalised groups in AAC.

3.3.2 Defining voice

Next, I explore the relevancy of components of voice to dementia and AAC research. The discussion defines voice as a concept in dementia research. This is also important in showing the relevance of voice-elicitation as a conceptual framework in methods contextualisation synthesis.

My definition of voice-elicitation for this thesis comes from Mental Health Service User Involvement guidance by Campbell (2009) which states voice is “*an expression of individuality in the face of negative stereotypes: an act of self-validation that can be examined as a metaphor for protest*” (p.116). This definition supports the idea of understanding the experience of people with dementia in a post-biomedical era. Indeed, Campbell (2009) argues the existence of voice “*presents a profound argument that we are conscious human beings rather than disease entities*” (p.116).

I will now explain why voice-elicitation is such an important issue. Voice-elicitation is associated with some of the fundamental concepts in qualitative research, authenticity and credibility in particular (James and Busher, 2006). James and Busher (2006, p.412) argue that a small number of significant scholars provided the philosophical foundation for voice-elicitation research (these scholars were: Lincoln and Guba, 1985; Denzin and Lincoln, 2000; Flick, 2002). Collectively, these seminal works provided an alternative way of judging quality in qualitative research through a different kind of criteria, in particular ways to determine the trustworthiness of the data presented. As a marginalised group (who may also have communication impairment), it is vital to ensure clarity and trustworthiness in data for people living with dementia.

Principles to determine quality in qualitative research originally emerged from grounded theory (Glaser and Strauss, 1967). The principles replaced existing positivist criteria for qualitative research (summarised by Denzin and Lincoln (1994b) as: internal validity, external validity, reliability and objectivity (p.14). Instead,

“Judgement [was] based on detailed elements of the actual strategies for collecting, coding, analysing, and presenting data when generating theory, and

on the way in which people read the theory” (Glaser and Strauss 1967, p.224 cited in Strauss and Corbin, 1994, p.274).

Preferable terms emerged as: credibility, transferability, dependability, and confirmability (Denzin and Lincoln, 1994b, p.14). The concept of voice, therefore, links to fundamental questions about research. Voice-themed research may use the term voice-elicitation to describe the role of methods directly; or, more indirectly for links between strategies to collect data that enhance the legitimacy of theory generation.

In exploring authenticity and credibility as components of voice in more detail, it is clear that methods contextualisation might help to answer broader questions about the value of research and, its integrity in representing participants with dementia. James (2008) explains how authenticity helps to establish trustworthiness in research.

“Authenticity involves shifting away from concerns about the reliability and validity of research to concerns about research that is worthwhile and thinking about its impact on members of the culture or community being researched” (James, 2008, p.45).

Conduct of the research must be credible in reflecting participants’ experience and the wider social and political implications.

“Credibility can be defined as the methodological procedures and sources used to establish a high level of harmony between the participants’ expressions and the researcher’s interpretations of them” Jensen (2008, p.139-140). (Procedures to establish credibility were based on Lincoln and Guba, 1985).

Therefore, both concepts would need to interpret the reproduction and representation of voices in the research process to be most effective. Both concepts are relevant to dementia research, because as principles they help to represent people with dementia in less stigmatising ways that reflect experiences as genuinely as possible.

The idea of voice is intrinsically related to research, the definition in the Sage Methodological Encyclopedia applies the term across all research perspectives (including deductive research). Although explanations of the phenomenon of voice vary, they share a common conception that voice is more than a metaphor for individual perspective. Voice

is conceptualised as “*part of a reciprocal creation of meaning intrinsic to and inseparable from any kind of social scientific research*” (Fabian, 2008, p.945). Most associated with qualitative research, the process of data collection to elicit voice is a way of understanding this concept as “*a process of the lived creation of meaning*” (ibid). I believe that regardless of research approach, voice describes communication that is inevitably interpreted and authenticated by the researcher. Fabian (2008) states, “*Ultimately, the notion of voice encompasses the interpretive confluence of participant and researcher and all of the reflexive processes following from it*” (ibid). The degree of reflexivity may depend on the research approach. I therefore would expect to see the concepts of meaning and reflexivity at the heart of dementia research that attempts to convey experiences.

As a conceptual framework, research that supports voice also supports the goals of methods contextualisation. There is however, an issue with the bias created from the inclusion of this concept in study selection. This is because voice is strongly associated with qualitative principles and therefore qualitative research.

“Voice in qualitative research refers to the multiple, and often conflicting, interpretive positions that must be engaged in the representation of data. There is a longstanding tradition in deductive research methods of amplifying the voice of the researcher to the limitation, or at times the exclusion, of the voices of those being studied... [These perspectives] call attention to the many intrinsic tensions that exist between the voices of researchers and the voices emerging from the data” (Fabian, 2008, p.944).

However, regardless of paradigm, I argue consideration of voice, authenticity and credibility of the data gathered through alternative methods remains a relevant issue. Voice is a fundamental factor in the adaptive style of methods associated with engaging with communicatively impaired individuals through AAC. Voice-elicitation is a way of gathering the perspectives of participants in a range of approaches to enquiry, indicative of the opportunity and depth of response available to participants. The reported *evidence* for voice may differ according to paradigm perspectives.

3.3.3 Evidence of voice in dementia research

Next, I turn to evidence of voice in dementia research to justify my topic selection. This was a key element of the Participant’s Needs’ genre (section 1.3) I identified as embodying

some of the elements of methods contextualisation for primary research methods choice and use. Research that aims to elicit voices of people with dementia is a central feature of the dementia literature. Three main aspects of this research are described here. First, research which explicitly explores **voice**. Secondly, research which explores **inclusivity** in research or care; and thirdly, research which explores the **perspectives** of people with dementia. I consider the latter two areas as indirect examples of voice-elicitation research. The discussion will show in general dementia research has *not* historically embraced adaptive or alternative communication methods despite a focus on forms of voice-elicitation research. In fact, given developments in the evolving approaches described above, dementia research has reproduced remarkably conventional styles of data gathering.

This section discusses key texts specifically about the **voice** of people with dementia by Goldsmith (1996) and Wilkinson (2002b). Goldsmith's (1996) theorisation of the three components of voice were described as: listening to the person with dementia; displaying the ability to accept the person as they are (including the possibilities of communication), and, thirdly to developing an understanding about the person with dementia (however long this may take) (p.56). Wilkinson's work (2002b) was a thoughtful and thought provoking series of accounts from researchers examining inclusive research methods to support inclusionary practice and policy in the UK. Another chapter in Wilkinson's book (Cook (2002)) examined the use of video data with people with mild to severe dementia symptoms. There were some examples of alternative data collection methods. In two subsequent chapters, a limited range of alternative communication methods are explored with reference to nonverbal methods and observations (Clarke and Keady, pp.39-42). The criteria emerging from this work is discussed in greater detail in the implementation-focused Narrative Synthesis study. Overall, I began to notice a discord between theory about voice in dementia research and the limited voice-elicitation methods.

Voice echoes the Participant Needs' genre (creative, individualistic and bottom-up approaches) in other ways. Wilkinson (2002a) wrote about voice in dementia research and reflected on the necessity of conducting research with people with dementia to find out about their experiences directly from them. Inclusion was an important concept, heralded as a way of addressing power inequalities. It was also a way to gain an understanding about the experience of people with dementia because this could not be gleaned from proxy reports (p.10). Wilkinson (2002a) was questioning to what extent researchers had developed effective methods through which the experiences of people with dementia can

be included to inform research policy and practice contexts (p.9). This comment is indicative of the kind of shifts in attitudes and practice required in dementia research to hear voices.

A stream of work fostered **inclusivity**-based approaches to research with people with dementia (Allan and Killick, 2008; Barnett, 2000; Cahill et al., 2004; Cheston, 2000; Cowdell, 2008; Dewing, 2002; Gillard et al., 2005; Hubbard et al., 2003; Hulko, 2009; Moore & Hollett, 2003; Nolan et al., 2002; Murphy, 2007 and Reid et al., 2001). However, the focus of inclusivity was narrow to begin with; it focused mainly on the consent process and the development of understanding about how researchers could interact with participants.

Of these inclusivity-themed methods, a small number referred to alternative research methods. Barnett (2000) used an adapted interview process (Sutton 1993, cited p.43) that focused on accessing emotions (also allowing interviewees to sing their own songs (p.44)). Kitwood (Kitwood and Benson, 1995 cited p.37) used an observational technique. Cowdell's (2008) ethnographic research was designed to engage people with dementia. The author found that by using appropriate research methods people with advanced dementia, could contribute. Murphy et al (2007) utilised Talking Mats™, a word board AAC system. Dewing's (2002) methodical paper stated "*As yet there is little in the way of academic publications on developing methodologies or practical methods of inclusionary consent, despite the rapid development of so-called person-centred participatory research in dementia*"(abstract). The author describes predominantly dementia-specific verbal interview methods (p.165-168) rather than alternative methods.

Despite the centrality of interview methods in inclusivity research, researchers were beginning to notice the different aspects of the limitations of data gathered via interviews (including limitations in form of interaction and analysis). Gillard (2005) argued that researchers and practitioners should view behaviour as a form of communication. Moore and Hollett (2003) had previously mentioned the interpretation of qualitative data as another aspect of the research process that was not fully realised during this period. Moore and Hollett (2003) surmised "*meaning does not just exist in the data, rather the researcher creates meaning in interaction with the data.*" (p.166). Inclusivity research began to target new areas. For instance, Hulko (2009) interpreted voice and inclusivity, advocating inclusive research across ethnic and class boundaries. There were some examples of

alternative communication of nonverbal methods and photo elicitation (Allan, 2001; Allan and Killick, 2008; Hulko, 2009). Yet, it appears that the development of this type of research, with its additional levels of complexity for the researcher, struggled to become viewed as mainstream practice.

Now, I explore the final element of research surrounding voice-elicitation research, that is, the **perspectives** of people with dementia. Kitwood (1997) theorised about the twelve categories of Positive Person Work (pp.119-20). These could be related to voice and communication, and perhaps indirectly, to research methods approach. The theory focused on the ways care workers could enhance interactions. Categories included facilitative elements: recognition (1); negotiation (2); collaboration (3) validation (8); facilitation (10). It also included prompts for alternative forms of interaction or communication: play (4) and creation (11). This theory seems to suggest the need to facilitate and interpret complex and dynamic interactions, perhaps in ways that traditional interviewing methods would be unable to provide.

There were other influential studies on the perspective of people with dementia. An early study by Cotrell and Schulz (1993) was important in emphasising alternative ways to collect data:

“One of the more difficult problems in research with this population is the limited capability of subjects to participate in conventional interviews and provide reliable data given their memory impairment (George, 1989)...As the person with dementia becomes more verbally incompetent, the use of proxy respondents and observation becomes increasingly necessary” (p.209).

In contrast, Downs’s (1997) review of research highlighted a growing body of research in the perspective of people with dementia (pp.601-4). However, it refers only to interview methods.

In the next decade, Droes (2007) reviewed the research on the voice of people with dementia and their coping strategies (such as: Clare (2003), Keady, Nolan and Gilliard (1995), Pearce, Clare and Pistrang (2002) and van Dijkhuizen, Clare and Pearce (2006) cited p.116). However, the emphasis on alternative forms of communication was absent from all of these examples and it represents a trend in research for using exclusively verbal interview methods. More recently, there are some indications this has changed. For

instance, Boyle (2014) combined the elicitation of perspectives of people with dementia the use of alternative communication (such as photo elicitation) to understand agency. However, conventional interviewing methods are still being used in research (e.g. McDermott et al., 2014).

Finally, a range of systematic reviews indicated that researchers thought there was a need for synthesis across both themes of inclusivity and the perspective of people with dementia (examples include: Ablitt et al., 2009; Bunn et al., 2012; De Boer et al., 2007; Robinson et al 2011 and Steeman et al., 2006; Von Kutzleben et al., 2012). However, none of these reviews specifically addressed the synthesis of alternative communication research. One such rare example is the review of art therapies in dementia care (Beard, 2012). This paper is discussed in greater depth in the scoping study chapter five.

In summary, researcher preference for interview-based data collection methods remains an issue in dementia research. Recently, Bartlett and O'Connor (2010) commented:

“While attempts are being made to include the voices of people with dementia, there remains a tendency still only to include those voices that retain the ability to do ‘research speak’. In other words, interviews still rely heavily on intact verbal skills even though this is an area that is known to deteriorate with dementia” (p.105).

Literature that seeks to promote the voice of people with dementia has made progress in recognising the need to expand clinical and research practice in forms of communication. The streams of research in fields such as inclusivity, and the perspective of the person with dementia, ascribe value to the person with dementia and seek to communicate with them in meaningful ways. Amongst the literature explicitly employing the concept of voice, it is clear that holistic forms of communication and nuanced understanding are significant issues to understand the context of research methods. Therefore, it is clear that supporting voice is a significant feature of dementia research, but practices to maximise this voice are limited.

3.4 The justification of the topic as a source of rich data for interpretation

The suitability of the topic as a source of rich data is the second justification for my interest in this area of research. The section outlines the broad range of dementia research

operating across three distinctive perspectives. The presence of these perspectives adds a level of complexity to synthesis. It is this complexity which is one of the ways data can be viewed as rich. Data about the use of AAC for people with dementia (i.e. methods narratives in reported studies) is suitable for fine-grain analysis because it tends to be more detailed and rich. This is because alternative data collection methods represent a departure from more familiar interviewing techniques, and therefore requires explanation to the audience. Analysis may also be more subjective, particularly where data cannot be transcribed in the same ways as a fluent verbal interview. This discussion also outlines the different approaches to AAC, indicating there is variety of communication research approaches in the literature base. I also explain the conceptual lens applied in AAC.

First, this discussion will explore perspectives across the social sciences which have been categorised into three broad approaches: **biomedical**, **social psychological** and **critical social gerontological** (Innes, 2009). Innes' theorisation of dementia literature associated these three perspectives with policy and evolving debates in dementia. This work became significant within the thesis for identifying different research paradigm perspectives in the literature. Each perspective approaches research about the experience of dementia in different ways, with different areas of enquiry. Their different approaches also have implications for the choices and uses of data collection methods.

Before describing the perspectives, I will outline the structure and contribution of Innes works which developed theory in regard to these perspectives. *Dementia Studies: A social Science perspective* (2009) introduced the idea of the study of dementia, and corresponding dementia perspectives, as 'sociology of knowledge' (p.2). The book charted the rise of different research perspectives. The final chapter provided a model for the study of dementia (p.140, figure, 6.3). The book also introduced the concept of a 'web' of understanding across areas of dementia research, theory, policy and practice (p.146, figure 6.4)). Innes' second contribution (Innes et al., 2012a) had a more international focus. The introductory chapter provided critique of the three perspectives (McCabe et al., 2012, pp.13-22). The chapter presented an integrated model for a holistic web of understanding that could be applied from any of three perspectives (Innes, 2012, p.34, figure 1.1). This model attempted to show how research, theory, policy and practice were interlinked, and how different theoretical gazes created different interpretations of the model and provided different contributions to understanding. Finally, the 2013 paper by Innes and Manthorpe used the integrated model (p.692, figure 4- copy of figure 1.1 in Innes et al., 2012) to

show how UK policy could be understood differently through different theoretical perspectives.

In all three works, Innes and her contributors *problematised* the concept of a single theory through which all research and practice would, or could, view dementia. Instead, they focused on ways to *integrate* our understanding about research, theory, policy and practice. Innes (2009) stated that “*adopting a social science perspective (of which there are many) can help us to begin to challenge the knowledge and underlying assumptions about what is ‘known’ about dementia*” (p.25). Dementia is a recognised multi-disciplinary subject and therefore, “*it is important not to discard ‘knowledge’ produced by any discipline, rather the task is to explore and critique such knowledge*” (2009, p.144). Thus, “*a more holistic approach to theoretical understandings of dementia could be used to shape and inform policy practice and research*” (Innes, 2012, p.24). This may be summarised as a web of understanding dementia from an integrated perspective (Innes and Manthorpe, 2013, p.692 figure 4). This thesis echoes this position, arguing the co-existence of perspectives is a more helpful conceptualisation for synthesis.

Broadly, the approaches (biomedical, social psychological and critical social gerontological) developed as popular eras of social research, although to a large extent, the **biomedical** approach has been eclipsed within the social sciences. The biomedical perspective is based on a medicalised understanding of dementia and the associated symptoms (the medical understanding of dementia has dominated for 100 years (Innes, 2009, p.22). Thus, in the sciences, work still continues on prevalence, symptoms and cure. In the social sciences, perspectives that emphasised the organic causes of dementia and medical assessments to diagnose dementia were limited in understanding the experience of the person with dementia (as discussion about definitions of dementia in 3.2 has argued). Historically, biomedical research in the social sciences focused on “*neurobiological factors*” relating to areas of research such as depression and dementia, psychosocial components of ‘problem’ behaviour and treatment efforts (Cottrell and Schultz, 1993, p. 205).

Innes (2012) argued that, whilst the treatment concerns regarding dementia cannot be ignored, labelling dementia as a disease actually increased stigmatisation associated with a mental health label (which they were attempting to reduce) (p.28). Innes argued the dominance of this perspective helped to raise the profile of dementia in policy. The

medicalised assessments and the emphasis on prevalence drove the agenda to increase early diagnoses (Innes, 2012, p.33). However, this perspective led to a largely deficit-based approach centred on diminishing aspects of physical and mental health, criticised by Lyman (1989) amongst others. The voice of the person with dementia was also absent from this approach. I have already alluded to the tendency of the medicalised viewpoint to homogenise people with dementia, diminishing the uniqueness of the experience (section 3.2).

The **psychosocial** approach is associated with ‘relational’ research (Bartlett and O’Connor, 2010) surrounding ways to understand the dementia experience that were absent in the biomedical perspective. The influence of Kitwood’s Personhood theory (1990; 1993; 1997; Kitwood and Bredin, 1992) is difficult to overstate. Personhood was defined as, “*A status or standing bestowed upon one human being, by others, in the context of a social relationship and social being. It implies recognition, respect and trust*” (Kitwood, 1997, p.8). As Innes (2012), argued, maintaining personhood calls for a partnership between carers or practitioners and people living with dementia. The nature of interactions (including communication strategies) supports people with dementia to maintain a sense of identity and worth and therefore remains highly relevant to care practice (p.29).

The psychosocial perspective also calls for dementia to be reconsidered as a social-constructed experience. This is the fundamental principle governing this approach, and the data collection methods which may be used. The Disability Model is one way of explaining features of this social construction, insofar as societal structures could be viewed as disabling aspects of the experience of dementia (Innes, 2009, p.137). Innes (2009) likened changes to progress made in disability rights; however, Innes acknowledges inclusionary practice in research still “*lags behind*” by comparison (p.148). Kitwood relocated the theoretical basis of dementia research to incorporate social psychology (1990). The negative experiences of people with dementia were expressed in ten forms of ‘Malignant Social Psychology’ (1997, p. 46-7). It was argued these social practices inhibited the acceptance of people with dementia in society, depriving them of Personhood. Invalidation (the eighth form of malignant social psychology) was highly relevant to communication. Invalidation was defined as the failures to acceptance or understand the experience of people with dementia (especially their emotions and feelings), and, failure to acknowledge their subjectivity (Kitwood, 1990, p.183). One may argue that appropriate communication methods in research and practice are essential to avoiding invalidation.

Kitwood developed theories on Personhood and person-centred care, in his highly influential work *Dementia Reconsidered: the person comes first* (1997). The values in Personhood are anchored in ethics, humanitarianism and respect for people with dementia (Edvardsson, 2008, p. 365). Innes (2012) suggests the values in Kitwood's Personhood theory can function as a framework, or set of principles in practice and delivery of care (p.30), (citing the work of Edvardsson et al., 2008). Edvardsson et al (2008) emphasised a need to focus on the outcomes of social interactions including: reminiscence, personalisation of surroundings through sensory aids, and management of the psychosocial environment. Thus, *forms* of communication are brought to the fore through social psychological perspectives. Personhood theory also emphasises the importance of the nuances of the facilitation of the communication interaction.

Sabat (1998; 2001; 2002; Sabat and Harré, 1992) contributed to this social psychology perspective (Innes, 2012, p.29), developing understanding about the profound impact of the disease on the individual. In many ways, this era was so significant because it helped to establish the position of social research in ways to understand the experience of people with dementia. Sabat and Harré (1992) used constructionist theory to show empirically that the sense of self persisted up until the end stages of the disease. In connection to the concept of personhood (Kitwood and Bredin, 1992), the loss of self was a result of the negative interactions people with dementia had with others. Sabat (2002) challenged the established ways of thinking in regards to the existence and maintenance of 'insight' for people with dementia into their situation and experience (Sabat 2002, p. 280). This work established the legitimacy of in-depth research about the voices or perspectives of people with dementia.

Sabat (2002) also tried to emphasise the importance of the nature of researcher, professional or lawmaker's interactions in retaining a sense of personhood for the person with dementia. This, he argued had the effect of providing the 'interviewer' with a sense that the person with dementia had insight into their experience and helped people with dementia to avoid socially or legally compromised positions (p.280). In other words, the interpersonal interactions had an effect on disclosure of experience and deficits. Insight should be determined by psychological, social as well as biological factors (Sabat, 2002, p.290). Thus, the research made strides in changing practice as well as theory and helped to lay the groundwork for the future dementia strategies and adoption of legal frameworks

based on a sense of ‘legal competency’ (p.283). Therefore, from a reviewer’s perspective, the role of the interviewer is another avenue for analysis of this data.

In addition to statistical research methods, Sabat (2002) recommended fine grained analysis of discourse, personal histories and determination of the quality of relationships with caregivers. This emphasised the role of contextual factors in the facilitation of successful research. However, Innes (2012) argued that this perspective could overemphasise the individual (the micro levels of experience) and individual models of care (p.33). For instance, Sabat and Harré (1992) talked about projections of self in the public arena and the discursive convention as the context for behaviour (p.447-448), without extending their gaze as far as contextualising societal structures. Thus, the work of Sabat and Kitwood provided a new map for understanding the implications of positive or negative interactions with people with dementia in shaping experiences. They also alerted researchers to new areas of richly interpretive research.

Critical Social gerontological perspectives introduced an even greater array of options for approaches to research with people with dementia (Bond, 1993; Bond and Corner, 2001). This perspective critiqued the biomedical and psychosocial understanding of dementia, arguing these were too narrow because they failed to incorporate the social context. In other words, they did not recognise the place and status of people with dementia in society (Innes, 2012, p. 32). Bond (1993) applies a gerontological lens because of his focus on the wider impact of the network of relationships. His analysis aimed to understand the social environment in which people lived; i.e. “*it is necessary to understand the social context as well as the clinical uncertainty of the illness trajectory of dementia*” (p. 401). Bond and Corner (2001) rejected the biomedical hegemony, urging researchers to consider sociological, anthropological, or social psychological alternatives (pp.96-97). This approach provides yet another layer of analysis for methods contextualisation.

The critical social gerontological approach encompasses many of the macro level understandings associated with contextualisation. According to this perspective, research would ensure the views of people with dementia were incorporated alongside social, political, cultural and economic contexts (Innes, 2012, p.33-34). In general, this approach aims to identify underlying social structures related to the experience of dementia and the influence these have on a person’s experience. Bartlett and O’Connor (2010) described a Social Participation approach to dementia based on citizenship- this has similarities with a

gerontological perspective (adapted from O'Connor, 2007, presented in p.27 figure 2.1). Therefore, the critical social gerontological approach provides a different window into the experience of dementia, possibly employing different data collection methods or techniques.

The three perspectives outlined by Innes (2009) can be identified in policy-making, highlighting the mirroring of the perspectives in policy, or, the discord between policy and research domains. For instance, Innes and Manthorpe (2013) charted the theoretical underpinning of UK-based dementia policy (pp.684-689). The paper refers to the influence of the topic of diagnosis in the National Dementia Strategy (Department of Health, 2009). They argue this represents a bio-medical perspective influence. Alternatively, they highlight the person-centeredness of the recent policy to emerge from Northern Ireland (Improving Dementia Services in Northern Ireland: A regional strategy, DHSSPS, 2010). This policy emphasis has clear association with the social psychological approach. Finally, the paper links the publication by the Scottish government Working Group for Strategy to a critical social gerontological perspective. The publication focused on Health Improvement, Public Attitudes and Stigma, an example of research on broader societal issues and dementia. This suggests policy context could be a valuable component of contextualising studies.

One of Innes' (2009) main conclusions is that the perspectives summarised in the three approaches described above are not located in relation to one another in research, policy or practice, i.e. the three theoretical approaches lack an integrated structure in which they can all be viewed. The exploration of perspectives by Innes (2012) culminated in an integrated holistic web of understanding across all three perspectives (p.34, figure 1.1; slightly reworded in Innes and Manthorpe, 2013). The web was based on the (re)generation, production and challenge to knowledge in order to illustrate a cyclical process in which policy, research and practice are informed by the different perspectives (2009, p.140). The 2012 web (or model) provides a commentary about how each of the perspectives would view aspects of policy, practice and research. It is described below. (The 2013 paper also distils the three approaches within the web – figures 1-3 p.690-691). The findings from the thesis are, therefore, located in relation to this integration debate (chapter eight). Methods contextualisation can be viewed as a way of questioning the legitimacy of knowledge in primary research through secondary synthesis. It is hoped methods contextualisation could strengthen the research element of the web.

To expand on Innes' web, she describes the ways dementia is perceived from three different vantage points in relation to **policy, practice and research**. In regards to **policy**, frameworks should incorporate: biomedical knowledge, psychosocial concerns about the individual and, critical gerontological concepts of people with dementia as older people and people with disabilities in society). In relation to **care**, practices should take account of individual neurological impairments *and* wider social structures. The final element in the web is **research**. "*Dementia research will focus on micro and macro level issues to promote a broader understanding of the worlds of professionals, carers and people with dementia. This would be contextualised within policy frameworks and societal expectations and beliefs about dementia and quality care*" (2012, p.34, fig 1.1). The web shows how conceptualisations of dementia have an effect on knowledge produced, policy made and the focus of research commissioned (Innes et al., 2012, p. 33). This theorisation appears to compliment the principles of methods contextualisation, strengthening the impact of research through processes to identify the most suitable primary research methods.

In summary, it is possible to identify a range of perspectives linked to different research approaches in dementia research. Social psychological perspectives may be rich in interactional detail whilst social gerontological may illuminate broader realms of social contexts for communication. Innes (2012) argued that the multidisciplinary nature of research means that assumptions behind the understanding of the research phenomena are sometimes blurred or implicit (p.26), and that an integrated conceptualisation of approaches is required- possibly through the holistic web of understanding as an integrated perspective. A review of the context of methods involves comparisons across perspectives in dementia research. The thesis offers one avenue of practice that can be analysed in terms of interpretation from different perspectives from an integrated understanding of a multidisciplinary field.

In addition to conceptualisations of dementia research perspectives, it is worth noting that Augmentative and Alternative Communication research also employs particular perspectives. This potentially enriches the data for methods contextualisation. It also creates the possibility that the principles of AAC are not carried forth in dementia research, due to contradicting perspectives. For instance, there are *Universalist* models of AAC which emphasise that anyone who can communicate can benefit from AAC use (Hourcade, 2004, p.235). Hourcade et al (2004) comment "*Perhaps the greatest change in*

augmentative and alternative communication has been the near-universal abandonment of prerequisites for AAC services” (p.240). However, dementia communication enhancement could be more selective, particularly from a biomedical perspective.

There are other ways to further conceptualise the AAC field. Other commentators have sub-divided AAC research into *aided* and *unaided* communication (Beukelman and Mirenda, 1998, pp.36-80). (Modes, mediums distinctions), or levels of technology input, these are summarised below:

- *No tech communication: Body language observation, natural gesture, manual signs, drama or arts-based intervention(unaided)*
- *Aided- low-tech communication- Picture cards or symbols, word boards, eye-pointing codes or photo-elicitation*
- *Light-tech communication text or speech output devices – visual display screen, (single message output)*
- *High tech communication speech generating devices - computer-based devices* (adapted from Murray and Goldbart, 2009 p.464)

However, dementia research may not conceptualise alternative communication methods according to technology levels. Differences between the dementia and AAC perspectives may be influenced by historical differences in intended audiences. In AAC practice and research, user groups are broad. They include: children with disabilities (children with autism, developmental dyspraxia or cerebral palsy); adults with disabilities and long-term conditions (MS, brain injury, developmental disabilities, Parkinson’s, dementia). AAC practitioners reconsidered the role of memory aids which were designed to support the individual rather than communication interactions. Therefore, a prominent perspective is AAC communication includes communication with oneself (Beukelman, 2007, p.239). This concept may be unfamiliar in dementia research. Thus, AAC contributes a rich source of evidence on the theorisation of communication, inviting comparisons with dementia literature. (Specialist literature about interpretive frameworks across participant population groups is the central focus of chapter six (the second empirical study in the thesis). (Previous examples of analysis of such frameworks include Edyburn et al., 2001 and Lenker and Paquet, 2003, are also discussed in chapter six).

Currently, there is limited interpretive evidence about the theorisation of communication and data collection methods in dementia and AAC research. For instance, AAC media

were designed to maximise memory functioning, compensate for lost function, and to maintain communicative or participative functions that remain intact (Beukelman, 2007, p. 238). AAC methods are conceptualised as ways to increase quality of life and to decrease stress for caregivers (Bourgeois and Hickey (2007) in Beukelman, p.238). Their role as a data collection method is less documented. The breadth and depth of this literature is explored in the scoping review. The bodies of involving AAC and dementia research are explored in the first empirical study into methods contextualisation, chapter five.

In conclusion, AAC use in dementia research is suitable as a topic due to the complexity and richness of data for interpretation. Three different perspectives have shaped dementia research. In AAC research, user groups are broad; the use of AAC in a dementia context may divert or distort the intended purpose of the communication method.

3.5 The justification for the topic as a priority issue for synthesis

Finally, I justify the selection of this topic because it is a priority issue in the research landscape. The exploration of methods contextualisation in AAC dementia research fills a genuine research gap. The extent of AAC is unknown and the choice and use of AAC had not been synthesised before. However, prior to the commencement of the scoping exercise I considered the topic potentially viable because dementia is a global issue in research. Secondary analysis of the literature provides an opportunity to synthesise international research. In addition, perspectives are distinctive, albeit potentially fragmented. Therefore, the selection of the topic has an ethical dimension, that is, to increase awareness of a range of research methods where their impact may be greatest.

“Dementia is one of the greatest societal policy challenges that we face” (Banerjee, 2012, p.106). The prevalence of dementia in the UK in people over 65 years of age is 7.1% (Alzheimer’s Society Report, 2014, p.26). The WHO made dementia a priority and it estimated 47.5 million people are living with dementia worldwide (WHO, 2015). Forecasts indicated this could increase to 65.7 million people by 2030 (Prince et al., 2013, p.69). Therefore, whilst there is no cure for dementia it remains a significant social policy issue on national and global levels. The challenges in dementia health care, social care, carer support and diagnosis have tremendous impacts in social, health and economic spheres. Thus, there is a global incentive to find out more about living with dementia.

Research about the global impact of dementia can improve our understanding of the scale of the challenge of dementia, yet governments have been slow to support dementia research. Spending in dementia research is low, particularly in comparison to other diseases with a similar impact in UK society. In 2012, £90 million was spent on research (including around £17 million from charities); this constituted just 11% of the total spending across dementia, cancer, CHD and stroke (Luengo-Fernandez et al., 2015, p.4, table 2). Counter narratives which emphasise a lack of resources for dementia can help to combat ageist discourses. Narratives about communication enhancement and enrichment are also important to promoting issues for people with dementia in social policy.

Care costs are an area which receive a great deal of attention. We know, for instance, dementia costs (including: health costs, social care, informal care and productivity losses) are estimated at £23 billion annually; this far outweighed cancer and stroke costs (Luengo-Fernandez et al., 2012 p. 151). A recent study looking at the impact of dementia on an estimated mean monthly costs per patient differed for France (€1881), Germany (€2349), and the UK (€2016), with informal care costs accounting for 50% to 61% (Dodel, et al., 2015). Proportionally, these costs occur in more developed countries (Wimo, 2005). Thus, countries who are least financially equipped with have fewer resources to deal with this demand on services, may experience the largest social policy impact. Again, it is important to raise the profile of this issue; however social research is fundamental to providing a humanising counterpoint to the discussion.

Syntheses of international research can highlight gaps or examples of best practice, at a meta (or global) level. This is especially important in alternative communication research because of the vast variation in contexts, and the impact of aspects such as culture. It may be possible to identify specialist *or* generalisable aspects of data collection practice through interpretive synthesis. For instance, social science research such as Innes (2009) discussed dementia in different countries with different cultural contexts (pp.84-88). Using a range of examples, the author notes the similarities in concerns across cultural groups, such as memory decline or inability to perform activities of daily living (p. 83). Responses tended to problematise factors or to accept and adapt when abilities changed. Alternatively, cultural traditions of family care were apparent in the developed and developing worlds (p.84). Cultural groupings across examples of research in North America, China and Korea in particular showed the experience of dementia was defined by reactions of family members and communities (Ikels 2002; Chee and Levkoff, 2001 cited pp.84-85 in Innes,

2009). Thus, memory problems, adaptability to change or, support of family as communication partners may be considered issues relevant to communication and the role of alternative data collection methods in a research environment.

Therefore, methods contextualisation synthesis could offer a way to scrutinise across international research about the use of AAC with those with dementia (identified as a social policy priority). The choice of this topic could enable me to learn lessons about data collection or communication methods choice above the level of individual study findings.

3.6 Summary

This chapter has discussed two central features of the development phase of the thesis. Firstly, I have explained the third rationale for methodological exploration. Secondly, I have justified the topic choice. The rationale concerned the influence of the topic on the direction of methodological exploration undertaken. Primarily, I reflect that the topic influenced the prominence given to contextualisation because of the entrenchment of the medicalised perspective on dementia. The topic also influenced my perception of the role of data collection methods within contextualisation because communication difficulties are a central feature of difficulties experienced by people with dementia.

The justification of the topic was explained in terms of: the ability of the topic to support voice, to provide rich data, and, to become a viable focus for synthesis. Voice-related research with marginalised groups were crystallised in the previously identified 'participant needs' genre (chapter 1.3), which contained the most advanced examples of consideration of the impact of data collection methods selection and use. I defined voice and looked for evidence of voice-related research in dementia. My findings suggested alternative communication methods were not extensively used. Voice is a relevant concept as it can help to frame important aspects of context and practice. Finally, I explained how the topic can be justified as a viable topic for conducting a synthesis. There is a precedent for international research and comparison of contexts, possibly identifying commonalities in appropriate communication methods for research. There is also an argument for choosing this topic as a way of raising the profile of alternative discourses to the global burden of dementia. In the next chapter, I will present the modified methodological templates from those selected in chapter two, in preparation for the presentation of the implementation phase of the thesis.

Chapter 4: Methods contextualisation: three modified methodology templates

4.1 Introduction

Chapter four represents the final contribution to the *development* phase of the thesis. Subsequently, the emphasis shifts towards implementation (chapters five to seven) and conceptualisation (chapters eight and nine). This chapter plays a pivotal role in the thesis as it presents my three approaches to methods contextualisation, through three modified methodology templates. The templates are a summary of adaptations and innovations I made to existing review methodologies to guide further use and development of this line of synthesis research. Three methodologies were selected to explore methods contextualisation through a mapping review, a (realist) theory-based evaluation review, and an interpretive review. (Chapter two provides a full explanation for the basis of their selection- 2.4 and 2.5).

I begin by discussing surrounding adaptations- I refer to what the adaptations were and why I targeted these areas for adaptation. I refer to the kinds of adaptations developed and the nature of those adaptations (as modifications or innovations). I also describe how each of the methodologies was used in light of the adaptations developed. Next, I describe the templates. Firstly, the current forms of the methodologies are described, followed by a summary of the methods contextualisation template. I highlight the nuances of major adaptations. (This structure allows the reader to differentiate between existing methodological approaches and processes, and the adaptations I made). Finally, I discuss which alternative methodologies could have been chosen and how they could have contributed.

This chapter enhances the methodological transparency of the review. Templates create a guide for reviewers and researchers to follow for methods contextualisation at a more general level. This is an important step in fulfilling the first rationale within the thesis: ‘to broaden the horizons of research’ to guide researchers in a systematic process of choosing and using research data collection methods (originally described in section 1.4). This chapter presents the methodological development which could be applied beyond this thesis. The discussion surrounding the templates demonstrates how adaptations adhered to the criteria for each of the three approaches to methods contextualisation presented in chapter two. (Subsequent ‘methods’ sections of empirical chapters focus on the ways each

review was tailored to the specific research questions addressed in the empirical studies (chapters five, six and seven)).

4.2 Methodological adaptations

I will begin this section by summarising which three methods were chosen and why. Next, I outline possible short-comings in chosen methodologies where adaptations were necessary. I explain the nature of the changes as forms of adaptation (as either alterations or unique innovations). Finally, I address how each of the methodologies were used in light of the adaptations I felt necessary for methods contextualisation.

Which methodologies were chosen and why?

I chose the three methodologies (scoping and mapping; Meta Study and Narrative Synthesis) based on a process of identifying characteristics of methods contextualisation and narrowing methodological options (stage one of selection), and evaluating these against the three sets of criteria (stage two). I chose the first methodological combination because I required a technique to locate studies (mapping) and a structure to analyse the dimensions of the literature (scoping). My next selection was Meta Study which contained clearer ways to guide a reviewer through the analysis of multiple methodological approaches in conjunction with analysis of methods factors. Thirdly, the Narrative Synthesis equipped me with a way to theorise the implementation of methods and to determine suitability. This methodology was also more adaptable to the range of non-experiential or quasi-experimental data I would encounter in analyses of a full range of communication methods.

Possible areas for adaptation

Next, I will explain how I identified necessary adaptations. I chose scoping as the framework for the methods contextualisation template *and* Systematic/Descriptive Mapping (Gough et al., 2003) - a specific component of EPPI Centre mapping reviews. I decided to begin designing the template from this basis because the two elements required specific roles in order to work in harmony together. In a broad sense, the scoping provided the apparatus for the first major searching and sifting stages of the review. The scoping led the process of identifying relevant studies; the mapping led the process of characterising the included (and excluded) studies once they had been identified. The template would

also need to find ways to integrate the two methodologies, perhaps through locating studies.

The second approach would be a singular methodology (Meta Study), however, it required adaptations to study identification to maximise methods contextualisation. Elements of tracking theory, or the influence of conceptual frameworks, could be imported through Clustering (Booth et al., 2013b). Clustering would ideally enhance understanding about perspectives embedded within studies how they developed over time.

The third approach consisted of a singular methodology (Narrative Synthesis). I would carry out a full review of this methodology. Selection of particular analytical tools and techniques depended on the specific nature of the research question; however, I felt methods contextualisation may require qualitzing approaches consistent with a largely narrative methodological commentary. Further adaptations to the technique included amendments to data charting and analysis to maximise the identification of theory.

The nature of the adaptations

Next, I discuss the *nature* of the adaptations to the methodology templates in more detail. The scoping synthesised pre-existing examples of research methods in the literature, thus helping to inform choice of communication methods. Scoping and mapping were amalgamated to *locate* choices of methods using contextual features. The scoping formed the framework for the structure of the methodology and the Systematic Mapping formed an additional component designed to scrutinise included and excluded sources (this stage followed identification and description of a relevant pool of studies).

It would not be correct to characterise any of the decisions taken in designing the scoping template and adapting its content as methodological *innovations*. The existing methodologies were subjected to a number of alterations. However, I would argue that the resulting template was constructed to emphasise layers of contextual attributes and to locate studies for methods contextualisation. The examination of the location of methods as the primary review product goes beyond the standard methods-centred mapping review; thus, I have described it as a type of adaptation.

The Meta Study was adaptations included methodological *innovation*. The Meta Study scrutinised the choice and use of methods in relation to perspectives underpinning the research. The main adaptation involved the substitution of a component of the review- a new application of a study identification technique called the Cluster technique (Booth et

al., 2013b). This particular adaptation has never been conducted before. Another adaptation was a sampling matrix that I created which had not been employed within a Cluster before.

The Narrative Synthesis analysed the use and implementation of communication methods as a central priority to create a broader theorisation of context. Adaptations to Narrative Synthesis could be summarised as alterations to the operationalisation of the review (including types of studies chosen). I adapted the identification of studies through new study identification procedures using a ‘sibling paper’ identification system. Adaptations in this method formed innovations for creating structures for categorising, charting and interpreting data in the Case Summaries. Adaptations helped to develop the interpretation of the implementation of a single phenomenon to the comparison of several methods and their contextual features in different contexts. The stages and components of the templates are described in more detail in this chapter (sections 4.3.3; 4.4.2; 4.5.2).

How the methodologies were used in light of adaptations made

I will now summarise how each of the methods were used in light of the adaptations I felt necessary for methods contextualisation. I extended the capacity of scoping reviews to analyse methodological characteristics by adding a mapping component. The Systematic Mapping (Gough, 2003) exercise introduced further analytical components to understand other dimensions of context, such as policy context, in order to establish the links between methods and other study attributes. This created amore detailed picture of the selection of those methods.

I applied Meta Study as an individual interpretive methodology for generating insight about research perspectives and methods context. The study identification procedure was changed to the Cluster technique (Booth et al., 2013b). I therefore married ‘global’ perspectives (research tradition narratives) and ‘local’ perspectives (individual study data about methods) to ideas surrounding context.

I applied Narrative Synthesis in the third approach in methods contextualisation. The emphasis on implementation naturally facilitated a focus on methods rather than outcomes of research. I wanted to pinpoint how each of the methods might invlove different forms of engagement based on conditions of use. Adaptations maximised the reviewer’s ability to identify and link methods components (such as mechanisms, facilitators or barriers). This was fundamental to the creation of theoretical models about methods. I also altered

the application of the methodological framework to include a wider variety of methods-oriented, as well as empirical, papers.

4.3 Mapping: The first approach to methods contextualisation

The first approach to methods contextualisation combined scoping and mapping (I matched features of scoping review and Systematic Mapping to criteria (section 2.5)). I determined that both of the methodological elements provided a contextualising function to locate methods in various contexts. Therefore, both methodologies were fused together. The criteria from chapter two are repeated below.

1. Ability to analyse method-context relationship
2. Capacity to *map* methodological attributes
3. Ability to locate findings within a broader literature
4. Rigorous methodological structure
5. Elements of descriptive and interpretive analysis
6. Ability to identify gaps in the literature

4.3.1 The Scoping Review Framework

This section has the additional function of describing why the particular forms of scoping and Systematic Mapping were chosen. The scoping exercise and the Systematic Mapping referred to specific iterations of methodologies (Levac et al., 2010) and (EPPI Centre, 2007). The scoping exercise framework provided the overriding structure for the template, and is therefore addressed first.

Levac et al's (2010) scoping review methodology was chosen because of the way it articulated the practical steps for building a picture of the literature landscape as a result of its rigorous methodological framework. The framework contained a structure with detailed explanation of processes in the following stages: identification of the research question; identification of relevant studies; study selection; charting data; collating the data, summarizing, and reporting the results; and consultation with stakeholders (Arksey and O'Malley 2005, p.22-3, applied by Levac, et al., 2010 table 3). Detailed processes are necessary because scoping reviews engage with the literature in a particular way, "*Scoping studies are, therefore, concerned with identifying the current state of understanding;*

identifying the sorts of things we know and do not know, and then setting this within policy and practice contexts” (Anderson et al., 2008, p.10).

Scoping reviews are, therefore, typically conducted in the initial stages of research, when the reviewer is least familiar with the field. I felt it was particularly important for subsequent interpretive reviews to be built on a firm foundation that provides key concepts, theory and knowledge. However, scoping reviews are challenging to implement because of the lack of familiarisation with terms and concepts required to conduct valuable searches. The processes of capturing and comprehending key information often happens in parallel. In other words, the picture of the field of enquiry emerges during the process. Therefore, a transparent and detailed framework is essential to glean the current state of understanding and to locate findings amongst the wider literature.

One of the practical steps in Levac et al’s (2010) methodology is the demand for clarification in the area of enquiry and clear planning (including the consideration of feasibility). A reviewer must clarify the dimensions of concept, population and outcome from the beginning. This is an important step even if iterations of the review focus emerge over time. Iteration is crucial in interpretive reviews in order to refine terms and parameters of the review. In other words, to ‘adjust the picture painted’ with the ‘view’ observed. Although Levac et al’s (2010) scoping methodology is robust and rigorous, it can incorporate iterative processes. Finally, the methodology comprises consultation with stakeholders. This can occur at the point of clarifying elements of the review or at the end when results are disseminated. This additional input helps to anchor scoping in relevant enquiries and to relay results back into relevant research or practice. (This element was not carried out in the empirical examples carried out in thesis but this may be a valuable addition to the template for further development of methods contextualisation in future reviews).

The final reason for choosing the Levac et al (2010) framework was the clear links to scoping objectives built into the process. Levac et al developed Arksey and O’Malley’s (2005) scoping stage. The authors identified four reasons for undertaking a scoping review: to examine research activity; to determine the value of a full review; to summarise and disseminate findings, and to identify research gaps (p.21-22). All these reasons resonated with the concept of a mapping review for methods contextualisation.

4.3.2 Systematic Mapping

The second element was the Systematic (or Descriptive) Mapping exercise. This type of mapping influenced the overall approach of the review and provided another analysis phase.

This section explains why the EPPI Centre approach was selected and the features of EPPI review Systematic Mapping exercises which were considered relevant to methods contextualisation. The EPPI Centre approach to reviewing adopts a social constructionist epistemological stance that urges the reviewer to configure and anchor findings in appropriate socio-cultural contexts (Gough and Thomas 2012, p.42). This perspective filters into the Systematic Mapping approach, emphasising dimensions of context. The approach includes the comparison of wider ‘pockets’ of literature to gauge the contexts surrounding the application of data collection methods, and analysis of additional dimensions of context that surround included studies. In practice, this means that Systematic Mapping extends the range of attributes for analysis (a criterion for methods contextualisation).

Systematic Mapping was developed by the EPPI Centre (Peersman 1996; Gough, 2003; EPPI Centre, 2007). The methodology entails: provision of a resource that provides a systematic description of a research area; a basis for narrowing inclusion criteria (similar to scoping reviews); and identification of future research objectives (EPPI Centre 2007, p.12). *“Readers are provided not only with in-depth detail and quality assessment of studies that meet all of the review's inclusion criteria and are synthesised but also with some overall description of the studies. Classification and description that aims primarily to illustrate the kinds of studies that exist has been termed a 'descriptive map' by the EPPI-Centre. (EPPI Centre, 2007, p.12).*

However, I feel a unique aspect of the contribution of Systematic Mapping to methods contextualisation could be described as ‘data attribute layering’. Layering occurs both in the analysis of included studies and in the analysis of a group of outlying ‘excluded’ studies. The comparison of excluded literature involves the analysis of features of literature. In other words, *“mapping reviews enabled the contextualization of in-depth systematic literature reviews within broader literature and identification of gaps in the evidence base”* (Grant and Booth, 2009, p.97). According to methodological guidance, mapping is achieved through analysis of the key-wording results (variables such as

language, topic, population focus, study design and any review-specific keywords) (EPPI Centre, 2007). This involves key-word coding of all full reports meeting the inclusion criteria using the EPPI Centre Educational Key-wording System. (However, mapping was not achieved through this means in my mapping review for methods contextualisation).

4.3.3 The modified Scoping Review template

The integrated scoping and systematic mapping study template is described in table 4.1 below.

Table 4.1 The modified Scoping Review template

(Based on Levac et al (2010) scoping framework (p.3 and 4, tables 2 and 3)). * Elements from Systematic Mapping (EPPI Centre, 2003; 2007)

Arksey and O'Malley's (2005) stages for scoping	Description of processes –including additional elements from descriptive mapping/adaptations to scoping in italics
1. Identify research question	Clarifying and linking purpose and research question. Consider concepts, populations and outcomes.
2. Identify relevant studies	Balancing feasibility with breadth and comprehensiveness of process. Plan comprehensive search but consider practicalities of scope of review also. (Select a suitable research team to undertake the review). <i>Identification of relevant research disciplines.</i>
3. Study selection	Process is iterative and non-linear. (Team undertakes double screening processes). Creation of post-hoc inclusion/exclusion criteria. <i>*Identify pockets of wider excluded literature relevant to analysis.</i>
4. Chart data	Extraction of data. Consider what contextual data may be gathered- create a charting form. (Team undertakes double data extraction). <i>*Chart pockets of excluded literature.</i>
5. Collate the data-summarize and report the results	Numeric summary and qualitative thematic analysis. Consider implications of findings for policy, practice and research. <i>*Collate pockets of excluded wider literature. Analysis of included studies according to additional systematic mapping criteria: approach, context, outcome measures and research design</i>
6. Consultation with stakeholders	Consider opportunities for knowledge transfer. (Optional consultation).

The process follows the scoping framework, with an additional research discipline identification technique, and Systematic Mapping techniques in data charting and collation phases. This process layers data. The bracketed information indicates what a review team would need to consider. (Involvement of other researchers was limited for the purposes of producing an individual contribution in the context of this review). The next section describes adaptations in more detail.

This section will expand on the adaptations made to produce the template. I will relate adaptations made (summarised in table 4.1) to the methods contextualisation criteria (presented at the beginning of this section). The first adaptation is the location of studies across literature landscapes (Stage 2 of the template). The incorporation of Systematic Mapping into the scoping framework is viewed as the second adaptation (stages 3 to 5).

The review attempted to locate studies across literature landscapes that capture specialist fields within the research topic (phase 2 in table 4.1). This ‘research discipline’ information would help to identify relevant journals, and was later collated as a study attribute.

This technique offers a systematic way to capture a scattered literature topic, or a topic which straddles a number of disciplines. The diagram in figure 4.1 below presents three interpretations of the relevant broad literature traditions (in this case: social sciences, behavioural sciences and the health and nursing sciences) and associated disciplines. Seven potentially relevant disciplines of research emerged from the research traditions identified through preliminary searches (these were then linked to databases containing material relevant to these disciplines). Literature traditions were identified from Journal database subject coverage, in particular, ProQuest’s (ASSIA) and the British Nursing Index database (BNI).

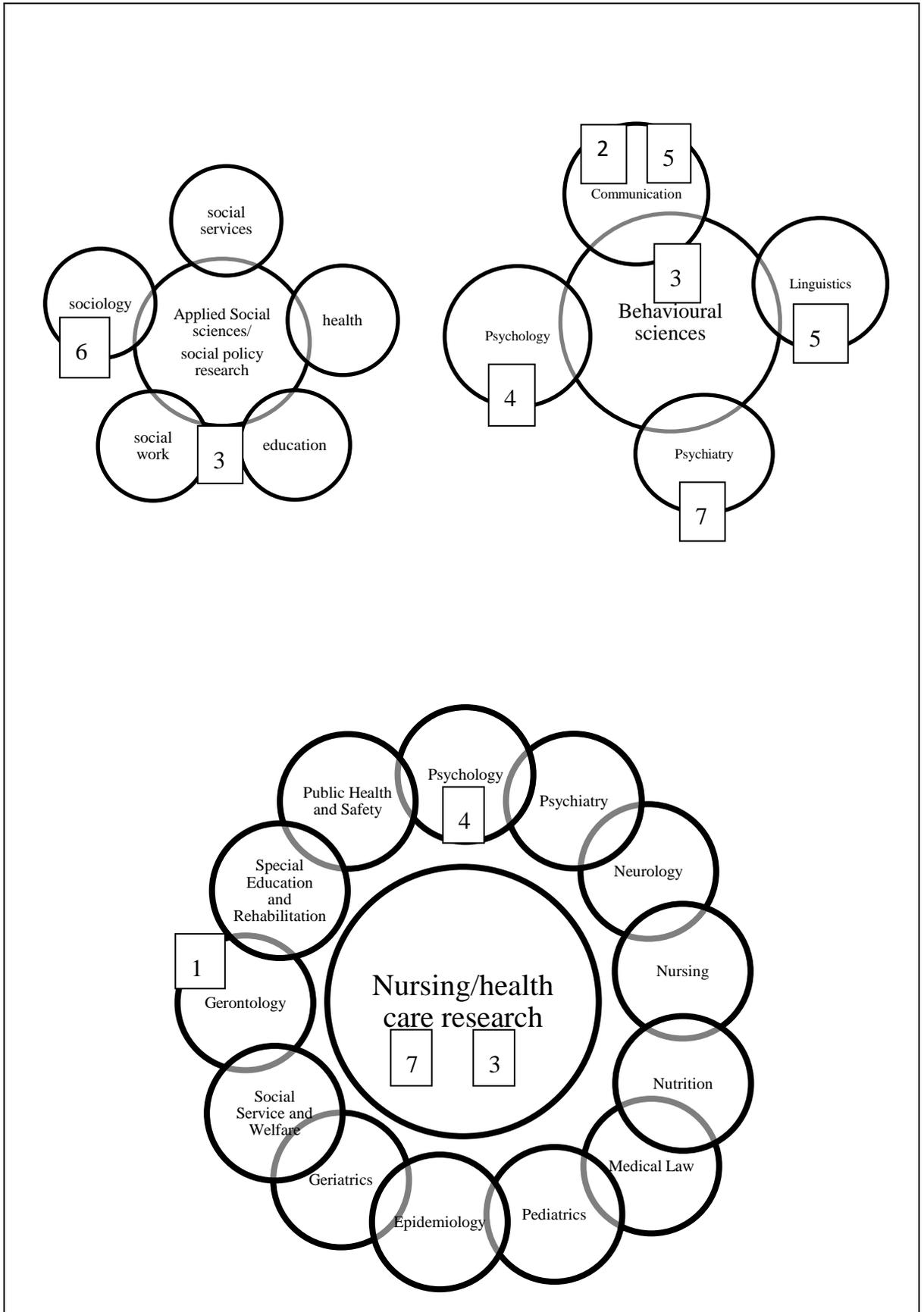


Figure 4.1 The location of relevant traditions and disciplines of literature across the social sciences

Key to the diagram above – the seven disciplines of relevant literature

1	Gerontology (Zetoc)
2	Communication-enhancing methods (Inspec, Lista)
3	Practitioner – focused (BNI)
4	Psychology (Cinahl)
5	Language and Communication (Psycinfo)
6	Policy (SPP)
7	Rehabilitation (Pubmed, Embase)

Databases were identified to index the range of disciplines identified as part of their subject coverage. (In the case of the scoping review, these were: the US National Institute of Health’s library of medicine (Pubmed Central), the British Nursing Index (BNI), the Biomedical database (Embase), the American Psychological Association’s (PsycInfo), Social Policy and Practice (SPP), Cumulative Index to Health and Allied Literature (CINAHL), the British Library’s Electronic Table of Contents (ZETOC), Institute of Engineering and Technology (INSPEC) and Library and Information Science Technology database (LISTA)). The technique encouraged the inclusion of a broad range of databases. Not only is this process systematic but the reviewer(s) can view the information visually.

The concept of isolating individual research traditions from disciplines was inspired by Greenhalgh et al’s (2005) Meta Narrative, whereby research traditions were identified within different research traditions. The methodology emphasises mapping paradigm perspectives using a pluralistic approach, and by extension, linking research to traditions to disciplines. (Ideally, there is a multi-disciplinary research team who possess different fields of expertise and different paradigm-based lenses (p.427). However, this technique has not been embedded in a scoping review before. I developed the idea in two ways. First, the depiction of fields of literature is a reflection of the categorisation in search platforms, and

these contain the specifically relevant disciplines. This two-tier distinction provides a greater level of transparency in the location of the discipline and legitimacy in terms applied.

The second development is only theoretical at this stage. I have proposed a graphical depiction of the research according to volume of studies identified in disciplines. The literature discipline number or symbol could be enlarged to reflect the number of included studies identified from within it. In the case of the scoping review presented in this thesis, the link between the journal categorisation and the content of the article did not prove to be an accurate way of classifying topics for the journals and in the identified papers. Therefore, I re-classified the studies using the article topic and presented this in the main data extraction table (item 5 in the appendix (p.295)). In this way, the classification of articles topics required a case-by-case analysis.

This adaptation was not an attempt to dismiss or downplay the complexity of the literature base. Research traditions and disciplines are not represented in an even and mutually exclusive form in journal topics. However, this initial adaptation attempts to make the reviewer perceive the literature base in a different way, as if it were a landscape. This is an important aspect of methods contextualisation, and it is the first step in determining the foundations for the various methods-context relationships. I considered configuration of the research disciplines as an important step in providing clues as to the perspective of the articles found. On this basis, the reviewer may anticipate broad differences in conventions between social science and behavioural sciences.

However, there is opportunity to further develop and test the visual representation of this adaptation. It was not carried out because of the weak relationship between the journal discipline and the topic of the article. This aspect needs further consideration. It would be an important step in conveying a sense of the commonality of topic (convergence between disciplines) or the separateness of the topic. Expressed in a different way, the process helps the reviewer to understand the 'colonisation' of research topics in the literature base. Overall, the transparent process of identifying broader perspectives that may influence research methods choice and use adds another facet to the exploration of the methods-context relationship (this is one of the research methodology criteria).

Systematic Mapping was the next adaptation to be added to stages 3, 4 and 5 of the scoping. It occurred in two main ways. Firstly, a 'Systematic Map' of included studies

was added to the scoping exercise as a way of enhancing data extraction and collation, in particular in relation to policy context. Secondly, it introduced the principle of mapping broader excluded literature in order to locate included studies.

In the case of the Systematic Map, a group of additional attributes identified from a Systematic Mapping exercise by Gough, et al (2003) were embedded into the scoping analysis (approach, context, outcome measures and research design (Gough et al, 2003, pp.3-4)). Thus, the Systematic Map increased the number of attributes mapped in the review (identified as one of my criteria for this type of methods contextualisation). The Systematic Map exercise attempted to access a deeper level of understanding of included studies by looking for indicators of wider context within and beyond studies, such as policy context, or implicit alignment with social science perspectives. Not only did the additional attributes provide other way to examine the methods-context relationship, but they helped the reviewer to avoid an oversimplified picture of the included studies. Grant and Booth (2009) refer to the disadvantages of broad description: “*Studies may be characterized at a broad descriptive level and thus oversimplify the picture or mask considerable variation (heterogeneity) between studies and their findings- depending on the degree of specificity of the coding process*” (Grant and Booth, 2009, p.98). In order to describe included studies within a systematic map I included: study approaches (focus of the question, conceptual approach); context of the studies (national focus, national policy context); study outcome measures (outcomes [adapted from outcome measures], variation across contexts) and research design (overall design of studies, setting, and population).

The second hallmark of Systematic Mapping in the review is the incorporation of excluded studies in the analysis. The Systematic Mapping approach enabled the reviewer to map out sub-sets of studies (or alternatively, to conduct several syntheses in different areas of the same map) (Gough et al., 2012, p.5). The analysis of excluded studies helped to highlight characteristics of included studies. The analysis of excluded studies was useful in identifying the use of other research methods with other participant populations not present in included studies. I felt this could help to inform future reviews of the use of research methods in other contexts. This enhanced my ability to locate findings in the broader literature and to identify gaps.

In summary, this type of methods contextualisation ‘mapping study’ had to harmonise a Systematic Mapping approach within a scoping framework. My approach attempted to

fuse the results from the Systematic Map with the results from the scoping exercise. The Systematic Mapping approach deepens the contextual focus, creating layers of data. The approach also made the review more configurative as it sought to analyse excluded studies and theory in parallel with included results. However, the additional layers of data made the collation and representation of the results more complex.

4.4 An interpretive review: the second approach to methods contextualisation

Meta Study (Paterson et al., 2001) methodology was selected from interpretive reviews to explore methods contextualisation. The methodological template presented in this section aimed to examine perspectives that shaped the contextual landscape.

This methodology represented the best fit for the criteria described below:

1. Capacity to explore the context of the perspectives behind methods
2. Subjective idealist methodology
3. Ability to analyse interpretation processes relating to multiple methods

4.4.1 The Meta Study

The section will describe the features of Meta Study in detail in order to compare the steps with the adaptations to this existing methodology. The Meta Study methodology encourages a critical approach. Epistemologically, the conceptual approach is governed by subjective idealist principles (Barnett-Page and Thomas, 2009, figure 1 in appendix) because the approach deals with “*constructions of constructions*” (Paterson et al, 2001, p.6). Meta study entails analysis, usually of qualitative studies, followed by a synthesis. The level of critique required produces mid-range theory (Paterson, 2001, p.14.). The methodology requires the reviewer to be critical, drawing conclusions about a field of research that go beyond a textual analysis. The phases of analysis help the reviewer to distinguish between methodological, empirical and theoretical contributions (these are separated out during the Meta Method, Meta Analysis and Meta Theory phases).

The phases are displayed in the template (figure 4.2 in the next section). These phases are the same summary format as originally presented by Paterson et al (2001). Meta Theory is essential to creating an in-depth understanding of study perspectives, drawing together theoretical and disciplinary influences. This phase helps the reviewer to understand the

underlying assumptions inherent to those perspectives. Meta Method methodology requires the reviewer to capture details about the research methodology designs. This typically involves the extraction of information about method, question, setting and data collection methods. The task of the Meta Analysis phase is to draw together analysis (and information about analytical processes) from the studies to understand the nature of relationships. Meta Synthesis involved the critical appraisal of underlying assumptions in all data and the identification of strengths and weaknesses in the evidence base synthesised in the review. Alternative theoretical structures may emerge.

4.4.2 The modified Meta Study template

Meta Study Phases (adapted from Paterson, 2001, p.11-12)

Formulating a research question

1. Formulating tentative questions
2. Choosing a theoretical framework
3. Generating workable definitions of key concepts under study

The next 8 steps were removed and replaced with the 10 cluster steps outlined below:

4. *Anticipating the outcomes of the study*
5. *Refining the questions*
6. *Developing the evaluation criteria for key studies*

Selection and appraisal of primary research

1. *Identifying inclusion/exclusion criteria*
2. *Specifying appropriate data sources*
3. *Screening and appraisal procedures*
4. *Retrieval of data*
5. *Developing a filing and coding system*

1. Create inclusion/exclusion criteria based on the previously identified research question
2. Conduct database searches
3. Screen records for relevant papers
4. Amend inclusion/exclusion criteria if necessary
5. Appraise most relevant records
6. Identify most relevant gateway citations to the rest of a cluster- these are called key pearl citations
7. Create a sampling framework if necessary
8. Build cluster through various searching and ‘berry-picking’ techniques
9. Pursue any other relevant papers through cluster materials already identified
10. Label cluster materials and graphically represent cluster

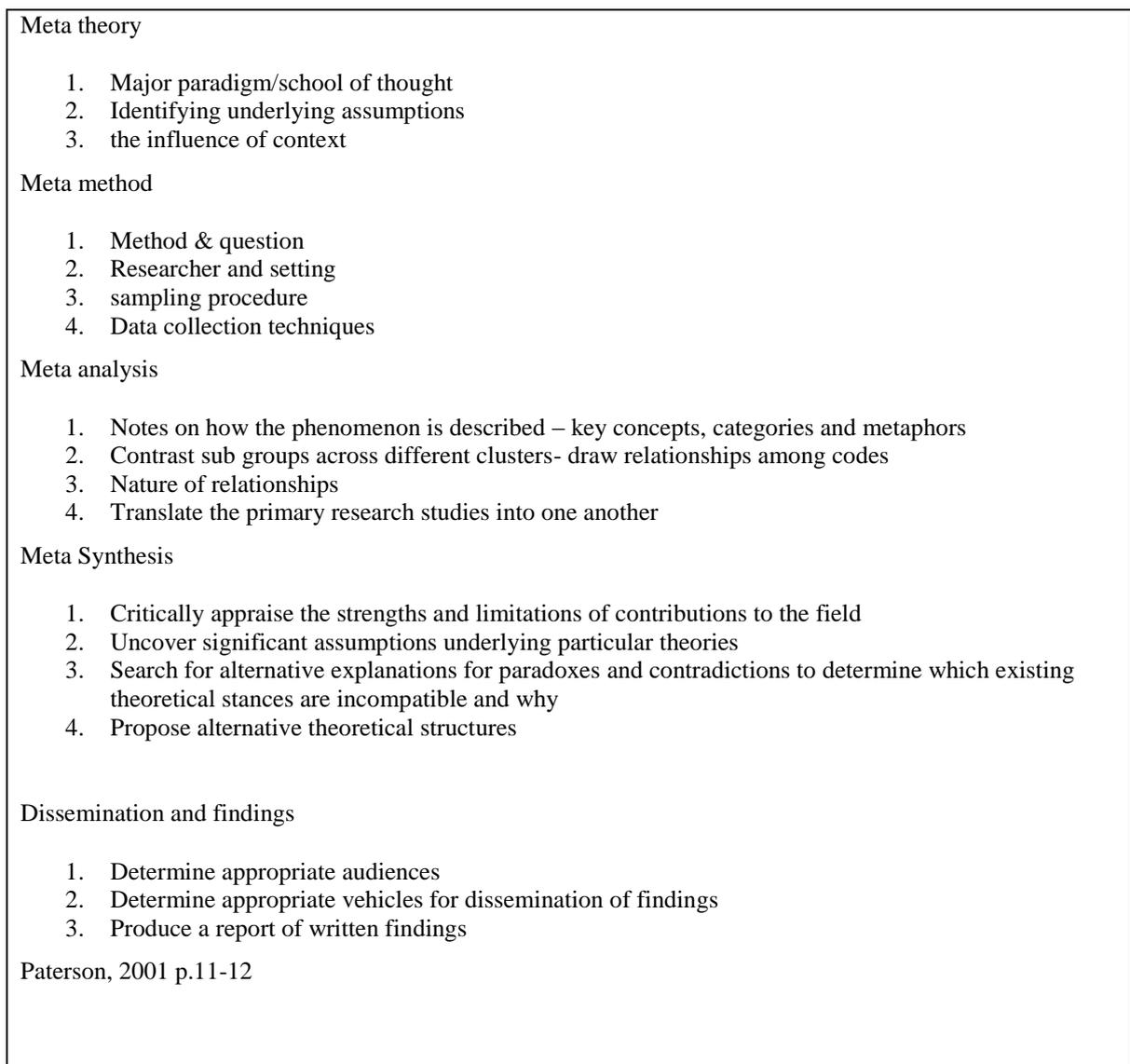


Figure 4.2 The modified Meta Study template

The highlighted sections of the Meta Study method in figure 4.2 represent areas where the method was changed to accommodate the ‘Cluster’ search strategy (Booth et al., 2013b) and study selection. The adaptations to this established methodology are explained in the next section. The Cluster technique actually had an impact on the whole process of the Meta Study; therefore, the whole process depicted in the template above is explained. The reasons why this adaptation helped the review to extend compliance with the selection criteria are also explained.

4.4.3 The Cluster technique

The Cluster technique devised by Booth, et al (2013b) was the main adaptation I made to the Meta Study methodology. The Cluster technique was originally designed to enrich the conceptual and contextual analysis, producing a panoramic view of a field of study i.e. the

publications linked to key projects. (Typically, systematic reviews use single empirical papers as a unit of analysis). Clustering is associated with the identification of conceptual factors to generate theoretical and methodological insights, which makes it ideal for methods contextualisation.

The central principles of Cluster emanate from the focus on studies (or projects) as opposed to single papers. A cluster is defined as “a *group of inter-related papers or other research outputs that relate to the same single research study* (Booth et al, 2013b, p.4 Table 2). Cluster searching is a systematised attempt to synthesise a mixture of research outputs linking directly or indirectly to a common source. The lateral searches were conducted after data base searches that identified key studies or projects. The lateral searches identified study/project outputs. Therefore, this technique offers an epidemiological dimension because the relationships between studies can be analysed over time. The disadvantage to this technique is the limit to the number of clusters which can be analysed feasibly. The technique offers an opportunity to analyse multiple clusters but, in a similar way to an analysis of multiple case studies, it is not designed to be an exhaustive analysis of all relevant research. The focus on contextual richness makes the technique a valuable tool. Booth et al (2013b) describe two requirements for ‘contextual richness’ for understanding complex interventions. Firstly, “*Sufficient detail to enable the reader to establish what exactly is going on, both associated with the intervention and associated with the wider context. Secondly, sufficient detail to enable the reader to infer whether the findings can be transferred to other people, places, situations or environments*” (Lincoln and Guba, 1985 cited in Booth et al, 2013b, p.4). However, the use of clusters changes the nature of the review parameters and goals from a comprehensive to a specialised synthesis.

The Cluster technique comprises a combination of lateral search techniques to find a range of associated papers or project outputs from related projects. It was built around the set of techniques called ‘berry-picking’ (Bates et al., 1989). The Cluster technique seeks to systematise these techniques. Projects were included based on their relevance to a research phenomenon or topic. As mentioned above, the cluster technique alters the way data is selected in comparison with typical lateral searches which do not link papers to a central source. The range of relationships between a publication and a key (‘pearl’) study are stated below. Several have been added by me to further define the antecedent and theoretical components.

Definitions of types of Cluster publications are presented in figure 4.3. The definitions are important in identifying the different kinds of evidence in a cluster based on the relationship with the key pearl citation. (The comments in quotations represent the original definitions provided and normal script depicts additions I made to the definitions as a result of the development process for methods contextualisation).

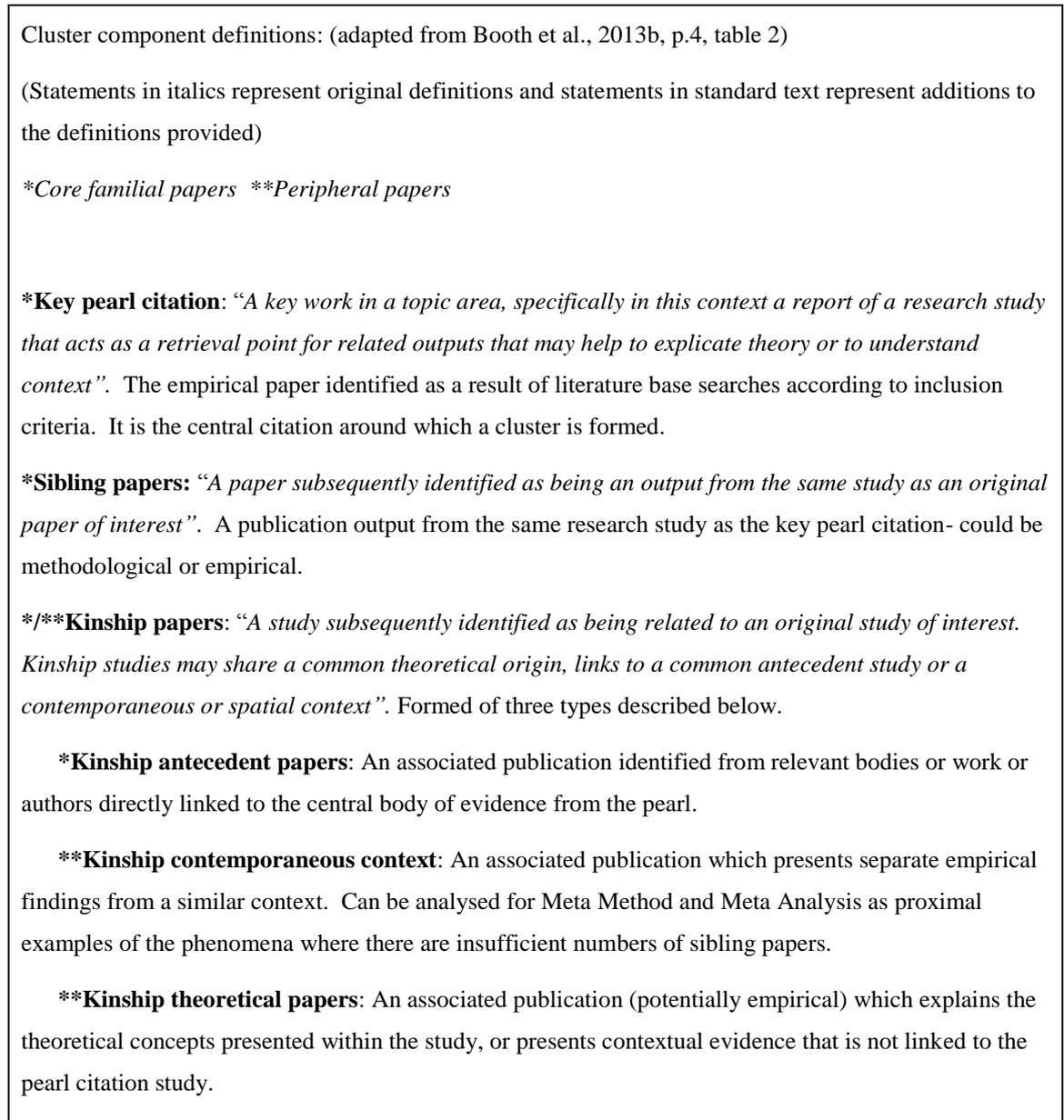


Figure 4.3 Cluster component definitions

As recommended in the original methodology, a single cluster can be constructed first in order to familiarise the reviewer with the process (steps 8 to 10 in figure 4.2). Booth et al (2013b) originally devised a process for obtaining clusters (p. 10, table 4); this comprised the thirteen procedures listed below.

- Identify at least one key pearl citation
- Check reference list for any other relevant citations by the same author
- Re-check for additional records by authors
- Search for lead author (publication list etc.)
- Conduct citation searches on key pearl citation
- Conduct searches on project name/identifier
- Make contact with lead author
- Follow up key pearl citation for mention of theory
- Recheck mentions of theory in citations/abstracts
- Optionally, conduct iterative searches of theory
- Follow pearl and other cluster documents for citations to project antecedents
- Conduct project and citation searches for other relevant projects
- Seek cross-case comparison between project name (in cluster) and other relevant projects

(Summary of procedures in Booth et al, 2013b, p.10 table 4)

These were streamlined into ten procedures for method contextualisation (see figure 4.2). The Meta Study process begins with formulation of the research question, taking into consideration the focus for the clusters included in the synthesis. The theoretical framework can be used to inform inclusion and exclusion criteria when searching for suitable key pearl citations. Once I searched databases for potential pearls, I embedded a screening process into the process to improve transparency.

The cluster technique enhanced the review's ability to interpret the processes behind multiple data collection methods phenomena. The technique produces a number of separate pools of data that can be analysed internally for processes relevant to methods choice and use. The clusters can be applied to individual methods and related studies, or conceptual frameworks which govern processes across methods in a more generalizable way. Potential pearl studies were screened based on a number of criteria (presented in appendix item 1 (p.286)). This was because I first wanted to make sure clusters would be viable sources for study according to the characteristics I considered favourable. Secondly, because there would be scope to conduct a small number of clusters only, due to the analytical depth required. This action did not conclusively select studies into the sampling matrix (described in more detail below); however, it did provide information about the

potential key pearl citation paper which informed the decision. Key criteria included confirmation that: the paper was conceptually or contextually rich; it was part of a project; and the size of the cluster was viable. Other criteria included: empirical content; status as an academic article; and features relating to the transferability of the topic across populations and across different research methods. Included studies fulfilled the highest number of criteria. Clusters were then selected purposively according to a theoretical or conceptual framework.

A sampling matrix was considered appropriate for the selection of clusters because Booth et al (2013b) argued that syntheses increasingly followed the logic of *appropriateness* of the sample rather than *comprehensiveness* of the sample. This has manifested in different sampling techniques associated with different kinds of reviews e.g. theoretical sampling (Realist Synthesis), snowball sampling (Meta Narrative approaches) and even theoretical saturation through purposive sampling. Other examples include where reviewers have used ‘qualitative’ principles to examine sub-groups from a larger pool of studies (Dixon-Woods et al., 2006b). Ultimately, this review applied purposive sampling to identify four papers containing frameworks, based on heterogeneous features.

Whilst screening may not produce a small enough sample of pearl papers, they filter the field based on characteristics suited to clusters and relevancy to the type of review. A sampling matrix (or framework) can be created to purposefully select heterogeneous or homogeneous cases for clusters. The sampling framework could be based on theoretical concepts or, more straightforwardly, data collection methods characteristics.

The final methodological innovation in the Meta Study was the representation of clusters (displayed in section 6.4 in figures 6.4, 6.5 and 6.7). This was an innovation for clusters I developed to enhance methods contextualisation (however, it could be applied more widely). The visual representation depicted the pearl citation and associated papers (in the form of a number of shapes). Theoretical papers were placed furthest away from the pearl paper to represent their indirect association with the cluster study. The diagrams were an effective way to ascertain the respective contributions of the cluster papers- the theoretical papers were the largest contingent. I felt this was more effective than the criteria which attempted to understand the context of various perspectives. This visual representation provides a way to compare the depth of empirical and theoretical data through the different types of papers represented with different relationships to the pearl paper. Clusters can

represent different entities, or phenomena. For example, the clusters can represent data collection methods and their theoretical and empirical basis. Therefore, the genesis of the theory can be traced and the volume of the empirical evidence can be judged. The cluster can also represent something more conceptual such as an interpretive framework. Therefore, the diagram can provide a sense of the origins of the framework and the examples of its application since its inception. The analysis phases of the Meta Study fill in the details in this picture, such as the relevancy or obscurity of theory, the assumptions in empirical analysis and the perceived impact of the method or framework in the literature.

4.4.4 Meta Study analysis

Next, the discussion turns to the overall impact the cluster has on the Meta Study analysis and synthesis. The first three categories in figure 4.3 were referred to as *core familial* papers. They were analysed in greater depth in the Meta Method and Meta Analysis phases. The Kinship Theoretical and Kinship Contemporaneous Context papers were referred to as *peripheral* papers; these were incorporated into the Meta Theory and Meta synthesis alongside all other papers. The exclusion of Meta Theory papers from Meta Method and Meta analysis was a result of a purely theoretical link to the pearl study (they may be non-empirical papers that pre-date the key study).

Traditionally, the Meta Study method has been applied to qualitative research synthesis only (Paterson, 2001, p.40). However, the template introduces a range of study types for analysis. Since this approach transforms a range of data, it may be viewed as a ‘qualitizing’ approach (Sandelowski et al, 2006) (a concept discussed in greater detail in chapter 2.3). Therefore, I changed the type of data originally envisaged for this Meta Study methodology in order to ensure it is an appropriate vehicle for methods contextualisation. This represents a significant change to the stance of the methodology. This change was necessary to incorporate the many data collection methods which appear in a range of study types and designs.

Despite the range of study types imported into Meta Study for the purposes of methods contextualisation, there are restrictions in whether all data can be analysed together. The original Meta Study Method used a Meta Ethnography (Noblitt and Hare, 1988) perspective with refutational synthesis processes. Thematic analysis was viewed as a more suitable method to conduct analysis across a range of data types. In addition, Meta Method

and Meta analysis phases were limited by the presence of data from other studies in Kinship Theoretical or Kinship Contemporaneous Context papers. Analysis was restricted to appropriate comparisons in the data.

In summary, the combination of the Meta Synthesis and the Cluster technique provided a transparent path to the origin of studies and their role in the analysis (particular cluster papers were included in different phases). Meta Study is a highly interpretive method which aims to derive meaning from across studies in a way that would result in common themes or narratives. Theoretical sources were not easily reconciled into themes, assumptions or alternative theoretical structures.

4.5 A theory-based evaluation review: the third approach to methods contextualisation

The Narrative Synthesis methodology was selected as the third approach to methods contextualisation. The methodology was selected from amongst the configurative reviews with a (realist) theory-based evaluation perspective as an implementation-focused methods contextualisation review. It had a broad aim to provide a broader theorisation of context. The methodology was selected according to the following criteria (see section 2.5):

1. Capacity to determine the appropriateness of implementation of methods
2. To contain methodological features to distinguish between context-specific and more general aspects of findings
3. Techniques to analyse a mixture of study approaches

4.5.1 The Narrative Synthesis

This school of evaluation uses context-theory-outcome categories to contextualise broader understanding about which interventions work. Narrative Synthesis has a critical realist epistemology ((textual) narrative synthesis in Barnett-Page, 2009, figure 1 in the appendix). According to Popay et al (2006) there are two kinds of Narrative Synthesis: effectiveness studies and implementation studies. I have classified the attributes of this methodology in section 2.4 table 2.2. It is a theory-based, implementation-focused Narrative Synthesis similar to “*a multi-component mixed methods*” interpretive reviews (Hansen and Trifkovic, 2013, p.31, table 5). *Appropriateness* of intervention is viewed as a suitable question focus for interpretive multi-component mixed-method reviews (op cit).

The methodology has both configurative and aggregative elements (Gough, et al., 2012, p.4 table 1).

It was not until relatively recently that a formal methodology for Narrative Synthesis was written (Popay et al., 2006). Unlike meta-analysis, the methodology does not rest on an authoritative body of knowledge. Nor has there has been any rigorous testing over time (Popay et al., 2006, p.6). An implementation focus appeared to best fit for the contextualisation of AAC methods (see criteria above). Narrative Synthesis sought to explore the context in which interventions (or the data collection method) has been implemented and the various barriers and facilitators to the use of research methods.

There are six stages to the review process. The synthesis (stage five) contains several elements (see figure 4.5 below). The four central elements of Narrative synthesis are: to develop a theoretical model of how the interventions work, why and for whom (a framework associated with Realist Synthesis); to develop a preliminary synthesis of findings of included studies; exploration of relationships within the data; and to assess the robustness of the synthesis.

Six stages of the review process	Methodological processes followed
Stage 1 Identify the review focus, searching for and mapping the available evidence	Conduct a mapping exercise
Stage 2 Specify the review question	Develop question- descriptive and interpretive question format
Stage 3 Identify studies to include in the	Conduct searches according to selection criteria.

review		
Stage 4 Data extraction and study quality assessment	Construct data extraction strategy Quality assessment procedures	
Stage 5 Main elements of synthesis	Implementation Reviews	Tools and techniques (to be selected as appropriate)
1. Developing a theoretical model of how the interventions work, why and for whom	Purpose: <ul style="list-style-type: none"> • To inform decisions about the review question and what types of studies to review • To contribute to the interpretation of the review’s findings • To assess how widely applicable those findings may be 	Develop a “Theory of change” (Weiss, 1998 cited in Popay et al. 2006 p.12)
2. Developing a preliminary synthesis	Purpose: <ul style="list-style-type: none"> • To organise findings from included studies in order to: <ul style="list-style-type: none"> o Identify and list the facilitators and barriers to implementation reported o Explore the relationship between reported facilitators and barriers 	Textual descriptions of studies Groupings and clusters Tabulation Translating the data into a common rubric Vote counting as a descriptive tool Translating data; thematic analysis
3. Exploring relationships in the data	Purpose: <ul style="list-style-type: none"> • To consider the factors that might explain any differences in the facilitators and/or barriers to successful implementation across included studies • To understand how and why interventions have an effect 	Graphs, Frequency distributions, funnel plots, and L’Abbe plots Moderator variables and sub-group analysis Idea webbing and conceptual mapping Translation: reciprocal and refutational Qualitative case descriptions

		Investigator methodological triangulation Conceptual triangulation
4. Assessing the robustness of the synthesis product	Purpose: To provide an assessment of the strength of the evidence for drawing conclusions about the facilitators and/or barriers to implementation identified in the synthesis. Generalising the product of the synthesis to different population groups and/or contexts	Weight of evidence e.g. the EPPI approach Best evidence synthesis Reflecting critically on synthesis process Checking with the authors of primary studies
Stage 6	Report and disseminate findings	

Figure 4.4 Narrative Synthesis methodological framework

(Adapted from Popay et al., 2006 pp.9-10, p.12 table 2 columns 1 and 3), and section 3.2 pp. 16-23)

In its original form, reviewers are urged to follow a process of choosing appropriate questions and designs for the review to capture the relevant contextual data surrounding implementation for the initial stages. Inclusion and exclusion criteria define the review parameters; they convey the key aspects of the review focus. Searches are comprehensive. Data extraction gathers data to assist comparisons across the data, in terms of groups or settings, for instance.

The first element within the Narrative synthesis called for a “Theory of Change” (Weiss, 1998 cited in Popay et al., 2006). This process requires examination of causal assumptions prior to the review. Popay et al. anticipated this would facilitate theoretical construction and testing (p.12). However, the Narrative Synthesis methodologists did not identify specific tools and techniques to carry out this stage (p.16)).

The second preliminary element assists reviewers in establishing how and why particular factors and processes impinged on implementation; the reviewer looks for patterns in these processes. Seven tools and techniques are suggested for this element (see figure 4.4 above). Full descriptions are provided in Popay et al., 2006, p.16-19). Tools which incorporated visual representations were important. (Methods recommended for methods

contextualisation were selected from the original options in the Narrative Synthesis methodology. These ranged from simple textual descriptions, to more interpretive transformation of data into common rubric and thematic analysis). Many of the qualitative options were employed in analysis because of the methodological emphasis on interpretation of methods contextualisation perspectives. According to the existing methodology, reviews would typically select appropriate data analysis techniques to suit the particular research focus in the second and third phases of synthesis.

The third element in the existing methodology was exploration of relationships within and across studies, this helped reviewers to understand how and why intervention facilitators and barriers operate. This element explored the influence of heterogeneity by investigating *variability* in outcomes and study designs, populations, interventions and settings. Popay et al (2006) urged reviewers to consider the influence of context. Popay et al (2006) also pointed out that *implementation study* analysis will be much richer than *effect studies* (p.15). Seven possible tools and techniques recommended for this element of the process (p.19-21); all depict patterns emerging in the data (graphs, diagrams (mapping or webbing) or narratives (case descriptions, methodological or conceptual translation and triangulation)).

The final element of the synthesis addressed robustness of the synthesis, by reviewing the volume and quality of the evidence base, weighting studies accordingly. Five different methods were suggested by Popay et al (2006 p.21-22). These surrounded identification of insufficient, inadequate and discrepant data. Analysis differed from quality appraisal which critiqued the design of individual studies. The process focused on the robustness of the synthesis itself. I identified the *critical reflection* process (Busse et al., 2002 cited in Popay et al., 2006, p.22) as most suitable for methods contextualisation because of the overwhelmingly narrative descriptive approach to the analysis. My critical reflection aimed to articulate the strength of the interpretive evidence within the review. Overviews of the review processes provided a critical understanding of the foundations for conclusions within the review. Reflective steps included:

1. Methodology of the synthesis used (especially focusing on limitations and their influence on the results)
2. Evidence used (quality, validity and generalisability). The process emphasised the impact of possible sources of bias

3. Assumptions made by the reviewer
4. Discrepancies and uncertainties identified in the evidence (in particular, differences in study conclusions on the same phenomenon and areas where there are gaps in research)
5. Expected changes in technology or evidence (historical developments in technology or evidence which could have an impact on findings)
6. Aspects of the research that would have an impact on implementation of technology or evidence in different settings (summarised from Popay et al., 2006, p.22).

4.5.2 The modified Narrative Synthesis template

This section discusses three adaptations that I made specifically to accommodate *methods contextualisation*- the broader aim of the empirical studies within the thesis. Two of the three changes are highlighted in the table (figure 4.5) below. These are: the identification of sibling papers within study selection procedures, secondly, the creation of case summaries and thirdly, the creation of Overarching Constructs derived from thematic analysis.

The first adaptation involved the identification of a methodological or empirical *sibling* papers from the included papers. This technique (created for this thesis) borrows from Cluster techniques (Booth et al., 2013b) because papers are identified with a link to the same study or methodology. I created a set of principles for identification of papers. These are presented below:

Principles for identifying ‘Sibling’ Papers

- Preference for directly linked papers from same study
- Minimisation of bias through a flooding of rich qualitative material from several studies acting as several narratives on the same method
- Selection of **methodology and empirical** paper where possible
- Where either above cannot be selected, proxies may be used in the form of reliance on method sections of previous key papers (generalizable statements used)
- Where there are an abundance of empirical papers, the most recent is selected
- Remaining empirical papers not used as a gateway papers (despite being identified through the

<p>review process) are mapped and considered in robustness of synthesis process</p> <ul style="list-style-type: none"> - Labelling for type and origin of papers should be used to show how a paper was identified and reviewer selections should be provided where judgement calls were made - Quality Assessments are conducted on empirical papers (including in cases where the methodology papers were also the ‘gateway’ papers initially identified within the literature searches).

Figure 4.5 Principles for identifying 'Sibling' papers

By including sibling papers I aimed to increase the depth of the review, and thereby increase the capacity of methods contextualisation review to determine the appropriateness of research methods use. Additional papers added more data into the synthesis. The method produced a broader overview of implementation, both in terms of practical and theoretical aspects throughout the review process. However, in the empirical example in chapter seven, the absence of a sibling empirical or methodological paper to represent each study through a pair of publications, created an imbalance in the data between studies (a phenomenon discussed in chapter 8.2).

The final two adaptations are described in the synthesis summary table below.

Stage of review process	Methodological process
Stage 1: Identify the review focus, searching for and mapping the available evidence	Conduct a mapping exercise
Stage 2: Specify the review question	Develop a question- descriptive and interpretive question format
Stage 3: Identify studies to include in the review	Conduct searches according to selection criteria <i>*Select additional Sibling papers according to principles (figure 4.5)</i>
Stage 4: Data extraction and study quality assessment	Construct data extraction strategy Conduct Quality Assessment procedures
Stage 5: 1. Developing a theoretical model of how the interventions work, why and for whom	No specific techniques provided by Narrative Synthesis methodology (programme theoretical model building described)

2.Developing a preliminary synthesis	1 Textual descriptions of studies 2 Groupings and clusters 3 Tabulation 4 Translating the data into a common rubric <i>5 Qualitative case descriptions – *Case Summaries created (method used commonly in element 3)</i>
3. Exploring relationships in the data	Tabulation <i>*Thematic analysis – including identification of ‘Overarching Constructs’</i>
4. Assessing the robustness of the synthesis product	3 Reflecting critically on synthesis process
Stage 6: Report findings	Report and disseminate findings

Figure 4.6 The modified Narrative Synthesis template

(Adapted from Popay et al., 2006 pp.9-10, p.12 figure 2 (columns 1 and 3), and section 3.2 pp. 16-23) My adaptations (*)

The existing methodological guidance stressed the importance of the *creation of a common rubric* (Popay et al., 2006, p.17) and described this process as a way of comparing statistical findings where results cannot be pooled to estimate an effect. The interpretive emphasis in methods contextualisation provided little opportunity to pool statistical results. Instead, I devised a common narrative rubric. I created a new way of formatting data called *Case Summaries*. I imported data from the data extraction tables (including textual descriptions) into case summaries so that barriers and facilitators could be compared in subsequent thematic tables. This idea of case summaries (displayed in figure 4.7) was inspired by *qualitative case descriptions* (Popay et al., 2006, p.20) who acknowledged there is little existing guidance on the implementation of this technique; however, the format of the case summaries is unique to this review. As an adaptation, the case summaries helped to distinguish between context-specific and more generalisable (or transferable) aspects of implementation (the first criteria for this approach to the

methodology). This also complies with the second criterion that permitted analysis of a range of study approaches.

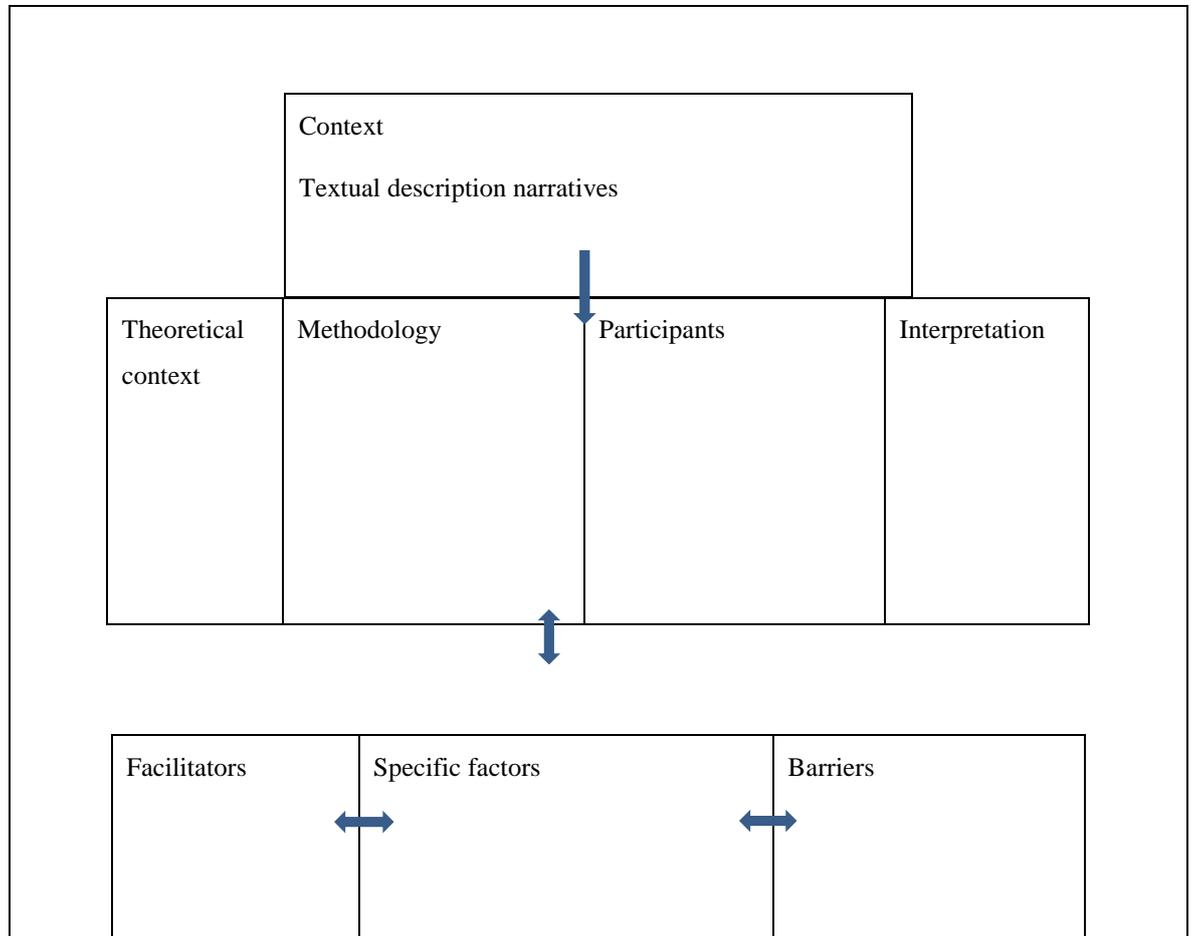


Figure 4.7 Case Summaries Framework

The second adaptation I made was the creation of Overarching Constructs. Analysis was largely *thematic*, involving further *tabulation*, in a departure from ethnographic methods described in the methodology (Noblit and Hare, 1988) a technique referred to as ‘*Translation as an approach to exploring relationships*’ (Popay et al., 2006, p.20). The thematic analysis resulted in *Overarching Constructs* created to summarise data similar to the function of Line of Argument (LOA) synthesis in Meta Ethnography, in which an interpretation is constructed that explains and links a set of synthetic parts (Barnett-Page and Thomas, 2009). This is a function of synthesis that goes beyond the interpretation of primary studies. The Overarching Constructs I created attempted to synthesise barriers and facilitators to implementation according to the theoretical model proposed in the review. This innovation helped to develop transferable factors within the categories of research methods identified. The Overarching Constructs were mapped onto the aspects of the

theoretical model identified in the first phase of the synthesis. This stage extracted the most ‘transferable’ aspects of the data (whilst reflecting the nuances of their relationship with certain types of research methods that emerged as possessing broadly similar approaches).

In summary, the interpretive focus for methods contextualisation and the inclusion of methodological papers increased the utility of a range of qualitative analysis techniques. The techniques chosen and the adaptations made were consistent with realist theory-based evaluation conventions, particularly transformation of data into common barriers and facilitators.

4.6 Other potential methodologies: selection and contribution

Following the completion of the templates, I reflected on the impact of my methodological choices. I will discuss the potential contribution of other methodologies. This exercise helped me to compare methodologies and the ways they could shape methods contextualisation processes.

My chosen methodology selection strategy matched review types with features of methods contextualisation (see section 2.4), ultimately selecting from a criteria based on perceived features of methods contextualisation (chapter 2.5). However, I could have chosen other methodologies. The two main alternative strategies were: selection of the original contextualisation reviews (identified in Gough and Thomas, 2012, pp.41-44), or pragmatic selection of existing types of methods-centred reviews (see historical development section 1.2). The former strategy would have resulted in selection of: EPPI Centre reviews, systematic reviews from the Traditions of Qualitative Enquiry (e.g. Critical Interpretive Synthesis, Meta Study or Meta Narrative), or Realist Synthesis (a Theory-Based Evaluation). Under the second strategy, I could have opted for mapping reviews, conceptual reviews, or meta reviews.

EPPI Centre review or Systematic Mapping Exercise

An EPPI Centre review framework would have changed the focus of the enquiry. The review would have become a *systematic review* with robust quality appraisal and synthesis elements. This might have altered ‘work done’ in the review. The EPPI Centre methodology does not focus primarily on locating studies and study attributes. It comprises of participative approaches to setting research questions, scoping reviews and

configurative interpretation of findings (Gough and Thomas, 2012 p.42). Arguably, this increased emphasis on assessing literature depth could compromise analysis of literature breadth i.e. exploration of the nature of the research topics and boundaries. This is essential in an area of scoping and mapping research which analyses data that crosses disciplines, research traditions and methodological approaches. Under mapping reviews the reviewer interprets different definitions, lexicon and terminology in disparate fields of interest. The EPPI Centre reviews operate best in well-defined areas of exploration- a reviewer may incorporate concept-mapping and text-mining techniques that require more standardised terms.

I used a Systematic Mapping review but I combined it with a scoping exercise (Levac et al., 2010). I reflect on the use of a single Systematic Map. This methodology maps the literature but tends not to scope its dimensions. By contrast, the scoping approach aims to identify the dimensions and boundaries of the literature base. Scoping helped to build a picture of the literature landscape and research gaps. This enhanced the Systematic Map which plotted the location of the included and excluded literature and refined the analysis of attributes. The combination of scoping and mapping enhanced my understanding about the literature landscape. Through scoping, I defined the dimensions of the landscape and methods choice. Through mapping, I probed and analysed those choices in greater depth. Each methodology played a different role in study identification. The scoping facilitated included study identification; whereas, mapping facilitated study analysis following study identification to a greater degree. Thus, I benefitted from my ability to describe and analyse different methods and context attributes (and the relationships between them) using two approaches.

Critical Interpretive Synthesis or Meta Narrative

Critical Interpretive Synthesis or Meta Narrative may have been viable choices for my second approach to methods contextualisation i.e. a review focused on understanding perspectives governing methods choices (figure 2.2, section 2.4). Both concentrate on conveying an authorial voice and narratives from across bodies of diverse literature. Narratives belonging to research perspectives (often defined by theory) would provide higher-level understanding in keeping with many of the proposed features of methods contextualisation. However, in Critical Interpretive Synthesis there would be less emphasis on understanding methods characteristics as part of a method (Gough and

Thomas, 2012, p.44) (especially those that can help to illustrate choices and uses of forms of communication). Methods characteristics are given less priority over theoretical relevance (op cit) in Critical Interpretive Synthesis. Similarly, Meta Narrative offers a critique of perspectives and research storylines but offers no specific mechanisms for understanding methods.

Realist Synthesis, Thematic Synthesis or Framework Synthesis

Realist Synthesis is designed to ask questions about impact of interventions. It asks in what circumstances interventions work and why. It is part of the Theory-Based School of Evaluations, utilising a generative understanding of intervention causality. Under my third approach to methods contextualisation Realist Synthesis methodology would require adaptation to incorporate a more diverse range of studies other than interventions. This was considered during the first phase of selection; however the central obstacle for Realist Synthesis selection was its emphasis on outcomes and impact. Due to this emphasis, it would be difficult to isolate contexts and mechanisms from outcomes. Realist Synthesis centres on questions of success, impact or effectiveness of intervention implementation rather than questions about appropriateness of implementation. For this reason, it may have been more challenging to adapt.

Thematic Synthesis and Framework Synthesis use critical realist approaches. The methodologies are limited in facilitating analysis of different forms of studies relating to methods and context. Both Thematic Synthesis and Framework Synthesis typically ask narrower questions than conceptual reviews; they also use a narrower range of study approaches (Barnett-Page and Thomas, 2009). Thematic Synthesis can identify general barriers and facilitators for interventions. However, both review methodologies were not designed to categorise different material that would be fundamental to understanding methods implementation- applicable to the third approach to methods contextualisation.

Meta review

The term meta review describes a number of review approaches (see historical development section 1.2). These can be summarised as: reviews of reviews, syntheses of review outcomes or synthesis of review narratives. A meta review/meta epidemiology (review of reviews) requires the presence of sub-reviews or many pre-existing synthesis. This is dependent on the field of interest and population of interest. Also, meta reviews tend to focus on the broader aspects of the literature landscape not study-level methods

data. Other types of meta reviews rely on quantitative or narrative aggregation or synthesis, attempting to understand the impact of methods characteristics on the outcomes of a single research phenomenon. This avenue would not offer as many opportunities to critique methods under the three methods contextualisation. Therefore, this approach tends to measure successfulness of the intervention or research (i.e. judging causality between variables linked to an outcome) rather than attributes, processes or appropriateness of implementation.

4.7 Summary

The chapter describes three interpretive strategies applied within the thesis. Each strategy had a different epistemological position, methodology and process. All the processes are tailored to achieve *method contextualisation* through the application of a range of adaptations. Adaptations were made in order to attempt to maximise the methodologies' potential to facilitate methods contextualisation. Across the reviews, these adaptations ranged from alterations (scoping and mapping); to innovative adaptations (and Narrative Synthesis) and a mixture of the two (Meta Study). Adaptations I made included: searching elements (such as purposive sampling of clusters); new study section or data analysis formats (such as Case Summaries); interpretive elements (such as analytical elements of the Narrative Synthesis); and procedural elements (such as dissemination). The reviews attempted to maintain the integrity of the original methodologies (epistemologically and empirically), whilst maximising the potential for contextualisation of methods.

More generally, the influence of methods contextualisation as a new review genre altered the nature of study selection. The Scoping review (Systematic Mapping approaches (EPPI Centre, 2007) analysed a wider pool of literature. The Meta Study used Cluster techniques incorporated a range of material associated with a study (Booth et al., 2013b)). The Narrative Synthesis used a study selection process that incorporated the principle of reviewing a pairs of publications (methodological or an empirical papers for each study depending on which type was originally identified). These techniques changed several aspects: the way that the review was designed, the papers selected and the outcomes of the review. I attempted to resolve as many of the challenges associated with creation and implementation of methodological adaptations as possible. My reflections on the successfulness of the implementation of the methodologies are presented in chapter 8.2.

Finally, I considered other methodologies that could have been used and how they could have contributed. The results of alternative selection strategies produced largely unsuitable methodologies. Most failed to capture the essence of the intended approach to methods contextualisation. Challenges ranged from: a lack of specialisation in methods contextualisation characteristics (EPPI Centre reviews), alternative focus on study outcomes (Realist Synthesis) and specific study type requirement (Meta Study, Framework Synthesis or Thematic Synthesis). Other methodologies such as Critical Interpretive Synthesis and Meta Narrative would have required more adaptation to extract information about study methods.

Chapter 5: The implementation of a Scoping Review according to the first approach to methods contextualisation

5.1 Introduction

This chapter represents the beginning of the implementation section of the thesis. The basis for the empirical studies was to show how the three approaches to *methodological contextualisation* can be carried out from the methodological templates that I created through adaptations to existing methodologies. The templates are presented in chapter four (4.3.3, 4.4.2 and 4.5.2). The mapping methodology used in this chapter is a combination of a scoping framework (Levac et al., 2010) and systematic mapping (EPPI Centre, 2007) were selected for adaptation according to methods contextualisation (explained in sections 2.4, 2.5 and 4.3.1). The scoping study is an example of the first approach to methods contextualisation: the exploration of the location of methods (and associated methods-context relationships). During the development of the methodological template I also identified suitable associated research characteristics. In the case of this review, I identified the examination of study attributes (table 2.2).

5.2 Wider literature

The chapter 3.3.3 provided an overview of the paucity of voice-elicitation research in dementia and AAC syntheses. Since the mid-1990s a raft of research attempted to capture the experiences of people with dementia, but it has been predominantly interview-based. Section 3.3.3 explained how research involving voice elicitation was identified in two additional topics within the literature; first, research which incorporated the perspectives of people with dementia, and secondly, those studies which focused on inclusivity as a topic. Two central texts (Goldsmith, 1996; Clarke and Keady, 2002) described the concept of voice in dementia research. Goldsmith (1996) focused on engagement; whilst Clarke and Keady explained the importance of a number of measures ranging from trust-based interviewer-interviewee rapport, non-verbal forms of communication, consideration of familiarisation periods with methods and multiple points of data collection (pp.41-2). Research across a number of cognitively impaired groups and AAC was established (see section 3.3.1). Chapter 3.3.3 referred to the few examples of AAC research in dementia fields (Allan, 2001; Allan and Killick, 2008) which all employed either nonverbal or photo elicitation methods. Allan (2001) actively evaluated ways for people with dementia to be

involved in services. Killick and Allan (2008) referred to communication as a key issue for people with dementia despite the progress that has been made in the last 20 years (p.214). Topics included nonverbal and communication through the arts but not AAC. The discussion recognised the emergence of arts-based communication methods from Killick's work with poetry (Killick, 1997; Killick and Cordonnier, 2000, cited in Killick and Allan, 2008, p.223).

Two bodies of research dominated the focus of dementia and AAC research in relation to understanding communication: biomedicalised assessments of alternative communication as a feature of care treatments or interventions and, secondly, AAC-focused research focused on improving outcomes. I expand on these separate bodies of literature here. The first strand of evidence surrounded psychosocial or communication-based interventions for people with dementia. These constituted a large body of largely biomedical literature on alternative communication mediums to manage services or care; such as 'Care Mapping' or to reduce agitated behaviours and increase memory (Bourgeois, 2003; Cohen-Mansfield, et al., 2001; Egan, et al., 2010; Gitlin et al., 2010; Kitwood and Bredin, 1992; Sambandham and Schirm, 1995). In parallel, AAC research focused on improving the outcomes of cognitively impaired populations, including dementia populations (Beukelman et al., 2007; Bourgeois 2001; Crema, 2009; Silverman and Schuyler, 1994). Synthesis of both perspectives remains absent from research reviews.

A review by Beard (2012) synthesised a sub-group of what I would classify as AAC methods i.e. art therapies in the context of dementia care. The review helpfully summarised previous research and reviews which increasingly utilised creative and nonverbal interventions in music, visual arts, drama and dance (such as, reminiscence and creative therapies (Killick and Allan, 1999; Moos and Bjorn, 2006 cited in Beard, 2012, p. 635). These symbolised a development in one element of dementia research. The review departed from traditional techniques to facilitate inclusion in research and practice. Beard (2012) remarked on the dominance of the biomedical approach (usually directed towards utilisation and efficacy of treatments) and the paucity of subjective accounts of experiences (p.634). The review also commented on the lack of consensus in arts therapy literature on concepts, definitions, study design, measurement, and evaluation. In her systematic review of art therapies with people with Alzheimer's, Beard (2012) argued that in later years, academics working in arts-based methods were among the first to recognise the disconnection between their creative methods and those with quantifying and experimental

research designs and the techniques they chose to appraise and analyse them (Berol, 2000; Moos and Bjorn, 2006; Meekums, 2010 cited in Beard, 2012, p.635).

The following methods, findings and discussion sections report the outcomes of the scoping review. There is a summary on the empirical contribution of the review and the knowledge gained for the next review, however detailed description on the review as an approach to contextualisation and the suitability of the elements of the methodology are presented in chapter 8.

5.3 Methods

The methodology was based on the first template presented in chapter 4.3.3. The approach is a combination of a scoping framework (Levac et al., 2010) and Systematic Mapping (Peersman et al 1996; EPPI Centre, 2007; Gough, 2003). This section describes the details specific to the question asked in this field of enquiry for that template. The implementation of the template is discussed in the following sections: a preliminary phase of searching, a research protocol, searches, conceptual framework and iterative adaptations to the protocol.

Preliminary phase

The focus of the review question was refined iteratively; this was consistent with the original scoping framework (Levac et al 2010, p.4 table 3) and the adapted approach for methods contextualisation (chapter 4.3.3). The review began with a broad focus on AAC research amongst cognitively impaired populations. During the process of constructing the review, the focus was gradually refined to include only studies working with people living with dementia. The review began with an intention to incorporate other cognitively impaired or communicatively impaired populations in order to make comparisons. However, this field of enquiry was too large. Evidence for this original intention can be found in the parameters of the preliminary searches and the analysis of a sub-set of excluded studies.

Definitions of AAC and voice have been discussed in chapter 3.2 and 3.3.2. The most relevant were used to help refine the scope of the review. They are repeated below.

The American Speech and Language and Hearing Association (2015) provided the following definition:

“Augmentative and alternative communication (AAC) includes all forms of communication (other than oral speech) that are used to express thoughts, needs, wants, and ideas. We all use AAC when we make facial expressions or gestures, use symbols or pictures, or write.” American speech and Language and Hearing Association (2015)

Refinement of study selection also included the concepts of *voice* and use of AAC and the comparison of different contexts. Voice has been described previously as *“an expression of individuality in the face of negative stereotypes: an act of self-validation that can be examined as a metaphor for protest”* (Campbell, 2009, p.116). However, this inadequately described the different ways voice elicitation is perceived by researchers, therefore, I re-conceptualised voice-elicitation. Voice-related research is interpreted differently according to discipline and approach. My first conceptualisation encapsulated the biomedical approach depicting function and frequency of speech or communication. My second conceptualisation denoted a social psychology approach which focused on the individual interaction and the level of interactional involvement. My third conceptualisation was associated with deeper reflection on the extent of elicitation of meaningful perspectives and viewpoints of people with dementia in research. (The third concept could be associated with a critical social gerontological approach to extending the role of people with dementia in society. These variations were directed by the social science perspectives on dementia (Innes, 2009; 2012) but beyond this, they had no specific empirical basis.

In summary, the conceptual framework attempted to capture voice-elicitation in three ways in the scoping review:

- Functional output of voice
- Interactional production of voice
- Interpretation of authenticity of voice

The first preliminary phase preceded the creation of the protocol (items 2 and 3 in the appendix, p.287 and p.289), records from searches were not included in the review however, and these informed the process. This phase is discussed first. Initial perceptions of the empirical field of enquiry described an unknown volume of AAC literature in dementia research (Chapter 3.4). I anticipated there was variation across AAC types and

study approaches. Thus, the field of enquiry generated many potential key terms across methodological, device-related, sensorial or behavioural and cognitive impairment-related research. A combination of all terms would have made the number of results unmanageable for screening. Therefore the preliminary phases strategized the best possible search terms (including multi-stage, multi-term strategies) to balance accuracy and comprehensiveness.

Table 5.1 (below) shows an example of the number of hits (i.e. results) generated from one database (Pubmed) in a single stage search. Terms were combined with OR operators, generating almost 1.2 million records. Details of other searches derived from Metalib (a University of York bibliographic search engine) conducted in the first phase are located in the appendix – item 2 (p.287). This database was not used in final searches as it was not an international database source that would provide the same functionality of other platforms. However, Metalib searches provided an indication of the search terms available in the literature surrounding treatments, interventions and training. The searches were designed to give an indication of numbers of hits per topic, however, results were not analysed beyond this point.

Table 5.1 Examples of experimentation with search terms in Pubmed

Methodological general	Sensory/behavioural	Device	Cognitive impairment
Nonverbal communication,	Photic stimulation, sensory art therapies, touch perception	Self-help devices, communication aids for disabled people, computer assisted instruction	Communication disorders
Qualitative research			Executive function, mental disorders diagnosed in childhood, brain diseases, delirium/dementia
Communication barriers, researcher-subject relations			amnesic/cognitive disorders

Search terms were then adapted to those displayed in table 5.2 below. The first category was broadly methodological but centred on researcher approach and the second and third made a distinction between the two groups of AAC methods. The fourth category

identified all types of cognitive impairment with which these methods could be used. The searches took into consideration the breadth of application of terms across disciplines, although the study was not regarded as a conceptual review.

	Methodological	Sensory/ behavioural	Device	Cognitive impairment
PUBMED ALL CATEGORIES (OR) <u>1243743</u> hits	Nonverbal communication, Qualitative research, Communication barriers, researcher-subject relations	Photic stimulation, sensory art therapies, touch perception	Self-help devices, communication aids for disabled, computer assisted instruction	Communication disorders, Executive function, mental disorders diagnosed in childhood, brain diseases, delirium/dementia amnesic/cognitive disorders

Table 5.2 Refinement of search terms

The details of other preliminary searches can be found in the appendix (item 3 p.289).

Databases used in the second preliminary stage were: the British Nursing Index (BNI), the American Psychological Association's PsycINFO (specialising in behavioural and social science research); the US National Institute of Health's library of medicine (Pubmed Central), Embase (Biomedical database), OVID Medline (US National library of Medicine's bibliographic database), Social Policy and Practice (SPP) and Cumulative Index to Health and Allied Literature (CINAHL). The searches experimented with grouping terms according to categories and the use of AND and OR operators between these groups. Thirty five of the studies were added to screening from the second preliminary phase; however, the main function of the phase was to use the process as an opportunity to refine search techniques prior to the main data base searches. Appendix item 2 (p.287) indicates how many references were viewed as potentially relevant from the first few records as a guide to the accuracy of the search. Embase, SPP, Medline, Cinahl all produced results deemed relevant to the topic at this stage.

Overall, the preliminary phase of experimentation resulted in the clarification of search terms. The process proved useful in determining what constituted narrow, broad, simple or complex searches in the context of this topic. In addition, the searches helped in to identify appropriate databases for particular disciplines relevant to this topic (the disciplines are displayed visually in chapter four, figure 4.1). Seven different disciplines were identified and relevant databases were identified and explored in the searches following the preliminary phase (appendix item 4, p.291). In learning how to represent different perspectives and operationalise searches, it became clear that different searching terms and techniques would be specific to databases and their capacities.

The protocol created for the scoping review was a way of translating the phases of the Scoping framework (Levac et al., 2010, p.4, table 3). The protocol was a strategy to address the specific question explored (see figure 5.1 below). The protocol was not rigid in all aspects. It was a way of adjusting parameters of the inclusion criteria in keeping with an iterative approach. The Systematic Mapping was embedded in the data collation and charting phase.

The proposed field of enquiry for the scoping was to explore the breadth and depth of research focused on AAC typologies. The question developed was: *What does the research evidence reveal about the use of AAC methods to hear the voices of participants living with dementia in different contexts?* The application of the stages of the scoping phases surround: the inclusion and exclusion criteria (including the conceptual framework); searches (lateral and electronic); the data extraction (through the creation of a database and Systematic Mapping attributes identification), and collation of data (through tabular, charting and descriptive summaries).

The scoping study framework

Structure based on (Levac et al., 2010, p.4 table 3)

Framework stage	Objective	Application
1: Identification of research question and field of enquiry	Scoping to focus on extent and nature of researcher consideration or critique of Augmentative and Alternative Communication methods	<p>Scoping research question:</p> <p>What does the research evidence reveal about the use of AAC methods to hear the voices of participants living with dementia in different contexts?</p> <p>Field of enquiry: The breadth and depth of research focused on AAC typologies.</p>
2: Identification of relevant studies	Identification of studies through categorisation of possible research traditions and elements of study/field of enquiry: typologies of cognitive impairment, AAC device focused studies and non-verbal behaviour/sensory expression focused studies and focus on researcher reflexivity/methodological credibility	<p>Preliminary search phases Identification of relevant research disciplines Creation of post-hoc inclusion/exclusion criteria Relevant excluded literature ‘parked’ for subsequent analysis Identification of included studies and wider pools of excluded literature</p> <p>INCLUSION CRITERIA</p> <p>Population: People with dementia, People with dementia and another condition (Parkinson’s, Huntington’s disease, Picks disease), People with dementia and an intellectual impairment (e.g. people with learning difficulties), People with dementia and another cognitive impairment (e.g. aphasia), People with dementia and a speech impairment People with mild cognitive impairment. (all ages)</p> <p>Method : AAC device and non-verbal behaviour/sensory expression</p> <p>Date : 1990 to present</p> <p>Type of evidence: Empirical studies from peer reviewed journals Language: International literature, English language translations Type of study: intervention/evaluation mixed methods, qualitative</p>

		<p>Study type</p> <p>Methodology focused study with qualitative design or mixed method design</p> <p>Conceptual framework</p> <p>The elicitation of voice – 2 conceptualisations</p> <ul style="list-style-type: none"> • Exploring interactions and production of voice (Labelled ‘2’ in literature body column of appendix item 6 p.296) • Interpreting the authenticity of voices (Labelled ‘3’ in literature body column in appendix item 6) (Category ‘1’ was excluded concerning the functionality of voice) <p>EXCLUSION CRITERIA</p> <p>Population:</p> <p>Children & young people People with cerebral palsy, autism, developmental dyspraxia, brain injury, locked-in syndrome, sclerosis/muscular dystrophy, aphasia (all are groups of AAC users) Cognitive, communication, neurological or developmental conditions without a dementia diagnosis</p> <p>Study focus/type:</p> <p>Exclusion of studies which:</p> <p>Evaluate the operational accuracy/effectiveness of an AAC device Explorations of professionals’ expertise/carer expertise in operating devices/interpreting nonverbal behaviour Economic evaluative studies Service appraisal focused studies</p>
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<p>3: Study selection</p>	<p>Lateral searches from early identification of highly relevant articles were the starting point for searching.</p> <p>Database searches were initiated using key words identified in the lateral searching and research questions.</p> <p>Review titles and abstracts to evidence the depth of knowledge that exists for each of the AAC typologies.</p>	<p>Iterative process of identifying relevant search terms, searching relevant databases, lateral search techniques</p> <p>SEARCH Databases: Pubmed, BNI, Embase, PsycINFO, SPP, CINAHL, ZETOC, INSPEC and LISTA. Manual searches of articles in relevant journals (see search terms & search strategies appendices).</p> <p>Identify pockets of wider literature relevant to analysis</p>
<p>4: Charting the data</p>	<p>Map data in matrix according to spectrum of AAC typologies - indicate extent of methodological reflection on method or consideration of validity/ reliability/ credibility.</p>	<p>Creation of Access database to extract key information from studies.</p> <p>(Quality appraisal not conducted). Overview of attributes of included studies. Systematic mapping- Overview of attributes of wider studies according to sub-group themes (other populations of AAC users and non-empirical papers).</p>
<p>5: Collating, summarising and reporting the results</p>	<p>Consider the meaning of the findings in relation to the overall study purpose and subsequent SR</p>	<p>Numeric and thematic analysis Data analysed according to all the data extraction variables to establish the ‘depth’ of evidence from amongst included and wider set of studies. Data presented in tabular form. Conclusions about the nature and location of available evidence for the field of enquiry and the appropriateness of the search strategies Systematic map conducted on included studies in key contextualising domains: study approaches (focus of the question, conceptual approach); context of the studies (national focus, national policy context); study outcome measures (outcomes [adapted from outcome measures], variation across contexts) and research design (overall design of studies, setting, and population)</p> <p>Collate pockets of excluded wider literature</p>
<p>6. Consultation</p>	<p>Consider the opportunities for knowledge transfer</p>	<p>Knowledge transfer section</p>

Figure 5.1 The Scoping Review Framework

This section discussed the considerations for search construction following the preliminary phase of searching. I describe database searches, lateral searches and summarise the finalised search parameters.

Database searches

Search examples are provided below (A full list of searches and results is located in the appendix (item 4, p.291).

Pubmed

Truncated free-text and MesH search terms

```
((("cognitive"[Title/Abstract])) OR (dementia*[Title/Abstract])) AND  
((((Communication disorder*[Title/Abstract])) OR ("communication aid")))  
OR ("self help devices"[MeSH Terms]))
```

```
((Communication disorder*[Title/Abstract])) OR ("communication aid")
```

Embase

Subject heading terms

1 facilitated communication.sh.

2 art therapy.sh.

3 1 or 2

1 verbal behavior.sh.

2 interpersonal communication.sh.

3 cognitive defect.sh.

4 1OR 2

5 3 OR 4

INSPEC-

Mesh terms

1 (augmentative and alternative communication).ab.

2 (Photic stimulation or computer assisted instruction or communication aids for disabled or Self-help devices or sensory art therapies or touch perception).ab.

3 (Communication disorders or dementia or Executive function or mental disorders diagnosed in childhood or brain diseases or cognitive disorders). ab.

4 2 or 3

5 1 or 4

Searches were conducted via the following nine databases: the US National Institute of Health's library of medicine (Pubmed Central), the British Nursing Index (BNI), the Biomedical database (Embase), the American Psychological Association's (PsycInfo), Social Policy and Practice (SPP), Cumulative Index to Health and Allied Literature (CINAHL), the British Library's Electronic Table of Contents (ZETOC), Institute of Engineering and Technology (INSPEC) and Library and Information Science Technology database (LISTA). Results of the searches are described within the findings section. The relevant literature disciplines included: gerontology, communication-enhancing methods, practitioner-focused, psychology, language and communication, policy and rehabilitation. These were categorised through the identification of three broader research traditions and relevant disciplines within them. The process followed is described in chapter 4.3.3, where the both categories are represented visually. The research traditions were applied social science and social policy research; behavioural sciences, and nursing and health care research. The tradition selection was guided by current categorisation of disciplines for journals (ProQuest platform and the British Nursing Index). The disciplines were then linked to relevant journals – see table in 5.3 in findings section.

The search construction process involved further experimentation with terms and combinations. Database searches identified the appearance of the key word in the title or the abstract of the indexed records. Certain specialist areas (such as methodology, technology, dementia or intervention) were suited to different databases. For example, specialist terms relating to areas such as touch and sensory methods were employed in searches in Psycinfo and Inspec. Major Subject Heading terms (Mesh terms) were utilised in searches, such as Embase and Pubmed (see example of search constructions above). The Pubmed searches centred on: communication, cognition, communication aids and dementia.

Simpler searches included the BNI platform which consisted of a single line search containing a handful of terms. Furthermore, certain search or 'advanced search' options had different levels of sophistication in each database. For instance, several databases offered multiple line searches (e.g. Embase, Lista, Inspec and SPP).

The searches highlighted the capacity of the Boolean operators to build a search and the potential for the use of MeSH (Major subject-heading) Terms. The Boolean operators allowed the reviewer to search pockets of literature (linked by specific search terms) then group together all of these pockets to get a final number of hits. The CINAHL search utilised a combination of operators, non-MeSH terms (such as ‘augmentative and alternative communication’) and MeSH terms, whereas, the search in Embase employed only terms relating to AAC. This refinement process showed that simple searches and core terms could also be very effective tools in searching; a style of searching that could complement broader searching techniques.

Key search terminology included: psychosocial perception, interactive communication applications, and speech and language therapy. Previously, the preliminary searches had highlighted the challenge of a review encompassing cognitively or communicatively impaired groups. The focus on dementia restricted the range of specific diagnostic terms required. The term ‘dementia’ often provided an effective filtering mechanism within searches. Some terms (e.g. ‘qualitative research’) were too broad and of little use. Subject-heading terms such as dementia also accessed all related types of dementia, without having to list them individually. Medicalised terms captured cognitive impairment-related research, such as: cognitive defect, executive function, mental disorders or cognitive impairments. AAC was referred to as augmentative and alternative communication, communication aids for disabled, self-help devices and, communication aids. The searches also incorporated other forms of AAC using qualitative methodology terms such as art therapy or photic stimulation.

Lateral searches were carried out in a mixture of more specialist journals (such as AAC and *Dementia*) and more generalist journals (such as the *International Journal of Language and Communication Disorders*). The full list is located in the appendix, item 5 (p.295). Preliminary lateral searches were conducted through Google Scholar and library catalogue and shelf searches. Another phase was hand-searches of the *Augmentative and Alternative Communication Journal* from the year 2000 to 2012 for relevant articles. In total, 310 papers were screened for relevance from these lateral searches.

‘Forward citation searching’ was a process of scanning the lists of ‘cited by’ papers associated with the key papers through forward citation searches in Google Scholar.

Approximately fifty citations were scanned in each case. Reference-scanning also took place; this involved scanning the cited reference lists in the bibliographies of key studies. Searches were intended to be comprehensive. The review did not use a saturation approach to study selection (most associated with qualitative reviews). Parameters for the included studies were developed as knowledge was developed from searches. Lateral and database searches were conducted in parallel. The studies were screened from title and abstracts in the reference manager programme Endnote. A database was created for data extraction in the software programme Access. Characteristics of the data were therefore reviewed at an individual level, and at a study wide level (through comparisons across the spreadsheet format). Characteristics abstracted into the Access database were represented in the categories in the full table of results (in appendix item 6, p.296). (Categories included: date, study type, AAC type, length use (of AAC), type of population, inclusion criteria category, literature body, comments on inclusion/exclusion decision). The Access database allowed the author to extract data using a mixture of drop-down lists and free text. A total of 85 studies (including the ten studies which met the final inclusion criteria) were included in data extraction due to the additional collation of contextual studies from the broader literature. These evolved into sub-groups of non-empirical (42 papers) and alternative AAC user populations (18 papers).

Searches were narrowed to: people with dementia, including Mild Cognitive Impairment (MCI) and any associated cognitive or intellectual conditions with dementia diagnosis. (The population provisionally proposed for this study included all cognitive impairments).

The date parameters were 1990 to 2012. This start date was chosen because it coincided with the changing culture of involving people with dementia in their care. It was not until after the early 1990s that policy began to prioritise views of dementia service users in the UK. Allan (2001) interpreted the (1992) Department of Health policy paper, *The Health of the Nation*, as a declaration of the duty of health authorities to consult fully with users about the services provided and to incorporate their involvement into decision-making and planning processes (p.12).

The conceptualisations of voice were incorporated into the inclusion criteria. However, the term 'voice' was not included as a term within the searching because it had been transformed into three subjective concepts. Screening for conceptual relevance was therefore a matter of my judgement as the reviewer. The functionality conceptualisation

was eventually dropped because it detracted from the experiential aspects of the review, putting more of a focus on measuring frequency and quality of speech.

Theoretical or discursive papers were also excluded from the final included studies. The final studies had to be empirical. This made the analysis of features of the data more consistent and provided a clearer picture of AAC studies conducted in research and practice as a function of the review. Theoretical papers were analysed within the wider set of studies to provide another layer of context.

5.4 Findings

Findings presented represent the results of the charting and collating phases of the methodology (chapter four, table 4.1). These combined scoping review methodology (Levac et al., 2010) and Systematic Mapping (EPPI Centre 2007; Gough et al, 2003; Peersman et al 1996). Systematic Mapping entailed the analysis of broader literature (85 studies) and also the additional analysis of attributes of the included studies.

Table 5.3 presents the final stages of database screening processes. Four studies were included from database searches, a further six were identified through lateral searches for the final set of ten studies. Included studies originated from CINAHL (Bober et al., 2002) from Embase (Kinney and Rentz 2005; Muller and Guendouzi 2009) and from Pubmed searches (Murphy et al., 2007). Papers were published in a range of social work and care, dementia, housing and care and speech and language themed journals. The table also presents penultimate stages of screening which created a set of 85 studies across all search methods. (This set was created prior to alternations in inclusion criteria relating to population and empirical content). Twenty one studies were considered relevant from database searches. These were added to lateral and preliminary searches to create a pool of 85 studies. Sixty six papers were identified from lateral searches (including sixteen from preliminary searches) from the 85 papers. There were four papers identified in more than one source.

Table 5.3 Results of database searches

Body of literature	Journal/database	Total hits (& date parameters)	N= papers found	N= included in 85	Included in 10 final papers
Gerontology	ZETOC	ZETOC #1 = 15 RECORDS ZETOC #2 = 4 RECORDS No date restriction	ZETOC =4/4, =0/15	1	0
Communication-enhancing Methods: AAC/Assistive technology	Communication matters publication INSPEC (1969 -) (OvidSP) Library, Information Science & Technology (EBSCO)	INSPEC (1969-2012) = 2592 RECORDS LISTA= 2003-2010 = 617 RECORDS	INSPEC = 15/2592 LISTA= 0/617	3 0	0 0
Practitioner – focused: Biomedical/ dementia/ nursing/medical /Primary Care research	BNI CINAHL (EBSCO)	BNI = 26 RECORDS CINAHL (EBSCO) (1980-2012) #1 = 95 RECORDS CINHAL (EBSCO) 2# =11 RECORDS	BNI = 2/26 CINAHL = 7/95, 4/11,	0 4	0 1
Psychology/ Social psychology/ behavioural science	Psycinfo	Psycinfo (1987-2012) = 2126 RECORDS	Psycinfo = 9/2126	0	0
Policy/social policy	SPP	SSP = 229 RECORDS	SSP= 1/229	1	0
Rehabilitation/long-term conditions/ mental health/ biomedical	Pubmed (Medline) Embase (Medline)	Pubmed #1 =944RECORDS Pubmed #2= 360RECORDS Embase (1980-2012) #1 = 2102 Embase (1980-2012) #2 = 1332	Pubmed= 11/944 & 13/360 Embase- 24/2102 , 16/1332	3 9	1 2

The PRISMA (Preferred reporting Items for Systematic Reviews and Meta-Analyses) diagram in figure 5.2 is the standard way of representing the search results of reviews and scoping reviews. The diagram presents numbers of papers screened out at different stages. However, it cannot fully represent the iterative nature of the process.

The scoping generated a relatively large number of results and provided a broad overview of the topic. The ratio between the numbers of studies from the lateral searches identified as potentially relevant against the number of studies identified by the database searches, is relatively standard (a ratio of 4 from databases to 6 from lateral searches). This is an inclusion ratio of 4/10502 for database searches and 6/310. Once de-duplicated, the overall success rate of included studies was 10/10551.

The initial screening phase eliminated a large number of records (10466 from 10551), but once initial relevance was determined, the process of shaping the parameters of the review continued. 85 papers (75 and 10 included papers) were 'parked' for further analysis, identified before inclusion criteria were narrowed. These are analysed separately. There was no formal appraisal of quality at this phase, which would play some part in eliminating a certain proportion of studies. However, this is not considered essential to a scoping exercise.

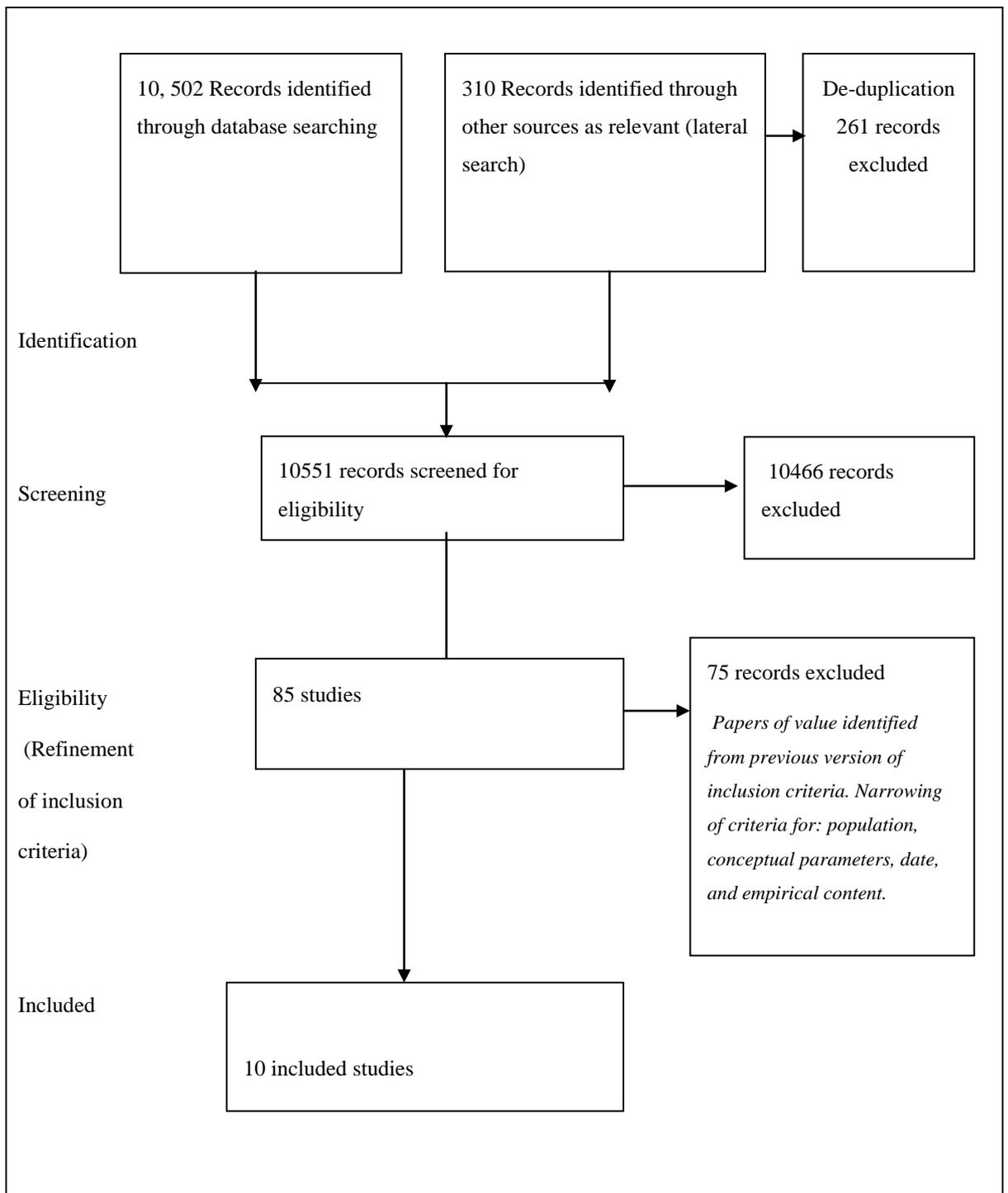


Figure 5.2 PRISMA diagram for the Scoping Review

The citations for the ten included studies are provided below (figure 5.3). The list of 85 (the 75 excluded studies and the 10 included studies) is provided in the extended table in the appendix (item 6, p.296).

Included studies in scoping review

- ALM, N., ASTELL, A., ELLIS, M., DYE, R., GOWANS, G. & CAMPBELL, J. 2004. A cognitive prosthesis and communication support for people with dementia. *Neuropsychological Rehabilitation*, 14, 117-134.
- BOBER, S. J., MCLELLAN, E., MCBEE, L. & WESTREICH, L. 2002. The Feelings Art Group: a vehicle for personal expression in skilled nursing home residents with dementia. *Journal of Social Work in Long-Term Care*, 1, 73-87.
- BOURGEOIS, M., DIJKSTRA, K., BURGIO, L. & ALLEN-BURGE, R. 2001. Memory aids as an augmentative and alternative communication strategy for nursing home residents with dementia. *Augmentative and Alternative Communication*, 17, 196-210.
- HANSON, E., MAGNUSSON, L., ARVIDSSON, H., CLAESSION, A., KEADY, J. & NOLAN, M. 2007. Working together with persons with early stage dementia and their family members to design a user-friendly technology-based support service. *Dementia*, 6, 411-434.
- KINNEY, J. M. & RENTZ, C. A. 2005. Observed well-being among individuals with dementia: Memories in the Making, an art program, versus other structured activity. *Am J Alzheimer's Dis Other Demen*, 20, 220-227.
- MCKEOWN, J., CLARKE, A., INGLETON, C., RYAN, T. & REPPER, J. 2010b. The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing*, 5, 148-158.
- MULLER, N. & GUENDOUZI, J. A. 2009. Discourses of dementia: A call for an ethnographic, action research approach to care in linguistically and culturally diverse environments. *Semin Speech Lang*, 30, 198-206.
- MURPHY, J., GRAY, C. M. & COX, S. 2007. The use of Talking Mats to improve communication and quality of care for people with dementia. *Housing, Care & Support*, 10, 21-27
- MURPHY, J., GRAY, C. M., VAN ACHTERBERG, T., WYKE, S. & COX, S. 2010. The effectiveness of the Talking Mats framework in helping people with dementia to express their views on well-being. *Dementia*, 9, 454-472.
- SIXSMITH, A. & GIBSON, G. 2007. Music and the wellbeing of people with dementia. *Ageing & Society*, 27, 127-145.

Figure 5.3 Included studies list

This section presents the range of information extracted from the studies during the data extraction and analysis. A summary of the ten included study attributes is provided within appendix item 6. (All included studies are highlighted grey).

Broadly speaking, the research traditions most frequently associated with the included studies were: practitioners, biomedical, dementia, nursing, medical and Primary Care research. The table in item 6 of the appendix (p.296) presents information about the types of AAC used in the included studies; this information has been summarised in the chart (figure 5.4 below). Three studies used low tech AAC (such as communication boards) (Bourgeois et al., 2001; Murphy et al., 2007; Murphy et al., 2010). Two studies used high tech, multimedia devices (Alm et al., 2004; Hanson et al., 2007). Arts-based methods featured in two of the studies (Bober et al., 2002; Kinney and Rentz, 2005). A single study was associated with music (Sixsmith and Gibson, 2007) and one with Life Story or Narrative methods (McKeown et al., 2010b). Finally, one study was classified as ‘other’ methods- the study by Muller and Guendouzi (2009) used ‘Participatory’ method.

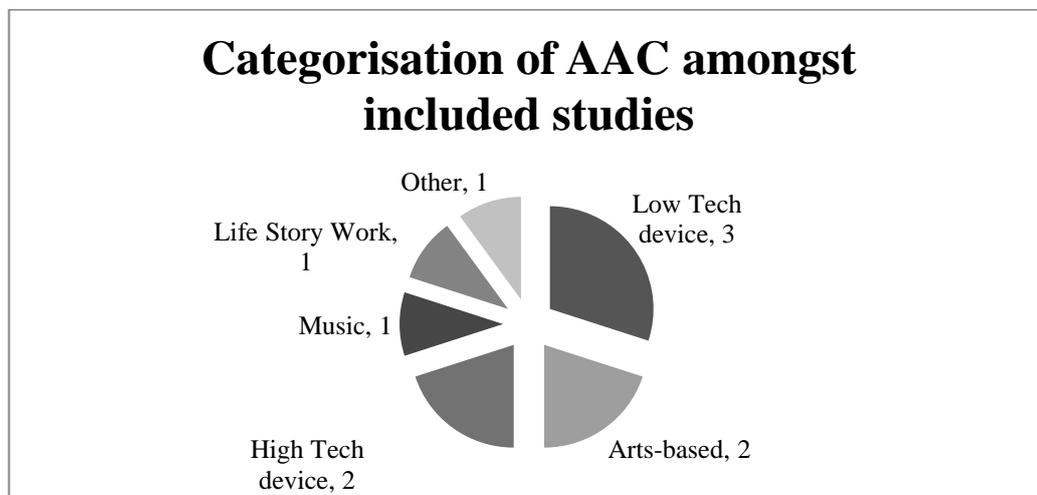


Figure 5.4 AAC categories for included studies

The attribute to illustrate length of use of AAC (a category in appendix item 6, p.296) was intended to provide some indication of length of use of the AAC system, method or device. Only three studies prioritised the familiarisation period with the AAC system during an intervention (Alm et al., 2004; Bourgeois et al., 2001; Sixsmith and Gibson, 2007).

There were no studies published before 2001, despite inclusion criteria to locate studies after 1990. The publication dates of study papers were evenly spread across a single

decade (see figure 5.5), ranging from 2001 to 2010. The most recent methods published were Life Story Work and Talking Mats™. Included studies were small in number to identify any patterns in the types of AACs being reported.

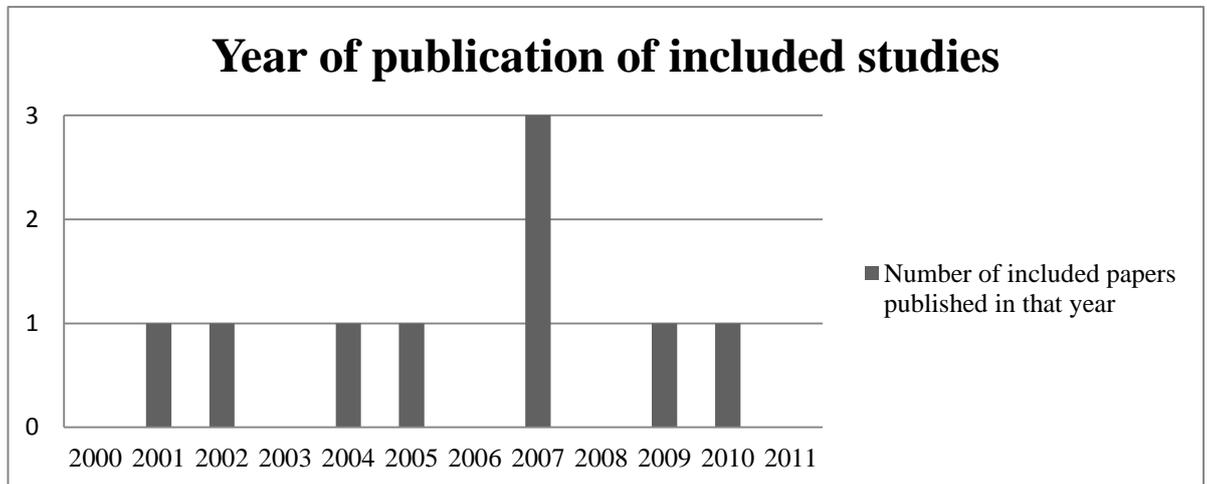


Figure 5.5 Year of publication of included studies graph

As a broad overview, all studies were classified as having populations with dementia. There were no studies that explicitly recruited people living with dementia who also had other conditions or forms of cognitive impairment. The included studies were identified according to the concept of voice elicitation (see appendix item 6, p.296). As described above, the functionality category was excluded. Two remaining categories (interactions to evoke voice and interpretation of voice) were included. All of the studies, except one, were classified as interactional representations of voice- Murphy et al. (2007) was the only study to be assigned the third criterion from the conceptual framework.

Study design features are listed below (see appendix item 5, p.295):

- Evaluation designs (Alm et al., 2009; Bourgeois et al., 2001; Kinney and Rentz, 2005; Murphy et al., 2007; Murphy et al., 2010)
- Intervention designs (Bober et al., 2002; Sixsmith and Gibson, 2007)
- Case Study designs (McKeown et al., 2010b)
- Participatory designs (Hanson et al., 2007; Muller and Guendouzi, 2009)

(Categories were re-defined during the Systematic Mapping phase. For further explanation refer to the latter part of this section).

Findings from a pool of excluded studies

Seventy five excluded studies were also analysed; they were gathered during the process of the review before search parameters were finalised. The 75 studies failed to meet revised inclusion criteria for dementia AAC user participants, empirical or non-primary content, date parameters (post 1990), or conceptual framework criteria (functionality conceptualisation was excluded). Sub-sets of the 75 were analysed according to particular attributes because I believed they contained information relevant to the scoping review. The first attribute analysed was papers without empirical or primary research content (42 papers). The second was a group of 18 papers which contained research about participant populations other than those with dementia. This analysis constitutes the first adaptation to the scoping framework methodology. It is a methodological feature of Systematic Mapping methodology (Peersman, 1996; EPPI Centre, 2007; Gough et al., 2003), which would help to locate the included studies in a wider literature. (Features of the 75 records (including the 10 final studies) were compiled into a table (appendix item 6, p.296)).

The 42 non-empirical or not primary research papers are listed as ‘review’ or editorial papers’ in the tabulation in appendix item 6. This group comprised the following papers:

Type of non-empirical/non-primary paper N= 42

- Theoretical overview/review (27)
- Methodological guidance (13)
- Systematic review excluded on the basis of topic (2)

Non-empirical or non-primary research papers were further classified as either methodology, theoretical or systematic review papers. Key aspects have been selected for discussion below. Non-empirical methodological papers discussed a range of AAC types (or systems) in the context of people with dementia, some expanded on methods identified in this review, for instance, the design of multimedia devices (Astell et al., 2009; Benveniste et al., 2010) or other participatory approaches with low tech devices, such as ‘Photovoice’ methods (Wiersma, 2011).

Amongst the 42 papers were two systematic reviews (non-primary research evidence). These were used to determine existing focus of synthesis but excluded from analysis because they did not meet the topic inclusion criteria, either as assistive technology or as AAC use. The first focused on the concept of use of Assistive Technology (Baxter et al

2012) rather than AAC, per se. A systematic review by Pennington et al (2007) failed to meet criteria on AAC use but highlighted the practical issues of adequate reporting in AAC studies (perhaps indicating the challenging aspects involved in a methods synthesis).

The sub-set contained twenty seven theoretical papers (including ‘overview’ and ‘review’ papers). Some papers built on concepts that subsequently featured in the Systematic Mapping exercise, such as conducting culturally sensitive research (Blake Huer and Saenz, 2002), or the development of strategies to ensure active engagement in research (Coddell, 2008). Participation also emerged as important issues (Huer and Lloyd, 1990; Nolan et al, 2002). The group of papers helped to contextualise the subsequent mapping exercise in the broader literature.

The second attribute analysed from the set of 75 excluded records concerned participant populations. The following section briefly discusses features of papers which featured participant populations other than those with dementia diagnoses (a total of 18 papers). The different population groups are presented in figure 5.6.

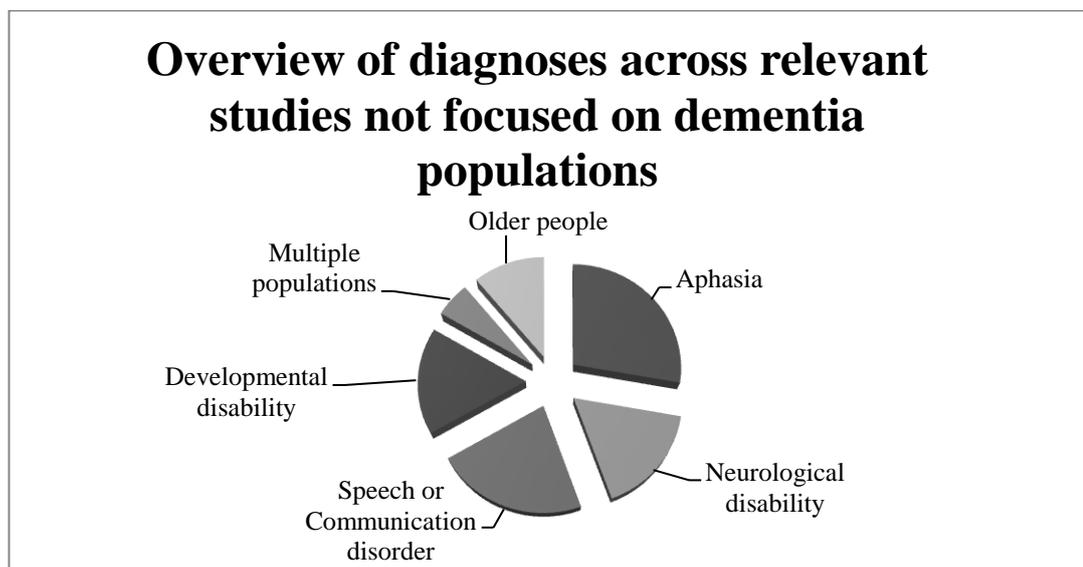


Figure 5.6 Participant population diagnoses (excluded studies) graph (studies N =18)

Five of the 18 studies which provided contextual information from broader groups of AAC users included five studies with people with aphasia (Barrow, 2008; Bruce et al., 2003; Cocks et al., 2011; Dalemans et al., 2010; Ho et al., 2005). There were four studies with people with speech or communication disorders (Bunyan, 1997; Dalemans et al., 2005; Mirenda and Mathy Laikko, 1989; Xuefei et al., 2010). Three studies contained

participants with a diagnosis of neurological disorders (Kikhia et al 2010; Langdon et al 2010; Stafstrom 2005). Three studies focused on populations with developmental disorders (Brewster, 2004; Millar et al., 2006; Nind, 2008); and two studies with populations of older people (Murphy et al 2005; Stuart 2000). Finally, there was one study containing multiple populations (Trudeau et al., 2010).

There was evidence that research with alternative AAC participant populations could be useful contextually, particularly with people with aphasia. For instance, Barrow's (2008) paper provided a gerontological perspective on listening to the voice of people living with aphasia. This highlighted the disabling barriers this population faced as a significant avenue for research.

A large proportion of the group of studies were about device-based interventions (14 studies). Three papers presented findings on narrative methods within an interview context (Barrow, 2008; Dalemans et al., 2010; Stuart, 2000). Another study could be classified as using artwork (Stafstrom, 2005).

The analysis of broader literature in the 75 excluded methodological, theoretical and empirical papers revealed a number of issues relevant to further study. Firstly, methodological papers could be a valuable resource for identifying further papers in subsequent reviews. Several papers were identified that indicated methodological papers could provide a rich resource of data for methods contextualisation. Furthermore, this evidence was focused on people with dementia (Astell et al., 2009; Benveniste et al., 2010; Wiersma, 2011). Theoretical papers indicated that concepts such as participation may be significant; specifically, the concept of inclusivity (Huer and Lloyd, 1990; Nolan et al., 2002).

Finally, the existence of topic-relevant papers in research conducted with other populations, such as people living with aphasia or people with learning difficulties, introduced me to the idea of making comparisons across participant population groups. Studies by Barrow (2008), Brewster (2004) and Ho et al (2005) engaged in the kind of areas of enquiry that I wanted to try to identify for a dementia population. These areas included listening to voices of participants (Barrow, 2008) and representational issues such as "*putting words in their mouths*" (Brewster, 2004). Another facet of this topic was trying to understand the effect of certain methods on communication interaction (Ho et al., 2005). (I pursued this avenue in the second empirical study in the thesis (the Meta Study)).

Systematic Map of included studies

This section describes the next phase of analysis. It was developed by drawing on Systematic Mapping techniques. This methodological strategy resulted in additional analysis of included studies according to another range of contextualising criteria (Gough, 2003, p.3-4). This step provided another layer of information about study attributes through further scrutiny of the ten included study papers. However, the emphasis of the process was focused on characteristics as opposed to micro-level textual analysis. The process involved four areas of description: *study approaches* (focus of the question, conceptual approach); *context of the studies* (national focus, national policy context); *study outcome measures* (outcomes- I changed this variable from the original ‘outcome measures’ description), variation across contexts) and *research design* (overall design of studies, setting, and population) (Gough et al., 2003, p.3-4). The four areas of description are tabulated below.

Table 5.3 Characteristics of included studies

Study	Social science perspective	Focus of research question	Setting (including country)	Population characteristics	Outcomes
Alm et al., 2004	Social psychological	Evaluation of system: To develop reminiscence material as a cognitive communication aid Singing, touch screen, talking about memories & music	Scotland, UK Day care centres	People with dementia- mean Mini Mental State Examination (MMSE) 16 (with speech)	People with dementia found reminiscence worthwhile (task enjoyment as well as interactional enhancement)
Bober et al., 2002	Social psychological	Feelings Art Group	NY USA Jewish Care Home	People with severe dementia who cannot express themselves verbally	Provision of a number of arts-base stimuli, residents could be helped to find 'voice' for their feelings
Bourgeois et al., 2001	Social psychological	Memory books and their effect on conversation	Tallahassee, USA Nursing home residents	People with dementia Intact verbal abilities	Enhanced information sharing and social closeness
Hanson et al., 2007	Social psychological	Participatory project to evaluate a multimedia project 'ACTION'	Sweden People with dementia living in the community	People with dementia (mild or moderate) with intact speech and able to express feelings- MMSE above 20 (the development group); awareness of diagnosis- MMSE above 25 (in test	Enjoyment of sessions, continuation to use ACTION at home

				group)	
Kinney and Rentz, 2005	Social psychological	Use of a well-being scale to measure the difference in engagement of people with dementia in a Memories in the Making project versus adult day centre activities	Ohio USA People with dementia attending day care centres	People with dementia in mild or moderate stages	More attention and participation in the Memories in the making project
McKeown et al., 2010b 148-58	Social psychological	Use of life story work to enhance person-centred care	England Case studies within Social Care Trust	People with dementia who also have complex behavioural needs who were not nearing discharge	Life story work can enable staff to see the person behind the patient and to allow people with dementia to express their voice verbally and non-verbally. Practice development approach can ensure LSW is implemented sensitively.
Muller and Guendouzi, 2009	Critical social gerontological	Fieldwork example- Ethnographic and Action Research approaches to care in linguistically diverse environments (e.g. language choice, person with dementia as the expert, constructive use of repeated questions)	Louisiana, USA Care home setting	People with dementia with linguistically and ethnically diverse backgrounds	Ethnographic approaches to understand cultural structures and Action research to understand how the institution functions for the benefit of care practice

Murphy et al., 2007 21-17	Social psychological	Project to compare structured and unstructured and Talking Mats™ communication.	Scotland, UK Residents in care homes or sheltered housing	People with dementia in different stages	Talking Mats™ can improve people with dementia in expressing their views
Murphy et al., 2010 454-72)	Social psychological	Interviews with Talking Mats™ and usual communication methods	Scotland, UK Different care settings and community settings	People with dementia in different stages	More effective communication, engagement and ability to keep on track in TMs
Sixsmith and Gibson, 2007	Critical social gerontological	Study looks at the role of music and music-related activities in the everyday lives of people with dementia	England, UK Residential settings and care settings	People with dementia- all stages	Meaningful participation through music is possible, also leads to social cohesion and empowerment

The four areas charted in table 5.4 constituted a different way of describing the studies beyond the original data extraction process. There were some potential areas of repetition (AAC types and research design). However, I considered this an opportunity to refine categorisations (such as study types) or to provide alternative categories (such as social science dementia perspectives). The process produced rich description across and within the studies; drawing on new contextually relevant areas such as policy. The process also introduced analytical elements to the review.

The analysis of the study approaches (the second column in table 5.4) concerned study perspectives. These were important because they were indicative of the kinds of research undertaken. Three broad categories were devised relating to dementia research perspectives (biomedical, social psychology and critical social gerontological (described by Innes first in 2009 p.20, and built upon in 2012, p.24-37). (Chapter 3.4 includes a full explanation of the perspectives). This moved the analysis beyond the level of paradigm, or discipline, identification which had been recorded for all studies in the scoping exercise. It

can be argued that the majority of studies adopted social psychological perspectives on dementia because of their focus on the individual level experience of people with dementia and relational (or interactional) dimensions. I argue evidence for this perspective is the interactional focus between the participant and the communication facilitator. (For example, the various AACs could be viewed as: a communication support prosthesis (Alm et al, 2004); memory books and the way they influence communication (Bourgeois et al., 2001); interaction with a multimedia device at home as a support (Hanson et al., 2007); Life Story work as a way to increase voice (McKeown et al., 2010b); and, improvement in expression of views and communication with Talking Mats™ (Murphy et al., 2007; Murphy et al., 2010)). Another study focus I found to be indicative of the social psychological approach was in a focus on individual emotive responses. Examples of this approach are: The Feelings Art group as a vehicle for personal expression (Bober et al., 2002), and individual well-being and memory-making (Kinney and Rentz, 2005).

Two exceptions were participatory (or ethnographic) methods and a music intervention study (Muller and Guedouzi, 2009; Sixsmith and Gibson, 2007). I believe these studies exhibited characteristics of a critical social gerontological approach. These studies analysed the social structures or institutions surrounding a person with dementia and their status (or well-being). For instance, Muller and Guendouzi (2009,) analysed socially-produced discourses of dementia, calling for the use of ethnographic and action research approaches typically associated with actionable social change and empowerment, initiated by the disempowered group (pp.200-1). Ethnographic research can be used to understand social structures. Sixsmith and Gibson (2007) studied music and the wellbeing of people with dementia, conceptualising changes in communication practice beyond immediate individual benefits (p.141). They believed meaningful participation in music could lead to such as social cohesion and empowerment amongst people with dementia.

In the next stage of analysis I present study contexts, including policy contexts. All ten studies were conducted in western countries. Six were from European countries (three from Scotland, one from Sweden and two from England). The other studies (four out of ten) were conducted across the USA (see table 5.4). Whilst there is not scope to analyse study policy contexts in detail, the main policy considerations were summarised. A preliminary outline of transnational policy themes are provided first. Generally, the perspective of the person with dementia was central to the policy featured in the majority of studies (Alm et al., 2004; Bober et al., 2002; Kinney and Rentz, 2005; McKeown et al.,

2010b; Muller and Guendouzi, 2009; Murphy et al., 2007 and Murphy et al., 2010). Studies emphasised measurement of experiences through Quality of Life instruments and other measurements (Alm et al., 2004, p.121; Bourgeois et al., 2001, p.196; Kinney and Rentz, 2005, p.220). Evidence-based policy was a significant influence amongst a couple of the studies (Hanson et al., 2007, p.412; Bourgeois et al., 2001, p.197). Music or arts-based methods took place within a therapeutic framework or setting (Bober et al., 2002; Sixsmith and Gibson, 2007). Finally, there were two studies from third sector organisations. These were produced to influence policy (the Joseph Rowntree Foundation and the Alzheimer's Association in the US). These organisations helped to put dementia issues on the agenda (Kinney and Rentz, 2005; Murphy et al., 2007 and Murphy et al., 2010).

UK-based studies cited the theoretical work of Tim Kitwood (1990; 1993; 1997) as an influence on policy and practice frameworks (Alm et al., 2004, p.121; McKeown et al., 2010b, p. 109; Murphy et al., 2007, p.22; Murphy et al., 2010, p.455; Sixsmith and Gibson, 2007, p.129). Murphy et al. (2010, reflected on the increasing need for service-user involvement as a policy requirement (p. 455). Choice and decision-making were enshrined in policy and legislation. Therefore, service professionals were obliged to hear the voices of all people with dementia. Other studies emphasised changing professional practices and attitudes in care services. Often this appeared to be a response to changes in social care policy rhetoric (Hanson et al., 2007; McKeown et al., 2010b; Murphy et al., 2007 and Murphy et al., 2010). For example, study described the identification for specific support for people in the early stages of dementia in Sweden (Hanson et al., 2007, p.412). The study authors recognised the need for a knowledge base on evidence-based care delivery to inform policy. Finally, Muller and Guedouzi (2009) identified unique dementia communication policy requirements. Requirements were created by the unique setting of the research, that is bilingual and multicultural care homes in Louisiana, USA (p.201).

Study outcomes were also recorded. A brief explanation of the outcomes of the explorations or evaluations of the study outcomes were created from the Systematic Mapping exercise (the far right-hand column in table 5.4). The most frequent outcome characteristic was the sense that AAC *enhanced* interactions (Alm et al., 2004; Bober et al., 2002; Kinney and Rentz 2005; McKeown et al., 2010b; Murphy et al., 2007, Murphy et al., 2010; Sixsmith and Gibson, 2007). Other outcomes analysed the enjoyment of people with dementia in interacting with the AAC (Bober et al., 2002; Bourgeois et al., 2001). Finally,

Muller and Guedouzi (2009) used participatory and ethnographic perspectives. Study outcomes pursued wider cultural understandings of dementia based on ethnicity, bilingualism and other factors.

The forth facet of the Systematic Mapping analysed research design. This included study type, participant population, study settings, and function of the AAC. A key element of research design was the AAC data collection method employed. The range of AAC methods included: cognitive prosthesis (Alm et al., 2004); Feelings Art Group (Bober et al., 2002), memory aids (Bourgeois et al., 2001), multimedia devices (Hanson et al., 2007), a reminiscence art programme (Kinney and Rentz, 2005), Life Story Work (McKeown et al., 2010b), participatory/ethnographic methods (Muller and Guedouzi, 2009), Talking Mats™ (Murphy et al., 2007, Murphy et al., 2010), and music (Sixsmith and Gibson, 2007). Four of the studies used reminiscence as a focus to produce augmenting or alternative communication (Alm et al., 2004, Bourgeois et al., 2001; Kinney and Rentz, 2005; McKeown et al., 2010b). Multimodality (multiple methods) featured in over half of the studies (Alm et al., 2004; Bober et al., 2002; Hanson et al., 2007; Kinney and Rentz, 2005; McKeown et al., 2010b; Sixsmith and Gibson, 2007). Multimodality can be viewed as a central feature of reminiscence, and a key principle within AAC-based intervention programmes.

Turning to research design, two of the Talking Mats™ studies had comparative designs (Murphy et al., 2007; Murphy et al., 2010). Studies contrasted the Talking Mats™ communication framework with usual communication methods. Seven studies could be described as interventions or evaluations (Alm et al., 2004; Bober et al., 2002; Bourgeois et al., 2001; Kinney and Rentz, 2005; Murphy et al., 2007; Murphy et al., 2010; Sixsmith and Gibson, 2007). McKeown et al (2010b) was an exploratory study and Hanson et al (2007) and Muller and Guendouzi (2009) adopted participatory approaches.

Study participant populations were analysed according to characteristics such as: diagnoses, type of dementia, and severity of dementia. The studies tended to use the general terms *dementia* or *Alzheimer's disease* to describe participants. None of the studies targeted other types of dementia (such as early onset dementia or Huntington's dementia). However, some studies contained samples with a mixture of dementias (McKeown et al., 2010b). There was large variation in severity of dementia amongst the study samples. Three studies recruited from across all severities (Murphy et al., 2007;

Murphy et al., 2010; Sixsmith and Gibson, 2007). Two studies chose to include people only with mild or moderate symptoms (Hanson et al., 2007; Kinney and Rentz, 2005). One study included participants with mild symptoms (Alm et al., 2004); whilst Bober et al (2002) only recruited participants with severe symptoms. Other studies recruited participants according to other characteristics, including: intact verbal abilities (Bourgeois et al., 2001), complex behavioural needs (McKeown et al., 2010b), or ethnic diversity (Muller and Guendouzi, 2009).

The vast majority of study settings included participants from residential care settings, the exception (Hanson et al., 2007) designed an at-home multimedia device service (the participants were lived in the community). The variety of functions of AACs within the study settings was also apparent from analysis. Some studies envisaged the AAC method as a (communicative) tool (Alm et al., 2004; Bourgeois et al., 2001; McKeown et al., 2010b; Murphy et al., 2007; Murphy et al., 2010; Sixsmith and Gibson, 2007). Other papers evaluated the AAC method as a form of therapy (Bober et al., 2002), Kinney and Rentz, 2005). One study viewed AAC as an assistive technology service (Hanson et al., 2007) and another conceptualised AAC as an approach or strategy in research (Muller and Guedouzi, 2009).

5.5 Discussion

This section presents the fifth element of the scoping review, which includes considerations of implications for policy, practice and research. The research review explored the use of AAC methods to hear the voices of participants living with dementia in different contexts. The review identified many contexts of AAC studies. The small sample of ten included studies makes generalisable statements impossible, and the identification of patterns challenging. Nevertheless, the review highlighted commonalities and differences across study characteristics and principles in included studies (and the wider group of excluded studies identified). Findings also identified gaps in knowledge on population types, settings, national contexts, and the length of use of AAC relevant to future practice and research. Main findings are discussed below, followed by a summary of findings in relation to previous syntheses.

The included studies were all based in developed western countries. Despite a multitude of disciplinary approaches, the majority of studies were published in dementia, health or

nursing-related journals (Bober et al., 2002; Hanson et al., 2007; Kinney and Rentz, 2005; McKeown et al., 2010b; Murphy et al., 2010). They had an emphasis on the potential value of AAC methods to service users. Generally, the papers introduced AAC into a dementia research approach, rather than dementia into an AAC approach. Eight of the ten Studies adopted a social psychology orientation towards dementia research. Studies conceptualised voice elicitation most commonly through interactions, that is, exploring interactions using AAC in different contexts. This constituted one of the conceptualisations used in the study identified in nine of the ten included studies (the conceptualisation was labelled '2' in the appendix item 6, p.296). There was one exception, (Murphy et al., 2007) which used a more reflective line of enquiry i.e. the use of Talking Mats to improve communication and quality of care. This focused on the interpretation of communication, in particular, the interpretation of the value and contribution of the AAC device/medium. This constituted the other conceptualisation of voice (labelled '3' in appendix item 6).

The conceptual framework aligned with many of the principles of a psychosocial approach to dementia and the centrality of the individual experience. Another finding from the scoping highlighted the role of AACs as methods and methodologies. Methodological approaches to AAC were consistent with creative, bottom-up approaches for marginalised groups (Aldridge, 2014). For instance, studies undertook participatory approaches (Hanson et al., 2007; Muller and Geundouzi, 2009) and arts-based methods (Bober et al., 2002; Kinney and Rentz, 2005). Two studies adopted a perspective likened to critical social gerontology (Muller and Guedouzi, 2009; Sixsmith and Gibson, 2007). These studies focused on status and wider societal structures for people with dementia.

Policy contextualisation elements of the Systematic Map echoed the centrality of the perspective of the person living with dementia in research. It was possible to see the hallmarks of individually-focused service provision and service improvement policy across European and US studies. European studies linked the evidence to Kitwood's Personhood theory (1990; 1993; 1997) (Alm et al., 2004; McKeown et al., 2010b; Murphy et al., 2007; Murphy et al., 2010; Sixsmith and Gibson, 2007). They emphasised Person-Centred Care and the importance of understanding the experience of the service user. The findings from a Swedish study (Hanson et al., 2007) was viewed as a mechanism to build practitioner knowledge, whilst UK-based studies were influenced by policy which made service user

perspectives mandatory (especially in the Scottish policy context of Murphy et al., 2010). Study outcomes emphasised the use, utility, and benefits of alternative or augmentative forms of communication.

The most common forms of AAC were types of low tech and high tech devices (Bourgeois et al., 2001; Murphy et al., 2007; Murphy et al., 2010; Alm et al., 2004; Hanson et al., 2007). Participants were, in general exposed to, or familiarised with, AACs for a short time. Study designs generally collected a number of aspects of data, making them relatively complex interventions or evaluations. The two Talking Mats™ studies had comparative designs (Murphy et al., 2007; Murphy et al., 2010). Multimodality and reminiscence were considered important techniques also. Finally, there was variation in the *severity* of the dementia symptoms studied, but, there was very little diversity in the *types* of dementia studied.

Analysis of the wider pool of 75 excluded studies revealed a mixture of overviews, reviews and methodological papers. Reflexive research was a more common feature of this group of papers (conceptualising voice-elicitation through exploration of interactions rather than interpretation of the value of AAC). Theoretical or methodological content illuminated a number of the AAC perspectives on practice. The key themes identified alerted me to topics such as culturally sensitive research (Muller and Guendouzi, 2009) and reporting of AAC participants' issues (Pennington et al., 2007). Excluded papers from the wider literature contained a sub-set of 18 papers that highlighted research for broader groups of AAC users. Aphasia research emerged as a potential source of data (Barrow, 2008; Bruce et al., 2003; Cocks et al., 2011; Dalemans et al., 2010; Ho et al., 2005). This sub-group of studies highlighted the benefits of comparisons between populations in a future review.

The scoping study also offers some guidance for future reviews within the dementia field. The scoping review provides a broad and updated assessment of augmentative or alternative communication methods. Findings can be contrast with the review by Beard (2012), a study identified following the completion of the scoping review, which nevertheless provided a useful backdrop and findings were compared). The review by Beard (2012) analysed the focus of existing research in the context of arts-based methods and people with dementia. Analytical fields included: how studies were designed and evaluated, findings and what this told the reviewer about the ways the technology enriched the lives of people with dementia. Methodologically, my review has parallels with the

two-tiered approach to analysis employed by Beard (2012). However, Beard's review contained different user groups, or non/quasi empirical data that were not clearly differentiated from the rest. The 2012 Beard review identified 134 articles on art therapy methods and Alzheimer's disease (and an additional 26 papers with broader populations). However, the bulk of the data was derived from key studies identified in 14 systematic reviews (p.636). The studies included in the scoping review were much fewer in number (10) in comparison. Beard had used the concept of enrichment to filter results, whereas this scoping review developed a narrower lens of voice elicitation within which studies were judged.

The studies within the Beard (2012) review focused on music, art, drama and dance specialisms. Two of my included studies (Bober et al 2002; Kinney and Rentz, 2002) and one study from the wider pool of 85 studies (Rentz, 2002) were also identified in the Beard review. (Future research could integrate the two reviews). Methods in the Beard review encapsulated many of the same methods identified within this review, such as: interactive tools, nonverbal activity and reminiscence, drama therapy methods, life review studies and multimedia biography and multisensory art methods.

In relation to literature on the voice of people with dementia (most significantly the works of Goldsmith (1996) and Clarke and Keady (2002)), the scoping review findings suggest types of AAC methods have expanded beyond nonverbal and low tech methods commonly proposed for communicating with people with dementia. However, my scoping review echoes the aspect of the guidance about maximising voice elicitation. Clarke and Keady recommend multiple forms of data collection methods (p.41-2) and this review found that over half of the studies applied a multimodal approach. There was also evidence of efforts to *value* the perspective of the person with dementia in the findings of included studies which emphasised communication enhancement and enjoyment. However, my findings reflected a low level of familiarisation with AAC methods. Overall, the dominance of the social psychology perspective reflected the shifts away from the biomedical standpoint, and, the progress made since social scientists began to elicit the subjective experiences of people with dementia. This orientation of the majority of the included studies builds on voice research in the dementia literature landscape (centred on the perspective of the person with dementia and the inclusiveness of the processes). AAC offered new horizons for exploration.

I will now describe the limitations to my scoping review. The scoping review explored a specialist area of AAC for a single population group. Seventy five studies were excluded in the final phase of screening following adjustments to inclusion and exclusion procedures. However, the review collated data from all studies since 1990 and it used a broad interpretation of alternative or augmenting communication applied in any research or practice setting.

There are several ways in which findings must be treated with caution. Firstly, the scoping reviewed search terms used during in the preliminary review phase, however the review did not include a full conceptual map. I did not identify studies prior to 2000, whereas, Beard's (2012) review identified many studies prior to 2000. Perhaps, this is indicative of my alternative conceptual framework inclusion criterion, or, it could reflect a shift in the way studies conceptualised voice. (It is possible they alluded to voice more overtly as research on inclusivity gained traction and I therefore identified increasing numbers of studies after a certain time point).

Lateral searches and database searches were extensive; however, further studies may have been located through key author consultation. Stakeholders and service users were not included in the process (something associated with the scoping reviews and Systematic Maps undertaken by the EPPI Centre (2007)). The extension of the review to include all AAC users may have provided additional comparative data, but would probably have been difficult to conduct comprehensively. Overall, the review elements provided an opportunity to compare aggregative and configurative data extracted.

5.6 Translatable knowledge to next review

This section discusses translatable knowledge, or 'knowledge transfer' outlined in stage 6 of the scoping methodology. Outcomes from the scoping review are listed below. These three areas helped to shape subsequent reviews.

- Exploration and further clarification of voice-elicitation (especially in relation to the exploration of interactions using AAC as well as interpretation of the value of the AAC)
- Exploration of good practice in implementation of methods beyond the concept of use
- Exploration of the benefits of looking outside of the dementia population literature– to explore transfer of methods (perhaps involving comparison of AAC methods across user populations)

On a practical level, I concluded the scoping review can be utilised as a knowledge platform. The process helped to identify a variety of existing AAC methods in use, key papers and key sources of data. The review also connected national contexts, policy and dementia research. Finally, the included studies and the broader literature brought certain themes to the fore such as multimodality, cultural sensitivity, and reporting of AAC participants' issues e.g. (Pennington et al., 2007). The process of searching and mapping helped to refine reviewing strategies and to limit my preconceptions about the evidence that would be located from the literature landscape.

I determined a subsequent systematic review was justified. A full scale systematic review would help to break down further stereotypes about limitations of people with dementia. There are currently no syntheses in this area. Finally, gaps within AAC user in the context of people with dementia were identified.

5.7 Summary

The scoping review was the first approach to methods contextualisation, modified to analyse the location of methods. I collated the attributes of selected studies conducted with people with dementia using AAC. The methodology followed the phases of a scoping review and a Systematic Mapping to supplement contextualisation of data. Findings identified ten included studies using a variety of AAC methods to elicit the voices and experiences of people with dementia with different levels of severity. Systematic Mapping allowed me to analyse study approaches and illustrated the dominance of social psychology approaches. Many studies used evaluative or intervention-based designs. There was a clear policy emphasis on user-led initiatives in Europe and the USA. Broader literature indicated that the field of dementia and AAC responded to a number of the trends in research, such as multimodality.

The review identified three areas of knowledge that would potentially inform other reviews: exploration of the concept of voice; exploration of good practice in implementation of AAC, and exploration of the benefits of exploring other participant populations. The scoping established the need for a full-scale review and it identified gaps in knowledge such as setting, context and study designs (confirming the 'scattered' nature of the literature base). Methodological reflection underlined the restrictions inherent in the inclusion criteria, in particular, the emphasis on voice-elicitation.

Chapter 6: The implementation of a Meta Study Review according to the second approach to methods contextualisation

6.1 Introduction

This chapter is part of the implementation phase of the thesis. The basis for the empirical studies was to show how the three approaches to *methodological contextualisation* can be carried out from the methodological templates that I have created through adaptations to existing methodologies. The methodological templates are described in chapter four. A Meta Study was selected as an appropriate methodology for methods contextualisation (selection is explained in chapters two (2.4 and 2.5) and four (4.4.2)). The Meta Study is an example of the second approach to methods contextualisation: to examine the perspectives governing methods processes. Meta Study is an in-depth synthesis of theory, method and data to produce new ways of thinking about phenomena (Paterson et al., 2001, p.1). I combined the Meta Study methodology with a study Cluster technique; (Clustering was developed by Booth, et al., 2013b). Table 2.2 (section 2.5) summarised associated characteristics that could guide the direction of the review. In the case of this review, I identified the analysis of processes as a suitable angle of research.

6.2 Wider literature

The review contextualises the interpretation overarching theoretical frameworks for Augmentative or Alternative Communication data collection methods. There were two main examples of reviews of frameworks in the wider literature (Lenker and Paquet, 2003; Edyburn, 2001).

The review by Edyburn et al (2001) analysed twelve conceptual models for AAC. Edyburn et al's review focus examined models which attempted to harness the performance of AAC users. The selection of conceptual models demonstrated the lack of clarity in what were termed conceptual models and other kinds of frameworks or assessment instruments. Edyburn et al (2001) defined a broader range of entities that could conceptualise, frame and interpret AAC. Models were intended to understand "*key variables, relationships and systems*" (Edyburn, 2001, p.16). This could result in developments in theories, models, development, policy and practice (op cit.). This became a useful definition for models, frameworks structures and processes within the synthesis because it concentrated on function and purpose rather than categorisation of the tool itself.

In contrast, the review by Lenker and Paquet, (2003) used a general, itemised definition of models (Rosen, 1989 cited p.1-2). This list included unifying structures, hypotheses, models of function, and theories. The models reviewed specialised in Assistive Technology and outcomes. Therefore, Lenker and Paquet (2003) only focused on social psychology literature and Person-Environment-Interaction theory related to Assistive Technology fields. This could be considered a single branch of AAC. There were several useful features of the review. Firstly, the purposive selection of models (based on prevalence in the wider literature and the reviewer's interest in exploring models outside of the Assistive Technology field where possible). Lenker and Paquet (2003) commented that the previous review by Edyburn (2001) lacked sufficient depth because of the number of studies included.

The six models reviewed by Lenker and Paquet (2003) were: Human Activity Assistive Technology HAAT (Cook and Hussey, 2002 cited pp.3-4); The ICF (WHO, 2001 cited pp. 5-6); Matching Person and Technology MPT (Scherer, 1998 cited pp. 7-8); Assistive Technology User's 'Career' (Gitlin, 1998 cited pp. 8-9); Social Cognition decision-making theories (Carter, 1990 cited pp. 9-11) and Perceived Attributes Theory (Rogers, 1995 cited pp. 11-12). The models were analysed according to certain criteria. (For example: goals, technology systems, implicit outcome measures, predictive traits, validation in testing outcomes and utility). Their main findings argued that three of the frameworks (HAAT, ICF and MPT) were superior descriptive frameworks, according to the criteria they set out.

The Lenker and Paquet (2003) review recognised the role of theory and the role of theoretical frameworks in reducing the gap between theory and practice. My study adopted purposive sampling similar to Lenker and Paquet (2003), prioritising analytical depth. Finally, the breadth of the focus of my review expanded on Assistive Technology topics to look more broadly at AAC. My review targeted theoretical frameworks and how they helped researchers to interpret AAC methods.

A key piece of research providing an overview of frameworks was identified during the process of the Meta Study (Raghavendra et al., 2007). Previous investigations into this field by Schlosser and Raghavendra (2004, cited p.352) were identified as early *structures* (labelled as decision-tree frameworks, matrices and feature-match processes) used within AAC to guide intervention decision-making (such as Glennen and DeCoste, 1997; Reichle and Karlan, 1988; Shane and Bashir, 1980). Raghavendra (2007, p.352) differentiated

between structures and models; arguing that the structures emerged from clinical practices without research or theoretical grounding and little was known about how they were used in practice. In comparison, the three models mentioned were theoretically grounded in relation to either contexts or environments. The three models were: the Participation Model (Beukelman and Mirenda 1992; 2005); the International Classification for Functioning Disability and Health (World Health Organisation, 2001) and a Proposed Augmentative Alternative Communication Model (Lloyd, et al 1990). The first and second models from the three I have listed above had been identified during the course of my review (the second in the context of the Communication Matrix (Rowland 1990)). The third model described interactions with AAC technology models and was not identified from the Meta Study searches I have undertaken.

6.3 Methods

The methodology for the review is reported in chapter 4.4 of the thesis. I defined review parameters and a review question in order to address the particular focus of this empirical case. Firstly, the review incorporated a wider range of AAC users than the scoping review. (However, the review did not provide a clinical judgement on appropriateness of the interpretive frameworks (or other interventions) across populations unless appropriate transfer was indicated by the creators of the framework).

The Meta Study critiqued the *contexts* and *concepts* surrounding the frameworks to understand their role in interpreting AAC methods. The central empirical question in this review was: *What are the key conceptual and contextual aspects of frameworks which increase understanding about interpreting AAC methods?*

The methodology fourth chapter (4.4.1; 4.4.3) explains Meta Study (Paterson, 2001) and Clustering techniques (Booth et al., 2013b), including adaptations I made to the processes (4.4.2). This section presents a summary of the methods, i.e. the steps taken, the outcomes of the searching, and selection decisions for this particular review question.

Identifying a Cluster

The process of identification of a cluster began with identification of a ‘key pearl citation’ to base a cluster around.

The searches to identify key pearl citations are summarised below. Figure 6.1 provides detail about the search terms for three separate database searches, resulting in a total of

2776 records. The three searches comprised Pubmed MeSH Terms (retrieved 250 hits); Web of Science Search (retrieved 915 hits) and Scopus search (retrieved 1611 hits). The date range was from 2000 to 2013 (however, this did not prevent papers from the cluster pre-dating the year 2000).

The Pubmed search combined very broad subject headings to capture the concept of AAC (categorised as ‘communication aids for the disabled’ within the subject headings) and ‘methods’ - a term designed to retrieve reference to methodology in the absence of commands for interpretation. The Web of Science search used a combination of truncated terms for AAC divided between ‘augmentative’ and ‘alternative’ forms of communication. Searches were extended across a number of science and social science disciplines. The Scopus search was centred on the truncated term for augmentative communication. A broad variety of disciplines, including medicine, health, social science, psychology and computer science, were searched. Results were restricted to English language publications and publication dates later than 1999.

<p>Pubmed: ("Communication Aids for Disabled"[Majr]) 843 AND "methods" [Subheading:NoExp] 1741884 Filters activated: Publication date from 2000/01/01 to 2013/12/31 250</p>
<p>Web of Science: Topic=("augment* communicat*") 219 OR Topic=("alternative communicat*") 768 Timespan=2000-2013. Databases=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH. 915</p>
<p>Scopus: TITLE-ABS-KEY("augment*" AND "communicat*") AND SUBJAREA(mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci) AND PUBYEAR > 1999 AND (LIMIT-TO(LANGUAGE, "English")) AND (LIMIT-TO(DOCTYPE, "ar")) AND (LIMIT-TO(DOCTYPE, "ar")) AND (LIMIT-TO(SUBJAREA, "MEDI") OR LIMIT-TO(SUBJAREA, "HEAL") OR LIMIT-TO(SUBJAREA, "SOCI") OR LIMIT-TO(SUBJAREA, "PSYC") OR LIMIT-TO(SUBJAREA, "COMP")) AND (LIMIT-TO(LANGUAGE, "English")) Date restricted to 2000 onwards. 1611</p>

Figure 6.1 Database searches

Inclusion and Exclusion Criteria

The inclusion and exclusion criteria (presented in figure 6.2) helped to identify studies which might be appropriate as key pearl citations. My criteria specified that included papers had to be present a framework for interpreting AAC (conceptual, methodological or analytical). Eddyburn (2001) describes frameworks (and models) as tools in providing the discipline with “*an intellectual framework that stimulates advances in theory, research, development, policy and practice*” (p.16). This provided a useful definition for inclusion. The key paper had to convey contextually or conceptually rich content. This criterion helped to narrow the focus to frameworks capable of interpreting AAC. The inclusion parameters stipulated links to empirical sources in order to be classified as a viable cluster.

Inclusion	Exclusion
<p>Refers to a conceptual, methodological or analytical framework that can be used across AAC population</p> <p>Contains contextually or conceptually rich papers</p> <p>Contains a methodological explanation</p> <p>Evidence of effectiveness studies for the framework</p>	<p>Effect-driven or causal studies of AAC</p> <p>Intervention or treatment studies to ‘test’ language</p>
<p>Empirical basis</p>	<p>Non-empirical studies were either :</p> <p>-Secondary analysis i.e. reviews or summaries (can be examined for relevancy of papers)</p>
<p>Academic article</p>	<p>Irrelevant topic</p> <p>Article not produced by an academic journal</p>

Figure 6.2 Inclusion/exclusion criteria for key pearl citations

Clustering was an iterative process with systematic elements. Initially, the screening included 40 papers which covered the applicability and the acceptability of AAC. Frameworks focused on the interpretation of AAC were selected as a subset (13 papers). From these 13, four were selected according to a sampling matrix in figure 6.3 (explained in greater detail below). The four papers identified as pearl citations were: Murphy and Boa (2012): the use of the International Classification of Functioning, Disability and Health (ICF) for AAC; Nigam (2006): sociocultural development and validation of lexicon

for AAC users; Rowland (2011): the Communication Matrix, and Soto (2006): the Narrative Assessment Profile.

I limited the number of clusters to maximise analytical depth. (The key pearl citation selection indicator table (presented in the methodology chapter 4.4.3 and appendix item 1, p.286) highlighted the aspects of the papers before four were selected as candidates for the sampling matrix (see figure 6.2 below).

The ICF framework and the Communication Matrix (CM) were explicitly referred to as frameworks. However, the ICF was more conceptual than the CM, which suggested the framework represents a structure for practice. The Culturally Valid Lexicon was referred to as a systematic methodology. Finally, the Narrative Assessment Profile was considered an analytical framework to evaluate dimensions of narrative.

Justification for consideration as frameworks:

ICF Conceptual Framework - *“provides a framework that helps rehabilitation staff take a holistic view of the patient”* (abstract Murphy and Boa, 2012);

CVL Methodological Framework- *“a methodology for the cultural validation of lexicon to be used by AAC users that can be systematically replicated with other cultural and linguistic populations”* (Nigam, 2006, p.248)

CM Methodological Framework- *“A framework for determining logical communication goals”* (Rowland, 2011, p.192);

NAP Analytical Framework – Analytical structure used to *“evaluate the multidimensional nature of narrative discourse in people with communication impairments”* (Soto et al., 2006, p.234).

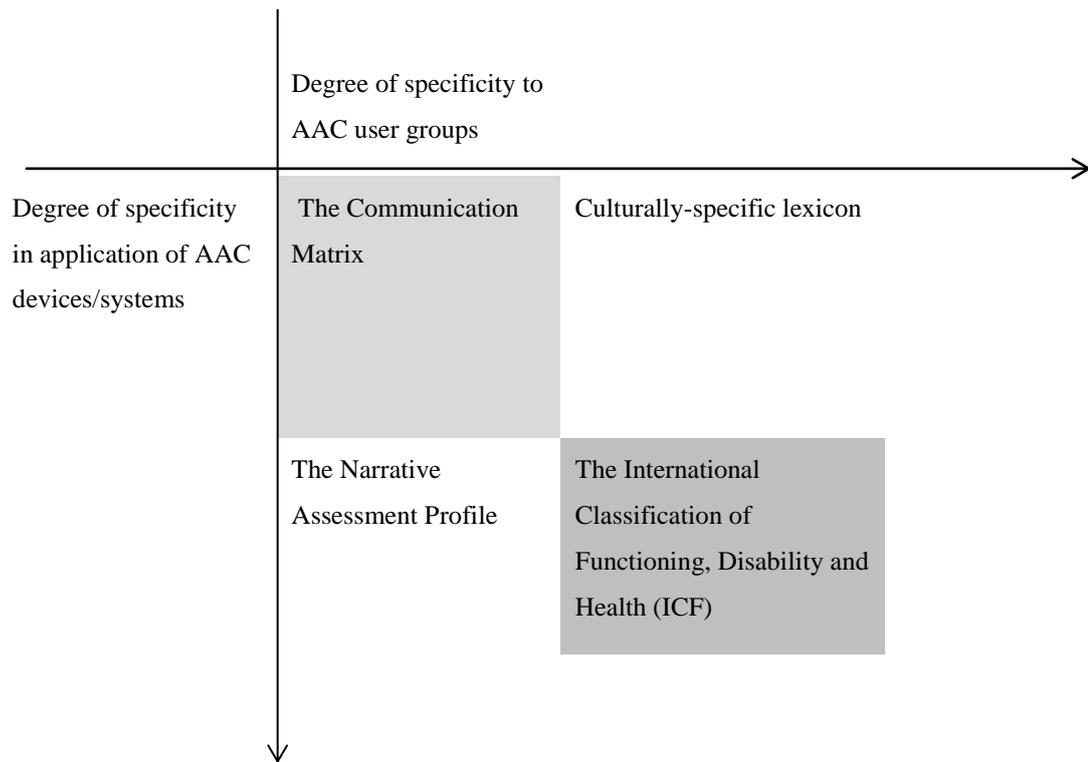


Figure 6.3 The sampling framework

The matrix (my sampling framework) was designed to present degrees of difference between frameworks that interpreted AAC. I devised the axes for the sampling matrix according to the types of frameworks that were used and to whom they applied i.e. the degree of specificity or universality implied. The frameworks were selected as examples of *broad* or *narrow* interpretive structures according to the breadth of the AAC user group targeted, and the specificity of the application of the AAC system or framework. The matrix sampling technique applied ‘qualitative’ principles to examine sub-groups from a larger pool of studies (Dixon-Woods et al., 2006b).

Studies were identified on the basis of information about which groups the frameworks were suitable for; and the range of methods they were suitable for. This is discussed further in the findings section 6.4.

Building a Cluster

Further detail about the methodology of a Cluster can be found in the methodology chapter 4.4.2. Inclusion of papers in the cluster was a matter of judgement (full lists of references are located in appendix item 7, p.317). Attempts were made to include the relevant empirical and theoretical papers. However, there was a discretionary aspect to the inclusion of data, especially in relation to peripheral papers.

6.4 Findings

I have presented the Meta Study findings in narrative form. This is consistent with the original methodological guidance (Paterson et al., 2001). The findings section addresses the main phases of the results. These phases are: the Meta Method and Meta Analysis (discussed jointly), Meta theory and Meta Synthesis (relating to the steps in Paterson's (2001) research process p.11 table 1.1). However, I begin with visual representations of the clusters (figures 6.4-6.7), and an overview of each cluster. Secondly, the main features of the cluster findings are addressed in turn. Meta Method Meta Analysis and Meta Theory phases are discussed, followed by the explanation of synthesis findings.

The four papers identified as pearl citations were: Murphy and Boa (2012) Use of the International Classification of Functioning, Disability and Health (ICF) for AAC; Nigam (2006) sociocultural development and validation of lexicon for AAC users; Rowland (2011) The Communication Matrix and Soto (2006) The Narrative Assessment Profile.

(Figures 6.4-6.6.7 represent the clusters. 'KT' refers to Kinship Theoretical'papers. All types of papers are listed in the table 6.1).

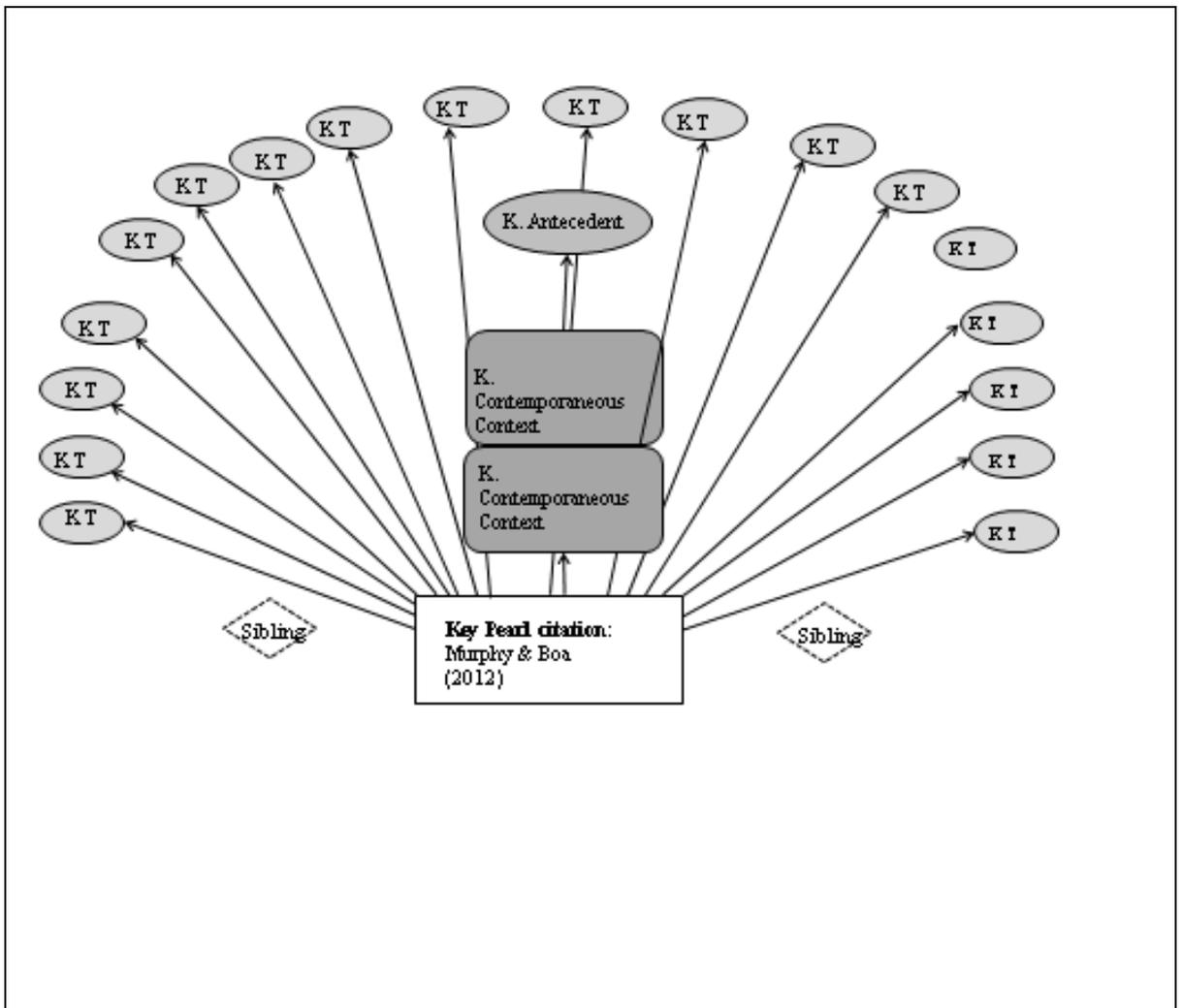


Figure 6.4 Visual representation of ICF Cluster

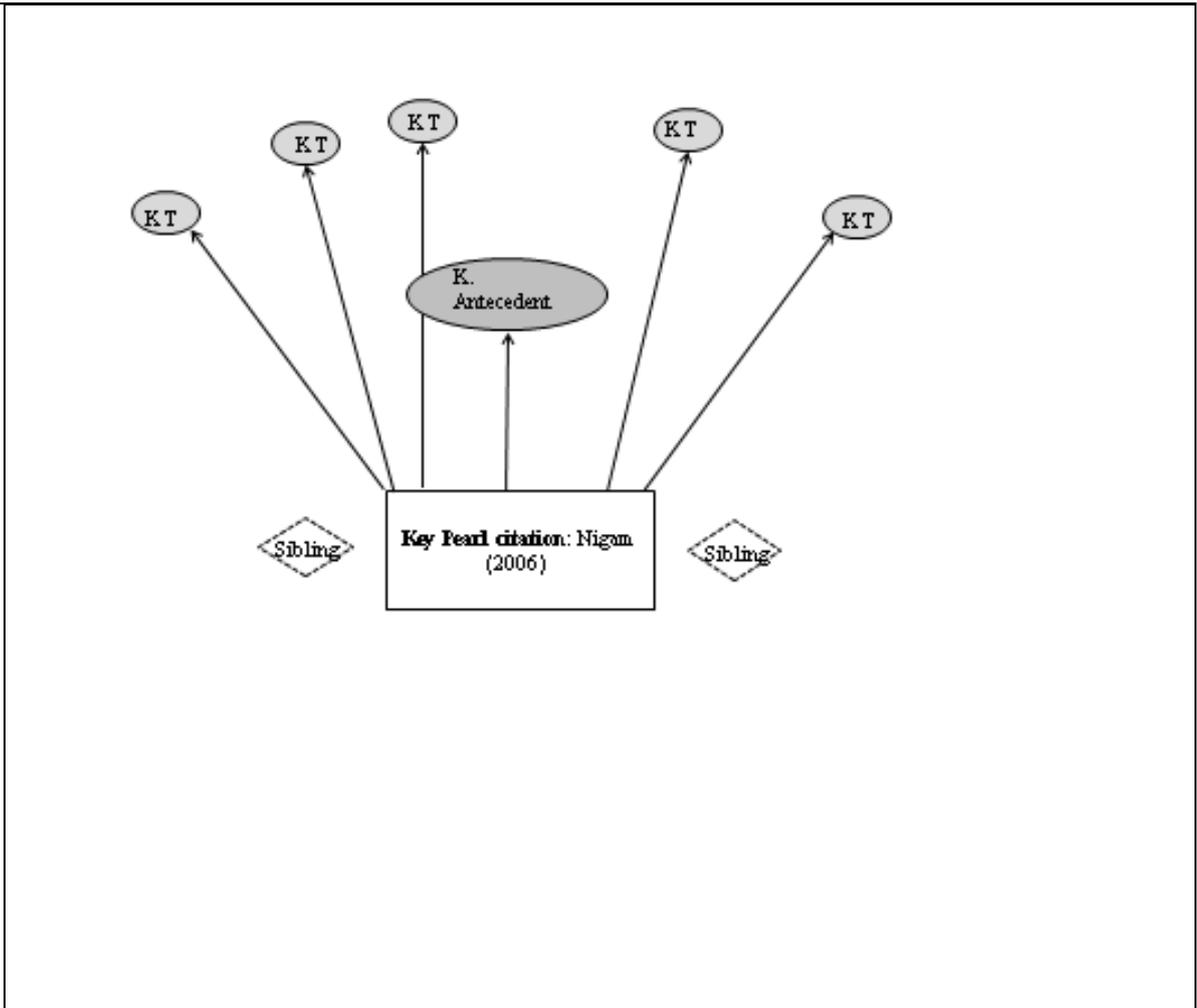


Figure 6.5 Visual Representation of Culturally Valid Lexicon Cluster

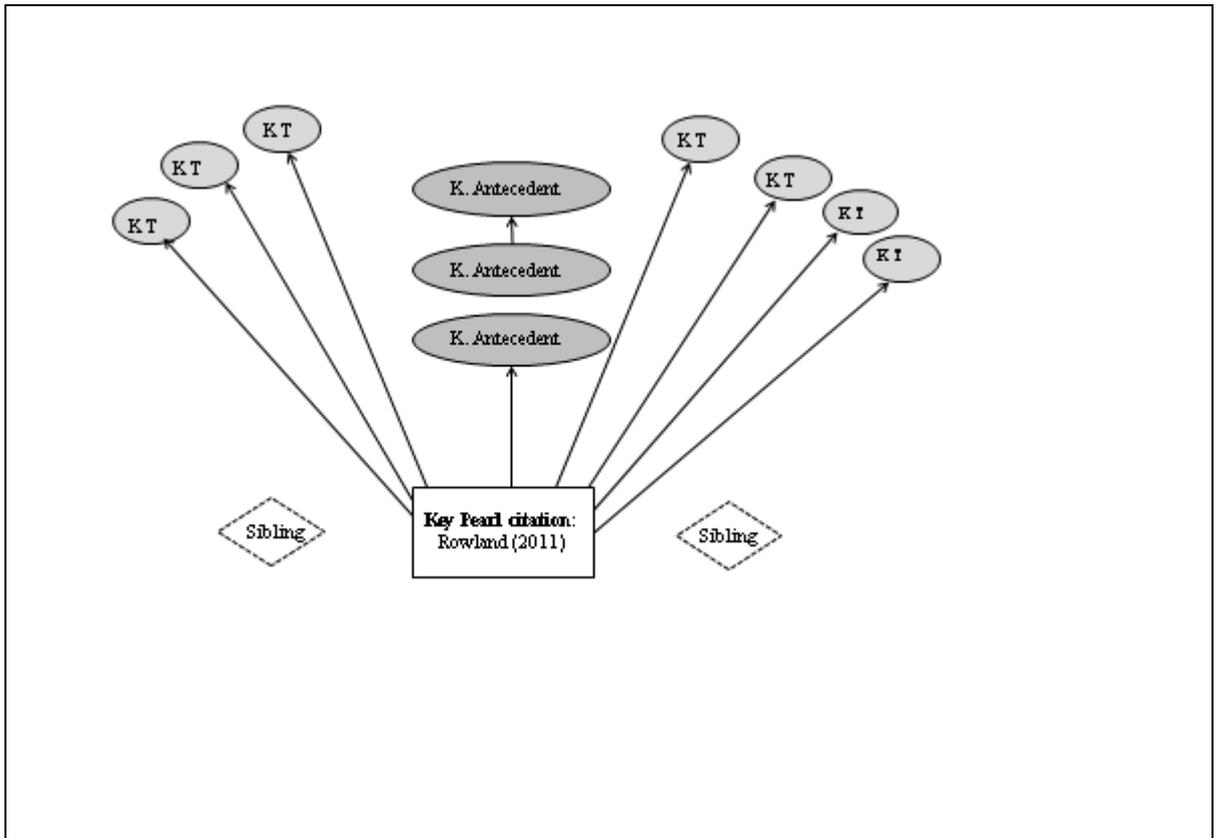


Figure 6.6 Visual Representation of the Communication Matrix Cluster

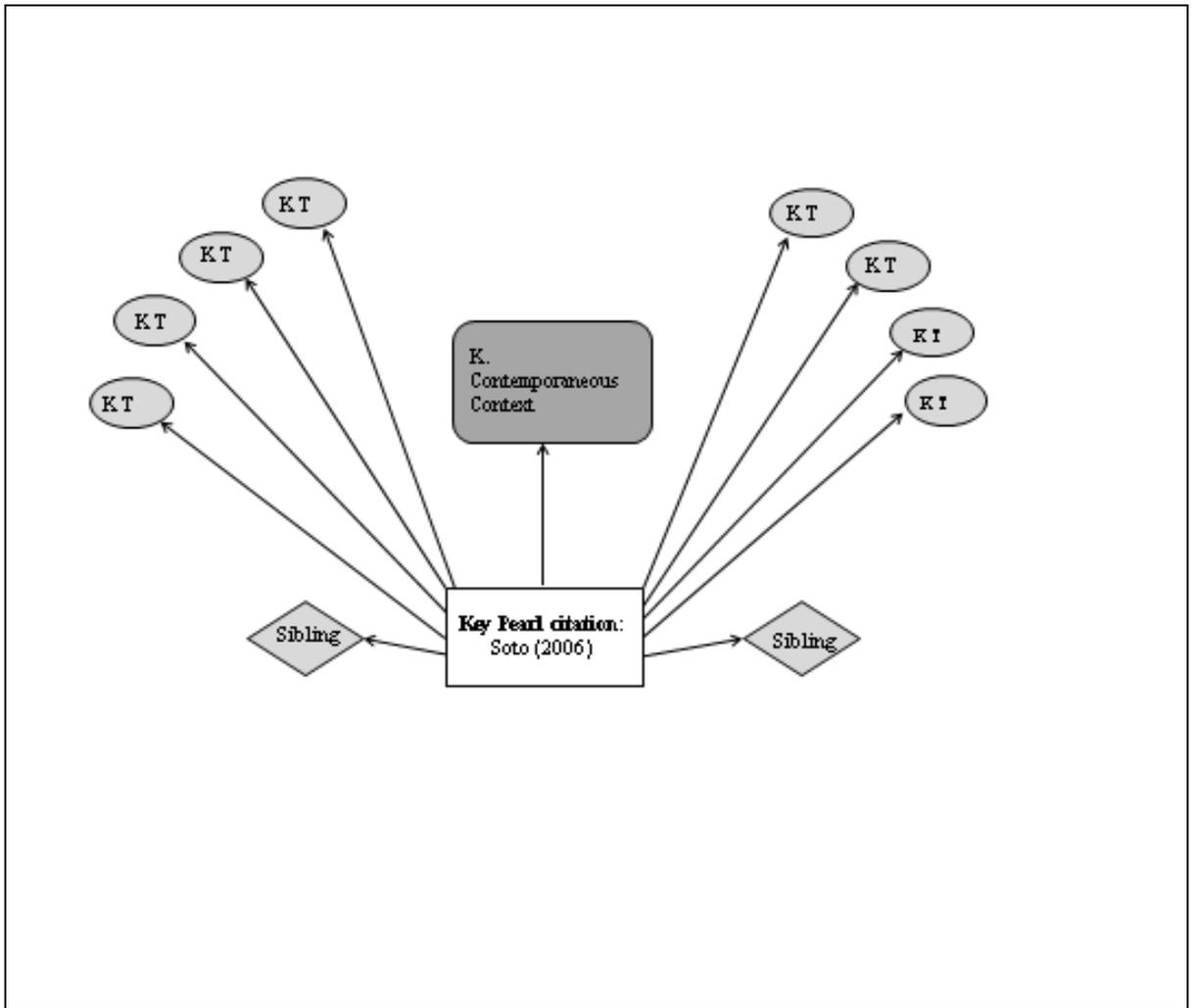


Figure 6.7 Visual Representation of the Narrative Assessment Profile Cluster

Table 6.1 Composition of Clusters

Key pearl citation	Sibling papers	Kinship antecedent papers	Kinship contemporaneous context	Kinship theoretical papers
ICF	0	1	2	18
CVL	0	1	0	5
CM	0	3	0	7
NAP	2	0	1	8

Table 6.1 above displays the total number of publications contained in each cluster: International Classification of Health and Functioning (ICF) framework cluster (21); Culturally Valid Lexicon (6); Communication Matrix (10) and Narrative Assessment Profile (12).

The visual representations of the clusters (figures 6.4, 6.5, 6.7) illustrate the composition of the clusters. The Kinship Theoretical papers or publications are represented on the outer edge to represent a proximal relationship- there were many more of these than any other type of publication, especially in the ICF cluster. The Narrative Assessment Profile contained the only example of sibling papers. The ICF, the Culturally Valid Lexicon and the Communication Matrix and clusters contained no sibling papers for analysis. The types of material contained in the cluster were: academic papers, literature reviews, evidence summaries/topic critiques and unpublished data analysis synopsis.

6.4.1 Overview of pearl citations

The next section presents a brief synopsis of the pearl citation. In the first cluster, Murphy and Boa (2012) wanted to transform the World Health Organisation's *International Classification of Functioning, Disability and Health* (ICF) (WHO, 2001) framework into a tool for service users to facilitate goal-setting (in combination with a form of low tech AAC. They use Talking Mats™ which involves a mat and picture or word cards. The process of using these cards frames and guides verbal interactions through symbol

placement). In order to do this the authors transformed two of the themes in the ICF structure into symbols. The authors envisaged the practical application of the ICF could help rehabilitation staff take a holistic view of the patient. Other uses of the ICF in AAC are explored in the cluster.

The second pearl citation was by Nigam (2006) who explored a framework to establish a socially and culturally valid lexicon. Lexicon describes the process of choosing a set of appropriate words or items from a pool of possibilities (p. 245). The paper emphasised the social and cultural heterogeneity of the AAC user population and argued that without considerations in these areas communication facilitators cannot predict appropriate symbols or words to enable the service user to control their own environment. However, appropriate lexicon must first exist. The paper developed a methodological framework to develop and validate lexicon selection. The population was Asian-Indian individuals who use AAC. I considered it to be a relevant framework for the interpretation of AAC because of the exploration of social and cultural meaningfulness which underpin lexical AAC systems.

The Communication Matrix (CM) was the focus of the third pearl citation (Rowland, 2011). The paper explored the use of the CM to assess expressive skills in early communicators. The outcome of this framework aimed to identify strengths in communication of children with speech difficulties, for whom it is more challenging to determine expressive communication skills. The CM is designed for children with a range of disabilities and was selected not because of its role in identifying appropriate interventions, but as a framework that interprets alternative communication through alternatives to speech.

Finally, the fourth study selected for cluster analysis was Soto et al (2006). The paper aimed to explore elements of Narrative that emerged from interactions between a child AAC user and her teacher. The Narrative Assessment Profile (Bliss, McCabe and Miranda, 1998) was used as an analysis framework. The profile explored narrative ability through the application of five tasks designed to elicit a spectrum of narrative features. The paper showcases the strengths and weaknesses of the profile, including the potential lack of clarity in evidencing the control of narrative.

6.4.2 Meta Method, Meta Analysis and Meta Theory

This section discusses the Meta Method, Meta Analysis and Meta Theory findings from the four clusters identified through the sampling matrix. Item 7 displayed in the appendix summarises the findings from the Meta Method and Meta Analysis characteristics of the core papers (p.317). Table 6.2 at the end of the section summarises the Meta Theory findings (from all studies).

6.4.2.1 The ICF Cluster: Meta Method, Meta Analysis and Meta Theory

The pearl citation identified the World Health Organisation's *International Classification of Functioning, Disability and Health* (ICF) (WHO, 2001) as a conceptual or theoretical framework. It belongs to a family of frameworks (e.g. WHO classification of health intervention (ICHI), 2006; Classification of Technical Aids for Persons with Disabilities (ISO9999) 1998). The frameworks were developed from the International Classification of Impairment, Disability and Handicap (ICIDH) (1989). (A separate children and youth version was also developed (ICF-CY WHO, 2007)). The ICF was explored in combination with Talking Mats™ to enable people with long-term communication difficulties to participate in goal-setting (Murphy and Boa, 2012). The ICF framework aimed to provide a standard language for the description of the complete range of health-related states and experiences of health. The ICF has been used by clinicians and researchers internationally for people with disabilities (Murphy and Boa, 2012, p.53). The use of the ICF helped practitioners to take a holistic view of the patient or participant with disabilities, taking into account environmental and personal factors and how these interact with each other (i.e. in an AAC context in conjunction with Talking Mats™).

The components for describing a complete range of health-related states and universal human experiences were set out by the WHO in the ICF in 2001. The components were: health condition, body functions and structures, activities, participation, environmental factors, and personal factors. The first component, health condition, relates to the disease or disorder. Function or structure refers to mental body or speech functions. Activities and participation components refer to a broad range of functions such as communication, mobility, and self-care. Environmental factors are the facilitators or barriers to the function activity or participation components. Personal factors relate to behaviour in relation to the social or physical environment and personal characteristics (descriptions summarised from Raghavendra et al., 2007, pp.351-2).

The ICF created a model to show how these components interacted (WHO 2001, p.18). This model displayed the components in a hierarchal system of tiers. The top tier was the outcome i.e. health condition. Below this, the second tier consisted of: body functions and structures, activities, and participation components. Finally, the third tier was environmental and personal factors components. The model describes *intrinsic* factors (i.e. the biomedical model of disability) and *extrinsic* environmental factors (i.e. the social model of disability). A third dimension of personal factors related the behaviour and interactions of the individual in a context. This created the biopsychosocial model (Bickenbach et al., 1999 cited in Raghavendra 2007, p.351). All components had bi-directional relationship with each other and the neighbouring tiers to link function, disability and health.

(Raghavendra et al., 2007).

A description of the model ‘Important ICF components in AAC’ (Adapted from Zachrisson et al., 2002 cited in Raghavendra et al., 2007, p.353).

The model operates on the same structure as the ICF components described above, each is presented from an AAC perspective. Three components interact with all levels of the AAC system in determining the function of an individual. These are: body function and structure (e.g. mental function, sensory function, and movement and speech functions), activity (e.g. to see listen and be alert; receptive language, expressive language, reading and writing, and skills to initiate interaction) and, participation (e.g. interaction with family and others, interaction in situations or tasks, and interactions in society).

Also, the roles of other components are displayed in the model. These include: environmental factors (e.g. service support from the environment, and attitudes towards communication device, availability of device) and personal factors (e.g. gender, age, motivation, acceptance of AAC system). In addition, AAC system characteristics are considered (e.g. cognitive demands, vocabulary selection and options, strategies, visual demands, auditory demands and motor demands). Together, all of these components present a multidimensional method of thinking about AAC clinical practice and intervention (Raghavendra et al., 2007, p.352).

Figure 6.8 A description of the ICF adapted for practitioners for an AAC context

ICF components envisaged from an AAC perspective adapted from Zachrisson et al., 2002 cited in Raghavendra et al., 2007, p.353.

The components described above (figure 6.8) demonstrated the adaptation of the ICF to incorporate AAC system characteristics referred to within the cluster. The ICF has also been adapted to incorporate AAC for other purposes, including the formulation of a

template to improve provision of participant information in AAC research (Pennington et al., 2007).

I now describe the Meta Method and Meta Analysis of the ICF cluster. The characteristics of the core empirical studies were examined first. The four studies (Murphy and Boa, 2012; Murphy and Strachan, 2011; Boa and McFayden, 2003 and Harty et al., 2011) were classified as intervention studies or evaluation studies. The papers contained a mixed method approach to evaluation (Murphy and Strachan, 2011), an evaluation using in-depth interviews with Talking Mats™ (Boa, 2003), and an intervention study containing descriptive case reports (Murphy and Boa, 2012). The full description of the characteristics of the papers is presented in item 8 in the appendix (p. 322). The features of the Meta Study and Meta Analysis findings are discussed below.

All the core familial papers (the pearl, Kinship Antecedent and Kinship Contemporaneous context) used Talking Mats™ in conjunction with the ICF framework. The rehabilitation perspective was the most common (Murphy and Boa, 2012; Murphy and Strachan, 2011; Boa and McFayden, 2003). All were conducted in the UK except the study conducted by Harty et al (2011) that was based in South Africa. Participants were all adults with different impairments: acquired communication disorders (Harty et al., 2011; Murphy and Boa, 2003) acquired neurological conditions (Boa and McFayden) 2003 and long-term-conditions (Murphy and Strachan, 2011). Participants' level of familiarity with AAC was low. Two of the studies collected data on a single occasion (Murphy and Strachan 2011; Harty et al., 2011) and another collected data at two time points set three months apart (Boa and McFayden, 2003). Findings across studies established the helpfulness of the Talking Mats™ framework in articulating aspects of the ICF framework (particularly in relation to goal-setting).

Three studies consisted of multiple components of data collection and analysis such as Talking Mats™ interviews, observation and staff surveying. (By comparison, the pearl reported on empirically weaker case examples). Scoring and rating systems of analysis were common to measure concepts such as service user involvement (Murphy and Strachan, 2011). Aspects of the analytical strategies involved the translation of ICF domains into symbols (Murphy and Boa 2012; Harty et al., 2011). Studies also undertook analysis of staff perspectives, service users and organisational-level analysis (Murphy and

Strachan 2011; Harty et al., 2011). Overall, the Talking Mats™ were used to good effect to scrutinise aspects of activity and participation.

Aggregative analysis within studies restricts in-depth narrative-based analysis. In contrast, the thematic structure presented by Boa and McFayden (2003) collated aspects from individual interviews, highlighting specific issues and goals. Overall, the role of care staff remained central to the success of the interaction (Murphy and Strachan, 2011). In addition, Talking Mats™ sub-topics were also suitable for the implementation of the ICF format because they mimicked the component and domain hierarchy of the ICF (Boa and McFayden, 2003).

I now describe the methodological characteristics of peripheral Kinship Theory papers. The methodologies of the peripheral papers were not explored in-depth. General characteristics have been briefly summarised. There were 18 kinship papers; five had analysed secondary data (Bauer et al., 2011; Pless and Grandlund, 2012, Pennington et al., 2007; O'Halloran et al., 2008; Mulhorne and Threats, 2008). There were 13 discursive or review papers or publications. Overall, topics could be divided between an emphasis on the *applicability* of the ICF within particular disciplines and how the ICF framework should be *used*. This was a distinction made by Pless and Grandlund (2012, p.12) the distribution of papers was evenly split between the two. (A point re-emphasised in table 6.3 in the synthesis section of the analysis to follow). (Contributions of the papers are discussed in the synthesis section).

Next, I turn to the Meta Theory of the ICF cluster. The perspectives represented across the papers in the cluster included: rehabilitation (Bornman and Murphy, 2006; Murphy and Boa, 2012; Murphy and Strachan, 2011; Pennington et al., 2007; Griffiths and Price, 2011; Bauer, 2011, Boa and McFayden, 2003; Üstün, 2003; Harty et al., 2011) physical therapy (Sykes, 2008; Jette, 2006), AAC practice (Fried-Oken and Grandlund, 2012; Pless and Grandlund, 2012; Rowland et al., 2012; Raghavendra et al., 2007) and speech and language therapy (O'Halloran et al., 2008; Mulhorne and Threats, 2008); disability (Jelsma 2009; Simeonsson et al., 2012). Collectively, the central school of thought or paradigm could be described as *health classification*. This was described explicitly by Raghavendra et al (2007) “*The development of the ICF builds on the revision of the ICIDH [1980 International Classification of Impairments, Disabilities and handicaps] and the ICIDH-2*

and represents a continuing paradigm shift from “a consequence of disease classification to a component of a health classification” (WHO, 2001 p.2)” (p.350).

Many of the sources cited the Disability Model (Nagi, 1965 cited in Jette p.727) as a theoretical anchor for the ICF framework (e.g. Raghavendra et al., 2007; O’Halloran 2008; Bornman and Murphy, 2006; Üstün et al., 2003; Jette, 2006; Pless and Grandlund, 2012; Simeonsson et al., 2012; Jette, 2006; Sykes, 2008; McLeod and Bleile, 2004). The Disability Model was a conceptualisation of disability stemming from the Disability Movement. The model viewed disability as an outcome of an interaction between a person with impairment and environmental or attitudinal barriers. The ICF was a compromise between two previous models i.e. The Social Model and the Biomedical Model. The Biomedical Model viewed disability as a deviation from biomedical norms (Borse 1977 cited in Raghavendra p.351), whereas, the Social Model defined disability as the loss of opportunities to take part in normal life due to physical and social barriers (Union of the Physically Impaired against segregation (UPIAS) 1976, pp. 3-4 cited in Raghavendra et al., 2007, p.351). Material within the cluster suggested the framework had a large impact in policy. For instance, the organisation Disabled People’s International (DPI) uses the ICF as their preferred framework (Mulcahy, 2005 cited in Bornman and Murphy, 2006, p.146).

Contextual factors affecting the upsurge in deployment of the ICF framework included the mandated provision of assistive devices in legislation in the US through the Assistive Technology Act (2004) and the Americans with Disabilities Act (2008) (Bauer et al., 2011 p.244). Increasingly, programmes turned their attention to facilitating communication. Objectives included support for educational achievement in the context of enhancing employment options and enabling full community participation (Bauer et al., 2011, pp.243-244). In the United States, intervention goals for school-aged children with disabilities were part of yearly Individualised Education Plans (Rowland et al., 2011, p.22). Protocols used the ICF (and the children and youth version of the ICF – the ICF-CY) to produce protocols for specialist areas such as AAC users (Rowland et al., 2012).

More broadly, the cluster reflects developments in international social policy to generate cross-national disability research (Üstün et al., 2003, p.569; Mulhorne and Threats, 2008, p. 69). However, Jelsma (2009) questioned the unknown development of the framework across countries, stating “...it is not known whether there is continued involvement of researchers from diverse countries and cultures in the utilization and further development

and use of the classification” (p.1). Subsequently, only Pless and Grandlund’s (2012) paper compared implementation of the framework cross-nationally.

There were two central themes which emerged from the cluster (summarised at the end of the section in table 6.2). These were increased pressure on *provision of* and *participation in* services for AAC users. The cluster contains a number of papers focused on goal-setting as a way of improving the client experience of services (Bornman and Murphy, 2006; Raghavendra et al., 2007; Boa and McFayden, 2003; McLeod and Bleile, 2004; Harty et al., 2011). This is an important process that related to service provision because *“it is now acknowledged that the clinical management of individuals requiring therapeutic intervention can be enhanced if they are involved in planning and setting their own goals in the process of their recovery”* (Bornman and Murphy, 2006, p.145). Consequently, the ICF and Talking Mats™ exposed different perspectives about service provision from client and staff.

The ICF was employed within goal-setting processes (Boa and McFayden, 2003; Harty et al., 2011; Murphy and Strachan, 2011). Murphy and Boa (2012) emphasise the purpose of such processes for people undergoing rehabilitation to be given a *“voice”* (p.52).

Participation was a frequently referred to throughout the cluster (Rowland et al., 2012; Murphy and Boa, 2012; Griffiths and Price, 2011; Raghavendra et al., 2007; O’Halloran et al., 2008; Simeonsson et al., 2012).

Scholars and practitioners tended to rely on the fact the ICF was completely holistic as a framework, often failing to challenge this assumption. For instance, academics used the term ‘holistic’ to underline the comprehensive nature of the ICF framework (Murphy and Boa, 2012; Simeonsson et al., 2012). The holism concept allowed professionals to justify their approach in comprehensively addressing a wide range of issues relevant for AAC users. Threats (2007) contrasted the ICF to other frameworks which only targeted speech and language characteristics (p.68). However, there was also evidence of a counter narrative. Criticisms were made about the inability of the framework to describe the strength of relationships between components (Raghavendra et al., 2007, p.358).

Commentators rarely stressed limitations to the framework, such as the difficulties associated with distinguishing between Activity and Participation domains (Jelsma, 2009; McLeod and Bleile, 2004).

Another assumption was the *universal* application of the framework for all people (including people with forms of communication impairment who may use AAC). The ICF was considered to have more potential for creating comparable research across common themes, partially because it described the characteristics of participants in common ways (Pennington et al., 2007) and the potential for many different applications (Üstün et al., 2003; Raghavendra et al., 2007). The ICF provided the opportunity to standardise language (Bauer et al., 2011; Boa and Murphy 2012; Pless and Grandlund, 2012; Simeonsson et al., 2012; Jette, 2006). However, Jelsma's (2009) review of ICF use argued many professionals interpreted the ICF so broadly (or incorrectly) that "*... authors might be accused of jumping on the ICF 'bandwagon' without fully addressing the classification in its entirety*" (p.5). Threats (2007) had reservations about the legitimacy of the integration of the social perspective in the framework, saying that despite the inclusion of 'Personal Factors' "*...the fact that it is a classification system with numbers, operational definitions, and reference to using standardised norms for most behaviours puts the ICF very much in line with traditional medical thinking. Whether the 'biological, individual and social perspective' is truly integrated within the ICF, or merely put in the same book, may be subject to lively debate*" (p.70).

6.4.2.2 The Culturally Valid Lexicon Cluster: Meta Method, Meta Analysis and Meta Theory

The pearl citation (Nigam, 2006) explored a framework attempted to establish a culturally valid lexicon. Although a methodological framework, the topic was considered central to the interpretation of AAC methods. It provided a more reliable lexical representation of AAC user expression. Social and cultural dimensions of lexical selection were considered. The study aimed to contribute to the effective communication skills of AAC users by encouraging researchers to develop and validate a culturally and socially appropriate lexicon (symbols and words for AAC technology and systems). The study applies the methodological framework to an Asian-Indian population, but the overarching objective was "*to develop a methodology for the cultural validation of lexicon to be used by AAC users that can be systematically replicated with other cultural and linguistic populations*" (p.248).

Validation procedures applied social and cultural dimensions to research practice procedure or methodological framework to produce a lexicon.

These included:

- Recruitment of participants
- Nomination of word categories
- Rating of Picture Communication Symbols' lexical items
- Analysis using computer software
- Development of a core list and a composite list of lexical items
- Exclusion and validation of lists

(Adapted from Nigam, 2006, p.250, figure 1)

The pearl citation alluded to a culturally based conceptual framework (Taylor and Clarke, 1994, derived from Taylor, 1986, the key theoretical text within the cluster). The framework incorporated a schematic for studying and treating communication disorders in culturally and linguistically diverse populations. It is summarised in a model which can be described as having four aspects:

Culture (processes and outcomes)

1. Developmental - *indigenous and external cultural interactions e.g. adult-child interaction within a culture, language and communication acquisition and competence.*
2. Precursors of pathology – *Cultural definitions of normal interaction, cognition, language and communication, unsatisfactory environmental conditions.*
3. Assessment – *Culturally valid assessment and diagnosis of communication, language and cognition*
4. Treatment – *application of culturally valid treatment procedures* (Taylor and Clarke, 1994, in Taylor (1986), p.10, fig 1.1.)

I will now expand on the elements in the theory above. Culture was argued to have the most fundamental impact on developmental processes. Culture could also affect contextual factors (*precursors to pathology*) which consisted of cultural and communication competencies and other unsatisfactory environmental factors. The model also urged practitioners to consider culture in outcomes related to assessment and treatment. Taylor (1986) recommended the use of an ethnographic perspective for assessing communication (p.15). A culturally inappropriate lexicon could affect the second, third and fourth aspects in particular. Other pieces of evidence within the cluster

explored the issue of cultural development in AAC. One such item was the Inventory of Guidelines for Cultural Assessment Intervention (Hetrozoni and Harris, 1996, p.57, table 1).

Next, I describe the Meta Method and Meta Analysis phases. The central pearl citation (Nigam, 2006) aimed to develop a culturally valid lexicon for Asian-Indian individuals who used AAC. Focusing on a single culture, Nigam (2006) identified sub-cultural groups and attempted to gather a representative cross-sample. The Contemporaneous Context paper by Huer (2000) was included as the nearest approximation of this methodological framework, as it examined the perception of graphic symbols, across groups using translucency ratings of graphic symbols across five ethnic groups. This study reached similar conclusions to those of Nigam (2006) about the inappropriateness of certain lexical icons for clients that are based on culture that were in widespread use. The focus of the study specialised in symbols, demonstrating the differences in translucency ratings in different groups. Comparison of the two studies indicated that the pearl study used a greater range of validation measures. Both groups used a large sample that might be expected from a statistical validity study. Nigam (2006) used insider expertise for the Asian-Indian culture under study but neither study supplemented their studies with ethnographic techniques recommended to interpret cultures (Taylor, 1986, p.15; Blackstone, 1993).

The methods used in the core familial papers had an effect on the related study findings. The studies viewed as core papers recruited unimpaired individuals (who were not AAC users) to validate vocabulary for AAC devices. The systems were therefore considered culturally valid but were not truly representative of the target user group. Other effects of methodology are explained below. The key pearl citation (Nigam 2006) was a large scale experimentally-designed study with statistical analysis of lexicon selection and de-selection. (The study considered self-selection of valid words and the validation of existing words and symbols). The study did not look in-depth at the reasons why certain words had no meaning to individuals. Participants consisted of the general adult population and not AAC users, raising representation issues. There were some attempts to make lexicon selection as independent as possible. The researchers also created suitable materials for data collection of new lexicon and demographic information to suit the literacy and language levels of participants. Huer (2000) also recruited participants from the general adult population. The study compared the perception of different types of

symbols without constructing a new lexical list. The methodological designs in both studies emphasised validity and reliability of methods in demonstrating insufficiency of current lexical systems for the general population.

None of the Kinship Theoretical publications in this cluster were empirical. Nor did they use Nigam's methodological framework. Three were discussion papers in a journal paper format (Huer, 1997; Hetrozoni and Harris, 1996; Beukelman et al., 2011). Papers adopted a cultural frame or perspective, and language was viewed as a cultural phenomenon (Huer, 2000). Researchers or theorists were communication or linguistic specialists within AAC fields (Beukelman, 1991; Huer, 1997; Nigam, 2006; Hetrozoni and Harris, 1996; Blackstone et al., 1993).

Next, I describe the Meta Theory phase. Taylor and Clarke's (1994) conceptual framework cited in the pearl study (Nigam et al., 2006, p.246) originated from Taylor's (1986) framework. The latter was included as a Kinship Theoretical paper. The framework encompassed four processes which act within the constraints of culture. Validation of culturally appropriate lexicon could be considered a fundamental element of the assessment process, although the conceptual framework pre-dated the methodological framework.

In addition, the cluster referred to Vygotskian theory (1962 cited in Taylor, 1986, p.11), which concerns the acquisition of verbal and nonverbal symbols in the socialisation processes of early interactions. (Developmental processes were considered by Vygotsky the most fundamental to deriving culturally-based language). Key messages from the theoretical texts emerged. Fundamentally, scholars such as Taylor (1986) and Blackstone (1993) attempted to diversify practice procedures to take into account cultural, linguistic and communication based differences. It was important to consider the influence of the facilitator of communication systems, including the preconceptions which helped to create the AAC, such as symbol selection. Ethnographic approaches were encouraged (Taylor 1986; Blackstone 1993) because they provided some level of emersion in culture, breaking down preconceptions and giving more prominence to the AAC user's cultural norms.

The cluster Meta Theory analysis showed how the culturally-based conceptual framework originated in the Civil Rights era of 1960s America, as an attempt to make educational services available to black children. The author of the framework initiated the debate (Michel vs. Taylor, 1968- cited in Taylor, 1986, p.2) from which the Black Caucus

emerged. A range of legal and legislative events drove forward the language and cultural equality agenda. This phenomenon would later help to reduce inequalities in access to assisted communication for those with communication disorders. The Bilingual Education Act (1968) was significant, as was the case of *Lau vs. Nichols* (1974). The latter opposed the absence of programmes to meet the educational needs of the San Francisco China Town community (Taylor 1986, p.6).

The publications and papers within the cluster addressed cultural and linguistic diversity in the context of the development of AAC. In addition to the cultural framework identified (Taylor, 1986, p.10, figure 1), Beukelman et al (1991) emphasised the linguistic diversity present in pre-literate or non-literate populations. Similarly, Huer (2000) showed how perceptions of symbols differed across cultural groups.

A second theme was the emphasis on using cultural frameworks to change practice. Huer (1997) emphasised the identification of the white, western, European ‘roots’ of practice (p.23). Hetrozoni and Harris (1996) argued there had been increasingly sensitive attitudes towards cultural diversity from the 1960s onwards as research began to focus on communication disorders in increasingly linguistic and culturally diverse populations (p.52). The same source also pointed out that AAC clients were dependent on the symbol selection undertaken by professionals. This determined the creation of their communication system, bringing cultural issues to the fore (p.52). Beukelman et al (1991) also espoused the need for practitioners to involve AAC users in vocabulary selection, suggesting that practitioners made assumptions about the potential involvement of AAC users (p.171). The evidence, therefore, emphasised the links between practice outcomes and cultural sensitivity.

Findings from the pearl study suggested that a proportion of the standard lexical items were indeed more culturally relevant to North American and western cultures (p.255). Professional bias was argued to be endemic to lexicon selection. However, to some extent, the cluster assumed professional bias could be mediated completely through a methodological framework. This highlighted a contradiction that the framework was intended to be replicable across groups yet the pearl study’s framework focused on a specific culture (Asian-Indian). The reason Beukelman et al (1991) gave for this selection was the author’s own cultural background and thus “*facilitated the collection and interpretation of data*” (p.248). Despite the creation of protocols for cultural sensitivity

(Huer 1997; Hetrozoni and Harris, 1996) ‘Ethnocentric’ (Taylor, 1986, p.9), influences remained a real possibility because cultural norms were not easily identified (Hetrozoni and Harris, 1996). Cultural validation frameworks only emerged relatively recently, perhaps indicating progression towards cultural considerations was slow.

6.4.2.3 The Communication Matrix Cluster: Meta Method, Meta Analysis and Meta Theory

The Communication Matrix (CM) was developed in 1990 (with revisions in 1996 and 2004). The CM can be described “*as an assessment tool that would operationalize a sociopragmatic approach to early communication development that emphasises the functional uses of communication in a social world*” (Rowland, 2011, p.192). The matrix was originally designed for speech practitioners and educators to document expressive language skills in children; the second version was developed to be administered by parents, and the third to be more user-friendly. A Spanish translation was created in 2009, as was an online version. More recently, the CM has been applied to a broader range of populations including AAC users in general (Beukelman and Mirenda, 2005 cited in Rowland, 2011, p.192).

The Communication Matrix can be viewed as a way of measuring performance (although it was conceptualised as a ‘test’). It incorporated Light’s (1988) theory of reasons to communicate (i.e. *to refuse things we do not want, to obtain things we do want, to engage in social interaction, and to provide or seek information*). The Communication Matrix (the basis of the cluster) can also be located within the broader Participation Model theory (Beukelman and Mirenda (1988) and updated in the 2005 model).

The pearl citation commented that the matrix had been used widely, with more than ten thousand online profiles created. The CM received grants from the US Department of Education to expand into other languages (Rowland, 2011, p.199). However, there were limitations in the volume of academic material available about the cluster, just two papers within the cluster were academically reviewed articles (Rowland and Schweigert, 2000; Rowland and Fried-Oken, 2010).

Having described the cluster, I turn to the Meta Method and Meta Analysis phases. All the core familial papers or publications surrounding the Matrix were authored or co-authored by its lead creator (Charity Rowland) (see item 7 and 8 in the appendix (p.317-325)). The intended recipients of the Matrix were children with complex disabilities of various types.

The pearl citation (Rowland, 2011) and the antecedent paper (Rowland and Fried-Oken, 2010) used sample data to provide examples of profiles. The study was field tested and validated as an assessment instrument (Rowland and Fried-Oken 2010, p.321; Rowland, 2012). However, the pearl study acknowledged that the Matrix had not been discussed in a scientific forum (Rowland 2011, p.191). I considered the papers which presented profile case examples (Rowland 2011; Rowland and Fried-Oken, 2010) as empirically weak. (The circumstances under which data was collected were not provided and therefore comparisons between cases were not possible).

Two of the papers were evaluations of the '*Learn to Learn*' project (Rowland and Schweigert, 2005a; Rowland and Schweigert, 2005b) and included the Communication Matrix as a single part of a larger studies. The Matrix results were expressed numerically as scores out of 148 and compared across different models of classroom for comparison. The Matrix monitored expressive and behavioural skills before and after the *Foundations for Learning* approach. This approach was implemented over the course of a year. Parents first administered the Communication Matrix, followed by teachers. Both reports were positive about the role of the Communication Matrix. Both also stipulated parental involvement was the key to the overall approach (2005b, p.46).

The case examples referred to within the pearl citation (Rowland, 2011; Rowland and Fried Oken, 2010) were descriptive. The case examples were intended to illustrate the utility of the Matrix in presenting individualised information about skills (Rowland and Fried-Oken, 2010, p.324). However, the creators of the framework restricted its capacity to "*a direct observational tool and a behavioural inventory*" (Rowland and Fried-Oken, 2010, p.321).

The Communication Matrix formed the basis for guidance on communication goals (Rowland and Schweigert, 2005a and 2005b). However, there was no data on the decision-making processes involved in administering the matrix (despite videotaping sessions to interpret behaviour present in other aspects of the project). The cluster focused on measures, yet the scoring lacked interpretative elements, such as expressive communication coding (Rowland and Schweigert, 2005b). Ethnicity was recorded for participants within the reports, in combination with age and diagnostic factors, but little other demographic detail was provided. Again this limited interpretive elements of the methodological framework.

The peripheral sources were limited in relation to quality and relevancy. The group can be summarised as: an unpublished manuscript (Rowland, 2012); theoretical texts (Beukelman and Mirenda, 2005; Light, 1988) and academic papers. The academic papers included studies on the concepts of physical and social environments (Rowland and Schweigert, 2009), and a study on the use of symbols (Rowland and Schweigert, 2000). Publications across the cluster were all focused on the development of communication in children. The cluster contained two theoretical texts (Beukelman and Mirenda, 2005; Light, 1988).

I now turn to the Meta Theory Phase. The cluster papers promoted the Communication Matrix as a clinical and research tool. The Communication Matrix was located within a broader assessment structure amongst the theoretical papers that accompanied the cluster. The objective of the Participation Model (summarised below in figure 6.9) was to identify participation patterns and communication needs. The Matrix was one of several options to conduct assessment of current communication levels. (Other options included: *Achieving Communication Independence* (Gillette, 2003) and *Social Networks-* a communication inventory for individuals with complex communication needs and their communication partners (Blackstone, Hunt and Berg, 2003) all cited in Beukelman and Mirenda, 2005, p.146).

The Participation Model

The Participation Model is a systematic process of conducting AAC assessments and designing interventions designed on functional participation requirements of peers without disabilities of the same chronological age as the person who may communicate through AAC. (Beukelman and Mirenda, 2005, p.136). Key principles include multiphase assessment and consensus building.

The model is a complex diamond structure with multiple phases occurring under the pathways of assessment of opportunity barriers, and assessment of access barriers. Each contains a number of assessments and profiles to build a picture, or consensus of the participant's participation. For instance, opportunity barriers include the identification of insufficient opportunities to participate in: policy, practice, facilitator skill and attitude of participant. Access barriers require the facilitator to judge the participant's potential: to increase their natural communicative ability, for adaptations in the environment, and to utilise AAC systems or devices (sub-divided into various forms of communication profiles).

The final steps identify four types of interventions: opportunity interventions (from the opportunity barriers pathway); natural ability interventions, environmental adaptations interventions; and, AAC system/device interventions. Finally, these interventions feed into 'plans for interventions today and tomorrow', and an 'evaluation of effectiveness'. If the person is not participating the assessor begins

from the top of the process once more.

The Communication Model is part of the assessment of access barrier. It is the first step in assessing current communication (one of the two pathways). The Matrix is used to identify communicative competence (socially and operationally). The assessor, therefore, gains a sense of how socially confident the participant is to use the AAC system and how well they can operate it.

The Communication Matrix (1990, 1996, 2004) pinpoints how a child is communicating and provides a framework for logical communication goals (summary in Beukelman and Mirenda, 2005, p.145).

(The Participation Model (Beukelman and Mirenda, 1988, cited in Beukelman and Mirenda, 2005, p.137 figure 6.1; described pp.136-157).

Figure 6.9 A Description of the Participation Model

Beukelman and Mirenda (2005) explained how and why the Participation Model was developed (p.135). Prior to the 1970s, educational facilities required a level of performance from candidates before interventions were provided. This actually had the effect of *excluding* those in need of interventions. Following the expansion of AAC systems to include strategies for those without literacy abilities, practice became more *inclusive*. The Communication Needs Model emerged. Under this model judgements were about individual's needs rather than their eligibility or 'inadequate capability' (Beukelman and Mirenda, 2005, p.135). The third progression of theoretical insight was the Participation Model (1988, revised in 2005). The model was influenced by Light's Communication Competence (1989) concept. The Participation Model therefore matched functional requirements to AAC users without disabilities to ensure greater levels of equality (p.136).

The Communication Matrix methodological framework (developed in 1990) focused on assessment (themes are presented in table 6.2). Administrators of the matrix were parents or teachers (rather than researchers or clinicians). Although not linked to a particular policy, evidence suggests the matrix was created from a need for speech pathologists and educators to document expressive communication skills (especially when speech-led methods would not be suitable). The Communication Matrix was not widely referred to within the literature. However, it was suggested as an appropriate assessment tool for a variety of population including AAC users generally (Beukelman and Mirenda, 2005 cited in Rowland, 2011, p.192).

The Matrix framework employed the concept of contextual barriers and facilitators. Rowland and Schewigert (2009) emphasised the need for the Communication Matrix

framework because the description of communicative environments had received relatively little attention (p.519). Interactions were located within social and physical worlds embedded in broader *Learn to Learn* strategy (Rowland and Schweigert 2005a and 2005b). Furthermore, the Matrix was based on the understanding that different environments will produce different interactions (Rowland and Fried-Oken, 2010, p.120).

The other major theme within the cluster was the identification of educational needs. The specified purpose for the administration of the Matrix was to target further interventions (Rowland, 2011, p.191). The projects within the cluster (Rowland and Schweigert, 2005a and b) showed how the Communication Matrix pinpointed functioning within a broader framework of communication development to assess, plan, teach and to monitor progress of learners (2005b, p.8).

The main assumption within the cluster emerged from limitations in the predominantly observational approach to administering the Communication Matrix. There were no opportunities for reflection on the interpretation of the results. There was no critical analysis of the observer perspective or incorporation of the child's perspective. In the other examples of studies in the same field, studies incorporated interpretive elements. For example, the descriptive study by Rowland and Schweigert (2009) attempted to understand the ways in which parent and teacher assessments differed.

6.4.2.4 The Narrative Assessment Profile Cluster: Meta Method, Meta Analysis and Meta Theory

The Narrative Assessment Profile (NAP) was developed by Bliss, McCabe and Miranda (1998) as a way of understanding narrative discourse. The profile required observations of narrative features. The framework was originally designed for use with children but as the model shows, it could be adapted for adult populations. I categorised the profile as an example of an analytical framework. The pearl citation (Soto et al., 2006) explored the use of this framework through the interactions in a case study of an 8-year-old child and his/her teacher. The same study also attempted to identify limitations in facilitating learning experiences, limitations of AAC systems, and limited access to social and physical environments. Analysis focused on the contextually relevant factors to assist communicative interactions. The creators of the NAP used a lifespan approach, which meant that they believed the principles of the assessment of narrative were the same across the lifespan (Bliss et al., 1998 cited in Soto et al., 2006).

The Narrative Assessment Profile represented a way of understanding narrative structures as an element of communication. It was a specialised interpretive tool. The profile employs six dimensions to analyse personal narrative discourse, elicited through a range of tasks. The six dimensions of the narrative are: topic maintenance (how well utterances in a narrative relate to a central topic); event sequencing (presentation of events in logical order); explicitness (relating to the extent to which the narrative makes sense and coherence of narrative); referencing (adequate identification of people, features and events); conjunctive cohesion (the extent to which words or phrases link utterances and events); and fluency (the extent of lexical or phrasal interruptions in phrases) (Bliss et al 1998).

The Narrative Assessment Profile could be adapted for individuals from other cultures (McCabe and Bliss 2003, p.19, table 1.1). In this instance, it was employed with European North American children and adults. When implementing the NAP according to each of the dimensions, a first step ascertains the positive characteristics of the narrative, and a second step identifies difficulties. *Topic utterance* assesses both material on topic and digressions. *Sequencing* involves the identification of chronological order and adequate patterns. *Informativeness* requires the assessor to judge if enough information is provided to allow them to understand the narrative, and also if the participant could elaborate further. *Referencing* refers to appropriate time, place and person references. Inappropriate, vague or omitted references are also considered. To determine *conjunctive cohesion* the assessor has to judge if the narrative has sufficient linking devices for semantic and pragmatic purposes. Finally, he or she must determine *fluency*, looking for false starts, corrections or repetitions.

I now explain the findings from the Meta Method and Meta Analysis phases. Two of the papers within the cluster (Soto et al., 2006; Soto and Hartmann, 2006) conducted empirical studies of the narratives of children who used AAC, using the Narrative Assessment Profile (see item 11 in the appendix, p.332). Participants were able to select their own communication modality of communication throughout the studies. Five tasks prompted the communication, such as wordless picture books or story book narration. The pearl was a case study of a single child. The second study undertook analysis of four children. Sibling papers were included within the cluster (Liborion and Soto, 2006; Soto and Hartmann, 2006). All papers linked to a wider investigation of AAC systems (Soto, 2004-not available for analysis). The final paper included within this group was a

contemporaneous context study of unimpaired children who did not use AAC. This employed the Narrative Assessment Profile to develop the design of tasks and to analyse data (Chang, 2006). Soto et al (2006) and Soto and Hartmann (2006) designed their studies around five tasks to elicit narrative (such as photo description and wordless picture book narration). Researchers visited five times to implement each task. The tasks facilitated a range of narrative structures to emerge which were “*explicitly designed to assess the in-depth skills of users of aided AAC*” (Soto and Hartmann, 2006, p.458). Soto and Hartmann’s (2006) sampling strategy included: AAC use, diagnoses and function, consideration of tasks to evoke narrative, data transcription (including transcription of visual video data) and coding techniques (including the creation of a protocol for coding through NAP, a separate analysis of unique words, measurement of narrative length). Individual performances were tabulated, and sample extracts of the NAP were presented. As mentioned above, participants were able to select their own modality of communication throughout the study. All transcribed materials were analysed, with the exception of the study by Chang (2006) who used a sample of narrative contributions. The final crucial difference between the Chinese study and those by Soto et al (2006) and Soto and Hartmann (2006), was the adaptation of the NAP outcomes to reflect a score rather than a binary term denoting appropriate or inappropriate use.

Small-scale study designs complemented the rich analysis needed for the NAP (Soto and Hartmann, 2006). The case study design used in the pearl citation produced rich contextual information on the participant. However, the findings from the pearl citation (Soto et al., 2006) were not conclusive with regards to the cause of deficiencies in narrative. The authors could not state whether the deficiencies were attributable to the context or the individual. Findings from Soto and Hartmann (2006) were able to show the extent to which narrative dimensions were compromised. They concluded that their judgements about the narrative abilities of the children using AAC were “*tenuous*” (p.457). Several analytically sophisticated interpretations were offered. The study by Chang (2006) used samples of narrative and converted these into scores to produce correlations between the following: narrative performances, later word definition, reading comprehension, receptive vocabulary and reading comprehension. Abilities of two age groups were compared. Overall, the scoring system had the effect of articulating the aggregating narrative dimensions into a single measure.

The Kinship Theoretical papers (eight in total) were descriptive. Several described the approach behind the narrative genre (Bliss and McCabe, 2003; Ochs and Capps, 2001), whilst others described related theory that formed the basis of the approach (Bruner, 1985; Ochs, 1983). The papers highlighted the strengths of the NAP for coding the construction of narrative. Other narrative analysis approaches included: high point microanalysis, story grammar, stanza analysis (McCabe and Bliss, 2003, p.10). (High point microanalysis involves comparative analysis of the constituent parts of speech, and whether the narrative selected for analysis is strong or weak in relation to other areas of speech or language proficiency (McCabe and Bliss, 2003 p.10-11). Story grammar analysis determines how far the narrative is structured around the individual's goals (McCabe and Bliss, 2003, pp.12-14). Stanza analysis involves breaking the narrative into parts, or stanzas, to determine the extent of a joint focus on a particular topic in the narrative (McCabe and Bliss, 2003, pp. 14-15)).

Theoretical papers within this group also introduced other methodological topics, such as: micro and macro analysis of co-construction (Ochs and Capps, 2001); culturally shared knowledge (Collins and Markova, 1999) and cultural difference (Bliss and McCabe 2008) and co-construction (Solomon-Rice and Soto, 2011). The cluster specialised in a personal narrative genre perspective for interventions with individuals who use AAC (Bliss and McCabe, 2008 p.162, McCabe and Bliss, 2003). The Narrative Assessment Profile adopted a lifespan approach because it is applicable for both child and adult narration (Bliss et al., 1998, p.348).

Next, I turn to the Meta Theory phase of the cluster. Ochs and Capps (2001) wrote, "*Narrative is a cognitively and discursively complex genre that routinely contains some or all of the following discourse components: description, chronology, evaluation, and explanation*" (p.18). Kinship Theoretical papers also argued that narrative discourse played a critical role in the development of discourse, literacy and socialisation abilities (Bliss et al., 1998). An extract from Soto et al. (2006) stated "*According to Bruner (1985), social interaction is fundamental to narrative intervention, as this is the medium in which story events occur. Effective narrative intervention is thus a social process that promotes authentic participation and interaction about stories in various activities in which supportive and reciprocal exchanges are maintained*" (Soto, 2006 p.239). The social interaction represented instances when control between adults and children shifted during activities. (Vygotsky called this phenomenon the *Zone of Proximal Development (ZPD)*

cited in Cole (1985), pp.154-158). The ZPD allowed children to understand culturally appropriate behaviour and communicative competence.

Researchers argued that the narrative facility of children who used AAC could be markedly different from non-users (Soto et al., 2006). This phenomenon was linked to successful school achievement. Impaired narrative facility was caused by differences in language learning experiences, limitations of AAC systems and limited access to physical and social environments (Soto et al., 2006). Chang et al (2006) used the NAP with unimpaired children. Thematic evidence indicated that narratives could be used to improve outcomes for children and adults. The pearl paper (Soto, 2006) argued narrative ability could provide greater opportunities to participate in conversations about the 'non-present' (i.e. emotions, fantasy and past and future events) (p.231). McCabe and Bliss (2003) dedicated a section of their book to examples of narrative intervention across groups including those with dementia (Chapter 10 pp.149-160). As mentioned the majority of papers linked the concept of narrative to educational attainment (Soto and Hartmann, 2006; Chang 2006; Liborion and Soto 2006; Bliss et al., 2008).

The context, or setting, for the NAP framework appeared to be important for communication facilitation. This was a central theme within the cluster. Factors such as the role of facilitators and the interpretation of communicative interactions appeared to influence how communication was perceived. There was also evidence that cultural aspects of discourse production needed to be taken into consideration (Collins and Markova 1999; Ochs and Capps 2001). Contextual awareness enhanced analysis of communicative strategies such as co-construction and accompanying micro and macro level processes (Solomon-Rice, 2011).

An assumption in the cluster concerned the ability of the profile to accurately and consistently represent narrative given the uncertainties involved in interpretation. Soto et al (2006) argued that AAC users had a unique method of narrative production, yet the central premise of the paper was the limitations in narrative facility to determine narrative ability which the NAP highlights. The Profile demonstrated structural accounts were of limited value. However, the conclusions of the study stated "*Given the nature of the interactional context, it is difficult to know whether or not [the participant's] contributions reflect problems with specific narrative features, a lack of experiential knowledge of how*

to tell a story and/or are the result of a communication system that does not afford a range of structures necessary for narrative discourse” (p.239).

The main contexts, themes and assumptions which have been discussed in Meta Method and Meta Synthesis are summarised in table 6.2 below.

Table 6.2 Summary of Meta Theory

Cluster	School of thought	Context	Themes	Assumptions about the nature of the framework
ICF	Health Classification	International social policy tool to promote the biopsychosocial approach Response to US legislation for Disability rights and equity of access to services	Service provision and participation	Holism Universalism
Culturally Valid Lexicon	Cultural frame	Topic stemmed from Civil Rights Movement reform of educational services for different ethnic minority groups in the US	Cultural and linguistic diversity Improving practice	Elimination of professional bias
Communication Matrix	Communication development	Communication specialists required an expressive communication documentation tool Gravitation towards Participation Model and away from exclusionary candidacy models.	Identification of educational needs Identification of contextual barriers and facilitators	Validity of purely observational approach
Narrative Assessment Profile	Personal narrative genre	Development of the narrative genre Analysis of interaction, including socio-communicative culture	Improvement of educational outcomes Understanding of the broader interactional setting	Representativeness of narrative interpretation in wider communication

6.4.3 Synthesis

The following section describes the synthesis of findings from familial papers (Sibling, Kinship Antecedent, and Kinship Contemporaneous Context). The strengths and weaknesses of papers are discussed.

First I will discuss the strengths and weaknesses of familial studies. The ICF enabled the researchers and practitioners to build contextual information about participants over four levels across many functional, environmental and personal domains. All the studies used only the *Activity* and *Participation* components (body structure or function components were not included). However, the coding and validation of the components were limited to a single coding structure and the distinctions between activities were not always clear (Harty et al., 2011, p.2). The key familial papers therefore, present a relatively narrow, but in-depth perspective on the use of the conceptual framework. The Talking Mats™ method was a mechanism for facilitating engagement with the framework. As a consequence, the domains within the Activity and Participation components were translated into symbols and scales- a process not defined by the WHO for the ICF, leading to variation in practice and research. Talking Mats™ appeared to be a viable mechanism to facilitate engagement but it was not successful in engaging everyone (Murphy and Boa, 2012, p.56-7). The main drawback to the use of the ICF and Talking Mats™ was the challenges associated with presenting the data in a way that conveyed the nuances of the placement of symbols and the links between domains. Boa and McFayden's (2003) thematic table (p.14-15) was an example of a comprehensive overview of the use of the Talking Mats™ and contextual barriers and facilitators to participation.

The Cultural Validation Lexicon cluster offered a different interpretation of a methodological framework for interpreting AAC. In contrast to the ICF, the method had a narrow purpose. The framework was not empirically well-established in the literature, perhaps as a result of its specialist purpose for providing validation of AAC systems. Nigam's (2006) framework was arguably more sensitive than the previous contemporaneous context study which tried to validate vocabulary (Huer, 2000). This is because it restricted its investigation to a single culture, exploring the nuances of cultural and social differences of sub-cultures. Limitations of the cluster surrounded the lack of interpretation of participation in perception of symbols and words.

The Kinship Antecedent papers within the Communication Matrix methodological framework were vital in providing methodological information about the framework and its implementation within the context of a wider research project (Rowland and Schweigert, 2005a; 2005b). The two reports provided information about the *Learning to Learn* (2005a) and *Design to Learn* (2005b) strategies (administered by the same individuals). These strategies embedded the Communication Matrix into their processes, which aimed to produce systematic models of learning for issues such as skills development. They were large-scale projects conducted for time periods up to two years. They secured the framework as a tool for establishing improvements in communication functions. However, the circumstances in which the Matrix was administered was not recorded, or evaluated (except in terms of reliability scores). Whilst the projects tried to imagine different physical and social worlds for the different populations in the projects, there were no descriptions of how to identify behaviours or to make subjective judgements about purposes of interaction (a prominent concept in the theory). The pearl citation (Rowland, 2011) and the final Kinship Antecedent paper (Rowland and Fired-Oken, 2010) offered no more insight into this aspect of the administration of the Communication Matrix. They did not focus on the perspective of the professional or parent in interpreting behaviour.

The case studies (Soto et al., 2006; Liborion and Soto, 2006) within the NAP analytical framework offered a wealth of empirically-based information about the framework. Arguably, short-comings in the implementation of the NAP are relevant in identifying the weaknesses in the evidence. This is because of the lack of familiarity of the authors with the framework in the contexts described. Soto and Hartmann (2006) describe the single opportunity to collect data per task (p.476). The authors of the key studies were not the creators of the framework; however, they illustrated expertise in the methodological process and purpose. The detailed description provided a strong link between context, method and analysis of the subject material. (In part, this is a result of the requirements which dictate the facilitation of a number of interactional tasks for different dimensions of discourse within the Narrative Assessment Profile). *Narrative interpretation* was more than identification of certain behaviours or functions; the interpretation of patterns of discourse required explanation. It is this element which exemplified transparency in facilitator actions and interpretation.

Next, I will discuss the contribution of kinship theoretical publications. A summary of study types, topics (or theory), and contributions are provided in table 6.3 below.

Table 6.3 Summary of the contributions of ‘Kinship Theoretical’ publications across Clusters

Study	Type	Topic/theory	Contribution
ICF 1-18			
1. Battaglia et al., 2004	1. Cohort study	1. Implementation/ use	1. Test of application of ICF
2. Bauer et al., 2011	2. Secondary data study	2. Implementation/ use	2. Assistive Technology classification and the ICF
3. Bornman and Murphy, 2006	3. Discussion	3. Approp. of application	3. Use of ICF with Talking Mats™ to set goals
4. Fried –Oken, 2012	4. Editorial	4. Approp. of application	4. Professionals question suitability of ICF
5. Griffiths and Price ,2011	5. Discussion	5. Approp. of application	5. Proposed framework for decision-making in AAC
6. Jelsma, 2009	6. Literature review	6. Implementation/ use	6. Review of use of ICF
7. Jette, 2006	7. Discussion	7. Approp. of application	7. Common language framework for physical therapy
8. McLeod and Bleile, 2004	8. Discussion	8. Approp. of application	8. ICF to understand social factors in goal-setting
9. Mulhorne, 2008	9. Secondary data review	9. Implementation/ use	9. Use of ICF to compare prevalence of impairments
10. O’Halloran et al., 2008	10. Secondary data review	10. Approp. of application	10. ICF as a framework for environmental factors
11. Pennington et al., 2007	11. Secondary data review	11. Implementation/ use	11. Response to lack of data on participants
12. Pless and Grandlund, 2012	12. Descriptive study	12. Implementation/ use	12. Examples of implementation of ICF
13. Raghavendra et al., 2007	13. Discussion	13. Approp. of application	13. Questions implementation theory
14. Rowland et al., 2012	14. Discussion	14. Implementation/ use	14. ICF as a profiling tool component

<p>15. Simeonsson et al., 2012</p> <p>16. Sykes, 2008</p> <p>17. Threats, 2007</p> <p>18. Üstün et al., 2003</p>	<p>15. Discussion</p> <p>16. Discussion</p> <p>17. Discussion</p> <p>18. Discussion</p>	<p>15. Implementation/ use</p> <p>16. Approp. of application</p> <p>17. Implementation/ use</p> <p>18. Approp. of application</p>	<p>15. ICF as a tool to enhance interventions</p> <p>16. Possible applications to physiotherapy</p> <p>17. Exploration of personal and environmental components</p> <p>18. Survey of existing interventions using the ICF</p>
<p>Culturally Valid Lexicon</p> <p>1. Beukelman, 1991</p> <p>2. Blackstone et al., 1993</p> <p>3. Hetrozoni and Harris, 1996</p> <p>4. Huer, 1997</p> <p>5. Taylor et al., 1986</p>	<p>1. Discussion</p> <p>2. Discussion</p> <p>3. Discussion</p> <p>4. Discussion</p> <p>5. Theoretical description</p>	<p>1. Theory- factors affecting vocabulary selection</p> <p>2. Theory- cultural awareness</p> <p>3. Theory- cultural aspects of AAC users</p> <p>4. Theory-cultural inclusivity</p> <p>5. Theory- cultural framework</p>	<p>1. Overview of vocabulary selection</p> <p>2. Journal articles offering bilingual context and tips for professionals in cultural awareness</p> <p>3. Exploration of enculturation processes and macro/micro perspectives</p> <p>4. Historical overview of mono-cultural AAC and cultural inclusivity protocol</p> <p>5. Culturally-based conceptual framework, historical perspective</p>
<p>Communication Matrix</p> <p>1. Beukelman and Mirenda, 2005</p> <p>2. Light, 1988</p>	<p>1. Theoretical description</p> <p>2. Theoretical</p>	<p>1. Theory- Participation Model</p> <p>2. Theory-</p>	<p>1. Development of model and location of CM within it</p> <p>2. Explanation of</p>

<ul style="list-style-type: none"> 3. Rowland, 2012 4. Rowland and Schweigert, 2000 5. Rowland and Schweigert, 2009 	<p style="text-align: center;">description</p> <ul style="list-style-type: none"> 3. Review (unpublished) 4. Study 5. Descriptive study 	<p style="text-align: center;">Communicative competence</p> <ul style="list-style-type: none"> 3. Topic- existing CM studies (field testing) 4. Topic- Tangible symbols 5. Topic- Object interaction 	<p style="text-align: center;">theory concerning intent of communication</p> <ul style="list-style-type: none"> 3. Presents validity and reliability tests and development of CM 4. 3 year study on use of tangible symbols in communication impaired children 5. Descriptive case study of ‘Hands on Learning’ approach and child interaction with objects in physical and social worlds
<p>Narrative Assessment Profile</p> <ul style="list-style-type: none"> 1. Bruner, 1985 2. Bliss et al., 1998 3. Bliss and McCabe, 2008 4. Collins and Markova, 1999 5. McCabe and Bliss, 2003 	<ul style="list-style-type: none"> 1. Discussion 2. Methodological paper 3. Discussion 4. Study 5. Theoretical description 	<ul style="list-style-type: none"> 1. Theory- Vygotskian theory development and contribution 2. Topic- discourse analysis and narrative 3. Topic- NAP and other analytical techniques 4. Topic- AAC users and non AAC users’ culturally shared knowledge 5. Theory- differences in narrative analysis techniques 	<ul style="list-style-type: none"> 1. Theoretical context and significance of Vygotskian ‘Proximal Zone of Development’ (1978) 2. Detailed examples and intervention guidelines 3. Discussion of cultural differences and implications for research 4. Comparison of interactions between impaired and non-impaired children in culturally shared knowledge 5. Describes aspects of appropriate narrative intervention with different groups

6. Ochs, 1983	6. Theoretical description	6. Theory- Communicative competence	6. Narrative dimensions explained
7. Ochs and Capps, 2001	7. Discussion	7. Theory- Living narrative	7. Cultural differences for language acquisition
8. Solomon-Rice and Soto, 2011	8. Case study	8. Topic- co-construction of narrative	8. Describes context for co-construction of narrative and micro/macro analysis examples

The Kinship Theory papers provided a link to resource to explain the adaptation of the ICF for AAC (Pennington et al., 2007; Pless and Grandlund, 2012; Simeonsson et al., 2012; Rowland et al., 2012; Bauer et al., 2011; Raghavendra et al., 2007; Griffiths and Price, 2011; Fried-Oken, 2012). They also identified specific population groups or practice disciplines (Bornman and Murphy, 2006; Sykes, 2008; Threats, 2007; McLeod and Bleile, 2004; Jelsma, 2009; Üstün et al., 2003; Mulhorne et al., 2008; Jette, 2006; O'Halloran et al., 2008; Battaglia et al., 2004). Theoretical sources broadened the context of the review beyond Activity and Participation components present in the core familial papers. The papers explained the various applications of the ICF. For instance, the ICF was considered: a tool for more accurately recording information about participants (Pennington et al., 2007); as a profiling tool (Rowland et al., 2012; Simeonsson et al., 2012); a proposed framework for decision-making in practice (Griffiths and Price, 2011) and a basis for classification of Assistive Technology (Bauer et al., 2011). In-depth analysis of the context of the framework highlighted the significance of the biopsychosocial approach and the Disability Model. The wider circle of publications also provided a greater array of critical commentary, underlining potential assumptions or contradictions in the data. For instance, the framework was not considered completely holistic because the strength of the relationships between components was not analysed (Raghavendra et al., 2007). In addition Activity and Participation lacked empirical underpinning from validated instruments (Sykes, 2008).

The wider theoretical papers in the Culturally Valid Lexicon cluster played an important role in contextualising the long history of increasing professional awareness of cultural diversity (Taylor, 1986; Huer, 1997, Beukelman et al., 1991). In addition, the evidence emphasised the increasing recognition of the negative impact of professional bias within

dominant cultural or linguistic groups (Blackstone, 1993; Hetrozoni and Harris, 1996; Taylor, 1986). The cultural conceptual framework (Taylor and Clarke (1994) originally presented in Taylor, 1986) was not based on a broad empirical foundation. Instead, it appeared to have been significant research which emerged as a result of shifting demographic and policy changes that emphasised equity for AAC users and people from alternative linguistic backgrounds at a more general level. The theoretical sources helped to explain why it was so important that the validation methodological framework did not generalise across a whole culture. It also explained the necessity for some level of autonomy for participants in selecting lexicon. The synthesis findings considered the theory used and the small number of antecedent or sibling papers analysed. Tentative conclusions emphasise efforts to avoid generalisation across culture and language, professionals became aware of “*ethnocentric*” practice (Taylor 1986, p.9) in AAC and tried to change it.

Within the Communication Matrix cluster, theoretical texts such as Beukelman and Mirinda (2005) showed how the matrix was based on Light’s four *Reasons to Communicate* (1988) and seven levels of communicative behaviour. These levels are based on a pragmatic approach to communication development first discussed by Bates et al (1979 cited in Rowland and Fried-Oken, 2010, p.321). The matrix was embedded within the Participation Model (originally described in 1988, cited in Beukelman and Mirinda (2005)). This paper outlined the history of the era of research from candidacy models to the Participation model (p.136). These eras were intertwined with the shifts in professional perspectives. Collectively, the theory prioritised objectivity in assessment at the expense of a more interpretive and pragmatic approach. Those administering the Matrix were not intended to interpret or document the impact of their judgements about the communication assessments. (This differs from prompts common to analytical frameworks). Thus, professionals (or parents) administering the framework did not interrogate their own perspective and biases. There were no independent reflections on its implementation, only the field testing and validation (Rowland, 2012). In the absence of transcribed micro analysis of dialogue or video footage, it was difficult to determine the nuances of interpretation.

Peripheral papers within the NAP cluster contributed to the role of theory on the analytical framework perspective (Vygotskian theoretical insights as the foundation for interactional analysis (1978 cited in Cole, 1985, p.155)). The findings conveyed the complexity of the

narrative genre concepts (McCabe and Bliss, 2003; Bliss and McCabe, 2008). Synthesis contextualised the role of the analytical framework as one of several processes for understanding narrative.

6.5 Translatable knowledge to next review

Overall, the Meta Study analysis enhanced my understanding of how each framework operated within particular contexts. Translatable or transferable knowledge for subsequent reviews can be separated into several elements including: context, concepts, methods, critical approaches and themes.

First, I discuss the ICF cluster. The guidance on reporting AACs through the ICF (Pennington et al., 2007) was considered a useful methodological reference point for future reviews. The classification components and domains were a useful guide for appraising the information gathered about participants. (For instance, bibliographic/demographic characteristics, such as: educational experience, previous interventions, ethnicity, socio-economic status and AAC use (Pennington et al., 2007 p.526-9 table 1)). Equally, the aided communication domain included features such as: modes of communication, communication aids, history of AAC use, comprehensibility and current use of AAC (Pennington et al., 2007, p.528-9, table 1). Characteristics of the communication partner were also significant (e.g. their bibliographic characteristics, relationship to users, relevant experience, training, exposure to the experience of AAC, attitude to user (Pennington et al., 2007, p.529, table 1)). Features of the environment also emerged as important (e.g. location, residence, social and communicative context of participants, attitude of others, support of others, exposure to language and other communication modes (op cit.)).

Secondly, I discuss the Culturally Valid Lexicon cluster. I argue the broader impact of the framework was conceptual. Further research can ask whether the AAC system included *cultural validation*. More broadly, the framework encouraged researchers and reviewers to question the perception of AAC relative to culture (Nigam, 2006; Huer, 2000). Protocols designed to encourage cultural awareness could prove useful to measure consideration of culture (Hetrozoni and Harris, 1996, p.57 table 1). Finally, the cluster showed that historical and policy contextual information from a single country could be vital in influencing a whole research area, such as bilingual and racial equity (Taylor, 1986).

Thirdly, I discuss the Communication Matrix cluster. The cluster highlighted some of the limitations of methodological frameworks which did not analyse the interpretation of data carried out by researchers or clinicians. This emphasised the importance of critical reflection. Finally, the contextual contribution of the cluster expressed the influence of shifts in broader attitudes, such as professional preference towards Participation Models over Candidacy Models (Beukelman and Mirenda, 2005).

Finally, the Narrative Assessment Profile cluster provided an example of analytical framework and a rich conceptual overview of narrative as a linguistic phenomenon. Narratives of AAC users were regarded as unique (Soto et al., 2006). Methodologically, the cluster demonstrated that for every interpretive option, such as narrative, there may be a group of options for analysis and transcription such as: high point, story grammar, stanza analysis, NAP (McCabe and Bliss, 2003 p.10) (discussed in greater detail in section 6.5). Subsequent reviews need to record the presence of interpretive frameworks or techniques.

6.6 Discussion

The Meta synthesis set out to understand key conceptual and the contextual aspects of frameworks to increase understanding of interpreting AAC methods. This focus was reflected in the phases of the review which incorporated conceptual and contextual analyses of perspectives, theory, historical and policy context, method and analytical strategies. Central themes, associated assumptions and translatable knowledge also emerged. This section discusses the purposes of different frameworks. Key areas of themes overlapped with the conceptual and contextual contributions of the synthesis. All three elements are discussed below.

The analysis of the four clusters attempted to make sense of the perspectives shaping their design and implementation. These were: health classification (the ICF), cultural framework (the CVL), communication development (the CM) and narrative genre (the NAP). The associated purpose of the frameworks could be summarised as: *classification* of health status, *validation* of AAC system according to cultural perspectives, *assessment* of expressive communication level, and *interpretation* of narrative. Therefore, frameworks had conceptual, methodological or analytical status.

Similar themes emerged across clusters. The first area concerned AAC practice. Specifically, the frameworks incorporated: improving service provision (ICF); making

changes to practice (CVL); identification of educational needs (CM) and educational outcomes (NAP) (all previously discussed in the findings section). Frameworks were designed to have a direct application to practice. However, this required a mechanism to link it to practice- such as Talking Mats™ (Murphy and Boa 2012; Harty et al., 2011; Boa and McFayden, 2003; Murphy and Strachan 2011; Rowland et al., 2012; Pless et al., 2012). The other three frameworks required links to theoretical models or concepts. For example, the CVL was associated with the Culturally-based conceptual framework (Taylor, 1986); the CM with the Participation Model (Beukelman and Mirenda, 2005) and the NAP were associated with the concept of Communicative Competence (Orchs and Capps, 2001). Synthesis also uncovered links to early theory such as Vygotsky ((1962, 1978) cited in Bruner (1985)) within the Narrative Assessment Profile, or Light's (1988) communication motivations theory influenced the Communication Matrix cluster (Rowland, 2011, p.193; Beukelman and Mirenda, 2005).

The second theme identified across clusters was the role of the framework in understanding the communicative or interactional context. Cluster material underlined the importance of: participation in identifying contextual factors (ICF); cultural context (CVL); barriers and facilitators for implementation (CM) and the broader interactional setting (NAP). The assumptions across the clusters bridged these key themes by identifying limitations of professional perception of context. For instance, the assumptions in the ICF (highlighted by critical reviews such as Raghavendra et al., 2007; Jelsma, 2009; McLeod and Bleile, 2004) problematized the universal and holistic nature of the framework. The main assumption in the CVL centred on the ability of the professionals to illuminate biases based on culture (Blackstone, 1993, Hetrozoni and Harris 1996; Nigam 2006). However, authors tended to assume this issue could be resolved completely with the right methods, protocols or training. The Communication Matrix, limited by its lack of transparency in interpretation, assumed observational judgements would be sufficient to represent all views (Rowland and Fired-Oken, 2010). Finally, the NAP made assumptions about the certainty of the properties of narrative to represent wider communication (Soto et al., 2006). The interpretation of narrative rarely offered a definitive judgement.

The review also reiterated the idea of context as an important feature of the models and processes. Policy contexts were instrumental in providing a sense on perspectives and purposes behind theories, often relating to American settings (legislation (Bauer et al.,

2011; Taylor, 1986), or, shifts in professional attitudes for instance (Beukelman and Mirenda, 2005)).

Overall, the review updated and expanded upon previous Assistive Technology model reviews (Edyburn, 2001; Lenker and Paquet 2003). This Meta Study review confirmed the significance of the ICF also analysed by Lenker and Paquet (2003). Findings from this review expanded Lenker and Paquet's (2003) conclusions. That is, the *classification* role of the ICF was previously identified (p.13). The parameters of the review identified frameworks developed for interpretive processes. This approach isolated new types of methodological and analytical frameworks in the form of the CM, CVL and NAP. The frameworks governed processes for rich analysis and equal opportunities for expression. However, there appeared to be some limitation in the data from the methodological frameworks. For instance, the Communication Matrix and the Culturally Valid Lexicon processes provided little guidance on how interpretive decisions or judgments were made. I suggest the frameworks opted to present an objective framework with maximum usability.

6.7 Summary

The four frameworks identified from the Meta Study were the World Health Organisation's *International Classification of Functioning, Disability and Health* (ICF) (WHO, 2001); Culturally Valid Lexicon, Nigam (2006); Communication Matrix, Rowland (1990) and the Narrative Assessment Profile, Bliss McCabe and Miranda (1998). The key findings from clusters related to context and concepts related to the implementation of AAC methods. The rich detail and representation of the interconnectivity between theoretical and methodological aspects of the clusters (also visually represented), was an essential part of understanding the contribution of study methods. Analysis and synthesis included interpreting theoretical models and concepts, identifying underlying assumptions in the literature and extracting themes. Key themes were analysed across clusters and the discussion indicated the underlying purposes of the frameworks.

Conceptual and contextual aspects of the frameworks emerged. Conceptually, all of the frameworks highlighted the framework as a way to affect practice. The frameworks embraced the concept of interpreting the communicative interaction context. However, many of the assumptions behind the frameworks entailed failures to recognise the limitations of professional perspectives about the context. The material which

contextualised the frameworks illuminated the policy context and the differences between the conceptual framework (the ICF) and others which were specific to a particular methodological framework (CVL and CM) or analytical framework (NAP). Broadly speaking, the ICF requires further action in order to be transformed into practical use (such as Talking Mats™). By comparison, the other frameworks had more of a practice-focused basis but required links to theoretical models.

Contextual and conceptual aspects of the cluster data set were deemed potentially useful to further research or reviews. For instance, papers such as Pennington et al (2007) illustrated how the ICF could be used to guide the format for gathering data extraction of participant demographic characteristics. The transferable elements from the review were helpful in subsequent reviews; in particular: concepts, contexts, methods, critical stances and concepts.

The modified Meta Study methodology provided an analysis of the framework's objectives, assumptions and connections to theory. However, all the clusters identified in this topic had a limited number of core papers relating directly to the study or evidence of repeated empirical adoption. Edyburn (2001) stated that frameworks were defined by their ability to "*stimulate advances in theory, research, development, policy and practice*" (p.16). The Meta Study synthesised evidence in these areas. Outcomes from the review also provided a way of understanding the interrelationship between a framework, its perspective and its purpose.

Chapter 7: The implementation of a Narrative Synthesis according to the third approach to methods contextualisation

7.1 Introduction

The Narrative Synthesis is the third and final empirical chapter in the thesis. The empirical studies in the thesis demonstrate how the three approaches to methods contextualisation reviews might be implemented. The studies adapt existing review methodologies that were developed into templates (presented in chapter four (4.5.2)). Narrative Synthesis is a way of summarising multiple studies. The methodology relies primarily on words and text to synthesise material, one strand focuses on factors shaping successful implementation of interventions (Popay et al., 2006). A Narrative Synthesis was selected as the most suitable platform to develop the third approach to methods contextualisation. That is, to understand the broader theorisation of context (especially, the implementation of data collection methods). The justification for this selection is discussed in relation to criteria presented in chapter 2.4 and 2.5. In section 2.5 I identified suitable characteristics to guide the review. In the absence of a specific reference to Narrative Synthesis in the classification table (Hansen and Trifkovic, 2013 p.30-31, table 5), I identified assess of appropriateness of interventions as a suitable research question for an interpretive, multi-component mixed method approach (see table 2.2 section 2.4). This helped me to define my approach to implementation.

7.2 Wider literature

I consider voice elicitation to be a cornerstone of appropriate research methods implementation. The scoping review developed my understanding of voice in AAC research contexts (either methods that would enhance understanding of interactions in different contexts, or research that would interpret the contribution of the AAC). Arguments located in the chapters one and three (1.3 and 3.3) link voice to primary researcher's choice and use of research methods. (This is exemplified in research with marginalised groups). I make links to principles of credible research also relevant to methods contextualisation. Chapter 3.3.2 provides justification for voice as a conceptual framework. Key texts introduced in chapter 3.3.3 viewed the concept of *voice* as a feature of dementia research: Goldsmith (1996) and Wilkinson (2002b). These texts are described in greater detail below. I explain how the texts envisaged *implementation* of voice-enhancing research.

Goldsmith's (1996) theorisation of the three components of voice were described as: listening to the person with dementia; displaying the ability to accept the person as they are (including the possibilities of communication) and thirdly to developing an understanding about the person with dementia (however long this may take) (p.56). These factors clearly have implications for the implementation of voice-eliciting research. This discussion is helpful but it does not contain enough detail to represent a comprehensive guide for researchers, especially in the context of using the array of alternative communication methods. This study will attempt to expand on these three principles. Goldsmith's (1996) work suggested that appropriate implementation of AACs with people with dementia was dependent on researcher engagement. His work cited the use of nonverbal communication in caring. However he used a predominantly verbal frame for communication itself. "*The ability to communicate, both verbally and nonverbally, is a critical component of caring.... We are slowly building up resource material which can help people in the process of communication- gaining eye contact, using simple sentence constructions, giving one -step instructions, minimising distractions and so forth...*"(p.54). The second chapter in Goldsmith's book tackles the issue of hearing views about services. He sets out the challenge for future research, stating "*We are not yet in a position to be able to speak easily with people with dementia, but we do know that **some** people seem to be able to communicate with **some** people with dementia. The challenge is – how can we enable **more people** to communicate **more easily** over a wider range of topics with **more** people with dementia?"* (p. 19). Here, Goldsmith acknowledges successful communication with people with dementia as a challenge, a mystery even. This extract also helps to convey the creation of biases when communication facilitation is inconsistent and, the needs of this diverse group are not well represented. I argue alternative communication methods may be fundamental to producing voice-elicitation guidance.

The book edited by Wilkinson (2002b) is a thoughtful and thought provoking series of accounts from researchers examining their inclusive research methods to support inclusionary practice and policy in the UK. It is argued that "*people with dementia remain a silent and excluded voice*" (Wilkinson 2002a, p.9). In the first chapter Wilkinson also argues that shifts in power are required to include people in research, including the exploration of selfhood. This notion of communication dynamics is indicative of another central issue: the implementation of voice research requires researchers to analyse social dynamics of interactions, not just alterations to practice. Wilkinson argues '*The Feeling*

Self can be distinguished from the cognitive self that may be affected by memory loss (Froggatt 1988 p.133 cited in Wilkinson 2002a, p.13). In two subsequent chapters a limited range of alternative communication methods are explored with reference to nonverbal methods and observations (Clarke and Keady, 2002, pp.39-42 in Wilkinson, 2002). Their work represents the most detailed guide to implementation of voice and alternative communication methods in dementia literature. The authors argue that “*Nonverbal communication may be crucial to our understanding of the meaning of the words spoken...*”(op cit. p.39). The authors even refer to early research with ‘photocharts’ and memory boards (Reed, 2000 cited in Clarke and Keady, 2002, p.40). Therefore, Clarke and Keady (2002) recognised the importance of contextual methodical factors and the management of the style of the communication interactions that extend beyond the elicitation of ‘data’ itself. These are summarised as ‘criteria’ to assist data collection:

- *“Data collection requires creativity and a positive approach to managing the challenges of researching people with dementia*
- *There must be opportunity for people to people to articulate and express their perspectives in a way that, as researchers, we have confidence in the data. This requires:*
 - *Sufficient engagement to allow confirmation of issues raised, for example repeated interviews.*
 - *A mutually trusting relationship*
 - *A collaborative approach with the person with dementia, allowing a mutual process of agenda setting*
 - *Minimising anxiety and tiredness, for example by considering the duration, pacing and location of data collection*
 - *Augmentation of data collection either through multiple corroborating sources or by structuring the data collection episode to maximise engagement*
- *The person must be valued, and know that they are valued, for their knowledge; this suggests that the researcher will need to be emotionally engaged with the individual.*
- *Detailed attention must be paid to data recording”* (Clarke and Keady, 2002, p.41-2)

In addition, in another chapter in Wilkinson's (2002b) book (Cook, 2002) examined the use of video data with people with mild to severe dementia symptoms. The nonverbal communication was analysed to capture the experiences of dementia. However, the work was observational; it lacked researcher-led interaction during the naturally occurring interactions in the day centre setting.

This Narrative Synthesis review attempted to provide clarification about the *implementation* of AAC methods. I wanted to compare the processes of implementation to discern which aspects were appropriate.

7.3 Methods

This section presents the aspects of the implementation of the methodological template tailored to my research question. (The template for Narrative Synthesis adapted for methods contextualisation is summarised in chapter 4.5.2). The methodological process began with: to re-visit data from the scoping study, refinement of the concept of voice, and initial efforts to identify social science perspectives. I then embarked on the six stages of the methodological process (see figure 4.6 in section 4.5.2).

Previously, the Meta Study I conducted (chapter six) provided knowledge about specific reporting guidelines for AAC to inform data extraction values (discussed in the translatable knowledge section 6.5, in particular, classification domains for reporting participant characteristics in Pennington et al., 2007, pp.524-529, table 1). The study also highlighted the value of related papers. (The transferable knowledge is discussed in greater detail in sections within chapters 5.6 and 6.5).

Narrative Synthesis (Popay et al, 2006) is a systematic and transparent review process that identifies, appraises and synthesises research through a textual approach. The method uses interpretive and aggregative approaches to transform evidence into textual form for interpretation. The main way the methodology was adapted for methods contextualisation was the study selection, namely the inclusion of additional 'sibling' papers (see stage 3).

The structure of the methods and results followed the sequential stages and synthesis elements phases in Popay, et al's Meta Synthesis guidance (2006, p.12, figure 2). These are: 1) identification of a research focus; 2) specification of research question; 3) identification of studies to include in the review; 4) data extraction and quality appraisal; 5) synthesis and, 6) Reporting and dissemination.

7.3.1 Identification of research focus and research questions (Stages 1 and 2)

1). Identification of a research focus

Papers were treated as textual sources from which narratives emerged. The exploration of data was intended to increase understanding of the contexts of each method to see how implementation strategies compared across methods; in other words, to consider the factors that might explain any differences in the facilitators or barriers to successful implementation.

2). Specifying the review question

In specifying the review questions, the aim was to inform the future implementation of AAC research methods and interventions. The research questions were:

Q1: Which AAC methods (and associated implementation strategies) have been used with people living with dementia to elicit voice? (Descriptive)

Q2: Which aspects of the methods processes are key to appropriate implementation? (Interpretive)

7.3.2 Summary of remaining stages of implementing methodological template

3). Identifying studies to include within the review

Searches took place laterally within key journals, key AAC or dementia support websites. Papers retrieved from the first scoping review were sifted through for relevancy, and additional ‘berry-picking’ techniques were applied to the papers identified such as reference scanning and Google scholar searches (see Appendix item 12, p.336). The database searches consisted of three updated scoping review searches and new searches in Pubmed, Embase (includes PsycInfo, Medline) and Cinahl. An example of the search terms used is below.

(dementia*[Title/Abstract] OR dementia[MeSH Terms] OR Alzheimer* OR mild cognitive impairment*) AND (augmentative alternative communication OR communication strategy OR synthesi* speech OR gesture OR photo elicitation OR music therapy OR nonverbal communication OR talking mats OR blissymbol* OR picture exchange communication system OR communication board OR communication display OR augmentative and alternative communications systems[MeSH Terms])

Broad search terms were used (such as ‘augmentative and alternative communication’) alongside more specific terms for various methods, modes and mediums of AAC to capture relevant literature. Both types of search terms were applied with dementia search terms using AND operators. Details of specific search terms in each of the databases can be found in the appendix (items 13-15 pp.339-342). All search results are presented in the next section.

The features of the study selection criteria are stated below (figure 7.1). The review sought to identify papers that focused on the use of AAC methods (including methods, systems or devices) with people living with dementia (or MCI). I decided to adapt the template to identify an empirical paper and a corresponding methodological paper. The exclusion criteria removed general discussions of the literature that were not linked to an empirical study. However, the decision was taken to include grey literature, or reports, and additional searches from key websites and search platforms. Therefore, not all material was peer-reviewed. The searches took place during May 2014 were limited to the year 2000 and beyond. The scoping review results informed this cut-off point. Although the searches were designed to be comprehensive, the process of translating papers was impractical. Non-English language studies were screened out at the abstract phase (see appendix items 13-15).

- Population has to include people with dementia or MCI (all levels of severity, diagnosed only, presence or absence of speech)
 - Use of AAC system or methodology
 - Data is directly reporting an empirical study or recounting a method from an empirical study (i.e. not a review of literature) (all study designs included)
 - (2000 and beyond)
 - Focus: process privileges voice
 - Focus: AAC as supportive communication
 - English language translation
- Additional criteria:
- Perspective of persons living with dementia captured
 - Experience of person with dementia discernible

Figure 7.1 Study selection criteria

The conceptual framework (voice-elicitation) was based on a judgement about whether the study exhibited meaningful interaction, or interpretation of the value of the methods in reproducing meaning throughout the study. The criterion (in figure 7.1) assisted me in this decision because it defined communication as a supportive interaction. The final criterion stated that data had to incorporate the perspective of the person with dementia (as opposed to carers or care staff perspectives). It also stipulated that if there were multiple populations the perspective of the persons with dementia must be easily distinguishable in the data. All papers or reports met all criteria. The included studies were double screened by supervisors who were provided with the inclusion criteria and checked against the inclusion criteria. A percentage of all records from all searches were double screened for accuracy of exclusion.

The review methodology guidance (Popay et al., 2006) used a ‘comprehensive search’ approach to the identification of literature. This was the guiding principle in the identification of studies for the review. However, adaptations to the recommended searches included the identification of additional papers belonging to the same study (so-called sibling papers) that could help create a narrative. This approach adds a purposive sample element to the body of data. The principles for the selection of sibling papers were provided in the methodology chapter 4.5.2 figure 4.5.

4). Data extraction and quality appraisal

This section provides an overview of data extraction and study quality appraisal. Details of the included papers are discussed in the findings section. The data extraction process was designed to organise data directly into a tabular format to assist in the descriptive and interpretive analysis. The form can be found in the appendix item 16 (p.343). (My domains (variables 13-15 and the AAC use aspects of the methodology (variables 4-10) were adaptations of parts of Pennington et al’s reporting guidelines designed to be compatible with the ICF (2007, pp. 526-529, table 1). The data was held on an Excel table which included general data extraction information (the first 13 fields). The 27 preliminary analysis fields derived from the outcomes from the third Meta Study review. There were also five textual fields at the end of the form that helped to initiate the analysis, based on the central elements of implementation of methods i.e. contextual factors, facilitators, barriers, specific factors to aid implementation and perceived strength of evidence. Data extraction took the form of verbatim quotes from papers. Multiple rows on

the Excel table linked papers from the same project where empirical papers were found that linked to a methodological paper (or vice versa).

The quality appraisal was derived from the adaptation of two checklists for qualitative and intervention research evidence COREQ (Tong et al., 2007) and TREND (Des Jarlais et al., 2004)). The decision was made to include them but to simplify the content. The process estimated quality of the study design to flag up any concerns for the analysis and synthesis phases. The quality assessment was applied to the empirical papers, highlighting studies of poor quality (including poor reporting quality) to be excluded or treated with caution within the synthesis.

5). Synthesis

Table 7.1 below is based on the synthesis section of the modified template -figure 4.5 in chapter 4.5.3. It provides an overview of and commentary on the modified elements within the synthesis. The core elements consisted of: developing a model of how the intervention works, a preliminary synthesis, exploration of relationships in the data and a *robustness of synthesis* assessment.

Table 7.1 Modified synthesis processes used within the Meta Narrative review

(Popay et al., 2006, p.12 figure 2 (columns 1), I have also added a commentary

Element of synthesis	Techniques Chosen	Comments
1. Developing a theoretical model of how the interventions work, why and for whom	No specific techniques provided (programme theoretical model building described)	<i>Meta Study findings informed the basis for the interconnected set of assumptions which form the backdrop to Narrative Synthesis review.</i>
2. Developing a preliminary synthesis	1 Textual descriptions of studies 2 Groupings and clusters 3 Tabulation 4 Translating the data into	<i>Further analysis- use raw data from Data Extraction as a framework which structured data to further extract key elements</i> <i>Case Summaries of all studies consisting of: qualitative textual description, implementation facilitators and</i>

	a common rubric <i>5 Qualitative case descriptions – Case Summary format created (method used commonly in element 3)</i>	<i>barriers</i> <i>Tabulation of key elements-Synthesis across studies and methods- probe data across studies using information from the Data Extraction phase as variables.</i>
3. Exploring relationships in the data	Tabulation Thematic analysis – including identification of ‘overarching constructs’	<i>Summarise data from the case summaries into tables of factors that relate to participants, researchers or the interpretation of data. Identify patterns in the data.</i> <i>A single table was created that cross references facilitators and barriers (and study contexts) with the different typologies of AAC. Distinct transferable and methodology specific factors were identified. Key themes were identified within the data and add references to the primary of sources of evidence so robustness of evidence can be viewed.</i> <i>Summarise conclusions with an ‘overarching construct’ statement- criteria for appropriate application and interpretation of components of methods.</i>
4. Assessing the robustness of the synthesis product	3 Reflecting critically on synthesis process	<i>Apply outcomes of Quality Assessment to the key themes identified through the synthesis.</i> <i>Reflect on aspects of the synthesis process using guide provided by Busse et al in Popay et al 2006, p.22.</i>

As the first element of synthesis, I developed a theoretical model for implementation. The model is displayed in the synthesis section 7.4.3.2 figure 7.3. The model views implementation of AAC methods as a process related to many aspects of research. All aspects of the research process are considered, in particular, researcher role, participant engagement and analytical strategies. The preliminary synthesis (element 2- see table 7.1 above) incorporated the first 24 variables of the data extraction to generate a large Excel table of textual data. Direct quotations were used as far as possible to retain a direct link to the original data. Textual descriptions were added into the table (Popay et al., 2006, p. 16). Re-organisation was vital in understanding the importance of contextual data. Case Summaries (created for this review) were similar to the principles of *qualitative case*

descriptions (Popay et al., 2006, p.20). The data was translated into a common rubric and presented in a visual way. This helped the reviewer to gauge how mechanistic factors related to each other. The purpose and format of the case summaries have been described in chapter 4.5.2, figure 4.7. An example of a Case Summary is provided in the synthesis section of this chapter 7.4.3 figure 7.4. Data from data extraction was analysed in terms of heterogeneity and variation across study designs, populations, interventions and settings, theory and methodologies. (These techniques were originally associated with the third element in the methodology Popay et al., 2006, p.14-15).

The third element of synthesis involved tabulation of key thematic data at increasing levels of abstraction. This was a productive way of examining elements of data across studies. The tabulation structure applied the structure of the model to help to organise data (researcher role, participant engagement and analytical strategies). This analytical phase enhanced the variation and heterogeneity information already gathered through the analysis of study attributes in the preliminary analysis. The thematic tables (table 7.5 (full version in item 17 of the appendix pp.348-367) scrutinised commonalities and differences in the data produced, in order to understand the type of barriers or facilitators to successful implementation and to understand why they operate (p.14). Eventually the thematic abstraction led to ‘Overarching Constructs’ described in chapter 4.5.2. Finally, the fourth element judged the robustness of the synthesis. I selected the Critical Reflection technique (Busse et al., 2002, cited in Popay et al., 2006, p.22). See chapter 4.5.1 for an explanation of the six key elements). The next section presents the results of the searches and quality appraisal (beginning with a PRISMA diagram) followed by a section presenting the analytical results of the synthesis.

6). Reporting and dissemination- Reporting of methods and synthesis findings presented via this chapter.

7.4 Findings

Section 7.3 discussed the way the methodological template was implemented for the specific research questions in all the stages of the Narrative Synthesis method. This section explains the findings from stages three, four and five of Narrative Synthesis. These stages convey ‘findings’ i.e. the identification of studies; data extraction and quality appraisal and synthesis. Stage six (reporting and dissemination) relates to the reporting of the study herein.

7.4.1 The identification of studies to include in the review (Stage three)

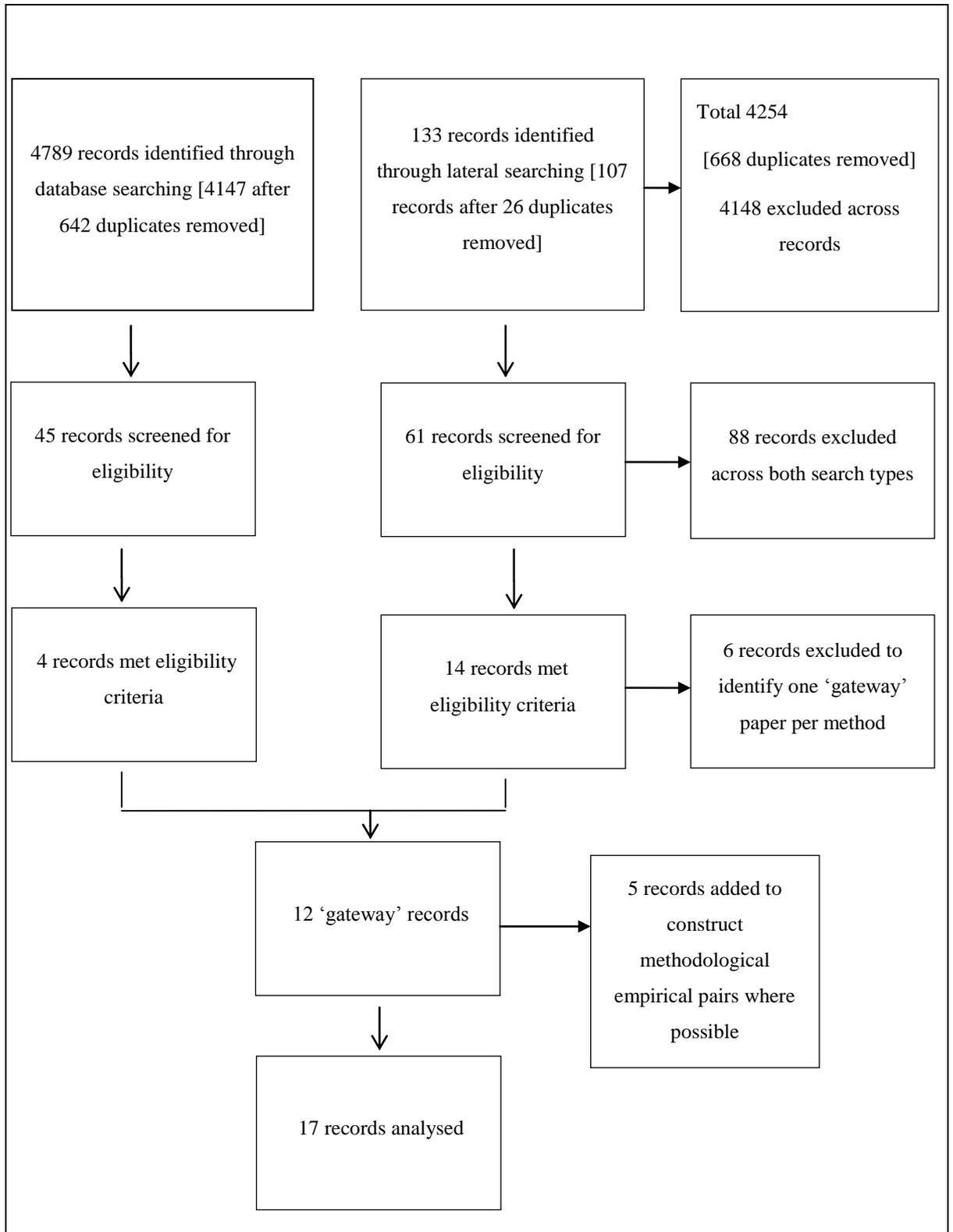


Figure 7.2 PRISMA diagram for the Narrative Synthesis

The PRISMA diagram in figure 7.2 illustrates the combined searches and ‘gateway papers’ identified from the review. It also presents the additional sibling papers added at the end of the process. The diagram illustrates the relative contributions of the database and lateral searches to make a total of 4254 records. The lateral searches produced 61 relevant records to be screened from a possible 107. By comparison, 4147 records from the combined database searches contributed 45 records to be screened. After this initial phase, a total of 88 records were excluded to result in four included records from the database searches and 14 from later searches. This shows that the inclusion criteria were relatively narrow. The process also shows the steps taken from the 18 records identified as relevant, to the exclusion of six to result in one paper per method. Finally, five records were added in the form of sibling papers. (Full lists of these papers can be found in table 7.4 in the findings section below).

Table 7.2 below provides more detail on the breakdown of specific searches prior to sifting or screening. This is a useful tool in showing the relative specificity of searches in the protocol. Most noteworthy is the relatively small number of hits produced from the new database searches (Cinahl-133; Embase- 22 and Pubmed- 509). It also demonstrates the significant contribution of the scoping results (and their associated updates). Collectively, these formed a total of 2928 of the overall 4147 number of records. The lateral searches took a large variety of routes including internet searches or grey literature searches with purposefully designed searches in well-known journals, citation tracking from important papers and websites to produce 48 potentially relevant papers. The 85 key papers from the scoping review also provided a richer list to mine for relevant papers.

Table 7.2 Breakdown of searches by database and lateral search types

Database searches	Number records	After duplicates removed	Lateral	Number of records
Embase scoping	752 1411	496 1321	AAC hand search	1
Pubmed scoping	285 536	250 413	Basic Google search	10
Cinahl scoping	72	59	Citation tracking	14
Cinahl new	190	133	Other literature	2 (0 after duplicates removed)
Pubmed new	511	509	Google scholar from CT	5
Embase new	34	22	Grey	5
Update Cinahl	49	43	Hand search Dementia	1
Update Embase	693	679	Reviews identified from scoping	5 (2 after duplicates removed)
Update Pubmed	256	222	websites	5
				Total 48
			Scoping	85
	4789	4147	total	133
			DE duplication	107 [43 lateral & 64 scoping]
			Combined total	4254

Table 7.3 demonstrates the relative success of the searches through tracing the origin of included studies. The table shows the relationship between the numbers of relevant records per search to the number of included records. The most successful method was the lateral searches with a total of seven included papers from the twelve (this takes into account the two lateral studies from the previous scoping review). The new database searches only yielded a total of three papers.

Table 7.3 Source of included papers

Source of literature	Number of papers (N=12)
Cinahl new	1
Pubmed new	2
Scoping review	4 (2 from lateral searches, 2 from database searches)
Citation tracking	2
Grey literature	1
Google scholar lateral searches	2

The first review question set out to document which AAC methods (and associated implementation strategies) have been used with people living with dementia to elicit voice. A total of 12 methods corresponding to 12 gateway papers were identified for the Narrative Synthesis (from a possible 18 papers containing multiple papers derived from the same method). Five additional sibling papers were added to the 12 (including papers not chosen to be gateway papers) to make pairs of papers (a full list of the papers is located in the references section).

Table 7.4 presents the included studies and the corresponding type of paper as well as any comments surrounding the decision to include it.

Table 7.4 Characteristics of papers which met inclusion criteria

Paper citation & AAC method	Type of paper	Comments
Allan 2001 <i>Working with pictures & nonverbal</i>	Gateway, Empirical	Published report, focus on exploring methods to enhance communication (data collected not analysed qualitatively)
Astell et al., 2010 <i>CIRCA™multimedia device</i>	Gateway, empirical	
Astell et al., 2009	Sibling, methodology	
Bartlett, 2012 <i>Diary interview method</i>	Gateway, Methodology	
Bartlett, 2014	Sibling, Empirical	
Bober,2002 <i>The Feelings Art Group</i>	Gateway, Empirical	
Jonas-Simpson, 2005 <i>Story, music and art expression</i>	Gateway, Empirical	
McKeown et al., 2010b <i>Life Story Work</i>	Gateway, Empirical	
McKeown, 2010a	Sibling, Methodology	
Murphy et al., 2013 <i>Talking Mats™</i>	Gateway, Empirical	
Murphy et al., 2005 [Four additional papers also located in review on Talking Mats™method]	Familial, Proxy-methodology	Referenced by the gateway paper as a project that preceded the most recent study. Murphy et al. (2005) selected instead of Murphy's (2009) doctorate as this was a by publication consisting of studies earlier than 2004 and with a range of populations with communication difficulties other than dementia.
Nygård 2006 <i>Nonverbal interviews and observations</i>	Gateway, Methodology	
Nygård and Starkhammer, 2007	Sibling, Empirical	This paper was selected as it was more recent than a 2003 empirical study.
Nyström and Lauritzen, 2005 <i>Dance therapy- including capturing nonverbal</i>	Gateway, Methodology	Sibling empirical paper not identified.

communication		
Shell, 2014- <i>Photo elicitation and Autodriving</i>	Gateway, Methodology	Paper reports on the methodology of a previous study but no associated findings presented. Sibling empirical paper not identified.
Smith et al., 2009 <i>Multimedia Biographies</i>	Gateway, Methodology	Paper reports study methodology, focusing on production and screening processes- no associated findings presented. Sibling empirical paper not identified.
Wiersma 2011 <i>Photovoice</i>	Gateway, Methodology	Pilot study methodology- no associated findings presented. Sibling empirical paper not identified.

7.4.2 Data extraction and quality appraisal (Stage 4)

The data extraction form is displayed in the appendix item 16 (p.343). This stage produced the findings for the synthesis findings and does not therefore constitute findings in its own right.

Results of the quality appraisal

The checklists have been simplified in the table in appendix items 18 and 19 (pp.368-371) to provide a guide to the relative quality of the overarching study design and reporting. An 'X' indicates that the measure was not carried out or not reported.

Studies were assigned to either checklist according to their approach. The vast majority of the studies were judged according to the 'qualitative' checklist. However, there was in fact a mixture of research designs (see variability results in the next section of this chapter 7.4.3). The best way of appraising the quality of those studies or interventions was through a *qualitative study checklist*, rather than the positivist (theory-testing) criteria which often implied a quasi-experimental design. Findings suggest quality ratings were higher within the studies (assessed under the intervention appraisal criteria) (Murphy et al., 2013; Astell et al., 2010). A group of seven of the studies met between 9 and 11 of the qualitative quality appraisal criteria. This was a relatively low number. Some of the indicators provided valuable insights into the unsatisfactory study design components in which AAC methods were introduced. Components such as: unknown sampling design (Nyström and Lauritzen, 2005); repetition of interviewing (familiarisation) (Allan, 2001;

Bartlett, 2014; Bober, 2002; Jonas- Simpson, 2005); lack of coding descriptions (Bober, 2002; Jonas- Simpson, 2005; Smith et al., 2009; Wiersma, 2011). However, the findings may also reflect the lack of highly suitable criteria in this field, stemming from the polarised options for quality assessment. Overall, only Wiersma's (2011) study (the Photovoice method) performed poorly in relation to this quality assessment (meeting just four of the criteria) so this was taken into consideration in the analysis.

7.4.3 Synthesis (Stage 5)

7.4.3.1 A theoretical model of how the intervention works (element 1)

This section presents the results of the synthesis. The first element of the synthesis was a theoretical model of how the intervention worked, why and for whom to identify underlying assumptions. A theoretical model conveyed how the intervention (AAC data collection method application) was intended to work (see figure 7.3 below). The model articulated the idea of embedding the augmentative and alternative methods within research processes. The model aimed to capture the perspectives of the researcher and the participant in the creation of an interactional exchange. Implementation was therefore defined as methods relating to various phases: *initiation, implementation, engagement and interpretation*. This process assumed AAC approaches involved different kinds of interpretation. In other words, the nuances of communication could not be understood without understanding the methodological implementation, which had an impact on the communication itself. For instance, methods should be carried out from appropriate perspectives, or paradigms; this had the effect of balancing interpretive questions with interpretive techniques and analysis.

The subcategories (located in grey boxes of figure 7.3) highlight what were thought to be important methodological and contextual factors. These included: the principles of assessment; the characteristics of communication; the role of the researcher; the importance of reporting information about the participants; reporting of contextual factors; appropriate analysis; inclusiveness of implementation; and the impact of contextual factors on engagements. Overall, these components of the model reveal my assumptions about this field i.e. no single methodological phase acts in isolation.

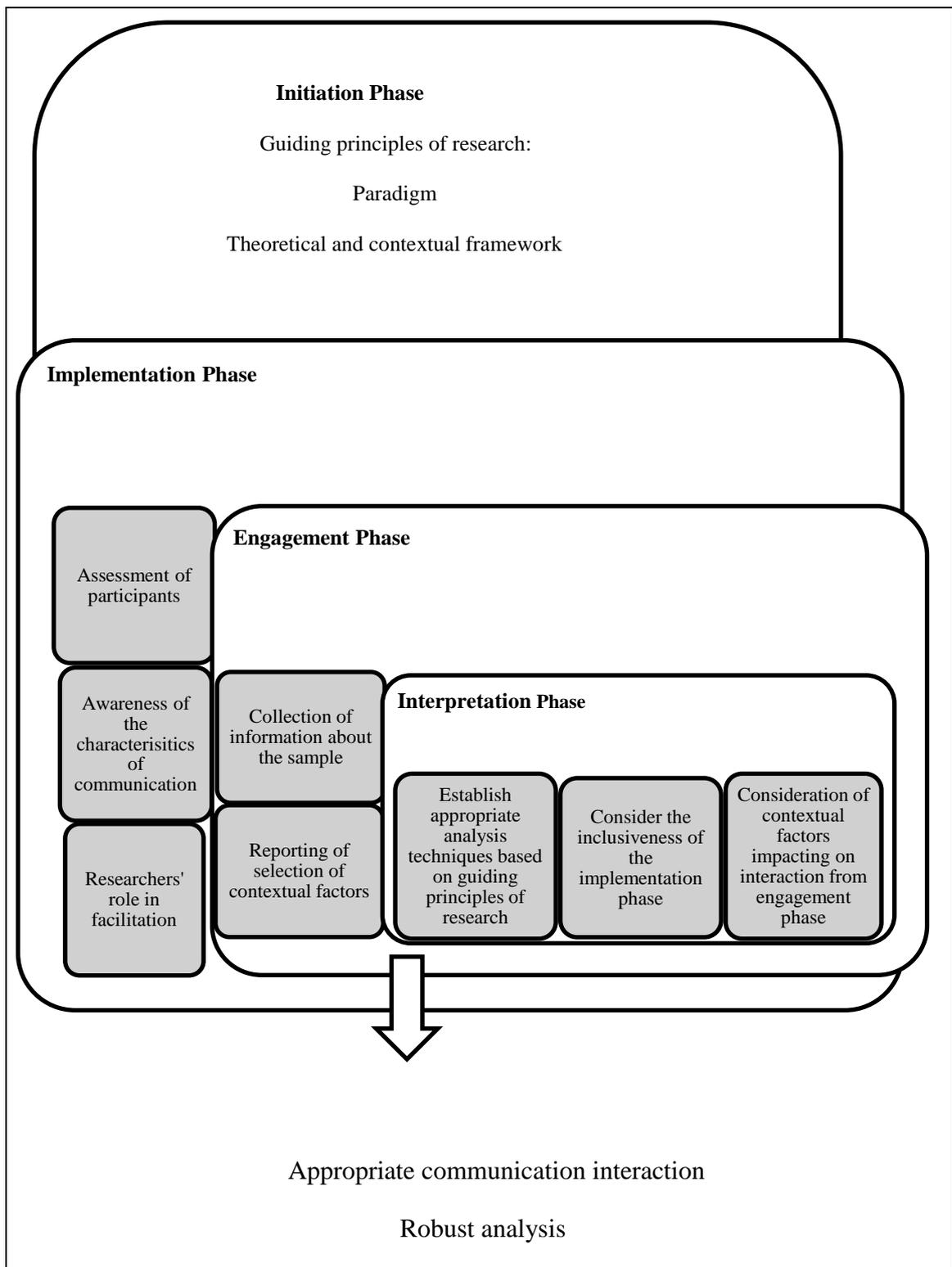


Figure 7.3 A Theoretical Model for the Narrative Synthesis

7.4.3.2 Preliminary analysis (element 2)

I now address the analysis of evidence from the second element of the synthesis-preliminary analysis. First, I provide an overview of how I constructed a Case Summary as an outcome of the preliminary synthesis phase.

Papers were labelled as either *gateway* or *sibling* papers indicating whether they were identified from the review or subsequently as a way of gathering further information for analysis. Additional papers were identified according to the principles laid out in the figure 4.5 (chapter four). Thus, I paired included papers with another related paper to increase data for analysis. The papers had a secondary label to indicate if they were a methodological or an empirical paper. Papers belonging to other projects were labelled as *familial*. The original included paper was called a *gateway paper*. (Where multiple possibilities existed, the most recent was selected). In the case that there was no methodological paper linked to the same study, I identified a substitute which provided a full methodology explanation; I labelled this a *proxy methodology* paper.

Unfortunately, it was not possible to find an associated methodological or empirical paper for all included papers. The 12 included AAC methods were: combined and nonverbal methods, multi-media devices, Diary interview, The Feelings Art Group, Life Story Work, Talking Mats™, nonverbal interviews, Dance Therapy, Auto-driving Photo Elicitation, Multimedia Biographies and Photovoice. This may suggest a variety of Augmentative and Alternative Communication in dementia research. Publication dates ranged from 2001 to 2013, however, according to the papers the most recent data collection period was 2012 (Shell, 2014).

A Case Summary was created for each method in order to analyse data *within* studies. Figure 7.4 is an example of the case Summary for the Diary Interview Method (Bartlett 2012, 2014). (The entire group of Case Summaries are included in appendix item 20, p372-409). The Case Summary includes a textual description narrative that highlights the methodological process, such as the exploratory nature of the research. I also provide a commentary about the strengths and weaknesses of the methodology and the perceived quality of the paper as evidence i.e. gaps in reporting or explanation of method.

Descriptive characteristics of the papers were recorded in the sections labelled *theoretical context, methodology, participants and interpretation*. Finally, the *facilitators, barriers, and specific factors* categorise the analytical observations about the method made by the

researcher (often quoting the opinions of the authors directly). This section helps to illuminate how aspects of the AAC method interacted.

Case Summary – Diary Interview method

Bartlett 2012 & 2014 - Context

Description: Study on dementia ‘Activists’ using dementia diary interview method

Papers: Method and empirical

Research design features: ethnographic, small-scale, longitudinal, multi-method, multimodal, participatory

Textual description:

This methodology is an account of Bartlett's 2012 research study into activism in dementia. The paper outlines the potential for modifying the Diary Interview method. This is a highly detailed reflective account that takes into consideration the methodological approach in the kinds of exploratory questions that are addressed. Whilst the research design is sound, there are shortcomings in the methodology from a perspective of familiarisation of AAC with participants, and also the reporting of the characteristics of the participants. Reporting did not provide a profile of each case in the small sample (16). There was also a lack of diagnostic and cognitive/intellectual/memory skills data recorded. The paper dealt with the conceptual issues well and the complex nature of analysing multimodal data, the analysis and analysis techniques were well illustrated but there was a lack of information about the nuances of the relationship between different kinds of data and how each were captured and 'translated' into common data. There was some reference to the researcher role and the role of others in facilitating communication although this was not addressed as a substantive topic. Finally, there was acknowledgement of the limitations in the perception of diary keeping and of the positive aspects of choice- but it was unclear how far this led to a greater sense of control in each case.

The empirical paper (2014) highlights the extra lengths researchers went to immerse themselves in the activism events in order to collect data in action and to experience some of the key events people were talking about in their diaries. Further detail on the analysis steps were also provided including the relationship between conceptual and analytical framework.

Theoretical context	Methodology	Participants	Interpretation
<ul style="list-style-type: none"> Ethnographic, qualitative (2012) Participatory Concepts: involvement of persons with dementia in society and activism, having 	<ul style="list-style-type: none"> People with dementia (PWD) were required to choose a diary method (1 of 3 mediums- photographic, audio, written) None previously had experience of a post reflective account 	<ul style="list-style-type: none"> Overall a narrow range of information about the sample provided, with the exception of contextual detail on activism Individuals had their own timeframe for 	<ul style="list-style-type: none"> Variation in diary length between participants No detail about transcription techniques Content analysis and thematic interpretation used Analysis of subjective

<p>their voices heard</p>	<ul style="list-style-type: none"> • Viewed as by researchers as an additional to the methodology tool box • Participants collaborated with others to create the diary • Researchers carried out the pre-diary interview, analysis and collected their own secondary data to contextualise the method and post-diary interview • There was some confusion over the purpose of the methodology amongst participants 	<p>completion of research</p> <ul style="list-style-type: none"> • Group characteristics- ‘activists’ may have been more likely to tell their story 	<p>experiences</p> <ul style="list-style-type: none"> • Combines textual, visual and field data • Choice of medium added to the understanding about that individual • Some participants found the process to demanding or even demeaning
<p>Facilitators</p> <ul style="list-style-type: none"> • Opportunity for participants to ask questions • Post diary interview at the participants home • Participants knew intuitively what was required in keeping a diary • Secondary data collected by the researcher gave them a sense of the “<i>material worlds of the participants</i>” (McCulloch, 2004 cited in Bartlett, 2012, p. 1721) • Multi-layered account of participant’s lives as campaigners and people • Audio Diaries added a new dimension to the data 	<p>Specific factors</p> <ul style="list-style-type: none"> • Choice of diary keeping medium • Participants offered control of content and pace of interactions • Offers a dynamic understanding of people’s lives (Pink, 2007 in Bartlett, 2012, p.1719) • Augmentation with observation- “<i>Observing allowed us to collect ethnographic data from participants ‘in action’, and to experience and visualise for ourselves some of the events they were reporting in their diaries</i>” (2012 p.1720) • Participants collected other additional material to contextualise their experiences • Researcher gained a more holistic view of the person • Sensorial ethnographic approach (2012) 	<p>Barriers/ limitations</p> <ul style="list-style-type: none"> • Photographic material had to be filtered by researchers • Participants became more aware of diminishing skills • Diaries could be particularly brief • Requires motivation and inspiration about the tasks to be performed • Some participants did not connect with the concept of diary keeping • Lack of familiarity with concept of diary keeping • Researcher had to filter the images prior to analysis 	

Figure 7.4 Example of a Case Summary

The findings for the Case Summaries were eventually transferred into a thematic table (table 7.5- a full version with all included evidence in appendix item 17, pp.348-367). The

table summarising key thematic aspects of the case studies (figure 7.5, is discussed in section 7.4.3.3 which presents element three of the synthesis i.e. exploring relationships in the data). However, Case Summaries and their unique format did present an opportunity to examine study characteristics in accordance with the second element of the synthesis methodology to develop a preliminary synthesis.

Now, I return to the results of the second element of synthesis (developing a preliminary synthesis). I looked at aspects of *variability* (summarised in tabular form in appendix items 21, 22 and 23, pp.410-417).

The subject matter of the included research ranged from the development of the AAC method (Smith et al., 2009; Astell et al., 2010; Murphy et al., 2013; Wiersma, 2011; Allan, 2001), to the experience of dementia such as the role of activism amongst people with dementia (Bartlett, 2012). Another feature of the studies was the range of conceptual frameworks such as: reminiscence (Smith et al., 2009), involvement (Murphy et al., 2013); Personhood (Astell et al., 2010; Nygård, 2006) or lived experience (Jonas-Simpson 2005). Another significant feature of the studies was the lack of sufficient reporting on study participants which was commented on in three studies (Bartlett, 2014; Astell et al., 2010; Wiersma, 2011).

There were a total of three papers without an accompanying methodological paper (Allan, 2001; Bober et al., 2002; Jonas-Simpson, 2005). By far the most empirically rich group of papers was the Talking Mats™ papers, where there was the highest number of potential sibling papers identified (see table 7.4). However, in the absence of a paper exclusively on methodology, a *proxy* paper was chosen (Murphy et al., 2005). There was one example of grey literature (Allan, 2001). The absence of empirical data within papers or reports had an impact on the Quality Appraisal scores, discussed below.

Dimensions of variability constituted the next section of the findings for this review.

Once the data extraction was completed, I began to analyse data from the studies. This involved aggregating attributes, grouping studies and tabulating data. A range of the data is presented narratively. Some analysis is also tabulated in the appendix (items 21- 23). There was a vast amount of data extracted and therefore, the review selected information which enhanced dimensions of variability most. Study designs were relatively small-scale. The Photovoice study (Wiersma, 2011) and the Life Story Work study (McKeown et al., 2010b) had the smallest sample (four participants). Allan's (2001) study of working with

pictures and nonverbal communication had the largest sample (25 participants). The average number of participants from the rest of the included studies was 14.5 participants (a range of 7 to 17). Based on study outcomes, seven studies employed AAC methods as a way of augmenting research methods, and five employed AAC with a view to a clinical or practice intervention application.

I identified complexity as a feature of the research designs (therapeutic intervention setting (Nyström and Lauritzen, 2005; Bober et al., 2002); multiple case study design (McKeown et al., 2010b); emphasis on deciphering nonverbal behaviour (Astell et al., 2010); longitudinal designs (Bartlett, 2014; Smith et al., 2009). Study outcomes (appendix item 21, p.410) were varied, as appendix item 21 shows. However, I believe the included studies had two different agendas in applying AAC. They can be grouped according to methods which either focused on AAC *use* in research (also in care settings, involving both familial and professional facilitators), or on the AAC as a research *method*. Five of the methods had an explicit research method focus (Bartlett, 2014; Nygård and Starkhammer, 2007; Shell, 2014; Smith et al., 2009). Therefore, these studies produced more directly relevant material for the review.

The main consideration in variability in population, intervention or setting was dementia diagnosis reporting. Six of the studies had reported poorly on participant information (Bartlett, 2014; Wiersma, 2011; Smith et al., 2009; Jonas-Simpson, 2005; Nyström and Lauritzen, 2005; Allan, 2001). Diagnosis characteristics of the participants could be quite broad and relatively difficult to judge; half of the authors recruited according to a general diagnosis of either dementia or Alzheimer's disease (Allan, 2001; McKeown et al., 2010b; Murphy et al., 2013; Nyström and Lauritzen, 2005). The other half of studies selected stages or general diagnostic severity ranges (see table in appendix item 22, p.412).

Diagnostic factors were important because they had the potential to illustrate limitations to the application of the AAC methods between groups of people living with dementia.

Interestingly, the studies did not tend to isolate a stage of dementia to focus on (with the exception of Bober et al (2002); Wiersma (2011)). Decisions to focus on a population were often guided by more specific factors such as verbal expression ability (Shell, 2012; Nygård and Starkhammer, 2007), complex behavioural needs (McKeown et al., 2010b), variable communication ability (Nyström and Lauritzen, 2005; Jonas-Simpson, 2005), ability to select and place symbols (Murphy et al., 2013) and existing involvement in

reminiscence activity (Astell et al., 2010). According to data extraction, bibliographic, health and communication information were the most widely reported areas (data extraction items 13, 15, 16 represented in column 2 of appendix item 22, p.422), but information on previous AAC use and environment were the least well reported (items 14 and 17 of data extraction in appendix item 16, p.343-347). Five of the 12 studies took place in a community setting and the rest took place in a residential setting (see table in appendix item 22).

The analysis also intended to isolate any methodological processes that were explicitly intended for certain populations with dementia. In fact, there was very little detail about the appropriateness of methods across the diverse population of people living with dementia. Murphy et al (2005) stated the method was not universally applicable and that participants needed to be aware of their surroundings and be able to use visual symbols (p.106). Bober et al (2002) also excluded participants who wandered or who were agitated. However, it is not clear how far this was due to their capacity to undertake the activity or to prevent disruption in the group (p.78). Many of the other studies hinted that people in the advanced stages of dementia could take part if they were assisted in participating. For instance, Shell (2009) explained that people with dementia were assisted in initiating the process of photography if they required it. In addition, the researcher recorded the rationale for their image section so that they did not have to remember it (p.177).

The exploration of theoretical and methodological variance involved an audit of concepts used. The study methodological approaches were summarised in appendix item 23 (p.415); these were a product of theoretical positions, paradigms and research disciplines. Two studies were ethnographic (Bartlett, 2014; Nygård and Starkhammer, 2007). Three were led by reminiscence methodologies (Astell et al., 2010; McKeown et al., 2010b; Smith et al., 2009). Three studies emerged within a qualitative participative methodology genre (Jonas-Simpson, 2005; Shell, 2012; Wiersma, 2011) and two a more realist approach to data, exhibiting characteristics of pragmatic applied-evaluation research (Allan, 2001; Murphy et al 2013). Therapeutic practice was the final approach displayed by two studies (Bober et al., 2002; Nyström and Lauritzen, 2005).

All studies except three discussed the conceptual or theoretical importance of *participation* (it was not identified in the study on The Feelings Art Group (Bober et al., 2002)), Nyström and Lauritzen (2005, Dance Therapy) or McKeown et al (2010b, Life Story

Work)). Key findings from explorations of methodological variance revealed a strong emphasis on: the preparatory work of the researcher (Bartlett, 2014 and Shell 2014); continued management of interaction (Wiersma 2011; Shell, 2014; Smith et al., 2009); and, the involvement of a multidisciplinary team (Astell et al., 2010; Mckeown et al., 2010b). This is explored in greater detail in the next stage of synthesis (section 7.4.3.3) through themes emerging *across* studies.

I explored characteristics of *data collection* and *interpretation*. These were explored broadly through the analysis of extracted data. Initial analysis of implementation of the methodologies indicated the depth and reporting of interpretation of data differed between studies. Results from item 23 of the appendix (p.415) showed that 10 of the 12 studies used an analytical framework. Only seven studies provided details about the interpretation data. I pursue this line of enquiry in subsequent thematic analysis (section 7.4.3.3).

Descriptive analysis across studies helped to answer the first research question. It provided a framework for the interpretation of methods through a *typology*. The AAC methods included into the review can be grouped into methods that: involve the elicitation of voice in the form of a *narrative*; those methods that elicit voice through an *expressive* medium or method (such as art or dance); and methods which interpret and enact voice through a *Communication Framework* (such as nonverbal observation or Talking Mats™). This *typology* was developed and embedded into the thematic analysis presented in table 7.5 below. (Appendix item 17 (pp.438-367) is an exploded version that includes the underlying data from Case Summaries).

7.4.3.3 The exploration of relationships in the data (element 3)

This section explores element 3 of the synthesis, that is, the exploration of relationships in the data. Table 7.5 (below) is the first part of the presentation of the synthesis. The degree of agreement between studies about aspects of implementation was not known. The method facilitated translation of themes into commonalities and differences. This process highlighted aspects of agreement *and* discord. The isolation of the nuances of implementation of the alternative methods helped to answer the second research question.

The synthesis framework consisted of: facilitators and barriers (sub-divided into the categories relating to the researcher's role, practices relating to the participant and interpretation of data) and the AAC typology. Two types of AAC within the typology provided a slightly richer source of data (*narrative* and *communication framework* AAC methods). This is reflected in the different volumes of data in the table collected for each AAC type. The analytical phases of this review provided consensus amongst studies about how to (appropriately) elicit voice using AACs for people living with dementia. This answers to this research question involved the identification of common narratives in the data. Yet, it was important not to ignore disconfirming evidence or cases. There were no obvious disconfirming cases. There were some contradictions in the data surrounding the role of involvement of other groups in research, such as carers or staff. Other areas lacked consensus. For instance, studies varied in their approach to claims of 'capturing voice' during the implementation of research. Some authors engaged with the concept of voice with naivety, whilst others were more reflexive. These issues are discussed in greater detail below.

The main messages within the data related to the *researcher facilitation of the method, the participant engagement created, and the appropriate interpretation of data*. (These are displayed as columns 2-7 in table 7.5 and appendix item 17 (pp.348-367). The table is split into thirds according to each AAC type- displayed in the first column). There were slightly different messages to emerge from each of the types of AAC and the differences hinged on the distinctive purpose of those methods. I theorised that the three purposes of method sought to create: a co-constructed narrative; to build an interactional platform to comprehend experience; or to facilitate an embodied expression of emotion and feelings. These messages emerged from the body of analytical themes relating to implementation

listed below (separated into facilitators and barriers). The themes are displayed in table 7.5 (this table corresponds to an expanded version in appendix item 17, pp.348-367).

This discussion of findings covers the key themes that emerged across studies in each of the three types of AAC methods identified. I took into consideration any gaps in the research base that would restrict my ability to understand the transferability of findings.

Table 7.5 Summary of themes across the AAC typology

		Facilitators			Barriers	
	Researcher	Participant	Data	Researcher	Participant	Data
<i>Narrative methods</i>	High levels of researcher involvement-preparation, mediation, familiarisation Researcher required to be flexible and adaptable to dynamic process Researchers in a supportive role	Element of representation al control of content also important Interactions centred on holistic understanding of participant Assistance of carers significant during research process	Array of forms of data promoted a richer understanding of the lives of people with dementia and their and experiences	-	The necessary time commitment required could act as a barrier	Implement-ation of methods must be sensitive to the potential of research to remind people of losses

<i>Communication framework methods</i>	<p>Researchers should consider the potentially personal nature of the experiences recalled by the people with dementia- the rapport should reflect this</p> <p>Researchers needed to use judgement on the ways to interact and the issues to explore with people with dementia</p>	<p>Key role of visual and nonverbal data to inform research</p> <p>Personalisation was possible in communication frameworks</p> <p>Frameworks make communication less direct and more comfortable for the people with dementia</p>	<p>Rich data and emerging patterns</p> <p>Video recording was a key element in analysis and interpretation</p> <p>Application of communication methods in daily life setting</p>		<p>Verbal and expressive skills play a part in the success of interactions</p>	<p>Familiarity with participants required to understand and analyse subjective experiences</p> <p>Researcher perspective needs to be considered during analysis</p>
<i>Expressive methods</i>	<p>Therapeutic skills may assist in delivering methods which are also interventions</p>	<p>Choices could be offered to participants even within expressive communication sessions</p>	<p>Multiple forms of data viewed as an advantage by researchers</p>	<p>Complex nature of research in dual roles and multiple forms of communication</p>	-	<p>Complex experiences need to be unravelled during analysis</p>

The AAC methods which can be conceptualised as *eliciting a narrative* (CIRCA, Diary interview method, Life Story Work, Photo elicitation, Multimedia Biographies and Photovoice) advocate a high level of researcher involvement, in relation to their own duties and management of the involvement of others, such as caregivers. Involvement from the

researcher took the form of *preparation, mediation and familiarisation*. McKeown et al (2010b) emphasised that the preparatory groundwork should be undertaken before the commencement of Life Story Work. This groundwork enabled the researcher to get to know the story of the person with dementia and aspects of their biography. Other strands of evidence within this theme highlight the complex social dynamic present in the implementation of AACs. On occasions researchers acted as a mediator, and, at other times the researchers established another person to act as mediator. Smith et al (2009) commented: “*Our researchers facilitated dialogue amongst families when there were differences of opinion and attempted to keep Multimedia Biography production on a timeline. So it would still be helpful to have an adult within the family or someone outside of the family with maturity and sensitivity to mediate disputes*” (p. 303). Therefore, the evidence indicated researchers should manage the level of control ascribed to agents within the research process.

Researchers assisted with even the smallest aspects of the practical implementation of research to facilitate participant-led data collection. One example was the development of photos to lessen the number of tasks required by participants (Wiersma, 2011). However, in a more general sense, researchers supported interviewees and other staff members throughout the process. This highlights one tension or contradiction across studies about the role of others in the process. On the one hand, external stakeholders were encouraged to adopt a central role in the process, acting as mediators or as facilitators. Choices were provided to family members in the co-construction of bibliographic material. For instance, “*family members engaged in telling the story of a life history, as they chose the content, designed the story, and provided the narration*” (Smith et al, 2009, p.300).

However, on the other hand, there was also a sense of protecting the levels of participation of the person with dementia from other individuals such as carers who could dominate interactions. Astell et al (2009) demonstrated that staff could be supported to provide a positive interaction to implement CIRCA. The content of CIRCA was randomised so that carers did not become too familiar with the content and lead interactions, during the design process the researchers “*tried to determine if people with dementia can be supported to take the lead in more conversations, rather than the contents and course of the interactions being determined by the carers*” (2009, p.55). Similarly, in the photo-elicitation through ‘autodriving’ method “*the inclusion and active engagement of the*

participants in picture-taking make them partners in the research process” (Shell, 2014 p.175).

Flexibility was another general principle. A flexible approach appeared to include an adaptable research process, perhaps to adjust to participant needs (such as preference of type of camera based on capabilities (Shell, 2009 p.176), or, to deal with different contexts and meanings (McKeown et al., 2010b, p.150). The ultimate aim of the narrative methods appeared to centre on understanding participant experiences. Narrative methods achieved this through multiple points of data collection and communicative modes. The studies suggested the ‘array’ of forms of data promoted a richer understanding of experiences. The implementation of the diary interview method, for instance, advocated a combination of textual, visual and field data. Regarding the observational field data the researcher argued “*Observing allowed us to collect ethnographic data from participants ‘in action’, and to experience and visualise for ourselves some of the events they were reporting in their diaries*” (Bartlett, 2012 p.1720).

Multiple forms of data were also derived from multiple forms of communication, for instance McKeown’s (2010a) study the analysis involved verbal and nonverbal codes. Therefore, the analysis allowed the researcher to create “*a dynamic understanding of people’s lives and motives*” (Pink, 2007 in Bartlett, 2012, p.1719). The layers of analysis are evident in the techniques used. For instance, Bartlett (2012) incorporated secondary data analysis and an Audio Diary data using a sensory participative approach. Similarly, in order to interpret the CIRCA device, Astell et al (2010) undertook verbal and nonverbal coding techniques and analysed instances of caregiver prompting using ‘scaffolding’ concepts.

Researchers using these methods wanted to generate a holistic understanding of persons living with dementia, possibly in order to create a richer story or narrative. In other words, facilitators tried to gain a “*rooted understanding of the whole person*” (Bartlett 2012, p.1723). McKeown et al (2010b) remarked staff “*...began to see the person behind the patient and [they] are able to make links between the past and present*” (p.155). A single narrative method (the Multimedia Biography implemented by Smith et al., 2009) provided evidence of opportunities for *representational* control of narrative for participants. Wiersma (2011), for instance, empowered participants to take photographs for a diary and to choose a small number that they viewed as important prior to analysis (p.6). The same

researcher comments, *“Because the data involves participants’ stories in both textual and visual form, my discomfort with being ‘in control’ of these stories has been heightened in comparison to doing more ‘traditional’ qualitative research”* (p.11). However, I treated this study with caution because the quality assessment outcome was poor. For instance, the authors provided no information about of coding strategies.

The length of time estimated to undertake this kind of bibliographic and participatory research was considerable; this could be viewed as a barrier to its implementation. Those undertaking Multimedia Biographies estimated it took between 60 to 100 hours of staff time to complete the biography (Smith et al., 2009 p.297). The barriers identified by researchers centred on the potential to cause distress because interactions could remind participants of losses (Astell 2009; Wiersma 2011; Smith et al., 2009; McKeown, 2010a). Astell et al (2009) also altered the design of CIRCA to more generic reminiscence material because people with dementia could become agitated or upset if they did not recognise someone in the photos (p.52).

The Narrative Synthesis of the *communication framework* studies consisted of: pictures and nonverbal communication consultation, Talking Mats™, nonverbal interviews and observations. Analysis suggested these methods depended on the judgement of the researcher, both in terms of the characteristics of the rapport, and the issues to explore with persons living with dementia. For instance, in facilitating parallel task prompting the researchers allowed the participant opportunity to recount personal experiences. Nygård and Starkhammer (2007) describe the development of this type of method,

“In the first session, the interviewer mainly focused on determining the activities that the participant engaged in at home, including the equipment that was most commonly used. In the subsequent sessions, the participant was continually encouraged to both show how and narrate when and why the equipment was used” (p.146).

Furthermore, researchers built relationships during these interactions. Once trust had been established, the researchers were invited into the *“experienced worlds of participants”* (Nygård 2006, p.103). In the case of Talking Mats™, the researchers argued

“...By facilitating such conversations, it may be possible to identify strengths and abilities, correct misperceptions about abilities and preferences, reduce anxiety

on the part of both the person with dementia and their carer, and give expression to their concerns in a safe, non-confrontational way” (Murphy et al., 2013, p.178).

Allan (2001) used a similar rationale to promote the systematic use of pictures and nonverbal communication as a way of allowing people to tell their story. They wanted to allow people to talk about services using these objects which facilitated less confrontational discussion, i.e. attention was focused on objects throughout the discussion as participants described services- this was less intense than direct face-to-face questions (p.49).

Another theme suggested researchers needed to find ways to *personalise* the process to the participant to ensure higher levels of engagement to communication (Murphy et al., 2013; Nygård 2006). One example of personalisation was the requirement for the researcher to ‘tune’ themselves to the subjective world of the participant. Allan (2001) explained this phenomenon as in the following extract, “...*the person could experience an alternative ‘frame’ for the situation, for example apparently believing that they were at school or at work, rather than attending a day centre”* (p.52). By adopting the participant’s ‘frame’, researchers can minimise the risk of confusing the participant.

One of the special features of the concept of a communication framework was its role in desensitising interactions by making them less direct or intense. There were opportunities for the content of the discussion to approach emotive topics less directly than face to face interactions. For instance, it is argued that a physical tool such as Talking Mats™ allowed participants to organise their thoughts because it contained a less direct focus in comparison to face to face interactions i.e. conversation occurred “*on the mat*” (Murphy et al., 2005, p. 105). Similarly, Allan’s (2001) study included: nonverbal communication, working with pictures, and cards with single words printed on them. These were also used as a stimulus to conversation about various subjects.

Next I turn to the *interpretation of data*. Evidence suggested the facilitators need to be able to utilise the communication framework at a level that allowed them to understand subjective experiences. ‘Giving voice’ to participants was not always assumed possible as a concept, as this extract demonstrates, “...*we cannot give voices that we do hear voice we record and interpret... In telling, there is an inevitable gap between the experience as I live it and any communication about it”*” (Reissman, 1991, pp. 8-10 cited in Nygård, 2006,

p. 110). This statement was mirrored by Smith et al (2009) during narrative elicitation in regard to problematising “*true representations*” of a participant, especially when this was carried out by another person. Analysis highlighted the levels of subjectivity in creation of Multimedia Biographies, including re-representation of the life of a loved one. It is reported that during the study a daughter of a participant queried, “*How do you highlight a person’s life? What do we think is important? What do you think is important*” (p.299). However, voice and subjectivity were not always treated in such a sophisticated way. The presentation of elicitation of voice is another inconsistency amongst studies. Studies which treat the concept of voice in a less interpretive way were McKeown, 2010a; Jonas-Simpson, 2005; Wiersma, 2011. For instance, Mckeown et al (2010b) state “...*the strength of Life Story Work is its emphasis on finding out about the person behind the patient and literally giving voice to the person with dementia*” (p.156). Additionally, the researcher needed to take into account their own perceptions and the influence of their role on the perceptions of participants. In other words, “...*the perspectives and images of self that a participant presents for a researcher will be influenced by the researcher*” (Nygård, 2006, p. 105).

Evidence indicated the AAC type I labelled ‘Communication Frameworks’ was intended to be embedded within naturalistic settings. Evidence stressed the importance of incorporating nonverbal behaviours. For instance, Nygård (2006) argued that nonverbal observations could allow participants to demonstrate the use of technology *in situ*. This approach enhanced the researcher’s perspective in a number of ways. The first way was ‘context sustained roles’. This is indicative of researcher awareness that different contexts would sustain different roles for participants, influencing how they expressed their perspective on life (p.105). The second way the approach enhanced the reviewer’s perspective is summarised as ‘accessing unknown dimensions’. This describes the tendency for exploratory research to focus on things which are not readily expressed or are not experienced consciously. Therefore, the same study suggested it was preferable for participants to ‘perform’ responses rather than verbalise them. It may also be a more accurate way of allowing the researcher to understand difficulties (p.106). Thirdly, researchers could introduce ‘reflecting while doing’ and ‘showing while doing’. This would require the researcher to encourage reflection or demonstration from the participant. It was considered beneficial because the researcher enhanced their understanding of the experience of living with dementia (p.106).

Perhaps, the aspects described above helped to increase the inclusiveness of the research, especially for those with limited verbal ability. The implementation of various nonverbal dimensions of research was explored within Allan's (2001) service consultation study. Analysis of nonverbal interactions highlighted the specific things that made positive interactions between staff and patients; however, they recognised that identification of exactly what was "*different*" in the successful interactions or setting was "*elusive*" (p. 63). Video recordings, visual and audio data were often an essential part of the analysis process. The Talking Mats™ method contained visual information in relation to the symbols selected. In addition, the placement of those symbols also contained meaning (Murphy et al, 2013, p.173). The authors of the study argued that participants found visual information easier to process, to stay on track and to organise their thoughts (op cit. p.178). It may also be true to say that communication framework methods could be used outside of research settings to capture experiences 'in the moment'. The same study cites Murphy's previous research which showed AAC was not evaluated in real-life situations (p.173). Another method builds on this principle by facilitating re-enactment of the situation which is then narrated by the participant. This was the '*Showing by doing*' technique for the use of everyday technology in Nygård and Starkhammer's study (2007). (I identified similarities to Bartlett's (2014) Dairy Interview method (p.1712), and Nyström and Lauritzen's (2005) use of (researcher-led) verbal translation of actions in the moment). Therefore, I suggest techniques that replicated the experience in question more 'immediately' i.e. through ethnographic or participatory approaches, were a powerful tool across methods (provided there are adequate mediums of data collection to capture them).

However, despite different media of data collection, I suggest modes of communication in AAC relied too heavily on verbal communication. I identified themes which promoted the use of verbal skills. In some methods, the AAC interaction reverted back to a reliance on verbal exchanges. For instance, the methods described by Allan (2001) showed verbal prompting played a large part in photo elicitation (pp.48-62). The communication frameworks also appeared to require certain cognitive and expressive skills from participants. For instance, people living with dementia needed to understand visual symbols in order to use Talking Mats™ (Murphy et al., 2013). However, there was insufficient data to present a clear picture about the extent of verbal communication used. It was often difficult to differentiate between what precluded participation and what was a researcher preference for communication mode.

The setting and context played a significant role in the implementation of the third group of AAC methods i.e. *expressive methods* (Story, music and art expression, Dance therapy and The Feelings Art group). The expressive methods were all set within a therapeutic intervention environment. In addition, all the methods outlined the advantages of a skilled clinician or therapist. The research team incorporated music and art therapists within Jonas-Simpson's (2005) study using story, music and art methods. In Nyström and Lauritzen's (2005) paper on dance therapy the research was carried out by dance therapists who followed a psychodynamic method. Alternatively, Bober's (2002) 'Feelings Art Group' was a social worker-led initiative which facilitated reminiscence, reality orientation and sensory stimulation. In cases of this 'dual role' between research and therapist, Bober et al (2002) explain, "*The researcher had to somehow disentangle his or her experiences as a therapist from the descriptions of the group processes that would form the material to be analysed*" (Nyström and Lauritzen, 2005, p.302).

Another theme was *the complexity of the interpretation* of the experiences shared by participants. Studies tended to synthesis various forms of data when implementing AAC methods. There were a number of examples of the complexity of interpretation. For instance, researchers were encouraged to experiment with a range of methods of communication within the Feelings Art group (including multisensory media). They used a total of twelve activities to understand connections between group members, reminiscence and expression of feelings (Bober et al., 2002, pp.81-83). Researchers also described conceptual frameworks. This sophisticated level of interpretation occurred for the interpretation of dance (Nyström and Lauritzen 2005); qualitative descriptive methods (Parse 1998 in Jonas-Simpson, 2005), and for The Feeling Art Group through Yalom's (1995) Curative Factors for interpretation of multisensory data (Bober, 2002).

By comparison, three techniques emerged from narrative methods: Conversational Analysis (in Bartlett, 2012); Scaffolding (Astell et al, 2009) and Thematic Framework Analysis (McKeown et al, 2010b). Nygård and Starkhammer (2007) utilised the Constant Comparison method of coding (Strauss and Corbin 1998); whilst Murphy used thematic analysis for qualitative data and other quantitative observational methods. However, research rarely explained knowledge of the range of analytical options available. This Narrative Synthesis collates the myriad of interpretive options available.

The synthesis also identified gaps in the research base. There was a limited amount of information about the specific ways the researcher or carer could assist in initiating the methodology without compromising the integrity of the findings. The evidence base was limited in relation to processes of decision-making and how to determine the suitability of AAC (beyond capacity issues). Finally, few studies provided detail on transcribing, coding and interpreting nonverbal behaviour, including the ways that researchers dealt with uncertainty in the interpretation of data.

The Overarching Constructs analysis was the last phase in my synthesis, aimed to transform the data into principles. Different elements were likely to be contingent on one another. However, the Narrative Synthesis did not set out to ‘prove’ causality between these relationships. Instead, the constructs help to summon narrative criteria about the implementation of AAC methods. Characteristics tended to differ depending on the type of AAC (figure 7.5 below). The key themes have been restructured according to the research phases, echoing the phases of research model.

<p>Overarching constructs from synthesis- factors that assist implementation of AAC methodology</p> <ul style="list-style-type: none"> • If the AAC methodology involves evoking a narrative, the researcher may want to incorporate different elements at different stages of the research process: <ul style="list-style-type: none"> Initiation Selection of appropriate approach and analysis technique Engagement Researcher preparation and groundwork, flexible approach to research design and response to or selection of AAC, consideration of time maximum time commitment, minimisation of reminding participant of losses Implementation Assume a supportive role with close contact with participants, consider representational control of AAC methods, provision of choice in selection of AAC, attempt to gather more holistic perspective of participant Interpretation Utilise multiple forms of data to co-construct narratives, attempt to understand experience through multiple forms of communication interpretation
<ul style="list-style-type: none"> • If the methodology involves a communication framework then the researcher may want to incorporate: <ul style="list-style-type: none"> Initiation Plan appropriate data collection and interpretation techniques- consider how to preserve record of interactions e.g. video, photo, observational records Engagement Cultivate a rapport that reflects the personal nature of interactions to elicit voice, consider a familiarisation phase with participants, maximise benefits of indirect nature of communication framework for approaching topics Implementation Prioritise visual and nonverbal data, balance the emphasis on verbal data with potential to diminish participation, reliance on researcher judgement in opportunity to engage participant and nature of interactions more generally Interpretation Consideration of researcher and caregiver/staff role on interpretation

- If the methodology involves an expressive medium the researcher may want to incorporate:

Initiation Consideration of appropriate skills of research team to deliver expressive methods, consider extraction of multiple modes of communication in research design

Engagement Offer the participant choice in how to communicate expressively

Implementation Balance dual role of researcher if therapeutic skills are also engaged

Interpretation Compile analytical strategies to prioritise deciphering experiential data

Figure 7.5 ‘Overarching Constructs’ in Narrative Synthesis analysis

In the context of *narrative methods*, initiation of the research process depended on selection of appropriate approach, such as ethnography. In order to engage participants, the researchers exhibited high levels of preparation prior to research. They maintained a flexible approach to research re-design, this included selection of AAC by participants or consideration of maximum time commitment. Researchers thought about the ways the research could remind participants of losses; they tried to minimise these in the design process. Researchers assumed a supportive role through close contact with participants. During the process of implementing the research, researchers considered how to provide adequate levels of representational control throughout. Ultimately, researchers attempted to gather more holistic perspective of participant. The co-construction narrative was a guiding principle for interpretation of these methods. This was achieved through analysis of multiple forms of data that attempted to understand experience.

Communication frameworks were initiated successfully (and appropriately) through a plan to manage data collection phases and interpretation techniques. Researchers considered how to preserve record of interactions e.g. video, photo, observational records. Researchers also cultivated a rapport that reflected the personal nature of interactions to elicit voice when they engaged people with the research. Ideally, researchers undertook a phase with participants to familiarise them with AAC. Generally, the techniques relied on the researcher’s ability to maximise benefits of the indirect nature of communication framework for approaching topics. In other words, evidence suggested the use of symbols (or abstract concepts) ‘through’ a framework, was less daunting than face to face communication. Researchers prioritised visual and nonverbal data, perhaps because of the active involving nature of the method. Verbal interactions were not prohibited. However, they were mixed with nonverbal interactions (according to the potential to diminish participation). Interpretation of communication frameworks included the role of those who administered the framework.

Evidence about the application of *expressive methods* suggested it was important to assess the role of facilitators and their skills. This included adding experts to the research team, if necessary. This type of method also urged researchers to consider extraction of multiple mediums of communication in research design. Appropriate engagement involved *choices* for participants in how to communicate expressively. I linked implementation to the initiation of research insofar as researchers balanced their dual role of researcher and therapist. Finally, appropriate interpretation of these methods centred on robust analytical strategies that were designed to decipher experiential data.

7.4.3.4 Robustness of synthesis (element 4)

This section attempts to provide an overview of the robustness of the narratives produced within the synthesis, including aspects of the methodology, evidence, assumptions and discrepancies in the evidence (parameters laid out by Popay et al., 2006, p. 22).

As a starting point, the discussion explored robustness of methodology. Major adaptations to the Narrative Synthesis method included: focus on the research methods rather than study findings; study identification (i.e. the introduction of sibling papers in combination with ‘gateway’ papers); and adaptations to the synthetic product i.e. ‘Overarching Constructs’. (The adaptations were explained in the methodology chapter (four). I have also reflected about their suitability in chapter 8.3). Overall, I suggest the Narrative Synthesis methodology is suited to the range of data, and the methodological techniques provided a rich, multi-layered analysis.

Amongst included studies methodological study design variance (heterogeneity) was reasonably significant. However, variance was less of an issue given the analysis techniques chosen. AAC methods were analysed through interpretive, rather than statistical techniques (regardless of ‘intervention’ label). The studies also varied in terms of population. For instance, six studies used one diagnostic label of ‘dementia’ for participants without defining the levels of severity, whilst a total of nine included a range of participants with different levels of dementia severity. The English language criterion was a limitation to exhaustive searching. Another limitation was the focus of the review itself. All the studies were derived from western countries; this implied several things. Firstly, it is possible the concept of ‘voice’ had less meaning or value within other countries or cultures. Alternatively, there was possibly a greater focus on other areas such as assistive technology; or, studies were not published in International journals.

The quality assessment isolated studies of lower quality. A single study (Wiersma 2011) was considered poor quality (my assessment incorporated quality of reporting). However, I regarded checklists as a rather blunt instrument. In relation to types of evidence, Narrative Synthesis incorporates a wide variety of research approaches and methodologies. However, qualitative approaches have a greater tradition for reporting richer narratives. Therefore, publication biases were possibly embedded within this methodology. Consequently, study selection possibly favoured qualitative studies or large-scale studies where pairings of methodological and empirical papers exist. The inclusion of reports and methodological papers introduced an even greater array of reporting conventions. The inclusion/exclusion criteria prohibited literature review papers or methods papers that were not drawn from empirical studies. The flexibility in the approach to empirical or methodology ‘sibling’ papers changed the configuration of papers analysed. Pairs of studies added another dimension to the process of identifying context. This made study selection more complex, but ultimately helped to enrich the narrative evidence gathered. The inclusion of additional papers was at the discretion of the reviewer (according to the principles already discussed in the methodology section). I believe this augmented the configuration of papers found through searching, instilling a purposive sampling element into the review. This was one of the reasons why it was so important to make the methodology process as transparent as possible. (The suitability of the design of the review and comparisons between the review methodology strengths and weaknesses are issues presented in chapter 8.2).

The key themes in the analysis linked to the verbatim extracts in the data extraction phase. Data was translated into a common rhetoric across and within studies. I did this to ensure I maintained the original meaning of the data, and I was able to analyse within and across studies for patterns. The thematic table (appendix item 17, pp.348-367) made the review as transparent as possible, especially in relation to the relative weight of different themes or gaps in the data (especially limits in reporting). The review inclusion criteria also incorporated a broad umbrella of AAC methods, out of which emerged a typology in addition to various reporting outputs (i.e. reports, reflective papers or findings papers). The legitimacy of the typology is not yet determined. AACs may have been implemented more critically or reflexively over time as the body of methodological knowledge expands. It is also possible that the application of methods was affected by the shifting interpretation

of the concept of voice towards inclusiveness. It is possible the popularity of methods changed in particular, multimedia devices which could become out-dated.

In summary, Narrative Synthesis identified gaps and areas of commonality in appropriateness of approach across studies. The review methodology analysed the nuances of implementation through the systematic extraction of information about AAC methods. The techniques carefully translated different types of information into different implementation functions and practices so that the analysis could pinpoint transferable characteristics, whilst preserving the proximity to the individual context of each method. From this perspective, the methodology could be defined as a robust approach to understanding implementation because of the comprehensive and consistent way implementation is envisaged. This allowed me to manage levels of study heterogeneity and variance.

7.5 Discussion

This review attempted to provide an evidence base for determining appropriate implementation of AAC methods. Whilst this review did not seek to identify universally applicable ‘rules’ for effectiveness, it examined the elements of implementation, decoding some of the practices that may be of benefit for future research. The research questions were: which AAC methods (and associated implementation strategies) have been used with people living with dementia to elicit voice? Secondly, which aspects of the methods processes were key to appropriate implementation? In order to address the second research question, the discussion drew together aspects of the synthesis. Next, the discussion explores the evidence that these methods can represent ‘voices’ of people with dementia as an alternative to traditional reach methods, with reference to the wider literature (in particular, previous criteria for eliciting voice (Clarke and Keady, 2002, p.41-2)). Finally, this section outlines the reasons why AAC methods are significant for the elicitation of voice. The contribution of the review to the integration of dementia theory, research and practice is discussed separately in chapter eight.

Analysis revealed the breadth of AAC methods, tentatively presenting findings in the form of a *typology* for AAC. Aspects of the processes that were key to the implementation of the AAC methods, were best understood within the context of type of AAC phase of the research process. Amongst narrative-based AAC methods, flexibility was important throughout the process. In administering communication frameworks, personalisation was

important in interactions; whilst in expressive forms of communication the nature of the engagement (activity or therapy) was most important. A number of factors were important across methods: consideration of analysis in planning phases; researcher engagement and multiple forms of communication modes and, therefore, multiple forms of data collection techniques.

As a broad indication of the viability of AAC methods, there was sufficient evidence from the review to explain the role of barriers and facilitators. The Narrative Synthesis identified common themes *within* and *across* twelve different AAC methods studies. Quality appraisal and robustness of evidence assessments were generally positive due to the rich data and depth of the interpretation techniques. The typology of methods emerged from the initial phases of analysis. This provided a mechanism for viewing AAC methods in relation to the form and function of communication they created. Two of the studies specifically contrasted AAC with traditional communication methods (Murphy et al., 2013; Astell et al., 2010) with favourable results. However, the application and reporting of the AAC methods could be improved in some areas. For instance, analysis across studies reveals data coding inadequacies. Only six of the qualitative design studies described coding techniques (Nyström and Lauritzen, 2005, Bober et al., 2002; Nygård and Starkhammer, 2007; Bartlett, 2012; Shell, 2014). A single study validated findings with participants (Murphy et al., 2013).

The review contributes to a wider literature base surrounding the elicitation of the voice of people with dementia. It improves understanding of capturing and re-representing voice in authentic ways. The findings resonated with literature previously identified as i) promoting the perspective of the person with dementia and ii) inclusivity in research (chapter 3.3.3). Certainly, it is clear that the process of the Augmentative and Alternative Communication methods in primary research prioritise the viewpoint of the individual. The methods value the participant and improve the quality of data in research. The process of implementing AACs supports the participant choice of communication medium and modes. By contrast, challenges to research implementation were generally framed as barriers that have to be overcome. Findings showed Augmentative and Alternative Communication methods were arguably more innovative than traditional verbal interview formats (the expressive methods were perhaps the best example of this). Goldsmith (1996) stated *“It is not acceptable at an early stage, nor at a later stage for that matter, to write off a person’s ability to communicate just because we find it difficult to comprehend what*

they are trying to convey to us. If there is a problem in understanding then the responsibility then lies with us to ensure that we are doing everything possible to facilitate communication” (Goldsmith, 1996, p.52). This sentiment was reflected in implementation rhetoric surrounding Augmentative and Alternative Communication methods.

Appropriate implementation was important. It is clear from some of the findings that implementation hinged on knowledge about the AAC method, a planned approach and sophisticated interpretation of many forms of data. Historically, nonverbal research has been regarded as challenging in qualitative research. A good understanding of the challenges was vital. Allan (2001) writes, *“From the outset [they] maintained a focus on the non-verbal ways that people used to express preferences and needs. On account of its subtlety and complexity, it was more challenging to find ways to explore this mode of communication”* (p.66). In other words, communication should be suited to the participant and failure to implement AAC (appropriately) has empirical and ethical implications.

The findings of the review reflected many of the central criteria outlined by Clarke and Keady (2002, p.41-2), particularly, in regards to the application of the methods and holism in the research process. The criteria they presented distilled the importance of the researcher role in engagement of the researcher, building trust with participants and collaboration. The implementation aspects of the findings were echoed in the research design adaptations and considerations, including the format of the data collection and the awareness of the potentially distressing aspects of the interaction and the considerations about setting. Common themes emerged, such as flexibility in approach and the collection of multiple forms of data. Interpretation of the process was mirrored in some respects in relation to the recommendations for ‘paying attention’ to data recording (Clarke and Keady, 2002, p.42).

However, the review findings expand knowledge about how researchers should approach to the implementation process for greater success. The review findings also offer greater explanation about the impact of the opportunity for choice by participants and some in-depth aspects of mechanistic facilitators (such as the advantages of indirect communication frameworks). The Narrative Synthesis was more critical in relation to researcher approach in the following areas: emotional responses; various representational issues of narrative and the multiple identities of the researcher. The findings offer an unprecedented volume

of analysis on the implementation of these methods, and may assist researchers in understanding of the crucial role of appropriate strategies to interpret data. (The empirical contribution of the review is discussed further in chapter eight).

Overall, the Narrative Synthesis demonstrated there have been developments in the way augmented or alternative communication issues were envisaged since initial guidance on eliciting voice in dementia research. Additional dimensions were considered by AAC methodologists, such as subjectivity, status and interpretation techniques.

7.6 Summary

The review synthesised twelve AAC methods and the ways they have been implemented in dementia research. The review provided a window into appropriate aspects of implementation across a typology of methods. I believe the narratives there may be a number of underlying principles (or ‘Overarching Constructs’) salient to the implementation of methods for each type of method in the AAC typology (consisting of *narrative*, *communication framework* and *expressive* methods). However, some aspects of implementation of methods continued to be context-specific. Each of the types of the AAC had slightly different permutations surrounding different implementation issues. Main examples include: representational control; prioritisation of narrative; and balance of the role of therapist and researcher (demonstrated through the Overarching Constructs). However, common ground included: the importance of planning for undertaking research and conducting groundwork with participants; establishing a rapport with participants in order to access participants; the consideration of offering participants choice in how to communicate; and the complexities associated with the interpretation of multiple forms of data.

Due to the limited amount of existing research identified, this review can only make tentative conclusions about the appropriate application of future methods. The synthetic products from this review provided guidance on key facilitators and barriers within the research process. This review emphasised the relevance of the whole research process and the continued strategies for engagement throughout the research in order to secure more meaningful engagement.

Chapter 8: Conceptualising the methodological and empirical aspects of the thesis

8.1 Introduction

Chapter eight represents the third and final phase of the thesis: *conceptualisation*. This phase conceptualises my methodological exploration of methods contextualisation. This chapter helps to summarise the answer to one of the three research questions outlined in chapter 1.5, that is, *how can methods contextualisation be developed in reviewing?* The central principle of this chapter is to conceptualise my methodological and empirical findings.

This discursive chapter attempts to describe the methodological development I have undertaken to arrive at the concept of methods contextualisation (including reflections about the aim and purpose of the conceptual development, benefits of methods contextualisation, strengths and weaknesses of the templates, and I describe a theoretical model for the approaches). I also reflect on the *suitability* of the empirical studies to illustrate the methodological aims, and the impact of the *sequence* of the reviews on the outcomes. (I include a discussion about to what extent they should be undertaken alone or in sequence). Next, this chapter conceptualises main empirical outcomes. I discuss how they relate more broadly to dementia theory and research. (Reflections about my own learning and the contributions of the review to policy and practice are located in the final chapter nine). I relate reflections back to the first rationale of the thesis which aimed to extend methodological horizons in reviewing. Thus, I suggest methods contextualisation is a systematic way of influencing the choice and use of data collection methods.

8.2 Conceptualising the development of approaches to *methods contextualisation*

This section reflects on the development of the three methods contextualisation approaches addressed in the thesis. I begin with my reflections about the central tenet of the thesis: methods contextualisation. I refer to its aim, purpose and what it has achieved. During the course of this section I conceptualise my approach to methods contextualisation. I attempt to present reflections on the implementation of the methodological templates, summarising strengths and weaknesses of the methods according to their original purpose. Next, I introduce a model for the three approaches to contextualisation as a way of describing the

way they interact with the literature landscape. This is a way of understanding methods contextualisation contains three approaches identified thus far.

The aim and purpose of methods contextualisation

This section of discussion is designed to re-emphasise the *aim* and *purpose* of the concept of methods contextualisation following of the completion of the thesis. I also describe what was *achieved* by the implementation of methods contextualisation. The central tenet of the thesis is the concept of methods contextualisation, upon which the development, implementation and conceptualisation phases rest. (This section links to discussion about empirical outcomes (section 8.5), the overall contribution of the thesis and, the implications for policy and practice (covered in the summary chapter nine in sections 9.3 and 9.4)).

Methods contextualisation was developed to convey the inseparability of data collection methods and our ability to contextualise them. Its purpose can be summarised as: *a concept to describe review processes for identifying suitable forms of communication (data collection methods) to employ with research participants from contextualised research evidence and synthesis*. Appropriately contextualised research methods should be the basis of interpreting data *and* deciding how to hear participants in the future. This term embodies a new methods-centred genre of systematic reviews, consisting of implemented methods contextualisation templates. The premise of the concept is to guide the reviewer to evidence linked to the previous application of communication methods in secondary data.

There are several things that have been achieved by the implementation of methods contextualisation. First, the implementation of the concept introduces the concept as a form of reviewing practice through methodological templates and empirical test cases. The objectives of methods contextualisation hinge on outcomes of review processes to identify and analyse suitable data collection methods. Implementation of methods contextualisation assisted me in developing the concept into three methodological strands, without which I would know less about the different forms of methods contextualisation (or how they could be translated into practice). The review methodology was designed to facilitate reviewers in reaching decisions about future methods in light of methods they have synthesised.

The adaptation of existing reviews and creation of methodological templates were designed to maximise the potential to identify data collection choices and uses and their impact. Implementation of the templates provided a way to refine the methodologies to make them appropriate for reviewers (and novice reviewers) to navigate. The templates were as transparent and replicable as possible to maximise their potential to assist reviewers in carrying out a systematic processes which would eventually inform their selection of data collection methods. The outcomes from the templates emphasise research method suitability rather than researcher preference or methodological convention (see chapter 1.3). Implementation of the reviews in the thesis could initiate future testing of methodological templates.

The empirical outcomes of the review are discussed in section 8.5. The contributions of the thesis are discussed in sections 9.3 and implications for policy and practice in 9.4. However, explanation of what was achieved by the implementation of methods contextualisation draws in some of these broader themes and discussions. Empirical outcomes are a product of implementation. Empirically, the implementation of methods contextualisation synthesised scattered literature (section 8.5). The reviews brought together several study types, (including methodological topics about data collection or findings-based papers on alternative topics). The reviews also incorporated a collection of other methodological and empirical study types to gather further layers of interpretive methods-based information (such as: theoretical sources, broader reports, narrative descriptions of historical developments in research and policy and reviews or overviews of research from disciplinary perspectives). Practical implementation of these methods unearthed relevant sources that were not necessarily well known beforehand.

There is no substitute for testing theoretical methodology templates. Testing provided a basis for scrutiny of the methodologies and future examination. Implementation provided a resource for a previously synthesised field (section 3.5 describes the underuse of alternative methods in this field). The synthesis highlighted the potential value of this process beyond dementia research to other vulnerable or hard-to-access groups. Implementation showed synthesis of a particularly complex and diverse body of evidence is possible.

The implementation also contributed to empirical theory (see also chapter 8.5.2 and 9.3). There were various levels of theory which the test cases of the templates contributed to.

The broadest contribution is the theory surrounding the study of dementia. This was not considered prior to the empirical stage of the thesis. I had considered the lower-level contribution to valuable concepts, interpretive frameworks or the legacy of theoretical assumptions. However, there is a place for the justification of participant-centred methods selection processes more widely. Scrutinising methods and interpreting research findings is fundamental to all research. Therefore, implementation of methods contextualisation allowed me to challenge current understanding about the way that research is done, owing to the richly critical processes in methods contextualisation.

The strengths and weaknesses of the methodological templates

I now turn to the strengths and weaknesses of the methodological templates (the methodological templates are described in full in chapter four). This answers one of the three research questions in the thesis outlined in chapter one: *What were the strengths and weaknesses of the methodologies chosen?* (Section 1.5).

Table 8.1 summarises the methodological foundation of the reviews. All the reviews were derived from established methodologies.

Table 8.1 Summary of the features of the methodological templates

Methodology	Adaptations & innovations
Scoping review Scoping framework (Levac et al., 2010) Combined with aspects of systematic mapping (Gough et al., 2003)	<ul style="list-style-type: none"> • Additional aspects of systematic mapping methodology – analysis of wider studies and further contextualisation of included studies- a Systematic Mapping exercise • Systematic approach to identification of research disciplines created
Meta study review Meta Study (Paterson et al., 2001) combined with Cluster technique (Booth et al., 2013b)	<ul style="list-style-type: none"> • Cluster technique for adding additional data (visual representations created) • Sampling matrix created
Narrative synthesis Narrative Synthesis (Popay et al., 2006)	<ul style="list-style-type: none"> • Study selection- sibling study selection criteria created • Case Summaries analysis technique created • Synthetic product- ‘Overarching Constructs’ created

The strengths and weaknesses of the methodologies are considered in relation to their intended purpose and approach to methods contextualisation. The development of a

structured approach to methodology was initiated in chapter one. Section 1.4 identified existing approaches to *contextualisation* from Gough and Thomas's section on approaches to reviewing (2012, pp.41-45). These were summarised as exploration of: the location of methods; perspectives that shape the contextual landscape, and theorisation of the broader context.

The approach for identifying suitable methodologies for *methods contextualisation* was described in chapter two. Stage one (section 2.4) first identified types of contextualisation (Gough and Thomas (2012, pp.41-45). I defined methods contextualisation objectives, followed by specific types of review or features of reviewing I considered relevant (preliminary reviews, reviews to examine research perspectives, and, theory-based evaluations). Thus, I identified a shortlist of possibilities. The second stage was a criteria-based assessment (section 2.5). Components and criteria are presented below.

Three approaches to methods contextualisation

- i). A way to sketch out the landscape of *choice* of methods through the **location of methods** and relevant contexts, and relationships between the two (requires examination of methods-context relationship)
- ii). A way of **examining perspectives** governing the methodological processes and the development of research methods (focus on perspectives that shape the contextual landscape)
- iii). A specific form of contextualisation that determines the **broader theorisation of context**

Identifying a type of review/systematic review:

- i). Emphasis on locating studies and their methods attributes - a **preparatory review type** would show what the attributes of the methods context were, and retain an emphasis on locating (or mapping) studies
- ii). Concentration on **examination of theoretical perspectives** because it would help to expose assumptions, particularly surrounding method choice and use
- iii). **Theory-based evaluations** to assess studies in terms of the characteristics of methods and their contexts, (including implementation if possible)

Shortlist of possibilities (ranges) checked against criteria:

- i). **Scoping and mapping reviews**
- ii). **Critical Interpretive Synthesis, Meta Narrative, Meta Study reviews**
- iii). **Realist Synthesis, (Textual) Narrative Synthesis evaluation reviews**

Epistemology

- I. Social constructionist
- II. Subjective idealist
- III. Realist

Most suitable Question focus amongst Complex, Interpretive Hermeneutic approaches

- I. *Attributes* of data collection methods
- II. *Processes* to determine data collection interpretation
- III. *Appropriateness* of implementation

Criterion for study selection

- I. Mapping review
 - 1. Ability to analyse method-context relationship
 - 2. Capacity to *map* methodological attributes
 - 3. Ability to locate findings within a broader literature
 - 4. Rigorous methodological structure
 - 5. Elements of descriptive and interpretive analysis
 - 6. To identify gaps in the literature
- II. Interpretive review
 - 1. Capacity to explore the context of the perspectives behind methods
 - 2. Subjective idealist
 - 3. Ability to analyse interpretation processes relating to multiple methods
- III. Realist (theory-based evaluation) review

1. Capacity to determine the appropriateness of implementation of methods
2. To contain methodological features to distinguish between context-specific and more general aspects of findings
3. Techniques to analyse a mixture of study approaches

The strengths and weaknesses of the methodologies are considered according to these criteria. Adaptations to the methodological templates were made according to the principles of the criteria also. These were described alongside the templates in chapter four. This discussion does not seek to directly compare these systematic approaches to the literature, or identify the 'best' methodology. Instead, the discussion seeks to explore the advantages and disadvantages of that process relative to the approach and outcome of that review.

The revised scoping review template was an example of methods contextualisation to locate methods in the literature landscape. The criteria involved several factors. The methodology/methodologies were able to explore the location of methods and methods-context relationships. I required a review that also focused on the attributes of data collection methods. Methodological prerequisites included a rigorous structure to analyse and map attributes (locating them within a broader literature). The remaining criteria set further parameters for the analysis using descriptive and analytical techniques, and capacity to identify gaps in the literature.

The Scoping review was implemented using the first template I presented for methods contextualisation. The template was modified to generate an understanding of the location of the topic within the research landscape. Analysis of wider literature (excluded from the pool of final included studies) occurred as a result of the influence of the Systematic Mapping approach. This layer of analysis also highlighted the absence of relevant data collection methods amongst included studies. The Systematic Mapping exercise illuminated the theoretical and methodological perspectives in the included studies. Although the review was considered both aggregative and configurative, the main drawback to the scoping methodology was its analytical depth, (particularly the reviewer's capacity to identify patterns across attributes). This was a predictable outcome given the way the template was designed to prioritise *breadth* over *depth*. (The specific research questions in the empirical examples will be addressed in section 8.3). Nevertheless, once

attributes were collected from a selection of excluded and included papers, analysis of the attributes created a comprehensive picture of study contexts. Layers of attributes provided a solid foundation for identifying the nuances of methods context for subsequent reviews.

Part of the reason for the lack of analysis across attributes was associated with the challenges of integrating the two distinct approaches i.e. the scoping framework and the Systematic Mapping (Levac et al 2010; Gough et al., 2003). The combination of the two approaches was designed to infuse the template with the structure of the scoping methodology with the superior ability to locate studies in the mapping approach. Levac's scoping review framework (2010) extracted more conventional scoping attributes for populations and settings such as study types and data collection characteristics, whilst the EPPI centre's Systematic Mapping exercise methodology introduced additional conceptual and contextual elements, such as identification of key theoretical perspectives, data collection methods focus, policy context, national context and study outcomes. Despite these separate layers of data, the combination of the two methodological approaches provided a vital range of characteristics from which to survey the potential avenues of further research.

The modified scoping template called for the identification of research disciplines and traditions. This was done to provide broad topic coverage through a systematic approach. However, the final step in this process was not carried out (i.e. the representation of the depth of research across research disciplines). This was due to the inaccuracy of the discipline as a way to describe the research topic; the included and excluded subsets of studies were subsequently re-classified. This element would require further empirical testing and, perhaps, further development to strengthen the link between research disciplines and the publication topic. Such a feature in the modified scoping template may increase the reviewer's ability to survey the literature.

Further aspects of the modified scoping template revealed a weakness in the lack of service-user perspectives integrated into the process. (The original scoping framework encourages consultation with service-users to inform the question and in dissemination). Finally, in addition, my revised template for methods contextualisation could consider conceptual mapping in the future (typically used in systematic maps). Keyword-coding of initially relevant papers may have provided a more robust conceptual framework which was created more transparency in the construction of search terms.

The adapted Meta Study template was an example of the second approach to methods contextualisation- that is, a systematic study to analyse the research perspectives governing methodological processes that shape the contextual landscape. Configurative reviews were identified as the most feasible prior to study methodology selection. Such reviews typically adopt a subjective idealist position, analysing processes. In the case of methods contextualisation, I focused on processes which govern data collection interpretation. Meta Study was selected, in part, because it incorporated the capacity to explore the theoretical perspectives behind the methods. It was also selected because it was most suited to analyse interpretation processes relating to a number of research methods.

The modified Meta Study template used a highly configurative approach to analysis. The synthesis process remained unchanged from the original methodology (Paterson et al., 2001). This produced an in-depth insight into theoretical, analytical and methodological aspects of included studies. Theoretical analysis was particularly important in identifying the influence of several dominant perspectives. I was, therefore, able to explore the theoretical and epistemological foundations of the research. The template could be used to isolate interpretive processes designed for use across multiple data collection methods- i.e. interpretive frameworks (the impact of the specific research question is discussed in section 8.3).

The adapted Meta Study methodology template was a revised version of the original selection process for included material. Instead of conventional searches, I incorporated the Cluster technique (Booth et al., 2013b). This technique resulted in a 'case study effect' for clusters of publications relating to a study. Analysis within clusters produced a sense of the empirical and theoretical 'genesis' of individual studies because of the transparent links between studies and study-related material that produces a trail of material. The process identified relevant concepts and contexts. The visual representation of the cluster was helpful because it was possible to understand impact of the framework through the size of the cluster. The results of clusters were compared, but due to the heterogeneous sampling matrix for cluster selection, analysis across clusters was relatively tentative. Features of the Cluster technique enhanced the comprehensiveness of the Meta Study procedure, such as contacting authors.

The strength of the adapted Meta Study methodology was the depth of analysis. The Meta Study dissected the processes that govern research methods interpretation. In part, it was

selected because of the specific strategies for analysing study methods. However, one drawback to this methodology was the differentiation between analysing the research methods in a study and data collection methods or methodologies. Also, the reviewer must select studies for Meta Method and Meta Analysis carefully. Kinship Theoretical papers were excluded from Meta Method and Meta Analysis phases as they were linked to separate studies. Also, the incorporation of Kinship Contemporaneous Context papers or Kinship Antecedent papers into the Meta Analysis phase could be considered contentious because there are fewer direct links to the primary study.

A final weakness associated with the Meta Study methodology was the difficulties of synthesising the data in meaningful ways (especially across clusters). Within clusters, materials were linked in a variety of ways such as: association with a study, common use of a range of theories, contemporaneous contexts, methodological content (such as a common interpretative framework). However, in relation to direct policy relevance, interpretive reviews are traditionally not viewed as a directly applicable synthetic product. Further interpretation by policy makers is typically required (Barnett-Page and Thomas, 2009, appendix figure 1).

The third approach to methods contextualisation was Narrative Synthesis, a (realist) theory-based evaluation. The specific criteria for this methods contextualisation approach included: the capacity of the review to determine the appropriateness of the implementation of data collection methods; features to distinguish between context-specific and more general aspects of findings; and, analytical techniques suitable for a range of study approaches.

The adapted Narrative Synthesis template for methods contextualisation captured the broader theorisation of context within the implementation of the data collection methods. The original template provided me with a comprehensive strategy for understanding the appropriateness of the implementation of methods based on the 'Theory of Change' I created as a requirement of the original methodology. The methodology encourages reviewers to identify barriers, facilitators and mechanistic factors about implementation to understand how and why data collection methods have an effect. In my adaptations, the Case Summaries, in particular, helped to show the interactions between types of facilitators or barriers.

The Narrative Synthesis methodology formalised by Popay et al (2006) was designed to be used with heterogeneous studies, making it suitable for analysis of a range of study types. The range of techniques and procedures available in the original methodology proved valuable in the implementation of the methodology. The range of approaches that synthesised qualitative material appeared conducive to a critical realist approach (this assumed reality was mediated by perceptions and beliefs, but could be compared to a single framework). This aspect of the review made it more straightforward to compare a range of data collection methods and determine which methods were carried out most appropriately.

The Case Summaries I created for the template isolated the context-specific elements in the data, bringing the material under a common rhetoric. This was especially important given the fact the review incorporated sibling papers. This created more methodological non-empirical content. Synthesis processes endeavoured to develop findings beyond common thematic features, translating data into *Overarching Constructs* which helped to produce theoretically-relevant constructs. This was a useful adaptation to the existing methodology because it distilled the more general aspects of implementation.

However, there were two main weaknesses in the application of Narrative Synthesis methodology. Firstly, data was analysed according to several thematic categories (such as types of barriers and facilitators or types of AAC methods). This had impinged on the depth of the data available under each theme. Secondly, the original methodology was designed for evaluations of intervention studies. This means there is a greater level of interpretation required by the reviewer to categorise data into implementation barriers and facilitators from a range of study types with a view to guiding contextualisation of methods in research contexts.

A methods contextualisation model

In summary, the first approach to methods contextualisation which fused scoping and Systematic Mapping methodologies to extract layers of data on research method attributes was suited to diverse and complex literature terrains. Consequently, it provided adequate groundwork for subsequent reviews because it could locate included studies against a wider landscape of literature. The second approach elicited a richly interpretive, critical stance suited to synthesise perspectives governing interpretations of methods (including interpretation frameworks). The Cluster technique (Booth et al., 2013b) enhanced my

ability to judge those perspectives, but inhibited comparisons across data collection methods. The critical realist Narrative Synthesis enabled me to organise and interpret data according to barriers and facilitators across a large number of study types. The adaptations to data analysis (case summaries and Overarching Constructs) helped to more clearly identify and theorise context-specific and more generalisable aspects of appropriate implementation of data collection methods.

A possible model for explaining the function of each of the approaches is provided below (figure 8.1). The model uses a model based on geology, representing the ‘excavation of the literature landscape’.

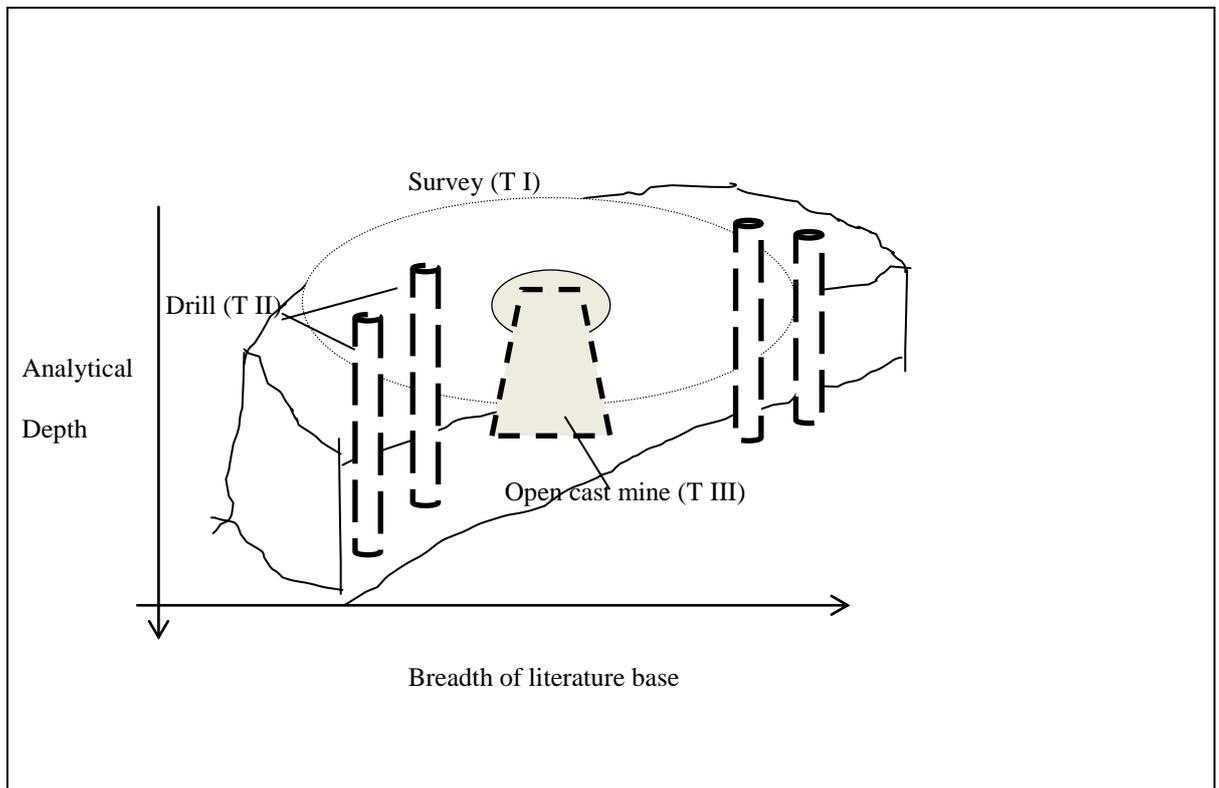


Figure 8.1 A theoretical model of the three functions of Methods Contextualisation

The model represents three approaches to research methods contextualisation operationalised in the templates tested in the thesis. The central location on the diagrammatic model is intended to show the ways the approaches interact with the literature landscape. The *survey* method represents the template (TI): *exploration of the location of methods and context* (a mapping review) in the scoping study. The *drilling* label relates to the second template (TII) which aimed to *examine research perspectives*

that shape the literature landscape (configurative review) in the Meta study. *Open cast mining* represents the third template (TIII), that is to *provide a broader theorisation of context (surrounding implementation)* (a realist methodology from a theory-based school of evaluation) in the Narrative Synthesis study.

The mapping approach surveys a broad span of literature bases, analysing several sub-sets of studies. Included studies can be contrast with wider literature landscape. Attributes of the wider literature can be analysed and contextual aspects of the included studies can be collated. The second approach, which analyses perspectives that shaped the contextual landscape, can capture a ‘snap-shot’ of the literature landscape. The methodology prioritises depth over breadth. The clustering techniques can provide a rich source of data surrounding a key study (providing methodological, analytical and theoretical knowledge). The option of purposively selecting a handful of clusters limits the breadth of the review. Clusters can be viewed as separate entities- represented as separate holes drilled in the literature landscape. Finally, the third template is represented as open cast mining to understand the implementation of methods in different contexts. The model envisages a single space where layers of the literature are ‘excavated’ on a specific topic. This review is potentially the most evenly balanced between depth and breadth. The richness of analysis techniques and the inclusion of ‘sibling’ papers may increase the depth of analysis.

8.3 Reflections on the suitability of dimensions of the reviews

This section assesses the suitability of the dimensions of the empirical examples within the thesis. In other words, the operationalisation of the specific research questions addressed. Operationalisation of methodologies are presented within the ‘methods’ sections of each empirical chapter (5.3, 6.3 and 7.3). The modified methodological templates devised for methods contextualisation are presented in chapter four (4.3.3, 4.4.2 and 4.5.2). This distinction was important because it indicated the difference between the intrinsic aspects of the newly adapted methodology templates, and the practical application of those methodologies.

In constructing the ‘methods’ for each study I considered a number of areas which are discussed within this section, such as: research topic and aims, the techniques chosen, and the depth of analysis undertaken. These areas constitute Gough et al’s (2012) dimensions of reviews. The first section will address the suitability of the topic according to the

justifications outlined in chapter three (3.3, 3.4 and 3.5). I will discuss the study aims, the logics of aggregation and configuration in each review and the type of synthetic or mapping components applied. Finally, in terms of the depth of the analysis, I will assess the ‘work done’ in addressing the research issue i.e. the detail in which the question was addressed.

First, I will reflect on the suitability of the topic. The third thesis rationale (presented in chapter 3.2) described the influence of the topic on the initiation of the methodological programme. In section 3.2, I argued my choice of topic alerted me to marginalisation of the social science perspective in dementia (emphasising the need for contextualisation); and, the exclusion of the alternative communication research perspective from dementia research. (I felt this was indicative of the lack of synthesis of communication alternatives and the potential role for methods contextualisation in promoting alternative or augmenting data collection methods). I also discussed the justification for the topic in chapter three. The justifications were: the topic supported voice; it was a source of rich data; and it was a viable focus for synthesis (sections 3.3-3.5).

The empirical research questions in the reviews were:

Template 1 (mapping review i.e. the scoping review): What does the research evidence reveal about the use of AAC to hear the voices of participants living with dementia in different contexts?

Template 2 (interpretive review i.e. the Meta Study): What are the key conceptual and contextual aspects of frameworks which increase understanding about interpreting AAC methods?

Template 3 (realist review – theory-based evaluation i.e. the Narrative Synthesis): i) Which AAC methods (and associated implementation strategies) have been used with people with dementia to elicit voice? ii) Which aspects of the methods processes are key to appropriate implementation?

The research questions echo the rationale and justifications mentioned above. The questions incorporated a number of features such as: the range of AAC methods, forms of contextualisation, the concept of voice, different perspectives and interpretive frameworks for rich analysis, a range of contexts to gather many perspectives as possible for a previously unsynthesised topic. Overall, the research questions emphasised *interpretation* of communicative data collection methods through interpretive methodologies.

Each implemented study had a different emphasis according to the methodological goals. The goals were: i). A way to sketch out the landscape of *choice* of methods through the **location of methods** and relevant contexts, and relationships between the two (requires examination of methods-context relationship) (a mapping review); ii). A way of **examining perspectives** governing the methodological processes and the development of research methods (focus on perspectives that shape the contextual landscape) (configurative review), iii). A specific form of contextualisation that determines the **broader theorisation of context** (theory-based evaluation review). For instance, the scoping review question specifically focused on different contexts as well as different methods to stress the location of methods and methods-context relationships. The Meta Study research question combined conceptual and contextual analysis to understand perspectives. The Meta Study review examined overarching theoretical perspectives and associated frameworks for interpreting AAC analysis. *I interpreted the interpretation of AAC in the secondary data.* The examination of interpretive frameworks was a more relevant topic to AAC more generally and outcomes from the review produced useful transferable knowledge. However, the interpretation of individual examples of interpretation may have been simpler to synthesise. The Narrative Synthesis used a two-part question to understand what the voice-eliciting methods were, and what the key aspects to facilitate appropriate implementation were.

Next, the discussion addresses configurative and/or aggregative elements in each synthesis. The Scoping and Narrative Synthesis review questions were designed to be descriptive as well as interpretive, facilitating aggregative and configurative analysis. The scoping assessed the breadth and depth of research across AAC methods to gather information about their use in different contexts. The Narrative Synthesis asked what AAC implementation strategies had been used to date, and which aspects were key to implementation. The Narrative Synthesis gathered descriptive (aggregative) data, but it also configured information about barriers, facilitators and context-specific factors. By contrast, the Meta Study configured perspectives and study components to identify underlying assumptions and alternative conceptualisations.

The next part of this discussion considers if the components of the empirical examples were suitable. The scoping components consisted of organising, describing and labelling data relating to AAC methods. Firstly, it is important to note there are practical issues with the identification of data collection methods. For example, it was sometimes difficult to

identify methods which augmented data collection from study abstracts and titles. Future refinement and expansion of the methodological templates could incorporate standardised terminologies or conceptual mapping, perhaps rendering the process of study selection more transparent. The conceptual framework provided by voice-elicitation also added a subjective aspect to the inclusion criteria. I possibly introduced a bias towards more interpretive study approaches, despite the concepts relevance to methods contextualisation principles.

Aspects of describing, analysing and labelling data were varied and complex. In the scoping study groups of included and excluded studies were compared according to different attributes. This created a layered dataset suited to the exploration of AAC research. This was essential in 'locating' included studies in a field which has evolved in a number of settings with a number of remits. The components of the Meta Study synthesis were produced from Cluster techniques (Booth et al., 2013b) (generated from a purposive sampling framework). Whilst it was important publications were collected systematically, relevancy and contextual richness of data were appropriate priorities because the AAC frameworks were anchored in unique contexts, which would need to be explained to a dementia research audience. The components of the Narrative Synthesis were many, covering analysis within and across studies. I chose the data extraction tabulation techniques carefully to produce a common rhetoric for analysis. This is especially relevant for interpretation of AAC methods (which are especially diverse).

This part of the discussion considers the suitability of the 'work done' in the studies. The scoping study was largely aggregative, with much less analytical depth than the other reviews. This element was suited to a preliminary analysis of the complex topic of AAC and dementia research. The review highlighted the lack of integration between these two research domains, as well as continuities. However, layers of attributes within, across and outside of the included studies provided a sense of detailed study setting context. The scope of the research question was relatively narrow by the end of the review; I decided to exclude other cognitively impaired populations from the final pool of studies. Whilst this created a focused platform for subsequent reviews, it lacked the breadth common to most scoping reviews. Another approach would have been to choose an additional AAC user group for comparison. In addition, the narrowness of the scope of the review was compounded by a conceptual framework for voice. Perhaps in the absence of such a framework, more studies could be identified. However, another conceptual framework

might have lacked the same richness or quality in data collection choice or use for methods contextualisation.

By contrast, the Meta Study analysis was very detailed. This suited the conceptual approach to the review and the need to unpick a raft of contextual material surrounding frameworks for the interpretation of AAC. Analysis attempted to synthesise a range of material into a coherent context-driven narrative. The Narrative Synthesis approach rested on the identification of empirical ‘gateway’ papers. This constituted a systematic approach to identify implementation-relevant papers. However, analysis was unbalanced insofar as only five of the twelve studies had accompanying methodological papers. Another concern in the Narrative Synthesis was the depth of the analysis following the compartmentalisation of data into different barriers, facilitators and AAC types. Types of AACs created sub-sets of data; these sub-sets sometimes lacked sufficient depth of data.

The scope of all three of the empirical studies was limited by the presence of a single reviewer (most reviews are ideally undertaken by a team). However, steps were taken to limit reviewer bias: formal independent assessments (e.g. double screening of a proportion of records and supervisory checks of included studies in the Narrative synthesis). There was a limited amount of multi-disciplinary input through supervisory meetings (including expertise from a dementia clinician). The study also lacked service user involvement or researcher involvement in any oversight capacity. However, summaries of interim findings were presented at ageing and dementia specific conferences and network meetings.

8.4 The impact of the sequence of the reviews

The next section will begin with a discussion of whether the reviews need to be undertaken in sequence or alone. Studies were conducted separately; however, the modified methodological templates for the second and third studies were created in light of knowledge gathered from previous reviews (see schematic of reviews in chapter two (figure 2.3)). I will then briefly summarise the elements of knowledge transfer between reviews. First, the discussion looks at *instrumental* knowledge passed between reviews (this means that their outcomes and processes had a practical influence on the design or structure of the next review), followed by transfer of *conceptual* forms of knowledge.

The impact of the sequence of the reviews

This section also addresses the impact of the sequence of the reviews and to what extent the reviews need to be undertaken together or in a sequence or alone. Section 9.4 will draw conclusions about the implications for sequencing in practice.

The reviews were not specifically designed to be conducted in a sequence. They cannot be considered either absolutely contingent on each other, nor are they separate. There are several reasons why it is not possible to provide more than general recommendations for future sequencing of the reviews. The reasons stem from how the three approaches were developed. First, this was a single example of the sequence; I have no basis for comparison. Secondly, the foci of the reviews were tailored to a different type of methods contextualisation, also making comparisons difficult. The design was not created to show the optimum configuration of the sequence. Finally, examples of knowledge transfer exist between reviews so there is limited scope for comparisons of outcomes. More effective comparisons of the sequencing of the reviews would constitute the next step in developing this genre of methodologies.

As a general recommendation, future selection of review templates would depend on the type of literature landscape being analysed by the reviewer. In cases where the data collection methods of interest were unknown to the reviewer, it would be logical to begin with the scoping and mapping template to scope the location of the studies. This would enable the reviewer to understand the basis of the methods and context relationships and the various attributes. However, if the choices of the methods were known but there had been little in-depth analysis of the theory or assumptions about the selection of methods, I believe the Meta Study would be a valuable choice. Finally, the Narrative Synthesis template provides the data outputs most translatable to policy (see synthetic product element of Barnett-Page and Thomas, 2009, Appendix item 1). However, the Theory-Based Evaluation approaches may require a sound knowledge of choice and use of methods to identify the components of implementation. Configurations of the methodologies would depend on the review focus and knowledge base.

Knowledge transfer between reviews

I now turn to the knowledge transfer between reviews. This explains further why reviews may not be viewed as separate entities. The eighty five studies from the scoping review findings were screened for inclusion in the Narrative Synthesis, as were the updated results

of three of the database searches. The scoping review identified a range of AAC methods and categorised many of their attributes. The scoping review established the viability of future systematic reviews and helped to establish suitable search terms. The principles of Systematic Mapping embedded within the scoping helped to gauge gaps in the application of AAC methods in the context of dementia research. The scoping incorporated the identification of social science perspectives into the study as attributes, perspectives which were later interrogated in the Narrative Synthesis. Finally, the scoping review first alerted me to the potential value of methodological papers in methods contextualisation synthesis. The Meta Study's ICF cluster identified Pennington et al's (2007) ICF reporting guidelines for AAC research. This paper informed the data extraction processes of the Narrative Synthesis. The Culturally Valid Lexicon cluster highlighted cultural appropriateness and cultural validation of methods in AAC research. The Communication Matrix cluster findings failed to fully articulate their methodological processes, underlining the importance of this in interpretive analysis. Finally, the Narrative Assessment Profile brought certain specialist AAC interpretation techniques to my attention, I would need to consider interpretation and analysis as important aspects of AAC use. I also developed the use of sibling papers from Clustering (Booth et al., 2013b) in the Meta Study to be applied in the Narrative Synthesis.

In summary, the sequence of the reviews is open to interpretation by the reviewer. It may depend on the requirements of the specific review question. I recommend consideration of sequencing on a case-by-case basis because this thesis was not designed to determine optimal review sequence or strategy. This area will require further research. I used forms of conceptual and instrumental knowledge between reviews to enhance the interpretation of AAC data collection methods. Reviews were not specifically designed to feed into one another. The sequence I used allowed me to understand the scope and location of methods (through the scoping study) and the conceptual underpinning of the literature landscape (through the Meta Study) prior to a fine-grained analysis of implementation (the Narrative Synthesis). Further refinement of the methodological templates could test the sequence of the reviews and confirm if they can be conducted in isolation.

8.5 Discussion of the empirical outcomes of the reviews

Each approach to methods contextualisation implemented in the thesis explored different empirical questions. Collectively, findings created a wider platform of knowledge. The

third research question for this thesis asked: *What is the contribution of methods contextualisation in the field of Augmentative and Alternative and Communication (AAC) methods with people with dementia?* This section will look at empirical contributions across the three reviews in relation to the following areas: characteristics of studies identified (including key themes and concepts) and comparisons to the wider literature.

8.5.1 Study characteristics

The characteristics of the scoping review (involving the exploration of the location of methods) are discussed first. Findings revealed a small number of studies (a total of ten) published from 2001 in western policy contexts, with half adopting evaluative designs. Table 8.2 displays the type of AAC methods found. Most were low tech or arts-based methods and all explored AAC and dementia populations (Alzheimer's disease was the only specific diagnosis of dementia targeted). Outcomes of the studies revealed how AAC enhanced communicative interactions. Papers were heavily influenced by social psychology approaches. In the group of seventy five wider (excluded) studies, findings illustrated the range of other AAC user populations, such as people with aphasia.

The Meta Study analysed four purposively selected frameworks in order to understand perspectives that shape the contextual landscape: The ICF (WHO, 2001 explored in Murphy and Boa, 2012), the Culturally Valid Lexicon (CVL) (Nigam, 2006), the Communication Matrix (CM) (Rowland, 1990 explored in Rowland, 2011) and the Narrative Assessment Profile (NAP) (Bliss, McCabe and Miranda, 1998) explored in Soto et al., 2006. Some were designed for a specific population (CM and NAP) and others were intended to have a more specific application function than others (e.g. the ICF had a broader application in contrast with the more specific application of the CVL). The largest cluster with the greatest impact in the literature was the ICF. There was an abundance of theoretical sources identified across clusters but relatively few 'kinship sibling' or 'kinship antecedent' papers more directly related to the study.

Twelve studies were identified as a result of the Narrative Synthesis, with five additional methodological sibling papers. As with the scoping review, there was a range of methods, methodological approaches and research designs employed (see table 8.2).

Table 8.2 AAC research methods included within three studies in the thesis

Review	Methods identified
Scoping study	<ul style="list-style-type: none"> • Cognitive prosthesis (Alm et al., 2004) • Feelings Art-Group (Bober et al., 2002) • Memory aids (Bourgeois et al., 2001) • Multimedia device (Hanson et al., 2007) • Reminiscence art programme (Kinney and Rentz, 2005) • Life Story Work (McKeown et al., 2010b) • Participatory methods (Muller and Guendouzi, 2009) • Talking Mats™ (Murphy et al., 2007; Murphy et al 2010) • Music therapy (Sixsmith and Gibson, 2007)
Meta Study	<ul style="list-style-type: none"> • ICF- Talking Mats™, general AAC • CVL- Symbol or words-based systems • CM- nonverbal expressive communication- observational tool and behavioural inventory • NAP- Narrative methods (employed different AAC tasks)
Narrative Synthesis study	<ul style="list-style-type: none"> • Nonverbal and picture elicitation Allan, 2001 • Multimedia device (CIRCA™) (Astell et al., 2010; Astell et al 2009) • Diary interview method (Bartlett 2012; Bartlett 2014) • Story, music, art expression (Jonas-Simpson, 2005) • Life Story Work (McKeown et al., 2010a; 2010b) • Talking Mats™ (Murphy et al 2013; 2005) • Nonverbal interviews and observations (Nygård et al., 2006) • Dance therapy (Nystrom and Lauritzen, 2005) • Photo elicitation and Autodriving (Shell, 2014) • Multimedia Biographies (Smith et al., 2009) • Photovoice (Wiersma, 2011)

Life Story work (McKeown et al., 2010a ; 2010b;) and Talking Mats™ (Murphy et al 2013; 2005; Murphy et al., 2007; Murphy et al 2010) methods featured in both the Scoping and Narrative Synthesis. The majority of AAC studies recruited participants using a general dementia diagnosis. Key themes identified across studies included the role of cultural perspectives. Cultural sensitivity was an important factor in using and facilitating AAC (emerging across all three reviews). AAC facilitation was complex, involving multiple forms of data collection and analysis techniques. The role of AAC varied across clinical, therapeutic, residential and research settings.

The Narrative Synthesis built on the previous reviews. Its main outcome was a proposed typology for AAC. This approach to methods contextualisation provided a broader theorisation of context. The typology was based on interaction with AAC (narrative, communication framework and expressive methods). Nuances of the implementation

phases of the Narrative Synthesis review emphasised: representational issues, data gathered through multiple points (for narrative methods), familiarisation with AAC, visual and nonverbal data, caregiver influence (for communication framework methods), choice of method, skill of researcher, and analytical strategy (for expressive methods).

AAC research attempted to capture perspectives of individual participants; this theme was echoed in the dominance of social psychology perspectives. The Meta Study analysis highlighted improving service provision (in ICF and CVL frameworks) and understanding the interactional context (emerging from contextual barriers in the CM framework and the awareness of interactional settings inherent in the NAP). This was consistent with much of social psychology-led practice.

However, assumptions in the Meta Study data revealed some examples of naïve professional rhetoric surrounding the use of protocols to illuminate forms of bias, particularly cultural bias. There were examples of practice that actually reinforced biases, such as purely observational approaches used in the CM. The findings from the final narrative review brought to light research with greater levels of awareness of biases. Findings highlighted reservations about representational issues in AAC analysis (Smith et al., 2009; Wiersma, 2011).

The Narrative Synthesis related all data to standard phases of research. I identified a Theoretical Model linked to general phases of research. These were: research initiation, implementation, engagement and interpretation. Along similar lines, the Meta Study showed how AAC interpretive frameworks appeared to specialise in phases of the research process (summarised as: method classification, validation, assessment, interpretation). This underlines the impact that AAC methods have on the methodological process of the study in primary research.

8.5.2 Contribution in relation to wider literature

In relation to the wider literature, the Scoping review expanded on the review by Beard (2012). The Meta Study expanded on the review by Edyburn (2001) and broadened analysis beyond Assistive Technology fields (Lenker and Paquet, 2003). Finally, the Narrative Synthesis expanded on Clarke and Keady's (2002) voice elicitation guidance. (Comparisons are discussed in detail in empirical chapters 5.5, 6.5 and 7.5).

Theoretical texts, already described in chapter 3.3, explored dementia research and the variety of ways it was conceptualised and developed. Innes (2009; Innes et al., 2012; Innes

and Manthorpe, 2013) theorised dementia research by exploring the contributions of the three dominant dementia perspectives (biomedical, psychosocial and critical social gerontological) and created a way of thinking about dementia care using the three perspectives as tools, acting together to frame knowledge. Collectively, the synthesis could contribute to the integrated structure (or ‘Web of Understanding’) of care, research and practice (Innes, 2009, p.140, figure 6.3; Innes, 2012, p. 34, fig 1.1; Innes and Manthorpe, 2013, p.692, figure 4).

To reiterate Innes’ (2009) premise, *“the interplay between theory, policy, practice and research is where the study of dementia sits. As such, the study of dementia can be visualised as a web, where various strands of theory, policy-making and practice ideas and research meet”* (Innes, 2009, p.140-1). The model of the study of dementia, on which the web is based, used the lenses of the three main social science perspectives to *“regenerate, produce and challenge”* different forms of knowledge (Innes, 2012, p.32). *“Essentially, the study of dementia involves asking epistemological questions that seek to explore and challenge the assumptions that underlie what is ‘known’ about the condition”* (Innes, 2009, p.144). Therefore, a multitude of perspectives and disciplinary vantage points are conceptualised as advantageous to *knowing* dementia (my explanation of the elements of web is in section 3.4). Innes and Manthorpe (2013) argued the development of research contributions to dementia had been *“stalled”* to some degree because of an overemphasis on dementia care models based on their theoretical origin (p.693). The researcher element in Innes’s Web of Understanding (2012) called for a dual focus on micro and macros level issues to understand the world of the person with dementia (Innes, 2012, p.34, figure 1.1). In addition, the web emphasised contextualisation of all forms of research within policy frameworks, societal expectations and beliefs about dementia and quality care (Innes, 2012, p.34).

Contextualisation is mentioned once more in reference to gerontological dementia research, specifically contextualising the lived experience (Innes and Manthorpe, 2013, p.691), but this process is not described more broadly in relation to the critique and selection of research methods. The remit of the researcher element of the web has already been quoted in section 3.4. This emphasised research to bring the broader perspectives and experiences of people with dementia to the fore (in addition to other stakeholders). Research could then engage with broader attitudes and debates about dementia and dementia care (Innes, 2012, p.34, figure 1.1). It was clear, therefore, that the voices of

people with dementia were important in the web to advance dementia knowledge. However, research methods were not given the prominence that may be required to achieve this goal.

The influence of research methods within the confines of a particular theoretical approach is dealt with to some extent in Innes' (2009) chapter, *Researching dementia and dementia care: implications for the generation of research knowledge for policy, practice and approaches to research* (pp. 102-132). Complexities surrounding how researchers can include people with dementia in research were acknowledged as significant (p.116). The section on the role of the researcher in facilitating the research process highlights the fact that "*researchers will need to locate their work in wider theoretical debate and be clear about the beliefs and understandings of dementia they are using and bringing to research*" (p.119). Innes' argument relays the fragmentation of the different approaches to dementia research that have occurred largely in isolation, and the fact they are rarely located within the context of one another. Innes' contention is that "*...the real crux of the problem on doing social research on dementia relates to the paucity of reflective accounts of the research process, which would help to inform others seeking to embark on researching an area of social life that has been categorized in a way that makes the starting point for doing research difficult*" (p.119-120).

Innes (2009) also argues that there had been a pressure to hear the views of people with dementia, but research with this intention often fails to articulate this aim (p.136). Overall, the perspectives of people with dementia, and the data collection methods used to elicit them, could be developed further. Alternative approaches to communication in research are linked to gathering the perspectives of people with dementia, without in-depth discussion of research data gathering methods. The insufficient analysis and under-promotion of alternative methods in dementia research undermines Innes' central argument: the inclusivity of perspectives of people with dementia to inform research, theory, policy, practice and care. The means to hear those voices is not fully realised.

In a more recent publication, Innes and Manthorpe (2013) suggest that regardless of the theoretical starting point, in order to successfully link policy to practice, participant expertise is important in research (Innes and Manthorpe, 2013, p.692). The relationship between research and policy is such that "*Deciding whose account to hear and which to act upon has huge implications when developing policy for all professional practices and*

system design“ (Innes and Manthorpe, 2013, p.692). However, this thesis demonstrates it is also important for researchers to consider *how* those accounts should be heard in a way that maximises representation. It is possible that the part methods play in operationalising challenges to political or social contexts has been underestimated. Together, dementia research approaches can achieve a number of things. They can help people with dementia to make sense of their symptoms (biomedical perspective). They can provide insights about interventions and highlight the individual (social psychological research). They can also contextualise wider social structures that influence the individual experience (gerontological research) (Innes, 2012). Research methods contextualisation should improve the opportunity to hear voices of people with dementia in this approach.

Therefore, this thesis provides evidence for the expansion of the Web of Understanding of dementia (Innes, 2012) in three respects. The model could encourage the identification of social science perspectives within research and reviewing. Secondly, the model places a focus on voice-enhancing AAC methods to understand the world of the person with dementia. Finally, *methods contextualisation* could help to guide primary research as a systematic and transparent process of data collection choice and use. The ways the thesis has provided these three strands of evidence is described below.

To expand on these points further, the Scoping review and the Meta Study review collected data on the perspectives within the studies. This was a way of summarising the approach to the focus of the research and the assumptions driving the research, including beliefs about dementia care. AAC methods were clearly a way for people with dementia to communicate their thoughts and feelings. The methods help to dismantle a fundamental contradiction in dementia research, that is, the emphasis on gleaning the perspective of people with dementia in research (i.e. inclusionary practices), in contrast with the inflexibility towards data collection methods to hear that perspective- which currently may be regarded as exclusionary. It is clear researcher preference towards traditional interview methods persists (explored in chapter 3.3.3). This thesis argues that traditional interview methods *close down* opportunities for communication. Therefore, Innes’ (2009) model could be amended to include AAC. AAC methods fit comfortably with the principles of the model, offering the potential for research and practice that communicates micro-level issues (in one-to-one communication). The AAC methods also offer the opportunity to explore macro-level issues through participatory, performative methods. AAC methods are more complex for researchers or practitioners to facilitate, yet the benefits are many.

Innes' (2009) web resonates with the contextualising features of *methods contextualisation*. The focus of the reviews was methods contextualisation and this included evidence from wider policy, practice and theoretical domains. Findings attempted to locate studies within settings of various kinds (location, policy, national contexts). Findings also elucidated the context of AAC theory. Arguably, AAC methods can channel communication between the person with dementia and research or practice, which helps to change attitudes in policy and society.

8.6 Summary

I have summarised my methodological and empirical findings in order to show how methods contextualisation could be developed in reviewing (one of the central research questions in the thesis). The main outcomes of this chapter have tried to conceptualise what has been accomplished within the thesis on methodological and empirical fields. I summarised the methodological contribution of methods contextualisation in terms of its aim and purpose and what implementation of this concept has achieved. I conceptualised development of approaches to methods contextualisation in a theoretical model (8.1). The studies used three 'methods contextualisation' approaches, associated with different modified review templates, to provide a sense of the ways they interacted, or functioned in the literature landscape. The *surveying*, *drilling* and *open-cast mining* labels were designed to convey function and purpose (i.e. the circumstances in which a reviewer may want to use the methodology).

Other methodological contributions included my reflections on the suitability of the dimensions of the reviews and the role of the sequence of the reviews. Overall, the review components were considered suitable in relation to aims, topic and depth of analysis in relation to the particular approach in the template. However, I note some limitations in the scope of the reviews resulting from a single reviewer. The thesis was an exploratory piece of research not ideal for comparative analysis. Therefore, I conclude outcomes of the thesis cannot provide definitive guides to the sequence of future methods contextualisation templates.

The empirical outcomes of the thesis contributed at a number of levels. First, there is the granular level of identification of studies relevant to the topic of AAC use in dementia research. Secondly, the thesis contributes to analysis and interpretation of this area through identification of key themes and concepts identified directly from studies and

through review analysis. Thirdly, the thesis makes a contribution to wider dementia research theory. It expands existing reviews that did not cover such a wide area of all AAC methods. It also contributed to theory on voice-elicitation in dementia and, highlighted the role of AAC in improving research- which can be embedded into Innes' (2009) Web of Understanding for dementia.

Chapter 9: Summary of contribution and implications of thesis

9.1 Introduction

This thesis set out to explore methods contextualisation as a new genre of reviewing. Three approaches were introduced, created by adapting existing methodological guidance. Empirical examples of each approach were undertaken, based a topic relating to the use of Alternative and Augmentative Communication (AAC) methods in dementia research. Thus, the thesis can be described as a methodological *exploration* that makes methodological and empirical contributions to research.

The following sections provide an overview of what I learned during the time I worked on the thesis. The first section is a reflective summary of my experience. It is structured according to the distinctive phases in the methodological journey, that is, the research development, implementation and, conceptualisation of the thesis. I present an overview of the contribution of the thesis and the issues surrounding why the methods contextualisation purpose is of benefit. Finally, I discuss implications for future policy and practice.

9.2 A summary of what I learnt during the process of completing the thesis

This section articulates what I learnt from the process of conducting this thesis. I have approached this reflection of my learning experience according to the three main phases in the thesis (the **development, implementation and conceptualisation** of the methodological programme). I discuss each in turn.

Fundamentally, I learned how challenging it is to make methodological contributions to research. My suggestions for a new methodological genre presented in the first development phase of the thesis were the culmination of my increasing knowledge and expertise. The first step was starting to think about the wider implications of my research. This was an additional lens I adopted. Through this lens, I attempted to assess the methodological as well as the empirical value of my work. Methodological development was an ambitious aim, and risked potentially failing to identify a contribution. The details of the development of the thesis emerged gradually. The processes of development, implementation and conceptualisation of the research were slow to materialise and they required patience! The development process in particular, involved meticulous (and

sometimes painstaking) preparation, planning and consideration. I was learning to perceive research not only as a reviewer might, but as a methodologist might.

The methodological agenda emerged, and I viewed it as an exciting opportunity. However, the development process was no guarantee of an original methodological contribution. Nor could I ensure the ideas could be successfully implemented, or coherently conceptualised. I attempted to remain receptive to what I later referred to as ‘extending the methodological horizon’ of the thesis i.e. a new methodological genre to assist researchers in choosing and using appropriate research methods to gather data. The three templates were not inevitable outcomes of development. I began to understand that this type of work requires a certain level of willingness to manage the uncertainties in the project, especially methodological contributions. Developments were systematically appraised as the best available options, or solutions to methods contextualisation. Eventually, such elements came into focus. For all the uncertainties, I discovered the rewards of methodological research.

In developing the reviews it was important to understand the characteristics of interpretive methodology (explained in chapter 2.2). I immersed myself in methodological theory and I learned a great deal about different approaches and perspectives. I also began to understand how the heritage of interpretive reviewing played a part in the way it developed (described in chapter 2.3). I learned about the plethora of review approaches and the similarities and differences between them. This included the broad range of theoretical and philosophical differences as well as implementation variation. This helped me to decide on the parameters for methodology selection (chapter 2.4). Hence, I made the case for adaptations according to criteria set out for each approach to methods contextualisation (criteria are set out in chapter 2.5; the adaptations were outlined throughout chapter four).

Overall, I learned to develop a programme of research that is presented throughout chapters one to eight. I believe this is a different skill to implementing and conceptualising a number of studies under a common research theme. A methodological programme such as methods contextualisation is a challenge because it represents a ‘meta structure’ within the research; it harbours an additional set of intentions. This process allowed me to learn how to manage a number of different strands during the course of a project. The development of a programme of research also enabled me to learn at what points to recognise the limitations of this first iteration of development. Whilst the thesis exists as a

complete methodological programme, it may only represent the first phase of the methodological genre development.

In relation to implementation aspects of the thesis, I carried out three different synthesis approaches. The individual reviews required implementation of three different methodologies and other methodological techniques (including systematic mapping and Clustering). I learned how to conduct a wide range of (mostly configurative) data extraction and analysis techniques. I also found the most appropriate way to implement the adaptations and alterations to the existing methodologies, some of which I had created (such as visual representations of Clusters or Overarching Constructs). The three empirical studies required different types of interpretive skill. The Meta Study, in particular, was challenging due to the highly conceptual content, whereas, the Narrative Synthesis involved the identification of mechanistic factors in rich methodological data.

More broadly, I learned how to implement challenging methodological processes, such as iterative reviewing. It is also important for all reviews to maintain a level of transparency and to be systematic. These factors were important in understanding the methodological journey and justifying decisions made, but also in isolating aspects of the reviews that would feed into the subsequent review in the sequence. Implementation was a long process which amassed a large volume of extracted data. The study results and the appendices provide a resource for further research. Finally, I learned the essential role that implementation plays in testing theory or methodological development. Implementation enabled me to understand what worked and what did not work, and why. Implementation helped me to understand the role of review components, for instance, the value of the Systematic Mapping exercise in supplying an added layer of study attributes for the scoping review. In other ways, implementation of aspects, such as the identification of disciplines, did not operate perfectly. Thus, shortcomings were identified to be improved in further empirical testing.

The final perspective on my learning experience is conceptualisation of methods contextualisation (the final two chapters eight and nine). In order to fully conceptualise a methodological programme of reviewing, I had to consider my role as a reviewer. As the only reviewer on the project, I had to combine the development and implementation aspects of the thesis into a coherent conceptualisation that would describe the processes. Most of the reflection on the conceptualisation of the thesis (including a model for the way

the three approaches to method contextualisation function) is located in chapter 8.2. However, conceptualisation also happened throughout the process of developing and implementing the studies. I learned to keep a sense of the Meta structure of the thesis throughout. The thesis structure had to introduce complex concepts gradually. I also developed a new lexicon for some of the ideas I have presented, such as the term methods contextualisation, and the corresponding approaches and functions described in the model 8.1. I view this process as crystallising my ideas to enhance methodological transparency.

9.3 The overall contribution of the thesis

Chapter eight has provided detailed discussion about the methodological conceptualisation of the thesis and the empirical outcomes. This section attempts to distil the overall contribution of the thesis. I begin by explaining why I believe the methods contextualisation is of benefit. It will also summarise its contribution.

Why the use of the methodologies for methods contextualisation purposes is of benefit

Section 8.2 has already explained what has been achieved by the implementation of methods contextualisation in light of its aim and purpose. This section summarises why the use of the methodologies for the purpose of methods contextualisation is of benefit. The main purpose of methods contextualisation is to identify a systematised process for identifying suitable data collection methods in research. This section reflects on the benefits of that intent.

Methods contextualisation could act as a guide for the future choice and application of data collection methods. I have already argued that the implementation of methods contextualisation assists reviewers in understanding the impact of data collection methods in their field of research, and I indicated that it could help to show the value of alternative methods (section 8.2). This area of research might influence research proposal design, perhaps in becoming a prerequisite for ethics applications. (I discuss general implications for policy and practice in chapter 9.4). Currently, practices do not involve the application of rigorous systematic methods such as systematic reviews. The nearest comparison is emancipatory research that requires researchers to select from a range of methods (including alternative methods) for primary research with vulnerable or hard-to-reach groups. This is an area where non-conventional creative and individualistic approaches are encouraged (section 1.3). However, this approach does not rely on the synthesis of

secondary data evidence. The reviews provide a methods-centred review technique, providing systematised processes that can be operationalised to analyse previous practice in order to reflect on suitable methods choices.

It could be argued methods contextualisation could help to challenge assumptions surrounding the role of interpretive reviewing. Methods contextualisation fulfils a perceived gap in the typology of reviews. Methods-centred reviews are not currently viewed as a specialist type of reviewing (unlike Complex Intervention Reviews or Rapid Reviews). Researchers will be able to employ an approach (or approaches) to ask specific questions about methods choice and/or use to inform application of research methods. There are a number of reasons why the specific methodologies may have been beneficial for methods contextualisation. The scoping review provided a particularly good way to understand the location of studies. The Systematic Mapping exercise helped to map studies and study attributes. I created a layered analysis of the location of studies and study attributes through the methodological template. The Meta Study methodological template facilitated rich critique of the impact of research perspectives in shaping interpretations of methods. Finally, the Narrative Synthesis template created a broader theorisation of context surrounding research methods, especially the processes of research implementation.

Aspects of the thesis could be used as a research resource, such as the methodological templates, empirical examples and methodological conceptualisations. The methodological programme presented enables the reader to trace the development, implementation and conceptualisation phases of the research. Researchers will be able to plan transparent and robust approaches to the interpretation of previous primary research methods and their application. The thesis could initiate debate over the current strategies for data collection choice and use in research, particularly with marginalised groups. I present arguments to show methods choice and use is an under-developed area in research, and that methods contextualisation is a viable solution (sections 1.3 and 1.4).

Finally, my three review templates could benefit future research because they explore the representativeness of participants, including the credibility of *voices* in research. This is because the templates increase knowledge about what the alternative forms of communication are and how to use them. The contextualisation of methods helps to authenticate voices heard, particularly those extracted through alternative forms of

communication. The templates provide a justification for further research in this methodological terrain, especially to demonstrate subsequent selection of communication methods is evidence-based (and not simply reviewer preference). In cases where communication is harder to access, this is an essential component of creating ethical research.

The contribution of the thesis

Methods contextualisation potentially represents a new addition to the typology of reviews. It may be considered a new genre in interpretive reviewing. The synthesis of methods data (rather than synthesis of thematic findings) is a departure from established methodologies. Reviews that qualitize data are also less common. The next step for this methods contextualisation genre is peer review and refinement. The methodologies addressed questions about methods choice and use, which is especially significant where the application of alternative forms of communication lack consensus. The findings from the thesis provide a starting point to broaden the methodological horizons of research.

Finally, the thesis makes a contribution to understanding dementia and alternative communication research. The thesis synthesises current methods in AAC research in dementia research contexts. Chapter three highlighted these forms of data collection and analysis, and pointed out that they are under-used in research (section 3.3.3). Findings from my empirical studies can shed light on study attributes (the scoping study), interpretive processes informed by particular perspectives (the Met Study) and, theorise appropriate methods implementation (the Narrative Synthesis). In addition to this knowledge base, the thesis contributes to dementia theory by showing the importance of alternative communication as a way to increase the credibility of research (section 8.3).

9.4 Implications for policy and practice

There are several ways the findings from the thesis could be useful to researchers and policymakers. The discussion will divide issues into methodological and empirical arenas.

The methodological aspects of the review challenge some of the assumptions surrounding the utility of interpretive review methods. Reviewers may want to replicate these methodological processes for other types of research methods that lack integration across disciplines or populations (especially where biomedical perspectives dominate the research landscape, or for other groups that rely on alternative communication methods for voice-

elicitation). The reviews may be viewed as a sequence, but they may be used in isolation to inform other systematic reviews- such as effectiveness reviews. The methods contextualisation methodologies I have modified emphasise the potential for reviews to illuminate different dimensions of context, and to analyse the full range of forms of communication open to researchers. These methodologies place the needs and preferences of participants at the heart of the review, another way of adhering to the central principles of participative, service user-led reviewing.

The thesis provides several bases of knowledge in relation to empirical findings and policy and practice. The impact on policy and practice is most likely to be made indirectly through adapted researcher practice, as opposed to directly influencing national or international level care policy or advocacy groups. The first rationale, explored in chapter one (sections 1.2, 1.3 and 1.4 outlined my intention to extend the methodological horizons of reviewing and thereby, contribute to researcher practice in the choice and use of data collection methods). Researchers need to understand what methods have been used and how to implement them before policy makers can decide which implementations to target (based on the evidence). The thesis represents the first syntheses of these types of Alternative or Augmentative Communication research methods. This links to the third justification for the choice of topic as a viable focus for synthesis (section 3.5).

The review produced a vast array of rich empirical data (the second justification for the topic- discussed in section 3.4). The reviews do more than simply audit the range of AAC methods out there. The scoping review may inform practice through the identification and appraisal of studies. The configurative nature of the reviews consolidates knowledge about the different perspectives and associated narratives- in dementia research and AAC.

However, there are limitations to the exhaustiveness of the range of methods presented due to the specificity of selection criteria. I have extended categorisation of AAC methods in dementia research. Findings from the implementation study (chapter seven) builds on Goldsmith (1996), Allan 2001, Clarke and Keady's (2002) existing guidance (p.41-2) (explained in the Narrative Synthesis review discussion section 7.5). In this way, the topic supports voice-elicitation, the first justification for the topic (identified in section 3.2).

The findings from the methods contextualisation reviews presented in the thesis illustrate ways of describing and classifying data collection methods through secondary analysis. Descriptions refer to a range of study attributes (explained in the scoping review), and

other theoretical tools such as interpretive frameworks (helping to classify, validate, assess and interpret those studies, analysed in the Meta Study in chapter six). Findings also highlight ways to classify methods and their respective implementation strategies through a typology of AAC (that is, the three types of AAC suggested as an outcome of the Narrative Synthesis in section 7.1). The reviews show that whilst AAC may be a successful clinical or therapeutic toolset, they have wider application in qualitative experiential research and beyond in the community. Greater familiarisation with AAC methods (with appropriate facilitation) could assist in providing grater channels for people with dementia to express themselves and expand their roles. Avenues for further research may analyse the different types of AAC in more depth, combining this investigation with primary research to test the theory produced in the reviews. The next steps for this research may explore the existence of the AAC typology.

Overall, this thesis provides a detailed overview of the development, implementation and conceptualisation of a new genre in systematic reviewing, namely, methods contextualisation. The three modified methodological templates I have presented provide researchers with three transparent and systematic processes to choose and use primary data collection methods in primary research. In exploring these areas of research, I have also increased understanding about augmentative and alternative forms of communication in dementia research. Therefore, my findings are intrinsically linked to maximising the elicitation of voices from participants in research.

Appendices

Appendix item 1: Key pearl citation selection indicators Meta study

Paper	Contextually or conceptually rich?	Based on empirical work?	Academic article?	Non AAC effectiveness study	Part of a project?	Viable size cluster (including kinship)?	Transferable framework across AACs?	Transferable framework across CI populations?	Comments
Murphy et al., 2012					X				INCLUDE*

*Murphy et al., 2012 may be counted as a methodological paper (rather than a review paper) and has not got a clear association with a named project. The ICF is the basis of the paper as a total framework for all AAC across all populations. Several projects are mentioned in association with the method. The pool of kinship papers appears rich with further links to the ICF and goal setting and the role of Talking Mats™ as a communication framework. INCLUDE

Item 2:

- **Pubmed** full search: 1243743 (see table 3 for full list of search terms)
 - No relevant articles in first 40 scanned
- 407 Column 4 AND 1 AND 2 OR 3 (**Cognitive impairment AND Methodological general AND Sensory/behavioural OR Device**

Relevant) topics include:

- Persons with multiple disabilities select environmental stimuli through a smile response monitored via a camera based study
- Literacy learning in users of AAC: a neuro-cognitive perspective
- Improving the social understanding of individuals of intellectual and developmental disabilities through a 3D facial expression intervention programme

➤ **Metalib:**

Sensory /behavioural (437) Metalib topics include treatment & stroke)

DATES: 2003-2011(8),

topics: *psychosocial perceptions*, spatial learning, communication protocol, quality of life in the community for people with a disability, training independent mental capacity, management of children with autism when attending hospital, sensory stimulation programme for comatose patients, considering the factors affecting nutritional status, integrated working, sensory interventions after a stroke

Device (312) (Metalib topics include: interventions & training)

Dates:2008-2011

Topics: evaluation of a computer assisted instruction resource for nurses, support groups for suicide bereavement, sleep apnea devices, *interactive communication applications for people with chronic disease*, *speech and language therapy to improve the communication skills of children with cerebral palsy*, robotic arm functioning,

electromechanical training after a stroke, collaboration between government agencies for health improvement, evidence based interventions for prescribing medicines.

>

AND Dementia (295) (METALIB topics: training and interventions)

Dates: 2008-2011

Topics: evaluation of a computer assisted instruction resource for nurses, interactive communication applications for people with chronic disease, robotic arm functioning, speech and language therapy to improve the communication skills of children with cerebral palsy, collaboration between government agencies for health improvement, evidence based interventions for prescribing medicines, electromechanical training after a stroke, information interventions for cancer care, computer-based interventions for sexual health, non-pharmacological interventions for diseases

Metalib search #2 (methods, devices, cognitive impairment): (247) (topics: interventions)

Dates: 2008-2011

Topics: interactive communication applications for people with chronic disease, speech and language therapy to improve the communication skills of children with cerebral palsy, robotic arm functioning, non-pharmacological interventions for diseases collaboration between government agencies for health improvement, evidence based interventions for prescribing medicines, electromechanical training after a stroke, computer-based interventions for sexual health, treadmill training after a stroke, audio-visual information presentation during trials.

Appendix item 3:

Databases used originally were: BNI, PsycINFO Pubmed, & Metalib (Databases: social policy & social work), Embase, OVID, Applied Social sciences Index and Abstract, CINAHL

Pubmed

Results 1245839

[\(\(\(self-help devices\) OR \(nonverbal communication\)\) OR \(\(qualitative research\) OR \(researcher-subject relations\)\) OR \(communication barriers\) OR \(communication disorders\) OR \(executive function\) OR \(mental disorders **diagnosis** in childhood\) OR \(brain diseases\) OR \(delirium, dementia amnestic, cognitive disorders\)\) OR \(communication aids for disabled\) OR \(sensory aids\) OR \(language arts\) OR \(touch perception\) OR \(sensory art therapies\) OR \(photic **stimulation**\) OR \(photic stimulation\) OR \(computer assisted instruction\)](#)

0 from first 20 relevant

BNI

BNI- SU.EXACT.EXPLODE("Cognition") OR SU.EXACT.EXPLODE("Interviews and Interviewing") OR SU.EXACT.EXPLODE("Research Methods") OR SU.EXACT.EXPLODE("Communication") OR SU.EXACT.EXPLODE("Children") OR SU.EXACT.EXPLODE("Reminiscence Therapy") OR SU.EXACT.EXPLODE("Evidence Based Practice") OR SU.EXACT.EXPLODE("Speech Disorders") OR SU.EXACT.EXPLODE("Rehabilitation") OR SU.EXACT.EXPLODE("Reflective Practice") OR SU.EXACT.EXPLODE("Mental Health") OR SU.EXACT.EXPLODE("Interpersonal Relations") OR SU.EXACT.EXPLODE("Learning Disabilities") AND voice*AND augment* OR alternative AND COMMUNICATION OR impair*

31468 results

1 relevant from first 20 (sev background)

EMbase

Augmentative and alternative communication AND voice OR Augmentative and alternative communication AND sensory OR Augmentative and alternative communication AND device OR Augmentative and alternative communication AND behaviours

56

Ovid- social policy and practice

‘augmentative and alternative communication’

21

10 in first 20 relevant

Ovid-medline

(augmentative and alternative communication and (device or sensory or behavioural or voice))ab

44

19 relevant from first 44

CINAHL

(augmentative and alternative communication) and (voice output communication and augmentative and alternative communication) OR (voice AND augmentative and alternative communication) OR (Nonverbal AND augmentative and alternative communication) OR (Behaviour and augmentative and alternative communication) OR sensory stimulation AND augmentative and alternative communication) or (sensory augmentative and alternative communication) OR (devices AND augmentative and alternative communication)

100

3 from first 10

PsycINFO

317 results

11 relevant

Item 4

Gerontology Literature body

Zetoc

No unique mesh terms used. Single search line available only.

1 "augmentative and alternative communication" experience

2 "augmentative and alternative communication" DEMENTIA journal articles only

#1= 15 RECORDS

#2 =4RECORDS

Assistive technology literature body

INSPEC-

(1969-2012)

Unique Mesh terms used within database

search re-run

1 (augmentative and alternative communication).ab.

96

2 (Photic stimulation or computer assisted instruction or communication aids for disabled or Self-help devices or sensory art therapies or touch perception).ab.

1380

3 (Communication disorders or dementia or Executive function or mental disorders diagnosed in childhood or brain diseases or cognitive disorders). ab.

1124

4 2 or 3

2503

5 1 or 4

2597

LISTA

1 AB augmentative and alternative communication

9

2 AB Photic stimulation, OR AB computer assisted instruction OR AB sensory art therapies

OR AB touch perception OR AB Self-help devices OR AB communication
476

3 (AB cognitive disorders OR AB Communication disorders OR AB Executive function
OR AB mental disorders diagnosed in childhood OR AB brain diseases OR AB dementia
amnesic) AND (S1 and S2)
133

4 S2 or S3

608

Health science/nursing/medical practitioner/primary care research literature body

BNI Proquest

(ab("augmentative and alternative communication") OR ab((senses* OR touch*)))

AND (ab(cognitive) OR ab(brain diseases) OR ab(mental health nursing) OR
ab(dementia*)) **26**

CINAHL (EBSCO)

(1980-2012) #1 = 95 2# 11

Search will suggest terms

Limiters - English Language

Search modes - Boolean/Phrase

#1 AB "alternative and augment* communication"

11

#2 **Search modes** - Boolean/Phrase

S3AB Touch OR AB (Communication and technology) OR AB Communication

devices for people with disabilities OR AB Sensory stimulation OR AB Art therapy

OR AB Computer-assisted instruction

5073

S4AB Dementia OR AB Cognition disorder

11248

S5 (AB Dementia OR AB Cognition disorder) AND (S3 and S4)

98

Psychology/Social psychology/behavioural science

Psycinfo (Ovid SP)

(Modified terms using *wildcard and truncation).

1987-2012 = **2126 HITS** (Example of same search re-run below to show breakdown across terms)

1. Nonverbal communication.ab.

993

2. (Communication barriers or researcher-subject relations).ab.

209

3. (Photic stimulation or sensory art therapies or touch perception).ab.

216

4. 1 or 2 or 3

1416

Policy/social policy Literature body

Social Policy and Practice (Ovid SP)

Search terms used:

1 communication aid.ab.

14

2 computer assist*.ab.

126

3 communicat* disorder*.ab

47

4 ("alternative" and "communication").ab.

116

5 1 OR 2 OR 3 OR 4

299

Biomedical AND disability/rehabilitation/long-term conditions/mental health literature body

Pubmed

(Mesh term searched- few methodological filter terms used).

((("cognitive"[Title/Abstract])) OR (dementia*[Title/Abstract])) AND
((((Communication disorder*[Title/Abstract])) OR ("communication aid")))
OR ("self help devices"[MeSH Terms]) **366**

((Communication disorder*[Title/Abstract])) OR ("communication aid") **944**

Embase

(1980-2012)

1 facilitated communication.sh.	194
2 art therapy.sh.	1908
3 1 or 2	2102
1 verbal behavior.sh.	11753
2 interpersonal communication.sh.	98061
3 cognitive defect.sh.	80229
4 1OR 2 108808	
5 3 OR 4	1334

Appendix item 5: Scoping Hand searches of literature

Discipline	Journal	Years searched
AAC	Augmentative and Alternative Communication (AAC) Journal	2000-2012
AAC	Full text AAC Journal search	All years
Rehabilitation/ long-term conditions	International Journal of Language and Communication Disorders	1993-2012
Policy/Social policy	Economic and Social Research Council outputs	1980-2012
Biomedical/dementia/medical practitioner/Primary Care research	Dementia Journal	2003-2012

Appendix item 6- Scoping included studies table

(Greyed out rows indicate included studies N=10).

Reference	Date	Study type	AAC type	Length use	Type of population	Inclusion criteria category (1-3)	Literature body (1-7)	Comments on Inclusion/exclusion decision 'Background' paper= excluded
AADLANDSVIK, R. 2008. The second sight. <i>Dementia</i> , 7, 321-339.	2008	phenomenological	arts based	short-term use for intervention	PWD	-	3	Background – inconsistent with conceptual f/w
ALANT, E., BORNMAN, J. & LLOYD, L. L. 2006. Issues in AAC research: How much do we really understand? <i>Disability & Rehabilitation</i> , 28, 143-150.	2006	review	not spec	one off/short term use for research	not specified	3	7	Background – theoretical
ALM, N., ASTELL, A., ELLIS, M., DYE, R., GOWANS, G. & CAMPBELL, J. 2004. A cognitive prosthesis and communication support for people with dementia. <i>Neuropsychological Rehabilitation</i> , 14, 117-134.	2004	evaluation	gesture, high tech device, words, symbols, low tech communication board, picture symbol, low tech photo object elicit, other	long term use for intervention	PWD	2	7	Included
ARMSTRONG, N., NUGENT, C., MOORE, G. & FINLAY, D. 2011. Using smartphones to address the needs of persons with Alzheimer's disease. <i>Annals of Telecommunication</i>	2011	review	high tech device, words, symbols	long term use for intervention	PWD	3	5	Background – theoretical

ns, 65, 485-495.								
ARUGA, M., ONO, S. & KATO, S. A consideration method of information content to be applied for the dementia situation and the "Yubitsuki" system. Proceedings Tenth International Conference on Enterprise Information Systems. ICEIS, 2008.	2008	[experimenta l]	high tech device, words, symbols	one off/short term use for research	PWD	2	5	Background- methodology
ASPLUND, K., JANSSON, L. & NORBERG, A. 1995. Facial Expressions of Patients With Dementia: A Comparison of Two Methods of Interpretation. International Psychogeriatrics, 7, 527-534.	1995	experimental	gesture	one off/short term use for research	PWD	1	1	Background- conceptual category excluded
ASTELL, A., ALM, N., GOWANS, G., ELLIS, M., DYE, R. & VAUGHAN, P. Involving older people with dementia and their carers in designing computer based support systems: some methodological considerations. Universal Access in the Information Society, vol.8, no.1, April 2009, 49-58.	2009	[evaluation]	high tech device, words, symbols	long term use for interventi on	PWD and spec h impai rment	2	5	Background - methodologi cal

BALANDIN, S. & MORGAN, J. 2001. Preparing for the future: aging and alternative and augmentative communication. <i>Augmentative and Alternative Communication</i> , 17, 99-108.	2001	survey	not spec	other	not specified	3	2	Background – theoretical
BALANDIN, S. & GOLDBART, J. 2011. Qualitative Research and AAC: Strong Methods and New Topics. <i>Augmentative and Alternative Communication</i> , 27, 227-228.	2011	editorial	not spec	other	not specified	3	2	Background – theoretical
BARROW, R. 2008. Listening to the voice of living life with aphasia: Anne's story. <i>International Journal of Language & Communication Disorders</i> , 43, 30-46.	2008	phenomenological	life story or narrative story tell, interview	short-term use for intervention	Other - aphasia	2	5	Background-other AAC population
BAXTER, S., ENDERBY, P., EVANS, P. & JUDGE, S. 2012. Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: a systematic review and qualitative synthesis. <i>International Journal of Language & Communication Disorders</i> , 47, 115-129.	2012	review	high tech device, words, symbols, low tech communication board, picture symbol	short-term use for intervention	not specified	1	5	Background-Systematic review

BAYLES, K. A. & KIM, E. S. Improving the functioning of individuals with Alzheimer's disease: emergence of behavioral interventions. Journal of Communication Disorders, 36, 327-343.	2003	experimental	other	long term use for intervention	PWD	1	5	Background-conceptual category excluded
BENVENISTE, S., JOUVELOT, P. & PE'QUIGNOT, R. 2010. The MINWii Project: Renarcissization of Patients Suffering from Alzheimer's Disease Through Video Game-based Music Therapy. Entertainment Computing ICEC.	2010	[intervention]	high tech device, words, symbols	short-term use for intervention	PWD	1	5	Background – methodology
BLACKSTONE, S. W., WILLIAMS, M. B. & WILKINS, D. P. 2007. Key principles underlying research and practice in AAC. Augmentative and Alternative Communication, 23, 191-203.	2007	review	not spec	pre-existing user	other	2	2	Background – theoretical
BLAIN, S. & MCKEEVER, P. 2011. Revealing Personhood Through Biomusic of Individuals Without Communicative Interaction Ability. Augmentative and Alternative Communication, 27, 1-4.	2011	review	music	long term use for intervention	other-spec h or communication disorder	3	2	Background – methodology

BLAKE HUER, M. & IRVINE SAENZ, T. 2002. Thinking about conducting culturally sensitive research in Augmentative and Alternative Communication. Augmentative and Alternative Communication, 18, 267-273.	2002	theoretical review	low tech communication board, picture symbol, low tech photo object elicit	pre-existing user	not specified	2	2	Background – theoretical
BOBER, S. J., MCLELLAN, E., MCBEE, L. & WESTREICH, L. 2002. The Feelings Art Group: a vehicle for personal expression in skilled nursing home residents with dementia. Journal of Social Work in Long-Term Care, 1, 73-87.	2002	intervention	arts based	short-term use for intervention	PWD	2	3	Included
BOURGEOIS, M., DIJKSTRA, K., BURGIO, L. & ALLEN-BURGE, R. 2001. Memory aids as an augmentative and alternative communication strategy for nursing home residents with dementia. Augmentative and Alternative Communication, 17, 196-210.	2001	evaluation	low tech communication board, picture symbol	long term use for intervention	PWD	2	2	Included
BOURGEOIS, M. S. 1992. Evaluating Memory Wallets in Conversations With Persons With Dementia. J Speech Hear Res, 35, 1344-1357.	1992	intervention	low tech photo object elicit	long term use for intervention	PWD	-	7	Background – inconsistent with conceptual f/w

BREWSTER, S. J. 2004. Putting words into their mouths? Interviewing people with learning disabilities and little/no speech. British Journal of Learning Disabilities, 32, 166-169.	2004	phenomenological	low tech communication board, picture symbol	long term use for intervention	other-developmental disability	3	3	Background-other AAC population
BRUCE, C., EDMUNDSON, A. & COLEMAN, M. 2003. Writing with voice: an investigation of the use of a voice recognition system as a writing aid for a man with aphasia. International Journal of Language & Communication Disorders, 38, 131-148.	2003	case study	high tech device, words, symbols	short-term use for intervention	other-aphasia	1	5	Background-other AAC population
BUNYAN, D. Odyssey of a Consumer : His personal experience with communication loss and his search for appropriate technology. Communication Outlook, 17, NUMBER 3, 34-38.	1997	phenomenological	high tech device, words, symbols, low tech communication board, picture symbol	pre-existing user	other-speech or communication disorder	2	5	Background-other AAC population
COCKS, N., DIPPER, L., MIDDLETON, R. & MORGAN, G. 2011. What can iconic gestures tell us about the language system? A case of conduction aphasia. International Journal of Language & Communication Disorders, 46, 423-436.	2011	experimental	gesture	other	other-aphasia	1	5	Background-other AAC population

COWDELL, F. 2008. Engaging older people with dementia in research: myth or possibility. International Journal of Older People Nursing, 3, 29-34.	2008	review	not spec	one off/short term use for research	PWD	3	3	Background-Methodology
CRYSTAL, D. 1986. ISAAC in chains: The future of communication systems. Augmentative and Alternative Communication, 2, 140-145.	1986	editorial	other	other	not specified	3	2	Background-theoretical
DALEMANS, R., DE WITTE, L., BEURSKENS, A., VAN DEN HEUVEL, W. & WADE, D. 2010. Social participation of people with aphasia and related factors International Journal of Language and Communication Disorders :, 45, 537-50.	2010	phenomenological	interview, life story or narrative story tell	short-term use for intervention	other-aphasia	2	5	Background-other AAC population
DALEMANS, R., WADE, D. T., VAN DEN HEUVEL, W. J. & DE WITTE, L. P. 2009. Facilitating the participation of people with aphasia in research: a description of strategies. Clinical Rehabilitation, 23, 948-959.	2009	evaluation	gesture, low tech communication board, picture symbol, low tech photo object elicit	one off/short term use for research	other-aphasia	1	7	Background-other AAC population
DUCHAN, J. F. & LEAHY, M. M. 2008. Hearing the voices of people with communication disabilities. International Journal of	2008	editorial	not spec	pre-existing user	other-speech or communication disorder	3	5	Background-methodology

Language & Communication Disorders, 43, 1-4.								
ESPINEL, C. H. 1996. De Kooning's late colours and forms: Dementia, creativity, and the healing power of art. Lancet, 347, 1096-1098.	2009	[phenomenological]	arts based	short-term use for intervention	PWD	3	3	Background-theoretical
FAZIO, S. & MITCHELL, D. B. 2009. Persistence of self in individuals with Alzheimer's disease. Dementia, 8, 39-59.	2009	phenomenological	low tech photo object elicit	short-term use for intervention	PWD	-	3	Background-inconsistent with conceptual f/w
FISHMAN, S., TIMLER, G. & YODER, D. 1985. Strategies for the prevention and repair of communication breakdown in interactions with communication board users. Augmentative and Alternative Communication, 1, 38-51.	1985	phenomenological	low tech communication board, picture symbol	pre-existing user	other	3	2	Background-other AAC population
FRIED-OKEN, M. & KING, J. 2001. Research to Practice: An Exciting Time in Augmentative and Alternative Communication. Augmentative and Alternative Communication, 17, 137-137.	2001	editorial	not spec	long term use for intervention	other-speech or communication disorder	3	2	Background-theoretical

FULLER, D. & STRATTON, M. 1991. Representativeness versus translucency: different theoretical backgrounds, but are they really different concepts? a position paper. <i>Augmentative and Alternative Communication</i> , 7, 51-58.	1991	[experimental]	low tech communication board, picture symbol	pre-existing user	other	3	2	Background-theoretical
HANSON, E., MAGNUSSON, L., ARVIDSSON, H., CLAEISSON, A., KEADY, J. & NOLAN, M. 2007. Working together with persons with early stage dementia and their family members to design a user-friendly technology-based support service. <i>Dementia</i> , 6, 411-434.	2007	participatory	other	short-term use for intervention	PWD	2	3	Included
HIGGINBOTHAM, D. J. 2007. Special issue: State of the science in AAC. <i>Augmentative and Alternative Communication</i> , 23, 271-272.	2007	editorial	not spec	pre-existing user	not specified	3	2	Background-theoretical
HIGGINBOTHAM, D. J. & WILKINS, D. P. 1999. Slipping through the timestream: Social issues of time and timing in augmented interactions. In: IN D. KORVASKY, J. D. A. M. M. E. (ed.) <i>Constructing (in) competence: Disabling evaluations in</i>	2007	theoretical review	not spec	pre-existing user	not specified	3	3	Background-methodology

clinical and social interaction. Mahwah, NJ, USA:: Lawrence Erlbaum.								
HO, K. M., WEISS, S. J., GARRETT, K. L. & LLOYD, L. L. 2005. The Effect of Remnant and Pictographic Books on the Communicative Interaction of Individuals with Global Aphasia. Augmentative and Alternative Communication, 21, 218-232.	2005	intervention	low tech photo object elicit	short-term use for intervention	other-aphasia	1	2	Background-other AAC population
HUER, M. B. & LLOYD, L. 1990. AAC users' perspectives on augmentative and alternative communication. Augmentative and Alternative Communication, 6, 242-249.	1990	survey	not spec	pre-existing user	not specified	3	2	Background-other AAC population
KIKHIA, B., HALLBERG, J., BENGTTSSON, J. E., SAVENSTEDT, S. & SYNNEK, K. 2010. Building digital life stories for memory support. International Journal of Computers in Healthcare, vol.1, no.2, 161-76.	2010	intervention	high tech device, words, symbols	short-term use for intervention	other-neurological disorder	2	3	Background-other AAC population

KINNEY, J. M. & RENTZ, C. A. 2005. Observed well-being among individuals with dementia: Memories in the Making, an art program, versus other structured activity. Am J Alzheimers Dis Other Demen, 20, 220-227.	2005	evaluation	arts based, gesture	short-term use for intervention	PWD	2	3	Included
KONTOS, P. C. & NAGLIE, G. 2006. Expressions of personhood in Alzheimer's: moving from ethnographic text to performing ethnography. Qualitative Research, 6, 301-317.	2006	participatory	arts based	short-term use for intervention	PWD	-	6	Background-inconsistent with conceptual f/w
LANGDON, P., PERSAD, U. & JOHN CLARKSON, P. 2010. Developing a model of cognitive interaction for analytical inclusive design evaluation. Interacting with Computers, 22, 510-529.	2010	review	high tech device, words, symbols	long term use for intervention	other-neurological disorder	3	5	Background-other AAC population
LEV-WIESEL, R. & HIRSHENZON-SEGEV, E. 2003. Alzheimer's disease as reflected in self-figure drawings of diagnosed patients. Arts in Psychotherapy, 30, 83-89.	2003	intervention	arts based	short-term use for intervention	PWD	-	4	Background-inconsistent with conceptual f/w
LIGHT, J. 1989. Toward a definition of communicative competence for individuals using augmentative and alternative communication systems.	1989	review	other	pre-existing user	not specified	3	2	Background-theoretical

Augmentative and Alternative Communication, 5, 137-144.								
LLOYD, L., QUIST, R. & WINDSOR, J. 1990. A proposed augmentative and alternative communication model. Augmentative and Alternative Communication, 6, 172-183.	1990	theoretical review	not spec	other	not specified	3	2	Background-theoretical
LONCKE, F. 2001. Augmentative and Alternative Communication in the 21st Century. Augmentative and Alternative Communication, 17, 61-61.	2006	theoretical review	gesture	short-term use for intervention	not specified	2	2	Background-theoretical
LONCKE, F. T., CAMPBELL, J., ENGLAND, A. M. & HALEY, T. 2006. Multimodality: a basis for augmentative and alternative communication—psycholinguistic, cognitive, and clinical/educational aspects. Disability and Rehabilitation, 28, 169-174.	2001	editorial	not spec	other	not specified	3	7	Background-methodology
MCCALL, F., MARKOVÁ, I., MURPHY, J., MOODIE, E. & COLLINS, S. 1997. Perspectives on AAC systems by the users and by their communication partners. International Journal of Language &	1997	review	high tech device, words, symbols, low tech communication board, picture symbol	pre-existing user	not specified	3	5	Background methodology

Communication Disorders, 32, 235-256.								
MCKEOWN, J., CLARKE, A., INGLETON, C. & REPPER, J. 2010a. Actively involving people with dementia in qualitative research. Journal of Clinical Nursing, 19, 1935-1943.	2010	review	life story or narrative story tell	one off/short term use for research	PWD	1	3	Background-methodology
MCKEOWN, J., CLARKE, A., INGLETON, C., RYAN, T. & REPPER, J. 2010b. The use of life story work with people with dementia to enhance person-centred care. International Journal of Older People Nursing, 5, 148-158.	2010	case study	interview, life story or narrative story tell	one off/short term use for research	PWD	2	3	Included
MEZA-KUBO, V., MORA'N, A. L. & RODRI'GUEZ, M. D. 2009. Intergenerational Communication Systems in Support for Elder Adults with Cognitive Decline. 3rd International Conference on Pervasive Computing Technologies for Healthcare.	2009	case study	gesture	short-term use for intervention	other-neurological disorder	-	5	Background-inconsistent with conceptual f/w
MILLAR, D. C., LIGHT, J. C. & SCHLOSSER, R. W. 2006. The impact of augmentative and alternative communication	2006	review	multiple	pre-existing user	other-developmental disability	1	3	Background-theoretical

intervention on the speech production of individuals with developmental disabilities: a research review. Journal of Speech, Language, and Hearing Research, 49, 248.								
MIRENDA, P. & MATHY-LAIKKO, P. 1989. Augmentative and alternative communication applications for persons with severe congenital communication disorders: an introduction. Augmentative and Alternative Communication, 5, 3-13.	1989	review	multiple	long term use for intervention	other-speech or communication disorder	3	2	Background-theoretical
MOORE, T. F. & HOLLETT, J. 2003. Giving Voice to Persons Living With Dementia: The Researcher's Opportunities and Challenges. Nursing Science Quarterly, 16, 163-167.	2003	review	not spec	one off/short term use for research	PWD	3	3	Background-theoretical
MULLER, N. & GUENDOUZI, J. A. 2009. Discourses of dementia: A call for an ethnographic, action research approach to care in linguistically and culturally diverse environments. Semin Speech Lang, 30, 198-206.	2009	participatory	other	short-term use for intervention	PWD	2	5	Included
MURPHY, J., GRAY, C. M. & COX, S. 2007. The use of Talking Mats to improve communication and	2007	evaluation	low tech communication board, picture symbol	short-term use for intervention	PWD	3	6	Included

quality of care for people with dementia. Housing, Care & Support, 10, 21-27								
MURPHY, J., MARKOVÁ, I., COLLINS, S. & MOODIE, E. 1996. AAC systems*: obstacles to effective use. International Journal of Language & Communication Disorders, 31, 31-44..	1996	review	high tech device, words, symbols, low tech communication board, picture symbol	long term use for intervention	not specified	1	5	Background-Other AAC population
MURPHY, J., GRAY, C. M. & COX, S. 2011. Communication and dementia. Joseph Rowntree Foundation.	2011	phenomenological	low tech communication board, picture symbol	short-term use for intervention	PWD	3	6	Background-not a journal
MURPHY, J., OLIVER, T. M. & COX, S. 2010. Talking Mats® and involvement in decision making for people with dementia and family carers. Final Report to Joseph Rowntree Foundation University of Stirling.	2010	phenomenological	low tech communication board, picture symbol	long term use for intervention	PWD	2	6	Background-not a journal
MURPHY, J., TESTER, S., HUBBARD, G., DOWNS, M. & MACDONALD, C. 2005. Enabling frail older people with a communication difficulty to express their views: the use of Talking Mats™ as an interview tool. Health & Social Care in the Community, 13,	2005	phenomenological	low tech communication board, picture symbol	one off/short term use for research	multiple populations	3	3	Background-other AAC population

95-107								
MURPHY, J., GRAY, C. M., VAN ACHTERBERG, T., WYKE, S. & COX, S. 2010. The effectiveness of the Talking Mats framework in helping people with dementia to express their views on well-being. <i>Dementia</i> , 9, 454-472.	2010	evaluation	low tech communication board, picture symbol	one off/short term use for research	PWD	2	3	Included
NEWELL, A. F. & ALM, N. 1994. Developing AAC technologies: a personal story and philosophy*. <i>International Journal of Language & Communication Disorders</i> , 29, 399-411.	1994	theoretical review	high tech device, words, symbols	short-term use for intervention	not specified	3	5	Background-theoretical
NIND, M. 2008. Conducting qualitative research with people with learning, communication and other disabilities: . Methodological challenges. ESRC National Centre for Research Methods Review Paper.: NCRM	2008	theoretical review	not spec	one off/short term use for research	other-developmental disability	3	6	Background-other AAC population
NOLAN, M., RYAN, T., ENDERBY, P. & REID, D. 2002. Towards a more inclusive vision of dementia care practice and research.	2002	theoretical review	not spec	long term use for intervention	PWD	3	3	Background-theoretical

Dementia, 1, 193-211.								
NYGÅRD, L. 2006. How can we get access to the experiences of people with dementia? Scandinavian Journal of Occupational Therapy, 13, 101-112.	2006	review	gesture	one off/short term use for research	PWD	3	3	Background-methodological
PENNINGTON, L., MARSHALL, J. & GOLDBART, J. 2007. Describing participants in AAC research and their communicative environments: Guidelines for research and practice. Disability and Rehabilitation, 29, 521-535.	2007	systematic review	not spec	pre-existing user	not specified	3	7	Background-systematic review
POLITANO, P. A. 2007. Understanding factors contributing to interactions of people who use augmentative communication methods. UNIVERSITY OF ILLINOIS AT CHICAGO, HEALTH SCIENCES CENTER.	2007	[phenomenological]	gesture, high tech device, words, symbols, low tech communication board, picture symbol, low tech photo object elicit	pre-existing user	not specified	3	2	Background methodological
RENTZ, C. A. 2002. Memories in the making: outcome-based evaluation of an art program for individuals with dementing illnesses. Am J Alzheimers Dis Other Demen, 17, 175-181.	2002	evaluation	arts based	long term use for intervention	PWD	-	3	Background-inconsistent with conceptual f/w/

SAFAR, L. T. & PRESS, D. Z. 2011. Art and the Brain: Effects of Dementia on Art Production in Art Therapy. Art Therapy: Journal of the American Art Therapy Association, 28, 96-103.	2011	case study	arts based	short-term use for intervention	PWD	2	7	Background-theoretical
SCHLOSSER, R. W., WENDT, O., ANGERMEIER, K. L. & SHETTY, M. 2004. Searching for evidence in augmentative and alternative communication: Navigating a scattered literature. Augmentative and Alternative Communication, 21, 233-255.	2004	review	not spec	other	not specified	3	2	Background-methodological
SCHLOSSER, R. W. & RAGHAVENDRA, P. 2004. Evidence-Based Practice in Augmentative and Alternative Communication. Augmentative and Alternative Communication, 20, 1-21.	2004	review	not spec	long term use for intervention	multiple populations	3	2	Background-theoretical
SHEPHERD, T. A., CAMPBELL, K. A., RENZONI, A. M. & SLOAN, N. 2009. Reliability of Speech Generating Devices: A 5-Year Review. Augmentative and Alternative Communication, 25, 145-153.	2009	[experimental]	high tech device, words, symbols	one off/short term use for research	multiple populations	1	2	Background theoretical

SILVERMAN, F. H. and SCHUYLER 1994. Can AAC Help Persons with Dementia? Augmentative and Alternative Communication, 10, NUMB 1, 60.	1994	review	not spec	long term use for intervention	PWD	3	2	Background-theoretical
SIXSMITH, A. & GIBSON, G. 2007. Music and the wellbeing of people with dementia. Ageing & Society, 27, 127-145.	2007	intervention	music	long term use for intervention	PWD	2	1	Included
SMITH, M. M. & MURRAY, J. 2011. Parachute Without a Ripcord: The Skydive of Communication Interaction. Augmentative and Alternative Communication, 27, 292-303.	2011	review	high tech device, words, symbols	pre-existing user	not specified	3	2	Background-theoretical
STAFSTROM, C. E. 2005. Using artwork to better understand patients with neurologic disorders. Epilepsy and Behavior, 6, 113-114.	2005	phenomenological	arts based	short-term use for intervention	other-neurological disorder	2	4	Background-other AAC population
STENHOUSE, R., TAIT, J., HARDY, P. & SUMNER, T. 2012. Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early-stage dementia. Journal of Psychiatric and Mental Health Nursing.	2012	[case study]	life story or narrative story tell, low tech photo object elicit	one off/short term use for research	PWD	3	3	Background-theoretical
STUART, S. 2000. Understanding the storytelling of older adults for AAC system design.	2000	phenomenological	life story or narrative story tell	other	other	3	2	Background-other AAC population

Augmentative and Alternative Communication, 16, 1-12.								
SUTTON, A. 2010. Staying on the Cutting Edge. Augmentative and Alternative Communication, 26, 223-225.	2010	editorial	not spec	pre-existing user	not specified	1	2	Background-theoretical
TRUDEAU, N., SUTTON, A., MORFORD, J. P., CÔTÉ-GIROUX, P., PAUZÉ, A.-M. & VALLÉE, V. 2010. Strategies in Construction and Interpretation of Graphic-Symbol Sequences by Individuals who use AAC Systems. Augmentative and Alternative Communication, 26, 299-312.	2010	evaluation	low tech communication board, picture symbol	short-term use for intervention	not specified	1	2	Background-other AAC population
WALLER, A. & NEWELL, A. F. 1997. Towards a narrative-based augmentative communication system. International Journal of Language & Communication Disorders, 32, 289-306.	1997	theoretical review	high tech device, words, symbols, low tech communication board, picture symbol	pre-existing user	other-aphasia	3	5	Background-theoretical
WEEKES, B. 2000. Oral reading in Chinese: evidence from dementia of the Alzheimer's type. International Journal of Language & Communication Disorders, 35, 543-559.	2000	experimental	written	short-term use for intervention	PWD	-	5	Background-inconsistent with the conceptual f/w

WIERSMA, E. C. 2011. Using Photovoice with people with early-stage Alzheimer's disease: A discussion of methodology. <i>Dementia</i> , 10, 203-216.	2011	[phenomenological]	low tech photo object elicit	one off/short term use for research	PWD	3	3	Background-methodological
XUEFEI, Z., DONGJIE, W. & SHENGLI, L. Preliminary exploration on augmentative and alternative communication for Chinese adults with speech-language disorder. 2010. Singapore Therapeutic, Assistive & Rehabilitative Technologies (START) Centre, 4.	2010	review	gesture, high tech device, words, symbols, low tech communication board, picture symbol, low tech photo object elicit	long term use for intervention	other-speech or communication disorder	3	7	Background-other AAC population
ZANGARI, C., LLOYD, L. & VICKER, B. 1994. Augmentative and alternative communication: An historic perspective. <i>Augmentative and Alternative Communication</i> , 10, 27-59.	1994	review	not spec	pre-existing user	not specified	2	2	Background-theoretical

Appendix item 7: List of included references per cluster Meta Study

P- Pearl; S- Sibling; KA- Kinship Antecedent; KCC- Kinship Contemporaneous Context;
KT-Kinship Theory

Cluster 1: ICF

Murphy, J. and Boa, S. (2012). Using the WHO-ICF with Talking Mats™ to enable adults with long-term communication difficulties to participate in goal setting. <i>AAC: Augmentative and Alternative Communication</i> . 28(1), 52-60. P
Murphy, J. and Strachan Y. (2011). <i>Talking Mats™: Extending the reach into goal-setting practices for Health and Social Care Staff in Edinburgh. Final Report</i> . Stirling, Scotland: Talking Mats Centre. KA
Boa S. and MacFayden L. (2003). <i>Goal-setting for people with communication difficulties. Pilot study Funded by Forth Valley Primary Care NHS Trust. Final Report</i> . Stirling, Scotland: Talking Mats Centre. KCC
Harty M., Griesel, M. and Van Der Merwe, A. (2011). The ICF as a common language for rehabilitation Goal-setting: comparing client and professional priorities. <i>Health and Quality of life outcomes</i> . 9, 87. KCC
Battaglia, M., Russo, E., Bolla. A., Chiusso, A., Bertelli, S., Pellegri, A., Borri, G. and Martinuzzi, A. (2004). International Classification of functioning, Disability and Health in a cohort of children with cognitive, motor and complex disabilities. <i>Developmental Medicine & Child Neurology</i> . 46, 98-106. KT
Bauer, S., Elsaesser, L. J., and Arthanat, S. (2011). Assistive Technology device classification based upon the World Health Organisation's, International Classification of Functioning, Disability and Health (ICF). <i>Disability and Rehabilitation: Assistive Technology</i> . 6(3), 243-259. KT
Bornman J. and Murphy J. (2006). Using the ICF in Goal-setting: Clinical application sign Talking Mats. <i>Disability And Rehabilitation</i> . 1(3), 145-154. KT
Fried-Oken, M. and Granlund, M.(2012). AAC and ICF: A good fit to emphasize outcomes. <i>AAC: Augmentative and Alternative Communication</i> . 28(1), 1-2. KT
Griffiths, T. and Price, K. (2011). A proposed framework for decision-making for assistive communication technology support: Many perspectives, but one common goal. <i>Journal of Assistive Technologies</i> . 5(4), 242-248. KT
Jelsma, J. (2009). The use of the International Classification of Functioning, Disability and Health: a Literature Survey. <i>Journal of Rehabilitation and Medicine</i> . 41, 1-2. KT
Jette, A.M. (2006). Towards a common language for Function, <i>Disability and Health</i> . <i>Physical Therapy</i> . 86, 726-734. KT
McLeod, s. and Bleile, K. (2004). Speech pathologists' application of the ICF to children with speech impairment. <i>Advances in Speech-Language Pathology</i> . 6(1), 75-81. KT
Mulhorne, K., Threats, T. (2008). Speech, hearing and communication across five national disability surveys: Results of a DISTAB study using the ICF to compare prevalence patterns. <i>International journal of speech</i>

<i>and language pathology. 10 (1-2) 61-71. KT</i>
O'Halloran, R., Hickson, L., and Worrall, L. (2008). Environmental factors that influence communication between people with communication disability and their healthcare providers in hospital: A review. <i>International Journal of Language and Communication Disorders. 43(6), 601-632. KT</i>
Pennington, L., Marshall, J. and Goldbart, J. (2007). Describing participants in AAC research and their communicative environments: Guidelines for research and practice. <i>Disability and Rehabilitation. 29(7), 521-535. KT</i>
Pless, M., and Grandlund, M. (2012). Implementation of the International Classification of functioning, Disability and Health (ICF) and the ICF children and Youth version (ICF-CY) within the context of Augmentative and Alternative Communication. <i>Augmentative and Alternative Communication. 28(1), 11-20. KT</i>
Raghavendra, P., Bornman, J., Grandlund, M. and Björck-Åkesson, E. (2007). The World Health Organization's International Classification of Functioning, Disability and Health: Implications for clinical and research practice in the field of augmentative and alternative communication. <i>AAC: Augmentative and Alternative Communication. 23(4), 349-361. KT</i>
Rowland, C., Fried-Oken, M., Steiner S. A. M., Lollar, D., Phelps, R., Simeonsson, R. J. and Grandlund, M. (2012). Developing the ICF-CY for AAC profile and code set for children who rely on AAC. <i>AAC: Augmentative and Alternative Communication. 28(1), 21-32. KT</i>
Simeonsson, R.J., Bjorck-Akesson, E. and Lollar, D. (2012). Communication Disability and the ICF-CY. <i>Augmentative and Alternative Communication. 28(1) 3-10. KT</i>
Sykes, C. (2008). The International Classification of Functioning, Disability and Health: Relevance and applicability to physiotherapy. <i>Advances in Physiotherapy. 10, 110-118. KT</i>
Threats, T. (2007). Access for persons with neurogenic communication disorders: influences of Personal and Environmental factors of the ICF. <i>Aphasiology 21(1), 67-80. KT</i>
Üstün T.B., Chatterji S., Bickenbach J., Kostanjsek N. and Schneider M (2003). The International Classification of Functioning, Disability and Health: a new tool for understanding disability and health. <i>Disability and Rehabilitation. 25(11-12), 565-571.KT</i>

Cluster 2: Culturally Valid Lexicon Methodology

Nigam, R. (2006). Sociocultural development and validation of lexicon for Asian-Indian individuals who use augmentative and alternative communication. <i>Disability And Rehabilitation: Assistive Technology</i> . 1(4): 245-256. P
Huer, M. B. (2000). Examining perspectives of graphic symbols across cultures: Preliminary study of the impact of culture/ethnicity. <i>Augmentative and Alternative Communication</i> . 16(3), 180-185. KA
Beukelman, D. R., McGinnis, J. and Morrow, D. (1991) Vocabulary selection in augmentative and alternative communication. <i>AAC: Augmentative and Alternative Communication</i> . 7(3), 171-185. KT
Blackstone, S., (1993) Augmentative Communication News. Augmentative Communication incorporated. 6 (2). KT
Taylor, O., L. <i>Historical perspectives and conceptual framework</i> . In: Taylor, O., L. Editor (1986) <i>Nature of Communication Disorders in culturally and linguistically diverse populations</i> . (pp.1-18). College Hill Press: San Diego. KT
Hetzroni, O.E., and Harris, O.L., (1996) Cultural aspects in the development of AAC users. <i>Augmentative and alternative communication</i> . 12(1), 52-58. KT
Huer, M. B. (1997). Culturally Inclusive Assessments for children using augmentative and alternative communication (AAC). <i>Children's Communication Disorders</i> . 19(1), 23-34. KT

Cluster 3: The Communication Matrix

<p>Rowland, C. (2011). Using the Communication Matrix to assess expressive skills in early communicators. <i>Communication disorders quarterly</i>. 32 (3), 190-201. P</p>
<p>Rowland, C. and Fried-Oken, M. (2010). Communication Matrix: A clinical and research tool for children with severe communication disorders. <i>Journal of Paediatric Rehabilitation & Medicine</i>. 3, 319-329 KA</p>
<p>Rowland, C. and Schweigert, P. (2005a). <i>Learning to Learn: A systematic and child-centred model skill development in young children who are deafblind. Final Report. Oregon Institute on Disability and Development, Oregon Health and Science University. Retrieved from: http://www.ohsu.edu/oidd/d21/doc/121_final_rep.pdf</i> KA</p>
<p>Rowland, C. and Schweigert, P. (2005b). <i>Establishing the foundations for self-determination in young children with low-incidence disabilities. Oregon Institute on Disability and Development, Oregon Health and Science University. Retrieved from: http://www.ohsu.edu/oidd/d21/found%20final1%20report11-25-08%20CR%20editsx.pdf</i> KA</p>
<p>Beukelman, D. R. and Mirenda, P. (2005). <i>Augmentative and Alternative Communication: Supporting children and adults with Complex communication needs</i>. Paul H Brookes: Maryland. KT</p>
<p>Light, J. (1988). Interaction involving individuals using Augmentative and Alternative Communication systems: state of the art and future directions. <i>Augmentative and Alternative Communication</i>. 4 (2): 66-82. KT</p>
<p>Rowland, C. (2012). <i>Communication Matrix: Description, Research Basis and Data</i>. (Unpublished manuscript). Retrieved from: www.communicationmatrix.org KT</p>
<p>Rowland, C., and Schweigert, P. (2000). Tangible symbols, tangible outcomes. <i>Augmentative and Alternative Communication</i>. 16, 61–78. KT</p>
<p>Rowland, C. and Schweigert, P. (2009). Object lessons: How children with autism spectrum disorders use objects to interact with physical and social environments. <i>Research in Autism spectrum disorders</i>. 3, 517-527.</p>

Cluster 4: Narrative Assessment Profile

<p>Soto, G., Hartman, E. and Wilkins, D.P. (2006). Exploring elements of narrative that emerge in the interactions between an 8 year old child who uses AAC and her teacher. <i>Augmentative and Alternative Communication</i>. 22(4). 231-241. P</p>
<p>Liborion, N. and Soto G. (2006). Shared storybook reading with a student who uses alternative and augmentative communication: A description of scaffolding practices. <i>Child Language and Teaching Therapy</i>. 22(1) 69-95. S</p>
<p>Soto, G. and Hartmann, E. (2006). Analysis of narratives produced by four children who use augmentative and alternative communication. <i>Journal of Communication Disorders</i>. 39, 456-480. S</p>
<p>Chang, C. J. (2006). Linking early narrative skill to later language and reading ability in Mandarin-speaking children: A longitudinal study over eight years. <i>Narrative Inquiry</i>, 16(2), 275-293. KCC</p>
<p>Bliss, L., McCabe, A. and Miranda, A.E. (1998). Narrative Assessment Profile: Discourse Analysis for school-age children. <i>Journal of Communication Disorders</i>. 31:,347-363.KT</p>
<p>McCabe, A. and Bliss, A. (2003). <i>Patterns of Narrative Discourse: A multicultural, Lifespan approach</i>. Pearson Education: Boston. KT</p>
<p>Solomon-Rice, P. and Soto, G. (2011). Co-construction as a facilitative factor in supporting the personal narratives of children who use Augmentative and Alternative Communication. <i>Communication Disorders Quarterly</i>. 32(2)70-82. KT</p>
<p>Bruner, J. (1985) <i>Vygotsky: A historical and conceptual perspective</i>. In Wertsch, J. (Ed) <i>Culture, communication and cognition: Vygotskian perspectives (pp.21-34)</i>. Cambridge: Cambridge University Press. KT</p>
<p>Bliss, L. S. and McCabe, A. (2008). Personal narratives: Cultural differences and clinical implications. <i>Topics in Language Disorders</i>. 28(2), 162-177.KT</p>
<p>Ochs, E. <i>Cultural dimensions of language acquisition</i>. In Ochs, E. and Schieffelin, B. (1983). <i>Acquiring Conversational Competence (pp.185-191)</i>. London: Routledge and Kegan Paul. KT</p>
<p>Collins, S. and Markova, I. (1999). Interaction between impaired and unimpaired speakers: inter-subjectivity and the interplay of culturally shared and situation-specific knowledge. <i>British Journal of Social Psychology</i>. 38, 339-368.KT</p>
<p>Ochs, E. and Capps, L. (2001). <i>Living Narrative: Creating lives in everyday storytelling</i>. London: Harvard University Press. KT</p>

Appendix item 8: Table to summarise the main themes emerging from the Meta Study (Meta Method and Meta Analysis) for the ICF

Papers – ICF Cluster	How have the methodological characteristics influenced research findings?	Analytical strategy & categories of data	What do the findings add to the context or concepts surrounding the framework?
<p><u>Murphy & Boa 2012 (pearl)</u></p> <p>Type of impairment/condition: People with communication difficulties and long-term conditions</p> <p>Type of study: Intervention study- case examples</p> <p>Research question: Description of Talking Mats™ framework in conjunction with the WHO ICF.</p> <p>Major findings: The Talking Mats™ framework can empower people with communication difficulties and long term conditions to become active participants in the rehabilitation process by identifying their own goals, indicating changing priorities and tracking their progress</p> <p>Theoretical Framework: The ICF as a holistic view of rehabilitation</p> <p>Sample:4</p> <p>Data collection: Talking Mats™ symbols were rated; this was compared to normal practice where Talking Mats were not used. Symbols were placed under a scale of ‘managing’/’not managing’</p>	<ul style="list-style-type: none"> • Managing/not managing dichotomy may simplify findings • Specific focus on Activity and Participation components • Talking Mats™ methodology allowed people more control- proxy respondent view was diminished 	<ul style="list-style-type: none"> • Coding according to management of activity or participation • The ICF categories (components and domains) and Talking Mats™ helps people to set their own goals • ICF domains are ‘translated’ into a Talking Mats format 	<ul style="list-style-type: none"> • The Talking Mats™ method as a way of goal-setting (using ICF components/ domains) provides a participative interactional environment • Authors are aware of Talking Mats™ limitations- it does not claim to be a ‘panacea’ for all cognitive impairments • The study shows how professionals can misinterpret service users’ views

<p>Conclusions: Talking Mats™ facilitates engagement because the professional and user are engaged in a joint task. The ICF framework gives a structure for thinking about the person as a whole. This encourages professionals to work in a person-centred way. An adapted version of the ICF in Talking Mats helps bridge the gap between theory and practice.</p>			
<p>Boa and McFayden 2003 (kinship contemporaneous context)</p> <p>Type of impairment/condition: People with communication difficulties</p> <p>Type of study: Intervention study</p> <p>Research question: Does the use of Talking Mats™ help people to become more involved in goal-setting and can it allow us to track a period of rehabilitation?</p> <p>Major findings: Project workers observations: some participants could be more precise about areas of concern through talking Mats; participant’s found Talking Mats™ helpful; Questionnaire indicated participants found Talking Mats™ non-threatening and enjoyable; case study revealed: community rehabilitation was more explainable visually, ability to raise issues that form from goals, problem solving thorough Talking Mats™ possible, some barriers existed (including expectations) and goals are not static</p> <p>Theoretical Framework: Goal-setting and Talking Mats™</p>	<ul style="list-style-type: none"> • Talking Mats interviews and case study allowed for a rich analysis of themes • Picture of personalised goals can be created through translated ICF domains • Topics can be drilled down into once the topic is introduced through Talking Mats™ • However, the questionnaire shows how difficult it is to evaluate the use of Talking Mats™(question asked ‘how easy was Talking Mats™ to use?’) • Possible to see changes over time 	<ul style="list-style-type: none"> • The ICF includes domains of activity and participation and divides them into 4 levels of detail 	<ul style="list-style-type: none"> • Specificity and choice in symbol selection • Range of topics advantageous • Active involvement (in determining involvement) • Concept-environment affects choices

<p>Sample: 12 newly referred patients (with 5 follow ups)</p> <p>Data collection: Semi-structured interviews, observation, questionnaires, includes a case study</p> <p>Conclusions: Talking Mats is a useful way of involving people in goal-setting</p>			
<p>Harty et al 2011 (Kinship Contemporaneous context)</p> <p>Type of impairment/condition: Range of acquired communication disorders</p> <p>Type of study: Comparative study</p> <p>Research question: Perception of importance of ICF's activities and participation domains for inclusion in rehabilitation programme</p> <p>Major findings: The ICF domains which consistently appear as very important across groups are mobility, self-care and communication, but there are differences between staff and service user perspectives</p> <p>Theoretical Framework: The ICF as a common language</p> <p>Sample: 12 service users 20 professionals</p> <p>Data collection: Rating measures using Talking Mats™ as a visual Framework</p> <p>Conclusions: Consensus is possible, Talking Mats™ is a viable framework</p>	<ul style="list-style-type: none"> • Comparison of groups underlines differences of perception of components and domains within ICF • Methodology identified similarities and differences in the perceptions • Rating system limited in understanding reasoning 	<ul style="list-style-type: none"> • Activity and Participation components • Value of components • Visual and receptive language skill of service users taken into account • Video analysis of session 	<ul style="list-style-type: none"> • Concept of attaching value or meaning to the component through rating

<p>Murphy & Strachan 2011 (kinship antecedent)</p> <p>Type of impairment/condition: Long term conditions</p> <p>Type of study: Evaluation report</p> <p>Research question: Evaluation approach involved elicitation of participant's opinions of Talking Mats™ training programmes and evaluation of staff and service user experience of goal-setting using Talking Mats™ (using involvement measure)</p> <p>Major findings: Talking Mats can be embedded in practice as a tool to help support self-management</p> <p>Theoretical Framework: The ICF and goal setting using Talking Mats™</p> <p>Sample: 19 staff, 25 service users (6 service users also took part in 25 sessions to determine Service User Involvement scores)</p> <p>Data collection: Talking Mats™ training, Focus groups, Goal-setting workshop, verbal comments, written comments, evaluation forms, staff evaluation quantitative- Service User Involvement measure</p> <p>Conclusions: Goal-setting should be further embedded as a core competency for staff in day centre settings.</p>	<ul style="list-style-type: none"> • Service user involvement measures quantify an experiential phenomena • Evaluation over time assists levels of reflection and familiarity with communication framework and communication system • Study highlights the crucial role of staff in eliciting the viewpoints of service users and interpreting the framework 	<ul style="list-style-type: none"> • Analysis of involvement measure scores included: importance of topic, understanding of topic, extent service user could express, how respected they felt,, involvement in conversation their views • Practitioner level findings and organisational level findings 	<ul style="list-style-type: none"> • Role, training and knowledge of staff vital in co-production (and co-construction of meaning) • Genuine involvement in goal-setting recognised as a critical aspect of service user involvement • Co-production also commented on as a key concept
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Appendix items 9: Tables to summarise the main themes emerging from the Meta Study (Meta Method, Meta Analysis) for the CVL

Papers – Culturally Valid Lexicon Cluster	How have the methodological characteristics influenced research findings?	Analytical strategy & categories of data	What do the findings add to the context or concepts surrounding the framework?
<p>Nigam 2006 (pearl)</p> <p>Type of impairment/condition: None</p> <p>Type of study: Intervention-development of a methodology</p> <p>Research question: i) what are the lexical items that are important for individuals from the Asian Indian culture?</p> <p>ii) Are these lexical items represented in the PCS set?</p> <p>iii) How many PCS lexical items are culturally appropriate for AAC users from the Asian Indian culture?</p> <p>Major findings:</p> <p>Theoretical Framework: Taylor and Clarke’s culturally-based conceptual framework (1994)</p> <p>Sample: 120 people selected from 5 Indian cities representing different familial and professional groups and rural and urban populations</p> <p>Data collection: Participants rate lexicon</p>	<ul style="list-style-type: none"> • Professional perspective • Large scale study with methodology focus on validation framework through quantitative analysis • In-depth recruitment procedure and demographic information gathering process to make findings as representative to that culture as possible 	<ul style="list-style-type: none"> • Process: Participants nominate words without categories, in categories and rate symbols • Words analysed using a software programme • Composite lists of words without meaning and absent words • Comparison , between categorical and non-categorical word nominations • Participants recruited to build a representative sample across Asian-Indian culture 	<ul style="list-style-type: none"> • Cultural framework origins • Reappraisal of universal meaning attached to AAC system symbols and words • Further levels of complexity attached to the finding that the needs of sub-cultures

<p>items, nominate words for lexicon lists that have meaning in their culture</p> <p>Conclusions: Whilst lexicon from symbol sets had overlapping meanings across cultures, the lexicons may not be an appropriate source for selecting lexicon for an AAC user from culturally and linguistically diverse culture.</p>			
<p>Huer 2000 (kinship antecedent)</p> <p>Type of impairment/condition: None</p> <p>Type of study: Experimental design</p> <p>Research question: Examination of the perception of graphic symbols across groups</p> <p>Major findings: People from different cultures perceive graphic symbols differently</p> <p>Theoretical Framework: Iconicity and cultural diversity</p> <p>Sample: 147 participants from four different ethnic groups</p> <p>Data collection: data gathered for comparison of 3 graphic symbol sets</p> <p>Conclusions: Methodological issues relating to graphic symbol recognition are described</p>	<ul style="list-style-type: none"> • Perspective of non-AAC users • Concept of ethnicity and culture is isolated as a single variable • Self-selection of participants from different cultures • Age range 30-64 	<ul style="list-style-type: none"> • PCS, Dynasymbols, Blissymbols analysed • Reliability checks • PCS were the most translucent of the 3 AAC systems analysed 	<ul style="list-style-type: none"> • Perception of symbols is different across cultures • Methodological challenges discussed (sensitivity issues) • Translucency rating may be significant in interpreting perception of AAC systems

Appendix item 10: Table to summarise the main themes emerging from the Meta Study (Meta Method and Meta Analysis) for the CM

Paper – Communication Matrix Cluster	How have the methodological characteristics	Analytical strategy & categories of data	What do the findings add to the context or concepts
<p>Rowland 2011 (pearl)</p> <p>Type of impairment/condition: Children with little or no speech and complex communication needs</p> <p>Type of study: Case Description</p> <p>Research question: To demonstrate the assessment of the skills of children through the Communication Matrix</p> <p>Major findings: Description of 4 different profiles. Description of the widespread use of the Communication Matrix,</p> <p>Theoretical Framework: (socio-pragmatism approach) Purpose of communication (Light 1988)</p>	<ul style="list-style-type: none"> • Case examples are descriptive - not designed to be generalised • Observational tool • Assessment indicators within the matrix can be over simplified- e.g. skilled/not skilled • Assessment is predominantly about AAC use rather than participation 	<ul style="list-style-type: none"> • Communication Matrix is built on Light’s 1988 theory of the 4 motivations for communication • Matrix breaks down the concept of communication into 24 states, functions and intents and 9 categories of communication behaviour 	<ul style="list-style-type: none"> • It is not possible to conceptualise how well the AAC user understand the matrix • The administration of the matrix is intended for parents as well as parents • Motivation for Communication Theory

<p>Rowland and Fried-Oken 2010 (Kinship antecedent)</p> <p>Type of impairment/condition: Children with severe communication disorders</p> <p>Type of study: Case Description</p> <p>Research question: Use of the CM in a case example to demonstrate the sensitivity of the assessment and its application to the paediatric rehabilitation population</p> <p>Major findings: Matrix expressed a great deal of information about the skills of the participant</p> <p>Theoretical Framework: Communication motivation Light 1988</p>	<ul style="list-style-type: none"> • Limitations of a case example- less information about extraction of data than a case study design and research conditions unknown 	<ul style="list-style-type: none"> • Unknown analytical strategies beyond communication levels identified through the CM • Matrix based on 'mastered' and 'emerging' behaviours 	<ul style="list-style-type: none"> • CM can produce a bank of population-based data • AAC framework as an assessment instrument in line with scientific paradigm • Interpretation of behaviours (and their purpose or motivation) largely not addressed
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<p>Rowland and Schweigert 2005a (kinship antecedent)</p> <p>Type of impairment/condition: Deafblind children and a child with Downs Syndrome</p> <p>Type of study: Evaluation</p> <p>Research question: Objective- to develop an instructional Learn to Learn model and a method for its implementation and to field test that model</p> <p>Major findings: Skill levels and performance improved in participants</p> <p>Theoretical Framework: Instructional approach to mastery of physical and social worlds</p> <p>Sample: 7 children in different years of schools in 4 states in Portland</p> <p>Data collection: CM administered twice, 2 observational days including coded videotaped data and the administration of the Communication Matrix at the start and end of the year.</p> <p>Conclusions: Parent involvement is the key to the 'learn to learn' approach, the Learn to learn project represents an approach to creation individualised educational goals which harnesses the learner's intrinsic motivation to learn.</p>	<ul style="list-style-type: none"> • Methodological characteristics put an emphasis on educational outcomes and improvement in skills to assist learning • CM a specific part of a wider approach employed at different points 	<ul style="list-style-type: none"> • CM administered twice to monitor performance • Quantitative coding of videotaped interactions • Expressive communication coding, Object interaction code and an inventory to assess communication • Analysis of use of symbolic communication 	<ul style="list-style-type: none"> • Communication matrix can be embedded into a broader education intervention plan • The mastery of physical and social environments
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<p>Rowland and Schweigert 2005b (kinship antecedent)</p> <p>Type of impairment/condition:</p> <p>children with low-incidence disabilities</p> <p>Type of study: Evaluation</p> <p>Research question: Establishing the foundations for self-determination in - Evaluation of Foundations for learning 'Design to Learn' model</p> <p>Major findings: Skill levels and performance improved in participants</p> <p>Theoretical Framework</p> <p>:Instructional approach to mastery of physical and social worlds</p> <p>Sample: 9 children aged 3-9 years</p> <p>Data collection: CM administered 3 times Conducted across 4 classrooms in 4 states (Portland) over one year.</p> <p>Other parts of the project videotaped interactions to code them.</p>	<ul style="list-style-type: none"> • 3 different models of classroom teaching compared • Emphasis on improvement in skills 	<ul style="list-style-type: none"> • Parents and teachers administered matrix • Teachers designed material to elicit different types of behaviour to be assessed in the matrix • Baseline scores were established to monitor improvements 	<ul style="list-style-type: none"> • CM as one part of a wider model which had more interactive elements within it • reliance on observational methods • Mastery of physical and social worlds • Key role of parents as a key aspect of approach
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Appendix item 11: Table to summarise the main themes emerging from the Meta Study (Meta Method and Meta Analysis) for the NAP

Paper –NAP Cluster	How have the methodological characteristics influenced research findings?	Analytical strategy & categories of data	What do the findings add to the context or concepts surrounding the framework?
<p>Soto (2006) (pearl)</p> <p>Type of impairment/condition: child with complex needs (AAC user)</p> <p>Type of study: Case study</p> <p>Research question: Which elements of narratives emerge in interactions with an 8 year-old child (who is also an AAC user) and their teacher</p> <p>Major findings: Interaction were difficult to assess in terms of if the child had control of the narrative</p> <p>Theoretical Framework: NAP</p> <p>Sample: 1 child</p> <p>Data collection: NAP tasks. Data from tasks were collected (and video was transcribed)</p> <p>Conclusions: structural analysis revealed the severely compromised dimensions of the narrative.</p>	<ul style="list-style-type: none"> • Method emphasises the presence or absence of elements of narrative • Limitation of method in judging cause of language deficiencies as a result of the individual’s skills or as a result of the limitations of communication system • Assessment central to methodology of the study- process described in detail • Case study weakens generalisability of findings • Narrative dimensions assessed through appropriate/inappropriate usage judgements 	<ul style="list-style-type: none"> • 6 narrative discourse dimensions • Analysis of narrative over time (5 visits by researcher) • Spontaneous message construction analysis • Utterances analysed through specialised video and audio transcription (method for transcription devised by Muller and Soto, 2002) 	<ul style="list-style-type: none"> • Level of individuality and complexity that can be achieved in narrative assessment • Structural accounts of narrative interactions are of limited use • Challenges identified in identifying and analysing narrative of augmented speech • Role of narrative unknown

<p>Chang 2006 (Kinship contemporaneous context)</p> <p>Type of impairment/condition:</p> <p>Children- no impairment</p> <p>Type of study: Intervention</p> <p>Research question: Assessment</p>	<ul style="list-style-type: none"> • Researchers adapted the NAP for the Chinese context • Scoring produced through assessment of methods • Not a study designed to assess communicatively impaired children • Role of language and culture not 	<ul style="list-style-type: none"> • NAP dimensions • Human Analysis of transcripts method-features: event sequencing, descriptiveness, evaluating, referencing, semantic/pragmatic 	<ul style="list-style-type: none"> • Different languages and cultures require an adapted NAP • Research objectives highlight the relevance of this area for

<p>of relationship between narrative skill and literacy</p> <p>Major findings:</p> <p>Theoretical Framework:</p> <p>NAP, Snow and Dickinson's contextualised and decontextualized language skill, Paterson and McCabe (1983)</p> <p>Conversational mapping</p> <p>Sample: 14 children</p> <p>Data collection: Narrative assessments – range of interactive skills analysed</p> <p>Conclusions: Links between narrative, language and literacy is also present in Mandarin speaking children</p>	<p>discussed</p> <ul style="list-style-type: none"> • Assessment administered like a 'test' unlike other frameworks 	<p>grammatical use of conjunctions and fluency.</p> <ul style="list-style-type: none"> • Topic maintenance score 	<p>attainment - may not be a relevant framework for communicatively impaired individuals</p>
<p>Liborion and Soto 2006 (Sibling)</p> <p>Type of impairment/condition:</p> <p>Student who uses AAC with cerebral palsy</p> <p>Type of study: Case study – part of wider study</p> <p>Research question: What</p>	<ul style="list-style-type: none"> • Limitations of single case study • Rich description of setting and procedures • No direct links to NAP in implementation of study 	<ul style="list-style-type: none"> • Conversational turns used as a unit of analysis • Videotaping of interactions and transcription 	<ul style="list-style-type: none"> • Coding of scaffolding techniques including concept of complexity • In-depth description of story book reading- a task used within

<p>scaffolding practices are used in interactions and what types of complex interactions are targeted by the practitioner</p> <p>Major findings: The majority of scaffolding practices target high levels of semantic complexity.</p> <p>Theoretical Framework:</p> <p>Sample: 1 dyad</p> <p>Data collection: Storybook reading as part of an everyday activity.</p> <p>Conclusions: Storybook reading could be a context for narrative interventions</p>			<p>NAP</p>
<p>Soto & Hartman (2006) (Sibling)</p> <p>Type of impairment/condition: children with communication impairment</p> <p>Type of study: Intervention – part of wider study</p> <p>Research question: Narrative</p>	<ul style="list-style-type: none"> • Sophisticated discussion of the issues involved in assessing various aspects of narrative skill • Small sample of participants but some comparisons between participants possible • Narrative 	<ul style="list-style-type: none"> • Dimensions: photo elicitation, shared reading, conversational narrative, story stem, wordless picture book • Discourse analysis 	<ul style="list-style-type: none"> • Add to understanding of narrative features and barriers to narrative • Several interpretation of results of NAP and narrative

<p>discourse abilities assessed</p> <p>Major findings: Most narrative discourse dimensions appeared to be compromised and in need of attention</p> <p>Theoretical Framework: Narrative</p> <p>Sample:4 children</p> <p>Data collection: 5 visits per day by researchers to administer various narrative assessments, video analysis</p> <p>Conclusions: Most narrative dimensions are in need of intervention</p>	<p>dimensions assessed through appropriate/inappropriate usage judgements</p>		<p>abilities may exist</p>
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Appendix item 12: Narrative Synthesis Searching techniques

<p>Sources for review papers</p> <p>Lateral:</p> <p>Key journals- update key journal searches 2010-2014</p> <p style="padding-left: 40px;">Dementia – 1 RELEVANT</p> <p style="padding-left: 40px;">AAC – 1 RELEVANT</p> <p>Key websites (AAC-specific, practitioner, methodology, institutes)- 3</p> <p style="padding-left: 40px;">Alzheimer’s Society; Dementia Advice and Support services ; Bradford dementia Group; DSDC Stirling – Dementia Now’ publication; SCIE; Communication Matters (UK); ASHA Perspectives on AAC Journal (US)</p> <p>Key papers from scoping exercise - 29 relevant papers</p> <p style="padding-left: 40px;">Reference scanning on 5 reviews; 2 discussion papers</p> <p>Additional ‘berry-picking’ techniques (citation tracking, Google scholar, reference scanning, author contact etc.) 30 new relevant references</p> <p>Grey literature SIGLE - 5</p>

Databases

Original searches

Embase **752** (post 2000- operators adjusted)

2102 (post 2000) **1411**

Pubmed

366 post 2000 **285**

944 post 2000 **536** =

Cinahl

98 post 2000 **72**

= 3 relevant across databases

Update searches- Pubmed (narrow and broad) Inspec, Embase, Cinahl (carried out 09/12)

Pubmed-366 > 420

0 new

Pubmed 944 > 1054

[**256** papers published between 2012 -2014 screened-= 1 relevant]

Embase: Previous search total records 2102 > 2214 = 2 relevant papers

852

[**693** published between 2012-2014 screened]

CINAHL: 98 records

[**49** published between 2012-2014 screened- 2 relevant]

New database searches:

22/5/14

Pubmed – **511** = 30 relevant

(Embase, Psycinfo, Medline) through Ovid N= **34** = 0 relevant

Cinahl through ebsco – **190** records = 7 relevant

Search terms:

ISSO 999- device/system names

Key terms from scoping

Dementia

Terms that focus on AAC as an augmenting research method

AAC

Device types

AAC system types

Interview augmenting tools

Other types of alternative communication interactions

Dementia

MCI

Example from Pubmed search:

(dementia*[Title/Abstract] OR dementia[MeSH Terms] OR Alzheimer* OR mild cognitive impairment*) AND (augmentative alternative communication OR communication strategy OR synthesi* speech OR gesture OR photo elicitation OR music therapy OR nonverbal communication OR talking mats OR blissymbol* OR picture exchange communication system OR communication board OR communication display OR augmentative and alternative communications systems[MeSH Terms])

Appendix Items 13 – 15: Specific searches for databases in Narrative Synthesis

Appendix item 13: CINAHL search

CINAHL SEARCH	
AB augmentative and alternative communication OR AB communication board OR AB wordboard OR AB symbolic communication OR AB speech synthesis OR AB gesture OR AB music OR AB photo OR AB nonverbal communication OR OR AB talking mats OR AB blissymbol OR AB communication wheel OR AB picture exchange communication system	4546
Dementia OR dementia patients OR alzheimer’s disease OR mild cognitive impairment	47264
Dementia OR dementia patients OR alzheimer’s disease OR mild cognitive impairment AND AB augmentative and alternative communication OR AB communication board OR AB wordboard OR AB symbolic communication OR AB speech synthesis OR AB gesture OR AB music OR AB photo OR AB nonverbal communication OR OR AB talking mats OR AB blissymbol OR AB communication wheel OR AB picture exchange communication system	248
Post-2000 publication	215
English language	190

Boolean or phrase search mode

Appendix item 14: PubMed search

PUBMED SEARCH	
(augmentative alternative communication OR communication strategy OR synthesi* speech OR gesture OR photo elicitation OR music therapy OR nonverbal communication OR talking mats OR 340lissymbol* OR picture exchange communication system OR communication board OR communication display OR augmentative and alternative communications systems[MeSH Terms])	35950
(dementia*[Title/Abstract] OR dementia[MeSH Terms] OR Alzheimer* OR mild cognitive impairment*)	167981
(dementia*[Title/Abstract] OR dementia[MeSH Terms] OR Alzheimer* OR mild cognitive impairment*) AND (augmentative alternative communication OR communication strategy OR synthesi* speech OR gesture OR photo elicitation OR music therapy OR nonverbal communication OR talking mats OR 340lissymbol* OR picture exchange communication system OR communication board OR communication display OR	

augmentative and alternative communications systems[MeSH Terms]	756
Post 2000 publication	590
English language	511
Mixture of independent search terms and MeSH terms used	

Appendix item 15: EMBASE, PSYCINFO, MEDLINE search

Augmentat* Comm*AB OR ALTERNAT* COMM* ab or AAC AB	9218
(wordboard* OR letter board* OR comm* board*) AB	450
(speech synth* OR comm* display OR comm* book* OR symbolic comm*) AB	927
(talking mats* OR blissymbol* OR comm* wheel OR picture exchange OR emotion cards OR boardmaker) AB	426

<p>(Dementia* OR Alzheimer OR MCI OR mild cognitive disorder) AB</p>	<p>216017</p>
<p>(Dementia* OR Alzheimer OR MCI OR mild cognitive disorder) AB</p> <p>AND</p> <p>Augmentat* Comm*AB OR Alternat* Comm* ab or AAC AB OR (wordboard* OR letter board* OR comm* board*) AB OR (speech synth* OR comm* display OR comm* book* OR symbolic comm*) AB OR (speech synth* OR comm* display OR comm* book* OR symbolic comm*) AB OR (talking mats* OR blissymbol* OR comm* wheel OR picture exchange OR emotion cards OR boardmaker) AB</p> <p>Post 2000 publication</p>	<p>37</p> <p>34</p>
<p>Independent search terms used</p>	

Appendix Item 16: Data abstraction and analysis- Narrative Synthesis

2 STUDY CHARACTERISTICS

- Overall study info (prior to scrutiny of AAC methodology intervention)

Paper: _____

Author/s	
Year of publication	
Country	
Research question	
Theoretical framework	
Intended outcome of study	
Research design	
Methodology	
AAC type	
Population	
Data collection method	
Method of evaluation	

Analysis	
Main findings	

Part 3

DATA EXTRACTION and PRELIMINARY ANALYSIS -Data extracted for analysis of rigour of AAC methodological intervention

Use extracts of studies to identify facilitators and barriers for the intervention and broader contextual factors that explain differences as per Popay's Narrative Synthesis methodology

<u>Context</u>	1
1 Associated paradigm	2
Presence of a:	3
2Theoretical framework for the method	
3 Conceptual framework for the study	
<u>Methodology</u>	4
4 Role of AAC in the context of the study	.5
5 Explanation of the skills required to use/take part in AAC method or medium	.6
6 AAC characteristics (intended enhancements or supported communication forms)	.7
7 Those involved in facilitating the methodology	.8
8 Their specified role	.9
9 Their estimated level of	

participation 10 Details about familiarisation period with AAC	4.10
<u>Participants</u> 11 Degree of information about the sample 12 Extent to which picture of each participant is holistic	11
Presence of information about sample categorised across domains: 13 Bibliographic/demographic 14 Previous AAC use information 15 Health and functioning 16 Communication 17 Environmental factors 18 Activity factors 19 Personal factors 20 Heterogeneity of the patterns of use of AAC across the sample	12
	.13
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	19

	20
<u>AAC interpretation</u>	21
21 Reference to conceptual framework in interpretation of AAC	
22 Consideration of cultural frame of reference for participants, for researcher .23 Inclusiveness of approach in achieving communicative participation	22
24 Data collection techniques	23
25 Details of capturing/recording data	
26 Transcription/translation techniques	
27 Details of analytical techniques	24
	25
	26
	27

Synthesis Part 4

Contextual information about how the AAC works , why and for whom	
Facilitators to implementation	
Barriers to implementation	
Specific factors aiding successful implementation	
Perceived strength of the richness of this contextual information	

Appendix item 17: Expanded thematic table- Narrative Synthesis

<p>Evoking a narrative e.g. Photo diaries, Photo elicitation, multimedia biographies, multimedia devices, life story work</p> <p>Astell et al., 2009 ; Astell et al., 2010 (CIRCA multimedia device)</p> <p>Bartlett 2012; 2014 (Diary interview method)</p> <p>McKeown et al., 2010a; 2010b (Life Story Work)</p> <p>Shell 2014 (Photo elicitation and Autodriving)</p> <p>Smith et al., 2009 (Multimedia Biographies)</p> <p>Wiersma, 2011 (Photovoice)</p> <p>FACILITATORS [PWD- Person with dementia]</p>			
General/ Context specific	Researcher	Participant	Data
	<p>Key themes:</p> <p>-High levels of researcher involvement- preparation, mediation, familiarisation</p> <p>Detailed research explanation and preparation (Wiersma, 2011)</p> <p>Researchers used a participation agenda to hear the voice of PWD (Wiersma, 2011)</p> <p>Researchers assisted with practical aspects such as the development of photos to lessen the number of tasks required by participants (Wiersma, 2011)</p>	<p>Key themes:</p> <p>Element of representational control of content also important</p> <p>Participants offered choice and control in what to include diary (Bartlett 2012)</p> <p>Choice of mode of expression in session (Astell et al., 2009)</p> <p>Individuals had their own timeframe for completion of research (Bartlett, 2012)</p> <p>348</p> <p>Participants could control the content and pace of</p>	<p>Key theme:</p> <p>Array of forms of data promoted a richer understanding of Person with dementia’s (PWD)’s lives and experiences</p> <p>Analysis creates a multi-layered understanding of participant’s lives (Bartlett, 2012)</p> <p>Researchers could observe the participants ‘in action’ (Bartlett, 2012, p.1720)</p> <p>Sensory participative approach (Bartlett, 2012)</p>

	<p>Researcher acted as a mediator (Smith et al., 2009)</p> <p>Researcher had to familiarise the whole multidisciplinary research team in best approach (Astell et al., 2009)</p> <p>The researcher facilitated the dialogue for multimedia biographies (Smith et al., 2009)</p> <p>The researcher is required to do a certain amount of groundwork before the commencement of Life Story Work- Jan Dewing's methods (2007) are recommended so that the researcher finds out something about that person's biography (McKeown, 2010b)</p> <p>It is important that the PWD and the careers are actively involved in the methodology (McKeown, 2010a p.1936)</p> <p>Researcher required to be flexible and adaptable to dynamic process</p> <p>Role of researcher is significant in research implementation, especially their ability to be adaptable. (Shell, 2014)</p>	<p>interactions and how they were represented (Bartlett, 2012)</p> <p>PWD can move between items as they choose (Astell et al., 2009)</p> <p>Participants were authors of the visual images (Wiersma, 2011)</p> <p>Participants chose a small number of key photos prior to analysis (Wiersma, 2011)</p> <p>Choice of type of camera based on ability to operate (Shell, 2009)</p> <p>Individualised approach (McKeown et al., 2010b)</p> <p>Participants were offered a choice in the type of life story book they wanted to make (McKeown et al., 2010ab)</p> <p>Interactions centred on holistic understanding of participant</p>	<p>Sensory ethnographic approach to expand 'ways of knowing' (Bartlett, 2012)</p> <p>Vast number of images created (Bartlett, 2012)</p> <p>Participants had the freedom to capture their experiences (Wiersma, 2011)</p> <p>A final screening of the multimedia biography allowed the participants and their families to reflect- the researcher could observe these interactions. (Smith et al., 2009)</p> <p>Coding techniques were developed to describe verbal and nonverbal behaviour (Astell et al., 2009)</p> <p>Caregiver instances of prompting were examined</p>
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	<p>Researchers employed a <i>flexible and sensitive approach</i> (McKeown et al., 2010b, p.150)</p> <p>Researchers in a supportive role</p> <p>Researchers supported interviewees throughout the process (Bartlett, 2012)</p> <p>Researchers working with the multimedia device CIRCA held the view that staff could always be supported to provide a positive interaction with PWD (Astell et al., 2009)</p> <p>---</p> <p>It was useful for the research team to seek assistance from someone more neutral than the family members (Smith et al., 2009)</p> <p>Post diary interview (Bartlett 2012)</p> <p>There was a 3 month timeframe for participants to collect data (Wiersma , 2011)</p> <p>Facilitators were skilled at life story work- nursing practitioners who were involved in the research were offered one hour of training</p>	<p>Method can offer a dynamic understanding of motives and a rooted understanding of the whole person (Bartlett., 2012)</p> <p>The researchers could make links between the participant’s past and present (McKeown et al., 2010b, p.155)</p> <p>Interactions centred on participation priorities and concerns (McKeown et al., 2010a; 2010b)</p> <p>Rich description of participant attributes through case studies (McKeown et al., 2010b)</p> <p>Inclusive approach to PWD and more severe impairments (Shell, 2014)</p> <p>Assistance of carers significant during research process</p> <p>Caregivers assisted interaction (Astell et al., 2009)</p> <p>The enthusiasm of staff to trial the AAC was an asset in the project (Astell et al.,</p>	<p>(Astell et al., 2009)</p> <p>None of the participants had kept a post-reflective account before (Bartlett, 2012)</p> <p>Audio data is a different way of understanding experiences- adds a different dimension to the data (Bartlett 2012)</p> <p>Analysis of subjective experiences (Bartlett, 2014)</p> <p>Combinations of textual, visual and field data (Bartlett, 2014)</p> <p>Data augmented with secondary data analysis (documentary and observational), helping researchers to immerse themselves in analysis - and to gain a sense of “<i>the material worlds of participants</i>” (McCulloch, 2004 cited in Bartlett, 2012 p.1721)</p> <p>Choice of AAC medium added to understanding about the individual</p>
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	<p>(McKeown et al., 2010b)</p> <p>(Shell, 2014)- Reflexive journaling to understand perspective on role</p>	<p>2009)</p> <p>Carer involvement in the research process to help PWD consent others for photos (Wiersma 2011)</p> <p>Method may require at least one family member to be involved (Smith et al., 2009)</p> <p>---</p> <p>Stakeholders were involved in the planning and implementation of the Life Story Work</p> <p>(McKeown et al.,2010b)</p> <p>All participants intuitively knew what was required in keeping a diary (Bartlett, 2012)</p> <p>PWD were involved in the user-centred design of the CIRCA device (Astell et al., 2009)</p> <p>Attempts to minimise memory loss between data collection and follow up interview (Shell, 2014)</p>	<p>(Bartlett, 2012)</p> <p>Scaffolding and intersubjectivity used to understand relationships in dementia (Astell et al., 2010)</p> <p>The behaviour of the dyad was examined as was use of music and time spent on reminiscence (Astell et al., 2009)</p> <p>Interpretation of data aimed at understanding the world of the PWD (Shell, 2014)</p> <p>Understanding the experience of PWD hinged on analysing the negotiated dialogue in interactions (Smith et al., 2009)</p> <p>Personalisation an important concept for the process of understanding lived experience (Smith et al., 2009)</p> <p>Analysis of nonverbal</p>
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		<p>CIRCA method also relieved carers of the burden of supporting conversation and therefore the interactions became more naturalistic (Astell et al., 2010)</p> <p>Different life story methods are recommended for people at different stages of dementia (McKeown et al., 2010b)</p> <p>Direct questions were not used (McKeown, 2010b)</p>	<p>communication through video occurred (Astell et al., 2009)</p> <p>Nonverbal analysis important in eliciting voice of PWD (McKeown et al., 2010b)</p> <p>Research in life story work gave the opportunity for the participant's voice to be heard (McKeown et al., 2010b)</p> <p>Power was an important concept – this involved an awareness of breaking down the different status afforded to health professionals (Wilkinson 2002 in McKeown, 2010a, p.1941)</p> <p>Visual data on environment (Bartlett, 2012)</p> <p>-----</p> <p>The content was randomised so that the caregivers didn't become too familiar with the order and pre-empt</p>
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			<p>responses/lead interaction (Astell et al, 2009)</p> <p>Caregiver role was central in understanding and interpreting communication (Wiersma, 2011)</p> <p>Research could illuminate continuity and discontinuity in interactions between staff and PWD (McKeown et al., 2010b)</p>
CONTEXT SPECIFIC			<p>Content Analysis (Bartlett, 2012)</p> <p>‘Scaffolding’ analysis (Astell et al., 2009)</p> <p>Scaffolding emphasis required the lower status partner to take ownership of the interaction (Greenfield, 1984 in Astell et al., 2010)</p> <p>Thematic Framework analysis – provided a visual structure (themes identified through a prior literature review) (McKeown et al., 2010b)</p> <p>Practice Development approach (McKeown et al., 2010a)</p>

BARRIERS (Evoking a narrative methods)			
	Researcher	Participant	Data
	<p>Researchers familiarised the whole multidisciplinary team with the challenges faced by PWD (Astell et al., 2010)</p> <p>Participant needed to be helped to initiate photo-taking and to understand creative process (Shell, 2014)</p> <p>Participants with AD required at least one family member to be involved- Researcher acted as a mediator (Smith et al., 2009)</p>	<p>Key theme:</p> <p>The necessary time commitment required could act as a barrier</p> <p>Time required (including from staff or carers) was an issue 1 year & 60-100 hrs (Smith et., al 2009)</p> <p>Time commitment required from care staff for CIRCA (Astell et al., 2009)</p> <p>---</p> <p>Staff or carers may be required to change habits such as playing music (Astell et al., 2009)</p> <p>Some ethical issues to consider in involving multiple people in a reflective focus group following Photovoice session. (Wiersma, 2011)</p> <p>Some participants found the process of diary keeping</p>	<p>Key themes:</p> <p>-Implementation of methods must be sensitive to the potential of research to remind people of losses</p> <p>The process can involve emotionally challenging elements (Smith et al., 2009)</p> <p>Method could remind a participant of losses (McKeown, 2010b)</p> <p>Participants became aware of the skills they had lost (Bartlett, 2012)</p> <p>----</p> <p>Participant had to be self-motivated to keep a diary (Bartlett, 2012)</p> <p>Some of the diaries contained a minimal amount of data (Bartlett, 2012)</p>

		<p>demeaning (Bartlett, 2012)</p> <p>Some participants felt that the demands of keeping a diary was too much (Bartlett, 2012)</p> <p>Some technical challenges to overcome (Smith et al., 2009)</p> <p>Life Story work stipulated that eligible participants were those who may gain a therapeutic or any other direct benefits from the work (McKeown et al., 2010b)</p>	<p>The researchers and carers had to recognise the complexity in analysing and representing the different aspects of “<i>highlighting a person’s life</i>” (Smith et al., 2009, p.299)</p> <p>There were sometimes disagreements within the family about what ‘truly’ represented a participant’s life (Smith et al., 2009)</p> <p>The researcher had to filter the images prior to analysis due to duplicates and volume (Bartlett., 2012)</p> <p>Participants could be unfamiliar with the concept of the method (Bartlett, 2012)</p> <p>Some participants could be more likely to tell their story if they were activists (Bartlett., 2014)</p> <p>Methods and research design have the potential to reveal diagnosis – this was avoided (Wiersma, 2011)</p>
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			<p>Technical challenges (Smith et al., 2009)</p> <p>Identification of or recognition of losses could cause distress – avoided use of personal photos in CIRCA (Astell et al., 2009)</p>
<p>Communication Framework Methods</p> <p>E.g. word boards, nonverbal observed tasks, nonverbal communication</p> <p>Allan (2001)</p> <p>Murphy et al., 2013; Murphy et al., 2005 (Talking Mats™ word boards)</p> <p>Nygård and Starkhammer, 2007; Nygård 2006 (Nonverbal interviews and observations)</p>			

FACILITATORS			
General/ Context specific	RESERACHER	PARTICIPANT	DATA
	<p>Key themes:</p> <p>-Researchers should consider the potentially personal nature of the experiences recalled by the PWD- the rapport should reflect this</p> <p>Researcher allows the participant opportunity to recount personal experiences (Nygård and Starkhammer, 2007)</p> <p>Researchers built up a good rapport with participants (Nygård and Starkhammer, 2007)</p>	<p>Key themes:</p> <p>-Key role of visual and nonverbal data to inform research</p> <p>Nonverbal observations that could allow participants to demonstrate the use of technology in situ helped to increase the inclusiveness of the research beyond those with a greater verbal ability (Nygård and Starkhammer, 2007)</p> <p>Gives greater length of time to participants to communicate (Nygård and Starkhammer, 2007)</p> <p>The use of pictures and nonverbal communication meant that participants did not have to address their feelings directly with the researcher (Allan, 2001)</p> <p>Selection of symbols was confirmed by participant</p>	<p>Key themes:</p> <p>-Rich data and emerging patterns</p> <p>Observations in situ created opportunities for spontaneous reflections (Nygård and Starkhammer, 2007)</p> <p>Observations alone lacked the comments and reflections that allowed full interpretation of data (Nygård, 2006)</p> <p>Implementation included multiple forms of data collection (Nygård and Starkhammer, 2007)</p> <p>Consideration of the context (environment) in analysis- comparison of individual strategies possible (Nygård and Starkhammer, 2007)</p>
	<p>Researchers built relationships with PWD with enough trust to be invited into the “<i>experienced worlds of participants</i>” p.103 (Nygård, 2006)</p> <p>Interviewees were remaindered by the Talking Mats™ facilitator that they didn’t have to discuss every topic. (Murphy et al., 2013)</p>		

	<p>The researcher had to develop an awareness that there could be assumptions or misperceptions about the views of PWD that could emerge from the research (Murphy et al., 2013)</p> <p>The researchers gave PWD the direct opportunity to tell a story through sensitive listening and prompting (Allan, 2001)</p> <p>Researchers need to create the opportunity for participants to take part in interactions and processes that are valued in any meaningful interactions – researchers need to be aware of engaging with these human processes in research (Allan, 2001)</p> <p>Researchers needed to use judgement on the ways to interact and the issues to explore with the PWD</p> <p>Researchers could use pictures in a much less focused way to assist communication interaction (Allan, 2001)</p> <p>It was particularly difficult for researchers to get started and maintain momentum in interactions – when working with pictures and nonverbal</p>	<p>during process to establish meaning (Murphy et al., 2013)</p> <p>Symbols act as a visual reminder and record-reduction of memory demands (Murphy et al., 2013)</p> <p>During Talking Mats™ sessions interviewees could stay on track, organise their thoughts and exchange information (Murphy et al., 2013)</p> <p>Analysis of nonverbal interactions could highlight the specific things that made positive interactions between staff and patients- prior to this identification of what was ‘different’ was elusive (Allan, 2001)</p> <p>Participants had time to place symbols- placement also contained meaning (Murphy et al., 2013)</p> <p>Low tech nature of the Mats was an advantage (Murphy et al., 2005)</p> <p>Visual symbols may be more easily processed</p>	<p>Micro-level analysis- participants could “<i>recall, retell, reflect</i>” (Paton 1987 cited in Nygård and Starkhammer, 2007)</p> <p>Methods incorporate verbal and nonverbal response (Murphy et al., 2013)</p> <p>Cognitive Mapping (Jones, 1985) allowed patterns to emerge (Murphy et al., 2013)</p> <p>It is possible to create a narrative from the participant’s placement of narrative events- e.g. time and theme (Nygård, 2006)</p> <p>The examination of pictures by PWD helped them to tell a story (Allan, 2001)</p> <p>Observations occurred over 3 weeks (Nygård and Starkhammer, 2007)</p> <p>Researchers adapted the Visual Involvement Measure for Talking Mats™ research (Murphy</p>
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	<p>Researcher skill involved by the facilitator in understanding what the PWD wanted to explore (Murphy et al., 2005)</p> <p>Researchers had to judge the right opportunity for communication (Allan, 2001)</p> <p>Researchers collected field notes (Murphy et al., 2005)</p> <p>Pictures can be used in a much less focused way during interactions to gain responses using the discretion of the researcher (Allan, 2001)</p> <p>Researchers needed to be able to understand how a PWD would comprehend a topic (Nygård, 2006)</p>	<p>(Murphy et al., 2005)</p> <p>Personalisation was possible in communication frameworks</p> <p>Personalisation of topics and preferences/opinions possible (Murphy et al., 2013)</p> <p>During Talking Mats™ sessions joint discussions take place between participants and carers (Murphy et al., 2013)</p> <p>Personal characteristics and status affected the relationships formed during fieldwork (Nygård 2006)</p> <p>Interviews alone rely on cognitive and verbal functions (Nygård, 2006)</p> <p>Participants were often in an alternate frame i.e. a different time or place as their reality (Allan, 2001)</p> <p>Frameworks make communication less direct</p>	<p>et al., 2013)</p> <p>Rich data yielded from observations (Nygård, 2006)</p> <p>Video recording was a key element in analysis and interpretation</p> <p>Video recording of interactions allowed researchers to examine data multiple times (Allan, 2001)</p> <p>Researchers also viewed the video footage to ascertain the security of the responses (Murphy et al., 2005)</p> <p>Application of communication methods in daily life setting</p> <p>Supports the expression of feelings (Allan, 2001)</p> <p>Method could establish a routine for communication work (Allan, 2001)</p> <p>Interactions for Talking Mats™ could involve day to day decision-making and elicitation of views (Murphy et al., 2013)</p>
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		<p>and more comfortable for the PWD</p> <p>Allows participant to organise their thoughts –less of a direct focus than a face to face interaction would be (Murphy et al., 2013, Murphy et al., 2005)</p> <p>Participants could discuss the possibility of having different feelings about things without having to discuss them directly (Allan, 2001)</p>	<p>Researchers gleaned sensorial information ‘in the moment’ including interpretation of silences (Nygård, 2006)</p> <p>Tasks were performed in context with the drama of the situation retained – this enabled the researcher to observe response strategies (Nygård, 2006)</p> <p>Ethnographic approach (Bogdan and Bilken, 1998 in Nygård and Starkhammer, 2007)</p> <p>-----</p> <p>Topics can be divided into manageable chunks (Murphy et al., 2005)</p> <p>Participants were debriefed about the outcomes of the Talking Mats™ and a picture of the Mat was given to them. The researcher summarised the discussion to check the validity of researcher understanding.</p>
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			(Murphy et al., 2013)
CONTEXT SPECIFIC			<p>Methods incorporated the participant's lived context-ethnographic approach to nonverbal observational tasks – data analysis through Constant Comparison method of coding (Strauss and Corbin 1998) (Nygård and Starkhammer, 2007)</p> <p>Thematic analysis of qualitative information & interpretation of Talking Mats™ as an activity-including interpretation of cues for placement of symbols and visual scales (Murphy et al., 2005)</p>
BARRIERS (Communication framework methods)			
	RESEARCHER	PARTICIPANT	DATA
	<p>Researchers should not assume someone with dementia can participate (Talking Mats™ is an unsuitable method if the person is unaware of their surroundings or if they have a lack of understanding of visual symbols) (Murphy et al., 2013)</p>	<p>Key theme:</p> <p>-Verbal skills and expressive skills play a part in the success of the interactions</p> <p>The final avenue for capturing the perspective of</p>	<p>Key themes:</p> <p>-Familiarity with participants required to understand and analyse subjective experiences</p> <p>Data must not be used to represent the permanent</p>

	<p>The researchers need to have an understanding the PWD (Murphy et al., 2013)</p> <p>The staff as well as the researchers could be required to collect data as the method is implemented and certain staff were deemed better than others at prompting conversation (Allan, 2001)</p>	<p>the PWD could be verbal (this is a limitation) Allan, 2001</p> <p>PWD needed to understand visual symbols (Murphy et al., 2013)</p> <p>PWD displayed different forms of reasoning on abstract issues (Nygård, 2006)</p> <p>PWD may find it difficult to present a story and so they may find it easier to present a ‘rehearsed ‘ story (Nygård, 2006)</p> <p>-----</p> <p>Carers may feel a greater sense of involvement than the PWD (Murphy et al., 2013)</p> <p>PWD have unique decision-making needs (Nygård, 2006)</p>	<p>response/perspective of the PWD (Murphy et al., 2005)</p> <p>A PWD could be experiencing a different frame for the situation e.g. a different time or place as a reality (Allan, 2001)</p> <p>Giving voice to participants not possible as a concept (Reissman 1991 in Nygård, 2006)</p> <p>Responses can be unpredictable (Allan 2001)</p> <p>The act of expressing feelings can be powerful and it can provoke anxiety (Allan, 2001)</p> <p>Researcher perspective needs to be considered during analysis</p> <p>Influence of researcher in the naturalistic setting needs to be considered (Nygård ,2006)</p> <p>The images of Self presented by the participants are inevitably influenced by the presence</p>
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			<p>of the researcher (Nygård and Starkhammer, 2007)</p> <p>Research does not capture naturalistic experience (Nygård and Starkhammer, 2007)</p> <p>-----</p> <p>Methods of nonverbal behaviour interpretation and pictures can be used in service user consultation, but in some cases the responses were not direct enough to be able to initiate this (Allan, 2001)</p> <p>(Murphy et al., 2010)- method may not be suitable for all PWD</p>
<p>Expressive medium- e.g. music, art, dance</p> <p>Jonas Simpson, 2005 (story, music and art)</p> <p>Nyström and Lauritzen 2005 (dance therapy including nonverbal communication)</p> <p>Bober et al., 2002 (The Feelings Art Group)</p> <p>BARRIERS</p>			
General/ context specific	RESEARCHER	PARTICIPANT	DATA
AAC c	<p>Key themes:</p> <p>Therapeutic skills may assist in delivering methods which are also interventions</p> <p>Researcher as a therapist</p>	<p>Key theme:</p> <p>Choices could be offered to participants even within expressive communication session</p>	<p>Key theme:</p> <p>Multiple forms of data viewed as an advantage by researchers</p>

	<p>possessed dual skills in delivering research and therapy (Jonas Simpson, 2005)</p> <p>Researchers were familiar with methods (Jonas-Simpson, 2005)</p> <p>Facilitator also had a clinical role (Bober et al., 2002)</p> <p>Facilitators tried to deliver a positive group environment (Bober et al., 2002)</p> <p>The researcher found it helpful to conceptualise the sessions as separate single sessions for the participants due to their memory problems (Bober et al., 2002)</p> <p>Dual researcher role – also a therapist (Nyström and Lauritzen, 2005)</p>	<p>Choices of communication methods given to participants on the ways to engage in research (Nyström and Lauritzen, 2005)</p> <p>Researchers were flexible in their approach to assessments of the Feelings Art Group (Bober et al., 2002)</p> <p>The researcher provided a choice of context for the Dance group which created possibilities as well as limitation for the research (Nyström and Lauritzen, 2005)</p>	<p>Different forms of data encourages inclusiveness (Jonas –Simpson, 2005)</p> <p>Video recording yielded rich data (Nyström and Lauritzen, 2005)</p> <p>Development of a multisensory methodology (Bober et al., 2002)</p> <p>Sensory stimulation was used as well as reminiscence methods (Bober et al., 2002)</p> <p>Data could be lost in the process of audio transcription so The Dance Therapy Group used video and observational analysis (Nyström and Lauritzen, 2005)</p> <p>----</p> <p>Analytical findings were discussed with the research team due to different meanings possible in interpreting dance (Nyström and Lauritzen, 2005)</p>
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			<p>Verbal translations of the interaction offered by the researcher in the moment (Nyström and Lauritzen, 2005)</p> <p>Dance offered an expression of embodied experience and allowed facilitation of communication with others (Nyström and Lauritzen 2005)</p>
CONTEXT SPECIFIC	<p>The group applied social work strategies to client interventions to focus on client's strengths not deficits (Bober et al., 2002)</p>	<p>Method fitted in with current therapeutic sessions (Bober et al., 2002)</p>	<p>Social Work informed strategies influenced the Feelings Art Group which focused on the remaining strengths the PWD had (Bober et al., 2002)</p> <p>The Feelings Art Group used conceptual framework from 'curative factors' (Yalom, 1995) such as universality, altruism, development of socialising technology and catharsis.(Bober et al., 2002)</p> <p>Conceptual framework- Types of expression identified in dance as: spoken dialogue, song and music, movement fantasy</p>

			(Nyström and Lauritzen, 2007)
BARRIERS (Expressive medium methods)			
	<p>RESEARCHER</p> <p>Key theme:</p> <p>-Complex nature of research in dual roles and multiple forms of communication</p> <p>Clinical role necessary to implement the method (Bober et al., 2002)</p> <p>Researchers who were part of the therapeutic as well as data collection processes could be problematic (Nyström and Lauritzen, 2005)</p> <p>Researcher had to negotiate dual role between research and therapeutic practice (Nyström and Lauritzen, 2005)</p> <p>Researcher were also therapists (Jonas-Simpson, 2005)</p> <p>Researchers encouraged to experiment with a range of</p>	<p>PARTICIPANT</p> <p>Participants were not included if they displayed wandering or displayed agitation (Bober et al., 2002)</p>	<p>DATA</p> <p>Key theme:</p> <p>Complex experiences needed to be unravelled during analysis</p> <p>Researcher needed to be familiar with different forms of research methods in order to interpret them (Jonas-Simpson, 2005)</p> <p>A therapeutic session with a different membership each time has implications for research data and interpretation (Bober et al., 2002)</p> <p>Researcher to disentangle their own experience from the interpretation of the participant's experience (Nyström and Lauritzen 2005)</p> <p>Nonverbal communications can have several meanings, (and</p>

	<p>methods of communication within the Feelings Art group, including multisensory devices/mediums (Bober et al., 2002)</p> <p>Researcher chose which medium of music, story or art to facilitate with the participant- perhaps removing some control (Jonas-Simpson, 2005)</p>		<p>Lauritzen, 2005)</p> <p>-----</p> <p>Precedent for research limited to a therapeutic context (Nyström and Lauritzen, 2005)</p>
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Appendix item 18: The results of the 18 item quality appraisal checklist for qualitative studies (adapted from COREQ) - Narrative Synthesis

Study	Large scale project	Interviewer characteristics explained	Methodological orientation stated	Sampling design	Number of participants stated	Non-participation reasoning provided	Interview guide (or equivalent)	Repetition of interview or equivalent	Data recording methods stated	Duration of data collection stated	Saturation of data explained (if appropriate)	Number of coders	Description of coding provided	Themes emerged from data (rather than identified in advance)	Findings validated with participants	Quotations provided in findings section	Consistency in presentation of research findings and conclusions drawn	Diverse case analysis	Total criteria met
Allan, 2001	x	y	y	y	y	x	x	x	y	y	x	x	x	x	x	y	y	x	10
Bartlett, 2014	x	x	y	y	y	x	y	x	y	x	x	x	y	x	x	y	y	y	9
Bober, 2002	x	x	y	y	x	y	x	x	x	y	x	x	y	x	x	y	y	x	7
Jonas-Simpson, 2005	x	y	y	y	y	x	x	x	y	x	x	x	x	x	x	y	y	x	7
McKeown <i>et al.</i> , 2010b	x	x	y	y	y	x	y	y	y	y	x	x	y	y	x	y	y	x	11
Nygaard and Starkhammer, 2007	x	y	y	y	y	x	y	y	y	y	x	y	y	y	x	y	y	y	11

Nyström and Lauritzen, 2005	x	y	x	x	y	x	x	y	y	y	x	x	y	y	x	y	y	x	9
Shell, 2014	x	y	y	y	y	y	x	y	y	y	y	y	y	y	x	x	x	x	11
Smith <i>et al.</i> , 2009	x	y	x	y	y	y	y	y	x	y	x	x	x	x	x	y	y	y	10
Wiersma, 2011	x	y	x	y	y	x	x	y	x	x	x	x	x	x	x	x	x	x	4

Appendix item 19: The 24 item quality appraisal checklist for the intervention-based studies (adapted from the TREND Statement) - Narrative Synthesis

Study**	* A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V
1	y	y	y	y	x	y	y	x	y	y	y	y	y	x	x	y	y	y	y	x	y	19
2	y	y	y	y	y	y	y	y	y	y	y	y	y	x	x	x	y	y	y	y	y	21

**Study 1- Astell et al (2010)

Study 2- Murphy et al (2013)

*Criterion	Corresponding letter in table
Rationale/hypothesis	A
Evidence of theoretical stance	B
Eligibility criteria for participants	C
Sample size	D
Sources of bias discussed	E
Setting described	F
Intervention delivery methodology	G
Discussion of those delivering intervention	H
Timespan stated	I
Outcomes stated	J

Data collection methods discussed	K
Validation instruments stated	L
Statistical methods to compare groups stated	M
Missing data explained	N
Follow up parts of interventions explained	O
Analysis compares with baseline measurements	P
Summary of results from the study	Q
Confidence Intervals provided	R
Discussion of results	S
Barriers and facilitators to implementation	T
Generalisability discussed	U
Wider interpretation of findings discussed	V

Appendix item 20: Case summaries (Ordered according to item 6 - analysis) - Narrative Synthesis

1. Astell et al., 2009 ; Astell et al., 2010 *CIRCA multimedia device*
2. Bartlett 2012; 2014 –*Diary interview method*
3. McKeown et al., 2010a; 2010b- *Life Story Work*
4. Shell 2014- *Photo elicitation and Autodriving*
5. Smith et al., 2009 *Multimedia Biographies*
6. Wiersma, 2011-*Photovoice*
7. Allan 2001 *Working with pictures & nonverbal communication*
8. Murphy et al., 2013; Murphy et al., 2005 *Talking Mats™*
9. Nygård and Starkhammer 2007; Nygård, 2006 *Nonverbal interviews and observations*
10. Jonas-Simpson 2005 -*Story, music and art expression*
11. Nyström and Lauritzen , 2005- *Dance therapy- including capturing nonverbal communication*
12. Bober et al., 2002- *The Feelings Art Group*

1 CIRCA™ Multimedia device

Astell et al., 2010 & Astell et al., 2009

Description: Involvement of older people and their carers in designing a computer based support system- CIRCA

Papers: Methodology and empirical

Research design features: evaluative design and assessment of product (2009), an empirical paper (2010) which was an evaluation. Quantifiable coding of CIRCA for verbal and nonverbal tasks compared with traditional communication methods

Case description:

The methodological paper is written for an information Science audience (Astell et al., 2009). The contextual features of the implementation are captured through the description of the development of the design process. Although not empirically structured, it is valuable in terms of consideration of needs and involvement measures. There is not, however, very much detail on the analytical tools used despite having a multitude of ways of capturing observed and recorded and assessed data. There are a variety of concepts here but the main appears to be personhood operationalised through enjoyment and involvement measures. There was very little information on participants or the skills they would need, including their reactions to technology in general. Neither, was there any detail on the levels of familiarisation required for this kind of cognitive prosthesis. The empirical paper (2010) provides information about the development of CIRCA, as well as key concepts like ‘scaffolding’ and ‘joint attention’ and exploring relationships in dementia. In addition to detailed hypothesis, the paper offers implementation insight in the form of a procedural summary.

1 Theoretical context	Methodology	Participants	Interpretation
<ul style="list-style-type: none"> • Positivist stance • Theoretical framework- reminiscence, objective measurement of subjective concepts (2010) • Enjoyment and involvement concepts 	<ul style="list-style-type: none"> • Multimedia touch screen technology • Carers were often very receptive to the technology • Study (examined the interaction behaviour of care staff and people with a dementia diagnosis during reminiscing using both verbal and nonverbal measures • Researchers felt it important to familiarise the whole team of software engineers and designers, as well as the psychologists, with the unique difficulties posed by this condition, by ensuring that they all spent time interacting with people with dementia MMSE conducted at start of the first session (2010) • CIRCA sessions: Each pair sat side-by-side in front of the touch screen. Each pair was shown how to start CIRCA and was then left to use it together.(2010) 	<ul style="list-style-type: none"> • Minimal information about participants- all recruited from same setting and MMSE scores taken (range of participant scores documented) (2010) 	<ul style="list-style-type: none"> • Linguistic concept of scaffolding used as an analytical framework- verbal and nonverbal conversational categories assessed (2010) • Video recording in all sessions (2010) • Coding techniques were developed for verbal and nonverbal measures (2010) • Caregiver instances of prompting examined (2010) • Scaffolding and inter-subjectivity concepts applied to analysis to understand relationships in dementia (2010)

1 Facilitators	Specific factors	Barriers
<ul style="list-style-type: none"> - CIRCA was envisaged as a multimedia system presented on a touchscreen that people with dementia and caregivers could sit down and use together. It was planned to use reminiscence content in order to prompt long-term memories, which are often well preserved relative to the working memory problems of people with dementia - During the design process the researchers “...tried to determine if people with dementia can be supported to take the lead in more conversations , rather than the contents and course of the interactions being determined by the carers” (2009, p.55) - The content of the CIRCA display was randomised so that carers did not become overfamiliar with content and start to pre-empt/lead interactions (2009) - Researchers held the view that staff could always be supported to provide a positive interaction with people with dementia 	<ul style="list-style-type: none"> - CIRCA sessions offer participants more choice of mode of expression to use during sessions - People with dementia can move between the CIRCA items as they choose (2009) - CIRCA sessions can encourage more singing and moving to music - Interconnected items in the image bank put less strain on an individual’s memory (2009) - Caregivers don’t have to work as hard to keep an interaction going (2010) 	<ul style="list-style-type: none"> - Caregivers do not spontaneously use music playing as a way of communicating with persons with dementia (2009) - People with dementia could become agitated or upset if they didn’t recognise someone in the photos (2009) - Designers avoided incorporation of personal photos - Large amount of time required by staff to learn the method (2009, 2010)

2 Diary interview method

Author: Bartlett, 2012; 2014

Description: Study on dementia 'Activists' using dementia diary interview method

Papers: Method and empirical

Research design features: ethnographic, small-scale, longitudinal, multi-method, multimodal, participatory

Case description narrative:

This methodology paper (Bartlett, 2012) is an account of Bartlett's research study into activism in dementia outlines the potential for modifying the diary interview method. This is a highly detailed reflective account that takes into consideration the methodological approach in the kinds of exploratory questions that are addressed. Whilst the research design is sound, there are shortcomings in the methodology from a perspective of familiarisation of AAC with participants and also the reporting of the characteristics of the participants. Reporting did not provide a profile of each case in the small sample (16). There was also a lack of diagnostic and cognitive/intellectual/memory skills data recorded. The paper dealt with the conceptual issues well. The complex nature of analysing multimodal data and the analysis and analysis techniques were well illustrated. However, there was a lack of information about the nuances of the relationship between different kinds of data and how each were captured and 'translated' into common data. There was some reference to the researcher role and the role of others in facilitating communication although this was not dealt with as a substantive topic. Finally, there was acknowledgement of the limitations in the perception of diary keeping and of the positive aspects of choice- but it was unclear how far this led to a greater sense of control in each case.

The empirical paper (2014) highlights the extra lengths researchers went to immerse themselves in the activism events in order to collect data in action and to experience some of the key events people were talking about in their diaries. Further detail on the analysis steps were also provided including the relationship between conceptual and analytical framework.

2 Theoretical context	Methodology	Participants	Interpretation
<ul style="list-style-type: none"> • Ethnographic, qualitative • Participatory • Concepts: involvement of persons with dementia in society and activism, having their voices heard 	<ul style="list-style-type: none"> • PWD required to choose a diary method (1 of 3 mediums- photographic, audio, written) • None previously had experience of a post reflective account • Viewed as by researchers as an additional to the methodology tool box • Participants collaborated with others to create the diary • Researchers carried out the pre-diary interview, analysis and collected their own secondary data to contextualise the method and post-diary interview • There was some confusion over the purpose of the 	<ul style="list-style-type: none"> • Overall a narrow range of information about the sample provided, with the exception of contextual detail on activism. • Individuals had their own timeframe for completion of research • Group characteristics- ‘activists’ may have been more likely to tell their story 	<ul style="list-style-type: none"> • Variation in diary length between participants • No detail about transcription techniques • Content analysis and thematic interpretation used • Analysis of subjective experiences • Combines textual, visual and field data • Choice of medium added to the understanding about that individual • Visual data on environment collected

	methodology amongst participants		
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2 Facilitators	Specific factors	Barriers/limitations
<ul style="list-style-type: none"> - Opportunity for participants to ask questions - Post diary interview at the participants home - Participants knew intuitively what was required in keeping a diary - Secondary data collected by the researcher gave them a sense of the “material worlds of the participants” (McCulloch 2004 cited in Bartlett (2012) p. 1721) - Multi-layered account of participant’s lives as campaigners and people - Audio diaries added a new dimension to the data 	<ul style="list-style-type: none"> - Choice of diary keeping medium - Participants offered control of content and pace of interactions - Offers a dynamic understanding of people’s lives (Pink 2007 in Bartlett 2012p1719) - Augmentation with observation- <i>“Observing allowed us to collect ethnographic data from participants ‘in action’, and to experience and visualise for ourselves some of the events they were reporting in their diaries”</i>(2012 p.1720) - Participants collected other additional material to contextualise their experiences - Researcher gained a more holistic view of the person - Sensorial ethnographic approach (2012) 	<ul style="list-style-type: none"> - Photographic material had to be filtered by researchers - Participants became more aware of diminishing skills - Diaries could be particularly brief - Requires motivation and inspiration about the tasks to be performed - Some participants didn’t connect with the concept of diary keeping - Lack of familiarity with concept of diary keeping - Researcher had to filter the images prior to analysis - Some participants found the process to demanding or even demeaning

3 Life Story Work

McKeown et al 2010a (methodology)(& McKeown et al 2010b empirical)

Description: The use of life story work in practice

Papers: Methodology and empirical

Research design features: multiple case study design

Case description:

This project (McKeown et al., 2010b) employs a case description methodology to understand how the use of life story work (LSW) with people with dementia can enhance person centred care. Subsidiary methods included life story book development and pen picture and the collection of alternative data through conversations and observations of with people with dementia and interviews and stakeholders. However, the interviews concentrated on verbal methods to elicit a response. Researchers recognised positive shifts in staff reactions to the effect of the life story work. The analysis methods are explicit and explained in depth. Case studies also provide individualised summaries of participants and the relevant information of their context.

The methodology paper sets out an understanding of the different methodologies and relates their appropriate use in different stages of the condition. The methods paper has a broader purpose to look at challenges to involvement of people with dementia in research, but also consent and capacity issues. The issue of disengagement also discussed, alongside researcher's ability to reflect and interpret on-going consent issues. The authors display an awareness of power imbalances in research. Overall, there is evidence of consideration of 'how best to involve people'- however, this has a verbal frame of reference.

3 Theoretical context	Methodology	Participants	Interpretation
<ul style="list-style-type: none"> • Constructivist paradigm • Theoretical framework-personhood • Person centred care concept was central 	<ul style="list-style-type: none"> • Conversations with observations took place with the person with dementia, these were centred on the person with dementia's priorities and concerns • The process of using the LSW were discussed with key 	<ul style="list-style-type: none"> • Participants had a diagnosis of dementia and had complex behavioural-stipulation of method that those who participated would directly benefit from experience in a therapeutic or 	<ul style="list-style-type: none"> • Use of a thematic framework identified through a systematic literature review • Framework Analysis method for interpretation • Researchers could make links between a person's past and present

	<p>stakeholders using semi structured interviews</p> <ul style="list-style-type: none"> • Three cases developed a life story book and one a pen picture. • Stakeholders were involved in the planning and implementation of LSW 	<p>other</p> <ul style="list-style-type: none"> • Different life story methods recommended for people at different stages of dementia • Rich description of cases • Good explanation of sampling rationale 	<p>(2010abp.155)</p> <ul style="list-style-type: none"> • Nonverbal analysis important in eliciting the voice of the person with dementia (2010b) • Power was an important concept- involved consideration of the different status afforded to professionals (Wilkinson 2002 p.1941 in McKeown 2010a) • Nonverbal interpretation reflection- <i>“care staff were able to ‘hear’ verbally the person with dementia but seemed less in tune to picking up bodily manifestations of self.”</i> (2010b p.156)
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3 Facilitators	Specific factors	Barriers
<ul style="list-style-type: none"> - Nonverbal responses analysed also - Staff got to know the person - Direct questions were not used - Researchers are required to do a significant amount of groundwork before commencement of the LSW getting to know their biography (Jan Dewing method) (2010a p.1939) - Staff were required to undertake one hour training about LSW - Researchers considered the issue of power between the researchers, staff and the researched - Participants could be offered a choice in the type of life story they wanted to make - Researchers had to be flexible and sensitive to different contexts and meanings (2010b p.150) 	<ul style="list-style-type: none"> - Previous research indicates that taking a planned approach to implementation does not always happen and can prevent LSW being sustained in practice - Persons with dementia and their carers need to be actively involved in the method <i>“increasingly there is consensus that people with dementia should be included in research as active participants, not purely as subjects (Cottrell & Schultz 1993, Downs, 1997, Dewing 2002, Hubbard et al 2003, Hellstrom et al 2007)”</i> in McKeown et al (2010a p.1936) 	<ul style="list-style-type: none"> - LSW has got the potential to remind participants what they have lost

4 Photo-elicitation and autodriving

Shell (2014)

Description: Photo elicitation and auto driving in research with person with dementia

Papers: Methodology paper

Research design features: Qualitative study

Case description:

Methodology paper detailing challenges, decisions and reflections- several 'lessons learned' and 'challenges sessions'. Consistent and detailed paradigm and theoretical stance. Researcher reflects on their dual role as a researcher and a clinician. The researcher demonstrates their understanding the implications of adapted role in helping to prompt participants to take photos and suggest what they should photograph. The paper explains the approach to inclusivity taken. That is, people with dementia can be involved in the 'here and now'. Autodriving in photo elicitation involves the examination of everyday experiences. In terms of skills as a prerequisite, the researcher suggests there may be a certain level of cognitive thought which may be required to do interviews. The researcher argues that a special focus on reflection, field notes and discussion can add dimensions to the interpretive research.

4 Theoretical context	Methodology	Participants	Interpretation
<ul style="list-style-type: none"> • Methodology was informed by symbolic interactionism (Blumer, 1969), principles of interpretive description theory (Thorne, Kirkham, & MacDonald-Emes, 1997), and positive psychology (Seligman & Csikszentmihalyi, 2000). • interpretive description theory • Key concepts: happiness-symbolic interactionism and positive psychology 	<ul style="list-style-type: none"> • Highly interpretive, could increase choice and inclusivity but intervention of the researcher is apparent • Lengthy introduction and preparatory phase • Participants had difficulty remembering the rationale for image selection. As a result, the research design was changed. • The photographs were not coded or analysed in this study. They were solely used as a catalyst for discussion at the final meeting. 	<ul style="list-style-type: none"> • Participants had to be capable and willing to express themselves verbally and score between 3 and 7 on the Short Portable Mental Status Questionnaire (SPMSQ) at the initial meeting to ensure mild to moderate level of AD at the time of the study. • The unfamiliarity of the digital camera posed different problems (P.176) • The inclusion criteria for the participating individuals with AD were: English-speaking adults age 70 or older, living in the community with a family member or an identified caregiver 	<ul style="list-style-type: none"> • <i>“In this study the ability of the individual to control his or her photographs supported the personhood of the individual by providing an opportunity for the expression of self” (P.175)</i> • <i>“The inclusion and active engagement of the participants in picture-taking make them partners in the research process” (P.175)</i> • Transcripts of interviews were analysed using interpretivist theory (Thorne et al., 1997) to gain access to the participant’s understanding of happiness.

4 Facilitators	Specific factors	Barriers
<ul style="list-style-type: none"> - Flexibility of approach- “As a result of the initial review, the methodology was changed and the last eight participants were accompanied by [the researcher] rather than a caregiver when taking the pictures.” (p. 175). This helped participants to understand the creative process. - Researchers spent time before interviews so that the participant could become comfortable with the researcher - Inclusive approach to participants with severe impairments - Minimizing the time between taking the photographs and the interview may reduce, but probably not erase, the challenges posed by memory impairment. - Journaling and discussions with a mentoring researcher-clinician could increase researchers’ awareness of themselves 	<ul style="list-style-type: none"> - The photographs and the ensuing dialogue provided the opportunity for reflection and the development of meaning - Having a choice of a traditional camera, a digital camera, and a camera phone was important to enable each participant to find a suitable option. - The methodology is ‘present-focused, subjective, and co-constructive’. (P. 180) 	<ul style="list-style-type: none"> - The unfamiliarity of the digital camera posed different problems. For instance, using the camera’s monitor or holding it. - In the interview which occurred approximately one week after taking the pictures, all four persons with AD had difficulty remembering both the experience of taking the picture and the rationale for its selection. - Some participants asked the researcher for suggestions on what they should take photos of

5 Multimedia Biographies

Authors: Smith et al., 2009

Description: Multimedia biographies for people with Alzheimer's disease

Papers: Methodology only

Research Design features: exploratory descriptive study looking at the production and screening processes for the methodology. Interview at 3 months' time point.

Case Description:

This paper is a descriptive reflection on the use of multimedia biographies as a reminiscence and social stimulus tool. The paper seeks to specifically highlight the methodological nuances of the production and screening of Multimedia Biographies (showing the final version of the film). The role of the family members was targeted as the facilitative factor in producing the materials, as opposed to staff. The dynamics of the decisions and challenges in production are discussed. The development of this multimedia tool is discussed. The screenings bridge the divide between the object and enhancement of communication but the space for reminiscence remains predominantly verbal. The timespan is lengthy at 1 year's production. The role of the researcher also appears vital to facilitate production. The reporting of the individual processes are demonstrated but other factors which may provide information about participant social contexts or background or other communicative information, is not present. Whilst the engagement and reminiscence theoretical frameworks are laid out here as a structure, there is very little in terms of data analysis or interpretation tools/structures. The screenings were recorded and there were semi-structured interviews with participant and families or caregivers at 3 and 6 months, again using a verbal format.

<p>5 Theoretical context</p> <ul style="list-style-type: none"> • Participatory • Reminiscence & social stimulus concepts 	<p>Methodology</p> <ul style="list-style-type: none"> • Researchers required at least one family member of the people with dementia to be involved in the project alongside them • Participants and their family had to commit to working with the researchers over a one-year period and to devote approximately 60 to 100 hours of time to the project. • The MBs averaged 39 minutes in length • As researchers became experienced with the process, they were able to produce MBs in 60 to 90 hours of work. 	<p>Participants</p> <ul style="list-style-type: none"> • Little info on each participant • However, some contextual information about hours off researcher production work, number of months to produce, length in minutes of MB 	<p>Interpretation</p> <ul style="list-style-type: none"> • The experience of the project was a negotiated dialogue • Screening experience allowed data collection about increasing personalisation • Inclusiveness of approach towards family members , however this may have been at the expense of some independence • Personal media such as family photographs were used alongside anonymous photos • Analysis highlighted the subjectivity of creation of MB and re-representing a life- a daughter queried “<i>“how do you highlight a person’s life? What do <u>we</u> think is important?”</i>”(p.29) • Analysis of the negotiated dialogue
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5 Facilitators	Specific factors	Barriers
<ul style="list-style-type: none"> - Assistance of family members “essential” (p.302) - Researcher facilitated the dialogue for the MB between family and person with dementia - Draw on the familiarity of television - Does not rely on staff to carry out reminiscence sessions- “<i>we attempt to create opportunities for life review at home, harnessing the support of family members to support older adults</i>” (p.292) 	<ul style="list-style-type: none"> - Mediator role of researcher within family useful to resolve disputes about context or format of MB - Enhancing participant’s view of personalisation (p.300) - Choices provided to family members “<i>family members engaged in telling the story of a life history, as they chose the content, designed the story, and, provided the narration.</i>” (p.300) - “Everyday technology concept” to facilitation and utilisation of method (p.292) - The screenings of the MBs with the participants and their families provided opportunities to observe and reflect on issues including personalization, music, interface, technical matters, and screening preferences. - Participants work extends to the use of personal materials themselves or the family members involved in MB production are the best guides to help to locate content and even interface enhancements for the MB that will be meaningful and engaging. - Researchers sought assistance for creation of MB from someone more neutral than family members “<i>Our researchers facilitated dialogue amongst families when there were differences of opinion and attempted to keep MB production on a timeline. So it would still be helpful to have an adult within the family or someone who is outside of</i> 	<ul style="list-style-type: none"> - Emotionally challenging elements - Time for family members and researchers - Technical challenges - Participants with AD required at least one family member to be involved- researcher acted as mediator

	<i>the family with maturity and sensitivity to mediate disputes or conflicts that may arise” (p.303)</i>	
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6 Photovoice

Author: Wiersma 2011

Description: Using Photovoice methodology with people with early stage Alzheimer’s disease

Papers: Methodology only

Research design features: Photo voice project undertaken and follow up interview plus a thank you session

Case description:

In this study, four people with early stage Alzheimer’s took part in a Photovoice study to understand in part their experiences and to allow the researcher could see how the methodology worked (including challenges and benefits). The article concentrates on implementation issues, as opposed to the analytical or representational issues that emerged. The challenges are approached through the lens of the ethics procedure. The author talks discusses how to adapt the method (using current methodological guidance from other vulnerable populations) to balance creative freedoms and capacity inclusiveness with protection of the rights of subjects in photos (consent for taking pictures of the public needed to be sought beforehand). There was also an augmenting element of the photos to the follow-up interviews. It is unclear how the analysis for the project output of photos. The follow up interviews complimented each other from an analytical point of view. It is also unclear how the theoretical framework of Creative Analytical Practice translates or analyses visual data. There is very little information recorded about participants.

6 Theoretical context	Methodology	Participants	Interpretation
<ul style="list-style-type: none"> • Participatory design to hear the voice of people with dementia • ‘Creative Analytic Practice’ framework “<i>designed to enable people to record and reflect on their community’s strengths and concerns</i>” (p.4) • Inclusion and concepts 	<ul style="list-style-type: none"> • Entrusts cameras to participants to allow them control on data collection but also to become potential catalysts for change in their communities • Caregiver played more of a central role in helping the people with dementia to collect data • Researcher engaged in lengthy process of explaining the stages of research • Method used in conjunction with a follow up interview to describe photos 	<ul style="list-style-type: none"> • Little participant information recorded 	<ul style="list-style-type: none"> • Little interpretive/analytical process information, although some representational issues discussed “<i>Because the data involves participants’ stories in both textual and visual form, my discomfort with being ‘in control’ of these stories has been heightened in comparison to doing more ‘traditional’ qualitative research.</i>” (p.11) • Creative analytic practice provides the frame for analysis • Participants chose a small number of key images prior to researcher analysis

6 Facilitators	Specific factors	Barriers
<ul style="list-style-type: none"> - Time scale - Explanation of research procedure - Degree of freedom to capture experiences. - Researchers assisted with the practical tasks such as the development of photos to lessen demands on participants 	<ul style="list-style-type: none"> - Perhaps the small number of people involved. - Researcher logistics assistance. - Assistance from carers in consent for subjects - Participants were authors of their own images - Photos and interviews used in combination <i>“the pictures provided me with a sense of ‘here and now’ , the interviews were crucial to providing a context to the participant’s photos”</i> (p.8) 	<ul style="list-style-type: none"> - Ethical considerations in being able to conduct a focus group- thank you session used as an alternative. - Issues around research potentially revealing diagnosis also an issue. - Uncertain whether this method can be applied with people with mid or later stages of Alzheimer’s or other dementias. - Consenting process requires a carer to be involved. - Concept of capturing experiences- using project for a catalyst for change in the community may be an over ambitious statement for the scope of the project.

7 Nonverbal communication and working with pictures

Allan, 2001

Description: Exploration of ways for staff to involve people with dementia in developing services (including alternative communication)

Paper: Empirical

Research design features: The aim was to develop and carry out individualised approaches to communication and consultation, which were devised by the staff in collaboration with the researcher. The fieldwork therefore comprises a set of small-scale Initiatives, some of which continued over 10 months.

Case description:

This study explored ways in which staff could involve people with dementia in providing feedback about services. The conceptual frameworks were: meaningful consultation, and capturing voice of persons with dementia. Due to the style of the report, perhaps there is little information about analysis or specifics about the way that data was converted into themes once conversations about services are prompted. The data is presented through type of communication such as finding the right type of verbal communication, pictures, consultation as part of another activity, nonverbal communication. The relevant exploration of augmenting or alternative communication is embedded within a project that also elicits the perspectives of staff and their experiences of collecting the data for the involvement study of persons with dementia. There are lengthy and rich explanations about how the researcher implemented the project and kept it going the different forms of communication. Challenges are also covered at length. There are also rich descriptions of the sub-categories of the types of communication such as the use of different personal pictures or generic pictures. However, there is little comparison between approaches. On balance, there is more of an emphasis on the outcomes for staff.

<p>7 Theoretical context</p> <ul style="list-style-type: none"> • Interpretive study but design lends from evaluation framework 	<p>Methodology</p> <ul style="list-style-type: none"> • Staff as well as researchers had to gather data-methods included audio recording of conversations with people with dementia, freeform notes, feedback and researcher field notes • The final form of consultation tended to be verbal • Cards with single words printed on them were also used as a stimulus to conversation about various subjects. In some cases the words were names of emotions such as 'happy', 'bored', 'sad', 'irritated', 'relieved' • The approach which most staff used at first was to identify times of the day (or night) when they felt that the participant was experiencing a specific state or emotion 	<p>Participants</p> <ul style="list-style-type: none"> • There was no formal attempt to classify participants in terms of the severity of their dementia 	<p>Interpretation</p> <ul style="list-style-type: none"> • Verbal conversations were often the resultant mode of communication having been prompted • The practice of recording and later examining recordings of conversations explained • It was recognised that different approaches to documentation suit different people, and that the nature of the work meant that it was sometimes difficult to keep notes at all. • Researchers stated It was recognised in many of the settings that particular members of staff were especially able to communicate with certain service users, although attempts to analyse exactly what was different about
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	<ul style="list-style-type: none"> • With some individuals with dementia it was indeed very difficult finding starting points, and took much longer to get going than for others • Involvement of staff to facilitate method was intensive 		<p>their approach often eluded the researchers</p>
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<p>7 Facilitators</p> <ul style="list-style-type: none"> • Negotiating flexible approach-seeking an alternative or changing the direction of the research • Researchers gave the participants the direct opportunity to tell their story through sensitive listening and prompting • Participants talked about the possibility of having certain feelings without necessarily having to admit to them directly • The staff were 	<p>Specific factors</p> <ul style="list-style-type: none"> • Discussion included strong emotional expressions about other services the person had used • <i>“The person could experience an alternative ‘frame’ for the situation, for example apparently believing that they were at school or at work, rather than attending a day centre” p.52</i> • Sometimes pictures were used in a much less focused way • Method could establish a routine for communication work • Ideal opportunities for communication may be found during personal care • As these examples 	<p>Barriers</p> <ul style="list-style-type: none"> • The researcher recognise that like anyone else, people with dementia experience variations in their moods and preoccupations, abilities and interests, and inclinations to participate in activities. it is clear that there are challenges in finding the right opportunity to undertake a specific piece of work • However, responses were not necessarily so direct • Interaction can be painful, frustrating and anxiety-provoking, we should also recognise that for staff the activity can also be difficult • Some responses to pictures were much less predictable. • Reliance on verbal within nonverbal methods • Some staff members were better at prompting than others
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<p>clearly very aware of the importance of this type of interpersonal behaviour, both in terms of what the person with dementia expressed and also in terms of their own approach and style of presentation and communication.</p>	<p>demonstrate, it is about creating “<i>opportunities for people to bring to bear those very human processes and qualities that we all value and appreciate in our relationships</i>” (p.66)</p>	
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8 Talking Mats™

Murphy et al., 2013 & Murphy et al., 2005

Description: Use of Talking Mats™ methodology to help people with dementia and their carers to make decisions together

Papers: Empirical (2013) & proxy methodology (2005)

Research Design features: Mixed method study. Comparison of Talking Mats™ and the use of ‘usual communication methods’

Case description:

The research design for this empirical paper is comparative. Talking Mats™ method is contrast with the person with dementia's usual communication method. The study shares common features with intervention and assessment research designs. The analysis measured subjective concepts such as involvement. The information about the sample was limited. However, the severity of dementia was recorded. The method was backed by effectiveness studies for other populations. The methodology paper examined the use of Talking Mats™ as an interview tool with frail older people. It is explorative study that concludes that Talking Mat™s was a useful and enjoyable method for allowing people to express views.

8 Theoretical context	Methodology	Participants	Interpretation
<ul style="list-style-type: none"> • Quantitative methods use an objective Involvement measure • Key concept is daily living decision management • Method designed to help people with dementia to understand and respond more effectively (Murphy 2005) 	<ul style="list-style-type: none"> • Requirements of a person with dementia to be aware of their diagnosis and comfortable with the terminology used • Requirements for living arrangements and English language are specific to topic under study • Talking Mats™ is accessible, inexpensive and adaptable for any setting • Designed to keep the conversation on track for longer by creating a 	<ul style="list-style-type: none"> • Little information about person with dementia or the carers involved • Minimum verbal input required (Murphy 2005) • Can help to clarify confused speech • Method may also be useful for those for whom English is a second language 	<ul style="list-style-type: none"> • Collaborative method privileging person with dementia symbol selection and placement • Development of a Visual Involvement Measure • In terms of data collection the concepts were simplified and an objective stance adopted • Video data

	<p>visual reminder</p> <ul style="list-style-type: none"> • Researchers did not collect data until the second and third visits • Researcher facilitated discussion between person with dementia and carer by asking open-ended questions • Based on 3 sets of symbols to navigate topics, options and a visual scale of opinion (Murphy 2005) • Used amongst person with dementia who have different communication abilities 		<p>generated- this enabled analysis of qualitative information also, however analysis description is brief – the identification of key themes</p> <ul style="list-style-type: none"> • Nonverbal communication is included
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8 Facilitators	Specific factors	Barriers
<p>Empirical: Murphy 2013</p> <ul style="list-style-type: none"> - An innovative and positive approach - Participants were reminded they didn't have to discuss every topic - Confirmation of selection of symbols - Enables joint discussions to take place - Selection and placement of symbols - Visual reminder through symbols- interviewees can stay on track (this assists memory) <p>Methodology: Murphy 2005</p> <ul style="list-style-type: none"> - Video analysed on repeated viewings to ascertain the security of responses - Cognitive mapping allows comparison of patterns in data and identify unique reflections p.103 Murphy et al 2013 - The method helps participants to understand and respond more effectively - Researcher collected field notes 	<ul style="list-style-type: none"> - <i>“By facilitating such conversations, it may be possible to identify strengths and abilities, correct misperceptions about abilities and preferences, reduce anxiety on the part of both the person with dementia and their carer, and give expression to their concerns in a safe, non-confrontational way” (2012) p.178</i> - Responses determined by verbal and nonverbal behavioural outputs - Participants had time to place symbols and placement of those symbols contained meaning - Indicators for picking up if the participant is unengaged or does not understand the topic have been built into the method- they provide triggers for researcher to stop the discussion if necessary <p>Methodology: Murphy 2005</p> <ul style="list-style-type: none"> - Choices confirmed by the participant - Topics are separated into manageable chunks - Picture symbols allow greater amount of personalisation 	<ul style="list-style-type: none"> - Carers could have a greater sense of involvement than the person with dementia - A researcher shouldn't assume a person's ability to take part- participation may not be appropriate of a person with dementia is unaware of their surroundings or if they cannot understand visual symbols - The method relies on the skills of a researcher to understand when a sub-topic should be pursued and more generally the view point of a person with dementia - Researcher skill also involved in starting and maintaining interactions (2005) - The method is only a snapshot of the view of the person with dementia- it is not a permanent representation

<ul style="list-style-type: none">- Method reduces memory and comprehension demands- During the interaction, the focus is on the mat rather than a more direct face-to-face interaction- Sub-mats can be used to explore sub-themes- Mats provide a structure for a conversation- The mats allow participants the time and space to think about the information they have been presented with		
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9 Nonverbal interviews and observations

Nygård, 2006; Nygård and Starkhammer, 2007

Description: The use of everyday technology by people with dementia living alone- use of nonverbal observational tasks and interviews

Papers: A methodology paper (2006) and an empirical paper (2007)

Research design features: exploratory & ethnographically inspired qualitative studies

Case description:

This is a methodology paper on the use of ethnographically inspired observational tasks and interviews. The observational tasks are viewed as a form of augmenting communication and the experience is interactional in, a way that observations normally are not. The study below is part of a later raft of research where tape recorders were used. This body of research is quoted in the methods paper and it includes the observational tasks mentioned. The data is rich as it outlines many of the benefits of the methods and how they are suitable to the declines in functioning experienced by people with dementia. However, the 'inclusive' approach and corresponding theoretical framework of personhood is well developed. The paper highlights some of the limitations of a purely biomedical understanding. There are many links between the way the method is conducted and analysed, and the advantages in accessing the voice of people with dementia. Much of this relates to support, and the researcher role in understanding their role and the role of the people with dementia. The empirical paper is an example of the method which encourages people to interact during observed interactions in their own environment. Participants are asked to show how and to narrate why and when they use the equipment being studied.

9 Theoretical context	Methodology	Participants	Interpretation
<ul style="list-style-type: none"> • Argues that the biomedical perspective is too limited, although this study is quasi experimental • Theoretical framework of understanding the experienced world of people with dementia 	<ul style="list-style-type: none"> • Qualitative observations used to complement to simultaneous, open-ended interviews • Method yielded rich data on the experiences of persons with memory deficit or dementia • Observations made possible the inclusion of people with dementia with more severe impairments whose verbal ability may have diminished • The images of self-presented by the participants will be influenced by the researcher • Portable recorder used during ethnographic approach • Spontaneous reflections are made concerning what happens while doing, often revealing sudden insights or feelings. • <i>“In the first session, the interviewer mainly focused on determining the activities that the</i> 	<ul style="list-style-type: none"> • Variation in the participants’ age, gender, educational background and social situation to achieve as rich and varied examples as possible • Taxonomy created describing hindrances and difficulties in the use of everyday technology in a person with dementia • They were interested in capturing the experiences of people who still needed to use everyday technology in their daily lives- participants in the mild to moderate stage of the disease. Administration of other independent living measures. 	<ul style="list-style-type: none"> • In completing the field notes, the data collector made use of the tape-recorded material from the same situation. Finally, she combined the field notes and the interview transcripts into coherent texts to analyse • It was possible to create a narrative from the participants placement of events in their explanation • <i>“When interviews and observations are combined and performed in a natural context, the comments made and actions executed will be more closely connected to the experience”</i> (Nygård, 2006 p.104) • The researcher argued that when the ability of people with dementia to is being assessed, it is vital to consider the compounded circumstances in each situation • Giving voice concept critiqued in Nygård, 2006 • Interpretation of silences

	<p><i>participant engaged in at home, including the equipment that was most commonly used. In the subsequent sessions ,the participant was continually encouraged to both show how and narrate when and why the equipment was used” (Nygård & Starkhammer 2007 p.146)</i></p> <ul style="list-style-type: none"> • Multiple points of data collection and observation, collecting a range of situated tasks, to evoke a response in action and narrative • Memos were continually recorded, covering the researcher’s ideas, comments and questions, as recommended 		
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9 Facilitators	Specific factors	Barriers
<ul style="list-style-type: none"> - The context may provide a reminder and support - Positive aspects of context were: the contribution of observation, speech adaptations, time allowed to participants, showing by doing - The researchers argue in qualitative interviews one of the key issues is building relationship with sufficient trust and rapport to enable the informants to open up and invite the researcher into their experienced world - Researcher tried to understand how personal characteristics and status might affect fieldwork relationships with individual subjects encountered - Determining activities a people with dementia wants to engage with, researchers encouraged participants to recount parallel experiences, researcher needed to observe the participant in the moment, researchers allowed the participants to try to solve problems, researchers made memos and field notes (Nygård & Starkhammer 2007) - Data enables comparison of strategies amongst 	<ul style="list-style-type: none"> - Ethnographic approach (Bogdan & Biklen, 1998) - Researchers built up enough trusts with participants to be invited in their '<i>experienced worlds</i>' (Nygård, 2006 p.103) - Each participant in his or her home or surroundings. - Each data collection session encompassed the situations and activities that were relevant for each particular participant, and their use of artefacts and services within this - Observations of people with dementia performing tasks in context -facilitates a micro level analysis e.g. turning handles and switches correctly (Nygård & Starkhammer 2007 p.152) Also allows comparison of individual strategies - "<i>The observations were invaluable when it came to uncovering difficulties, because the participants were very seldom able to explain the nature of their difficulties</i>" (Nygård & Starkhammer, 2007, p.154) - Observations occurred over 3 weeks - Observations 'in situ' created the opportunity for spontaneous reflection 	<ul style="list-style-type: none"> - As the research approach was explorative, the researchers made no attempt to interpret data as evidence of the participants' impairments - Differences remained between a real situation when a person and the quasi-experimental situation in the study

<p>participants</p> <ul style="list-style-type: none">- The interviews were conversational and were adjusted to each individual situation- People could find it easier to present a rehearsed story		
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10 Story, music and art

Jonas-Simpson, 2005

Description: Giving voice to expressions of quality of life for persons living with dementia through story, music and art.

Papers: Empirical

Research design features: qualitative descriptive study

Case description:

This is a qualitative case description which utilises a number of arts and music based methods to elicit voice about lived experience. Although in a therapeutic setting, this study is not designed to seek emotional or psychological improvements from participants. The main weakness of the reporting is the lack of detail about the different nuances of the methodologies either in: art, music or song writing. It is also unclear how the choices to use any of these emerged. The structural framework was a verbal interview where the different methodologies took an augmenting role to deliver a common output- a story. More information is needed about the communication skills and activity preferences of participants. There was also little reflection about the effect of the locked cognitive unit environment. Whilst theoretical frameworks and analytical techniques provided, there was a lack of implementation context.

10 Theoretical context	Methodology	Participants	Interpretation
<ul style="list-style-type: none"> • Qualitative and interpretive paradigm • Use of Human Becoming theoretical framework • Linkages to the lived experience of dementia concept- Kitwood 	<ul style="list-style-type: none"> • Special focus on communicating with those with limited verbal abilities • Methods can help establish meaning, rhythmicity and co-transcendence • Researcher-participant interviews were conducted with the participant and either a music therapist or an art therapist • Role of the researcher as: therapist, facilitator, song writing session facilitator 	<ul style="list-style-type: none"> • Location of the people with dementia as residents in a 'locked cognitive unit' • Little other information about participants 	<ul style="list-style-type: none"> • Data recorded by audio recording and written songs (unclear if art was used as data) • Reference for analysis techniques although no further detail on processes

<p>10 Facilitators</p> <ul style="list-style-type: none"> - Researchers as therapists. - Familiarity with different research methods 	<p>Specific factors</p> <ul style="list-style-type: none"> - Specific skills of researcher- they were either an art therapist or a music therapist. - An interview was set up within the planned music or art therapy session. 	<p>Barriers</p> <ul style="list-style-type: none"> • Inclusiveness in terms of choice of engaging in different methods although responses happened within a largely verbal framework during the interviews • Researcher chose method of expression the participant would engage with
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11 Dance therapy

Nystrom and Lauritzen, 2005

Description: Dance therapy with persons with dementia

Papers: Methodology paper

Research Design features: Group dance therapy sessions with elderly, demented persons were video-taped and analysed with a focus on how verbal and non-verbal modes of communication were used by the participants

Case description:

This is an empirical, reflexive paper. The analysis and findings sections are rich in detail of role of researcher and complexities of understanding the verbal and nonverbal modes of communication. The paper focuses on a patient's capacity rather than limitations. Group therapy dance sessions are the mechanism for generating verbal and nonverbal behaviours. However, the control of the choice of moving between different modes such as singing, body movement or speech belonged to the researcher. Interpretation of meaning rests solely with the researcher and still appears to be quite a 'top down' approach consistent with a therapeutic paradigm. This is important for a study which seeks to understand the conditions that allow for different types of expression. Links between capturing, transcribing and analysing data.

<p>11 Theoretical context</p> <ul style="list-style-type: none"> • Therapeutic context • Theoretical framework surrounding modes of expression 	<p>Methodology</p> <ul style="list-style-type: none"> • Video film is viewed as a medium in itself • Dance therapy has several mediums within it • The dance therapy sessions took place at the nursing home, once a week for ten weeks, with one of the nursing staff present to help and support the participants whenever needed • The therapist (Krister Nyström) has a long experience of dance therapy, also with elderly persons. In this project, he is a therapist as well as a researcher. This dual role of course raises some methodological questions. They argue that a dialogical perspective, with a focus on interaction and the joint construction of the communicative processes, could contribute to an understanding of the capacity of the patient 	<p>Participants</p> <ul style="list-style-type: none"> • Little information about participants with the exception of communication ability • participants vary in their capacity to use speech in their communication with others, including those with memory difficulties 	<p>Interpretation</p> <ul style="list-style-type: none"> • Questions about inclusiveness given that the choice of mode to communicate in was driven by the therapist • Video-film offers specific advantages, such as richness and permanence of data • A video film was created • Rich detail of analytical challenges-communication is translated into the 'digital symbolic system' • Transcription process included nonverbal and utterances • Analysis of non-verbal communication is problematic and can be interpreted in different ways and ascribed different meanings. • Attempts to capture 'the richness of human communication' p.314 • Joint construction of communication considered
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11 Facilitators	Specific factors	Barriers
<ul style="list-style-type: none"> - <i>“The choice of research contexts (such as the setting and the tasks given to the participants) creates possibilities as well as limitations” p.313</i> - <i>“observations of the demented persons’ activities in the dance therapy sessions helped us to identify even quite subtle expression of thoughts, wishes and experiences and these were revealed in communication with others” p.314</i> - Methodology can showcase the ‘embodied’ experience 	<ul style="list-style-type: none"> - Staff required to facilitate - Experience of dual researcher therapists beneficial - Different interpretations of meanings were discussed with a team of therapists to establish meaning - Verbal translations of the dance were offered by the researcher in the moment - In order to understand communication, it can be of particular interest to look at the modes of expression as well as different contexts or conditions that will help or hinder capacity to communicate (p.298) 	<ul style="list-style-type: none"> - Being part of the process can be problematic. The researcher has to somehow disentangle his or her experiences as a therapist from descriptions of the group processes Data could be lost in the process of audio transcription so the group used video and observational analysis

12 The Feelings Art Group

Bober et al., 2002

Description: 'The Feelings Art Group' as a vehicle for personal expression

Papers: Empirical only

Research Design features: The programme provided an on-going group intervention for moderately to severely demented nursing home residents that were focused on making life more meaningful in the present. Elements of the reminiscence and activity group models (including sensory stimulation and reality orientation were incorporated into the group design).

Case description:

The intervention uses a therapeutic model and occurs in a residential setting. The evidence is qualitative but described as anecdotal. There are a range of methods which are based on a range of sensory experiences which are delivered in a group and individual settings. The facilitators decide what is and what is not working for an individual at any stage. Differences in skills and preferences for different methods are discussed. There is some contextual information but the group sessions do not always occur with the same participants. The specifics of the staff role in strategies to elicit augmented responses via a mood thermometer assessment tool are discussed but the nuances and effect of their role are not. There is also a lack of analysis of the process of arriving at perceived outcomes.

12 Theoretical context	Methodology	Participants	Interpretation
<ul style="list-style-type: none"> Intervention (social work) Use of Yalom's theory of 'Here and Now' Links with reminiscence concepts 	<ul style="list-style-type: none"> The feelings art group met weekly for one hour over the course of 6 months for 26 sessions. Participation varied across individuals Some residents were focused on visual arts and expression. Others responded to the group on a social level. At the start and finish of the programme each group participant was asked individually 'how do you feel?' and was shown the Mood Thermometer, drawn on 	<ul style="list-style-type: none"> Little information about group demographics and other characteristics However, there was some consideration of the homogeneity of the group from a perspective of diagnostic and cognitive functioning capabilities Unsuitable candidates were said to be those 	<ul style="list-style-type: none"> Members of the groups were said to spontaneously engage in reminiscence Facilitators could experiment with a range of methods to connect with people Group members also communicated their memories nonverbally

	<p>a sheet of paper.</p> <ul style="list-style-type: none"> • Range of elements to the programme- -aside from the art segment the programme might also include added sensory stimulation such as listening to music, touching 3 dimensional objects or smelling essence oils • Clinician role used to facilitate methodology • Facilitator role was repeated week after week • Facilitators also chose topics 	<p>who were agitated or exhibited wandering</p> <ul style="list-style-type: none"> • Crucially the participants in changed every week – conceptualised as single sessions 	
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<p>12 Facilitators</p> <ul style="list-style-type: none"> - Using multisensory artistic devices as a stimulus for expression, the group applied social work strategies to client interventions and focused on resident’s remaining strengths rather than deficits. - Flexibility in recording a range of members responses - <i>“Group leaders provided direction, assistance, support and encouragement in each member’s efforts to participate” p.80</i> 	<p>Specific factors</p> <ul style="list-style-type: none"> - Sensory stimulation was linked to reminiscence (which in generally was not assumed to be verbal in nature - Facilitators tried to deliver a positive group environment 	<p>Barriers</p> <ul style="list-style-type: none"> - The facilitators decided who was a suitable candidate , sometimes based on wandering or agitation
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Appendix item 21: Variability in study design

Study	Study design	AAC	Outcomes
Allan, 2001	Large-scale project with multiple explorations of understanding consultation with services	Working with pictures & nonverbal communication	A set of training materials supporting staff and managers in exploring the area of service user consultation.
Astell et al., 2010	Evaluative design and assessment of product, an empirical paper which was an evaluation- quantifiable coding of CIRCA for verbal and nonverbal tasks compared with traditional communication methods	Computer based support system- CIRCA	To understand whether CIRCA device meets the need of PWD and caregivers in mutually satisfactory interactions for reminiscence
Bartlett, 2014	Ethnographic, small-scale, longitudinal, multi-method, multimodal, participatory	Diary interview method	To establish what motivates people with dementia to engage in activism, and to discover the impact activism on a person's well-being
Bober et al., 2002	Qualitative analysis of an intervention	The Feelings Art group	To understand the Feelings Art Group as a means of expression for thoughts and feelings in a group of older adults with moderate to severe stage Alzheimer's and Alzheimer's-type dementia
Jonas Simpson, 2005	Qualitative descriptive study	Story, music and art expression	To produce descriptions of quality of life through voices of lived experience through story, music and art
McKeown et al., 2010b	Multiple case study design	Life Story work	The value of LSW in delivering person-centred

			care
Murphy et al., 2013	Mixed method study. Comparative elements comparing structured, unstructured and Talking Mats™ enhanced conversations. Comparative quasi-experimental study	Talking Mats™	To use involvement measures to understand reasons behind increases of feelings of increased involvement & to demonstrate the effectiveness of Talking Mats™
Nygård and Starkhammer 2011	Exploratory & ethnographically inspired qualitative studies	Nonverbal interviews and observations	To describe and discuss methods and issues, make suggestions for context and to create a taxonomy of difficulties in the domains of uses of everyday technology
Nyström and Lauritzen, 2005	Exploratory qualitative (therapeutic intervention)	Dance therapy- including capturing nonverbal communication	To understand how alternative contexts of communication, other than those of the everyday life of the care institution, might allow for a better understanding of PWD's capacity to communicate with others
Shell, 2014	Qualitative study	Photo elicitation and autodriving	To explore the benefits and challenges in using photo-elicitation and autodriving with individuals diagnosed with mild to moderate Alzheimer's disease.
Smith et al 2009	Exploratory descriptive study looking at the production and screening processes for the	Multimedia biographies	To provide a space for reminiscence and for

	methodology. Interview at 3 months' time point.		researchers to develop understanding of practice
Wiersma, 2011	Photovoice project undertaken and follow up interview and a thank you session	Photovoice methodology	To understand and explore Photovoice methodology for Alzheimer's disease population

Appendix item 22: Variability in populations, interventions and settings- Narrative Synthesis

Presence of information about sample categorised across domains:

- 13 Bibliographic/demographic
- 14 Previous AAC use information
- 15 Health and functioning
- 16 Communication
- 17 Environmental factors
- 18 Activity factors
- 19 Personal factors
- 20 Heterogeneity of the patterns of use of AAC across the sample

Study	Categories addressed in reported information about participants (Categories 13-20 on data extraction- see key above)	Diagnostic information	Setting
Allan, 2001	13 15 17	Dementia	Residential setting
Astell et al., 2010	13 14 15 16	Mild to severe	Residential setting

	19		
Bartlett, 2014	13 17 19	Dementia	Community
Bober et al., 2002	13 15 16 17	Severe	Residential
Jonas Simpson, 2005	13 15 17	Mild to severe	Residential setting
McKeown et al., 2010b	13 15 16 17 18 19	Dementia	Residential setting
Murphy et al., 2013	13 15 16 19	Dementia	Community
Nygård and Starkhammer 2011	13 15 16	Mild to moderate	Residential setting

Nyström and Lauritzen, 2005	13 15 16	Dementia	Community
Shell, 2014	13 15 16 17	Mild to moderate	Community
Smith et al 2009	13 15 18	MCI and Alzheimer's disease	Residential setting
Wiersma, 2011	13 18	Mild	Community

Appendix item 23: Theoretical and methodological variance- Narrative Synthesis

Study	Approach	Facilitation elements (derived from methodology element of data extraction)	Analytical framework	Details about interpretation of data
Allan, 2001	Service evaluation-pragmatic, flexible approach	<p>Researchers tried to find out about the particular aspects of the service which were most significant or meaningful to the patient</p> <p>Staff-led intervention to research their interpretation of patient communication. Staff were asked to record when they recognised patient was in a particular state of mind and staff</p> <p>With some individuals with dementia it was indeed very difficult finding starting points, and took much longer to get going than for others.</p>	yes	no
Astell et al., 2010	Reminiscence	<p>Research was undertaken by experienced, multidisciplinary team</p> <p>The team had to overcome challenges in involving people with dementia in the design process, including understanding their requirements</p> <p>There were difficulties attached to including both family caregivers and professional care staff in the</p>	yes	Yes

		development process		
Bartlett, 2014	Ethnographic	Preparatory work to introduce participants to the study Secondary data collection and analysis was undertaken	yes	No
Bober et al., 2002	Therapeutic- Group therapy	Researchers had to be able to administer mood thermometer Researcher required to facilitate: art and sensory stimulation such as listening to music, touching three-dimensional objects or smelling essence oils	yes	No
Jonas Simpson, 2005	Qualitative participative methodology- quality of life through story	Informed consent negotiated through a proxy Consent in the moment also sought from participants Researcher-participant interviews were conducted with the participant and either a music therapist or an art therapist	yes	Yes
McKeown et al., 2010b	Reminiscence – active involvement approach	Required involvement of multiple stakeholders	yes	Yes
Murphy et al., 2013	Empirical evaluation of AAC system in real life	Researcher required to introduce and prepare project Familiarity with training PWD to use	yes	no

	situation	Talking mats™ Facilitation of structured and unstructured communication interactions- in replicable conditions		
Nygård and Starkhammer 2011	Ethnographic	Researchers experienced in ethnography Researchers had to be adaptable to the differing number , length , context of interviews or observations Researchers built relationships with sufficient trust and rapport Research memos were continually recorded	yes	Yes
Nyström and Lauritzen, 2005	Therapeutic- Dance therapy	The researcher was an experienced dance therapist Interpretation of subtle interactions is	yes	Yes
Shell, 2014	Qualitative participative methodology- photo-elicitation	Preparatory phone calls Researcher had to make adaptations to the protocol Researcher self-reflection - negotiated dual role of researcher and clinician	yes	Yes
Smith et al 2009	Reminiscence	Researcher helped to assist carers in compiling multimedia biographies Technological knowledge required Researchers monitored of the rapport with the family member and the	No	no

		PWD		
Wiersma, 2011	Qualitative participative methodology-creative Analytical Practice	<p>Researcher established themselves as the point of contact</p> <p>Researcher assisted in consenting process (participant took photos)</p> <p>researcher integrated pictures taken into interview process</p>	no	no

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