The Development of a 'CORE' for Health Settings

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Abstract

At present there is no outcome measure suitable for use across different health conditions seen within Clinical Health Psychology (CHP) settings which satisfactorily capture the main aspects relevant to service user outcomes. Several types of measure have previously been developed according to different assumptions about what and how best to measure outcomes. Measures may broadly be divided into symptom-focussed, theory-driven or pragmatically approached. Considering these in the context of psychological theories and the Recovery Approach suggests that superordinate concepts, such as distress; psychological mechanisms; satisfaction with functioning; the therapeutic alliance; and concepts such as hope, supportive relationships, empowerment and finding meaning, are relevant to CHP outcomes. The aim of this study was to begin to develop a global outcome measure for use in CHP. Consensus was sought regarding the most relevant concepts to measure by conducting a literature review and clinician interviews. Concepts were formed into items using a set of principles to ensure they were accessible and relevant to a broad range of service users. This item pool was refined, both conceptually and linguistically, using clinician feedback over three iterations of an online Delphi survey. Qualitative data was analysed thematically. Elicited themes were compared to those concepts thought to be relevant to CHP outcomes immediately before the Delphi study, in order to provide a quality control check on their relevance. Some consensus was reached by the end of the Delphi study, which provides partial support for the hypothesis that rather than each condition having its own unique psychological profile, concepts are shared across conditions. The lack of complete agreement may have been due to differences in service users' presentations, differences in concepts identified by clinician participants, or different interpretations of the language used to convey concepts. Whilst item construction may have been biased by subjective judgement, the Delphi methodology likely mitigated the effect of this on the final item pool. Recommendations are offered for how this pilot outcome measure may be developed into a final version.

Table of Contents

List of Tables

List of Figures

Abbreviations

ACT: Acceptance and Commitment Therapy

AIS: Acceptance of Illness Scale

AMH: Adult Mental Health

BDI: Beck Depression Inventory

BPS: British Psychological Society

CBT: Cognitive Behavioural Therapy

CHP: Clinical Health Psychology

CIQ: Community Integration Questionnaire

CORE-OM: Clinical Outcomes in Routine Evaluation

CP: Clinical Psychologist

DoH: Department of Health

DPM: Dual Process Model

DSM-IV: Diagnostic and Statistical Manual for Mental Disorders

FHSAs: Family Health Service Authorities

FNE: Fear of Negative Evaluation Scale

HADS: Hospital Anxiety and Depression Scale

IES-R: Impact of Events Scale-Revised

IIP: Inventory of Interpersonal Problems

LGI: Leeds General Infirmary

LoC: Locus of Control

LSAS: Liebowitz Social Anxiety Scale

MOCI: Maudsley Obsessive Compulsive Inventory

MSES: Mindfulness-Based Self-Efficacy Scale

NICE: National Institute for Health and Clinical Excellence

OAS: Obesity Adjustment Survey

PCA: Principal Components Analysis

PCIDD: Perceived Control of Insulin-Dependent Diabetes

PDQ-R: Personality Diagnostic Questionnaire

PHC: Previously Highlighted Concepts

PROM: Patient Reported Outcome Measure

PSEQ: Pain Self-Efficacy Questionnaire

PSYCHLOPS: Psychological Outcome Profiles

QoL: Quality of Life

QoL-CD: Quality of Life for Chronic Diseases

RCT: Randomised Controlled Trial

RVI: Royal Victoria Infirmary

SAS-SR: Social Adjustment Scale – Self Report

SCL-90-R: Symptom Checklist

SJUH: St. James' University Hospital

TAPES: Trinity Amputation and Prosthesis Experience Scales

YBOCS: Yale-Brown Obsessive Compulsive Scale

Introduction

At present none of the specialist outcome measures widely used in Clinical Health Psychology (CHP) are comparable in utility or accuracy to those used in Adult Mental Health: most are either suitable only for specific health conditions or specific aspects which apply across conditions. There does not appear to be an outcome measure which can be used across different health conditions seen within CHP, which captures the main aspects relevant to service users' outcomes. The aims of this research were to seek consensus from people working in CHP regarding which are the most relevant psychological concepts across health conditions and generate items which may inform a global outcome measure in CHP. Within this study, 'concept' refers to all aspects of treatment outcome, such as symptoms and psychological mechanisms.

Outcome measurement in Clinical Psychology

Why measure outcomes?

Services are increasingly encouraged to find ways of demonstrating their effectiveness. The development of the National Institute for Health and Clinical Excellence (NICE) in 1999 marked a drive towards evidence-based practice. NICE guidelines summarise the best available evidence for interventions, in order to improve the quality and cost-effectiveness of service provision. This evidence may come from many types of research, but Randomised Controlled Trials (RCTs) are frequently referred to as the 'gold standard' treatment design as they have the highest internal validity. However, RCTs require the employment of rigorous conditions and provide evidence for efficacy rather than effectiveness. Conversely, services can demonstrate their effectiveness by conducting outcomes research. It is comparatively easier to conduct outcomes research, and results have greater external validity. Consequently, services are encouraged to capture outcomes in routine clinical practice.

Recent legislation has focussed on capturing outcomes. One of the key objectives outlined in the White Paper, "Liberating the NHS" (DoH, 2010a), was to improve health outcomes. This led to the development of the NHS Outcomes Framework (DoH, 2010), which set out "outcomes and corresponding indicators that will be used to hold the NHS Commissioning Board to account for the outcomes it secures" (p3). Consequently, it is now imperative that services prove their effectiveness by measuring outcomes.

Measuring outcomes can be beneficial within therapy. They aid information gathering at assessment, facilitating service users' understanding of their difficulties, and communication between clinician and service user regarding the focus and effectiveness of therapy. During intermediate stages, measures can inform discussions about the suitability of various features of therapy, such as its pace. They also provide a relatively objective indication of the types and extent of changes achieved by the end of therapy. Outcome measures may be useful at many stages of clinical practice.

How are outcomes measured?

Whilst Patient Reported Outcome Measures (PROMs) have become increasingly popular in healthcare, there are various types of PROMs, each with their own advantages and disadvantages.

Nomothetic: Nomothetic measures are used to assess how known variables change over the course of an intervention, and to compare service users' outcomes against each other. A nomothetic measure can assess singular variables, such as social adjustment (e.g. the Social Adjustment Scale – Self Report (SAS-SR); Weissman, 1999), or multiple variables, such as symptoms of mental health (e.g. the Clinical Outcomes in Routine Evaluation (CORE-OM; Barkham, Evans, Margison, McGrath, Mellor-Clark, Milne, & Connell, 1998). The optimal number of variables assessed depends on the purpose of the measure. Within an individual service user's therapy, one variable may be selected for measurement, such as anxiety. Services often cater for people who differ in terms of their presentation and diagnosis; therefore multiple variables are relevant. Assessing multiple variables across a service can provide useful data as to its effectiveness.

A paradoxical feature of nomothetic measures is that they are ready-made despite encouragement for clinicians to collaboratively decide therapy goals with service users. The importance of shared decision-making has recently been highlighted in the Service User Experience in Adult Mental Health Guideline (NICE, 2011). This recommends that service users should be empowered to actively collaborate with clinicians in making decisions regarding their therapy. If a nomothetic measure is too prescriptive, then it could contradict and diminish the value of agreed therapy goals.

Idiographic: Idiographic measures assess service users' difficulties or treatment goals, but cannot be used to compare service users' outcomes against each other. Examples of idiographic measures include the Personal Questionnaire (Shapiro, 1961) and the Psychological Outcome Profiles (PSYCHLOPS; Ashworth, Shepherd, Christey, Matthews, Wright, Parmentier,

Robinson & Godfrey, 2004). These measures are collaborative and person-centred as service users define the question topics or even the questions themselves. As such, they have excellent construct and internal validity, at the expense of poor external validity. Consequently, whilst idiographic measures accurately evaluate treatment effectiveness, these data are less useful at a service-wide level.

The increasing drive towards outcome measurement has resulted in many services attempting to collect outcomes data routinely; however, the question remains as to which outcome measure is most appropriate. Whilst nomothetic measures provide data that enables service evaluation, idiographic measures facilitate collaborative goal planning. A balance between these two types of measure, which assesses a range of relevant concepts whilst allowing individual interpretation, would be valid at both of these levels.

Outcome measurement in Adult Mental Health (AMH)

What to measure?

Several types of AMH measure have been developed according to different assumptions about which outcomes are most important. Firstly there is the distinction between measuring outcome and process, and secondly the various ways in which outcome measurement has been operationalized.

Process: Both outcome and process measures are used within clinical practice (Morley, 1987). Whilst distinct measures have been developed to capture each (e.g. Outcome Rating Scale; Miller & Duncan, 2000; Session Rating Scale; Miller & Duncan, 2000), there may be overlap across them. Godfrey, Chalder, Ridsdale, Seed and Ogden (2007) defined process as "examining therapist behaviours, patient behaviours and the interactions between therapists and patients during treatment" (p254), whereas Andrews, Peters and Teesson (1994) defined outcomes as "the effect on a service user's health status attributable to an intervention by a health professional or health service" (p3). The outcome definition is broader than the process definition, and therefore some aspects of process may mediate outcomes. For example, the therapeutic alliance, a measure of process, is a reliable predictor of outcome (Horvath & Symonds, 1991). Consequently, it may be helpful for outcome measures to capture some aspects of process.

Outcome measurement has been operationalised in many ways, leading to the development of outcome measures based on symptoms, theory and pragmatics. This division can be used to navigate available measures, yet is somewhat artificial due to the overlap across these categories.

Symptom-focused measures: Outcome measures based on symptoms are very common. When service users attend AMH services they are often assessed according to diagnostic criteria, as described in the Diagnostic and Statistical Manual for Mental Disorders (DSM-IV; American Psychiatric Association, 1994). Diagnoses allow clinicians to consult NICE guidelines and identify which intervention has the best evidence base for the given disorder. It follows that symptom reduction is a desired outcome arising from psychological therapy. As such many measures have been based on DSM-IV diagnostic criteria. For example the PTSD Checklist (Weathers, Litz, Herman, Huska, & Keane, 1993), closely matches the symptoms necessary for a diagnosis of Post-Traumatic Stress Disorder as outlined in the DSM-IV (APA, 1994).

Nonetheless there are several disadvantages to symptom-focused outcome measures; examining these may help identify more appropriate measures. Firstly, service users with the same diagnosis can present differently; for example, some service users with a diagnosis of depression will present with low mood, insomnia and weight loss, others will present with anhedonia, fatigue and forgetfulness. Consequently, of all the possible symptoms of depression only some may apply to any one person with this diagnosis. Furthermore, most services cater to a range of diagnoses, each with many symptoms; it would be impractical to assess all of these. However perhaps there are overarching concepts which are common across diagnoses; these could be named 'superordinate' concepts, as this means 'of a higher rank'. Distress may be an example of a superordinate concept as other concepts such as low mood and stress, could be encompassed within this. Assessing superordinate concepts may be more efficient.

Secondly, there may be a more important outcome than symptom reduction. Howard, Moras, Brill, Martinovich and Lutz (1996) postulated the Phase Model of Psychotherapy, which suggests that therapy entails three phases. The first phase is 'Remoralisation' wherein service users feel hopeless and demoralised. In the second phase, 'Remediation', coping skills are developed in order to improve symptoms. The third phase, 'Rehabilitation', is where functioning improves. Howard and colleagues (1996) suggested that "the outcome criteria for each of these three phases are subjective well-being, symptoms and life functioning" (p1061). This suggests that solely assessing symptoms would fail to capture the full range of important outcomes. Furthermore some therapeutic approaches, such as Acceptance and Commitment Therapy (ACT), explicitly state that the treatment objective is not symptom reduction (Hayes, Luoma, Bond, Masuda, Lillis, 2006). Also, the aim for service users with chronic disorders such as Bipolar Affective Disorder is to better manage symptoms, rather than eliminate them. Therefore whilst fewer symptoms are often desirable, the main objective of therapy instead may be to improve symptom management or re-engage with activities.

Thirdly, this focus on symptoms contradicts the philosophy of the service user endorsed Recovery Approach. Broadly, the Recovery Approach to mental health may be considered a philosophical stance regarding individuals' 'journey to recovery'. Dickens (2009) explored how there is lack of clarity around the specific details of the Recovery Approach, although "the central tenets appear to be an emphasis on personal experience as opposed to medical expertise, (and) person-focus as opposed to illness-focus" (Dickens, 2009, p941). Important concepts within the Recovery Approach include hope, supportive relationships, empowerment and finding meaning (Repper & Perkins, 2006). The Recovery Approach seems to have received considerable interest within the NHS, in that the NHS Confederation's Mental Health Network and the Centre for Mental Health, commissioned by the Department for Health, piloted a "Supporting Recovery" programme. This became known as Implementing Recovery through Organisational Change (ImROC). ImROC defined 'recovery' as a "process through which people find ways to live meaningful lives, with or without the on-going symptoms of their condition" (2013, July 11th). This suggests that the Recovery Approach may be used as a framework for understanding treatment in AMH, and therefore is especially pertinent to outcome measurement. Furthermore, ImROC clearly state that 'recovery' does not concern symptom changes and therefore using a symptom-focused outcome measure appears to contradict a Recovery Approach.

In summary, symptom-focused outcome measures which focus on superordinate concepts may be more applicable to service users with a range of diagnoses and symptoms. However, solely assessing symptoms will omit other important outcomes including functioning, well-being, hope, supportive relationships, empowerment and meaning.

Theory-driven measures: Outcome measures which are based on psychological theories assess the effectiveness of particular types of therapy or psychological mechanisms. One of the main issues with theory-driven outcome measures is that many different psychological theories influence therapy. Clinical Psychologists (CPs) within one service often use different psychological models, or integrate several models. Therefore assessing outcomes based on just one psychological theory or model may miss a lot of important data.

An example of a theory-driven measure is the Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), as this is based on a cognitive behavioural conceptualisation. Whilst Cognitive Behavioural Therapy (CBT) is a common psychological approach, it is not used ubiquitously and even 'third wave' CBT such as Mindfulness focuses on significantly different aspects of service users' presentations. Indeed, comparison of the BDI to

the Mindfulness-Based Self-Efficacy Scale (MSES; Cayoun & Freestun, 2004) demonstrates this well. Theory-driven measures appear to be therapy-specific, such as the MSES and the BDI.

A theory-driven measure that is valid across therapies and diagnoses may be more useful; this may be achieved by assessing psychological mechanisms. By the end of therapy, service users may not fully recover from their presenting problems, but have learnt the skills to better manage these. Drawing from the Transtheoretical Model of Change (Prochaska & DiClemente, 2005), service users who attend therapy whilst in the 'Preparation' stage are ready to make small changes. If therapy is terminated when skills are learned but before they are regularly implemented, then service users are likely to continue improving post-therapy. If the current state is assessed, rather than altered psychological mechanisms or coping strategies, then the outcome measure may underestimate the effectiveness of this therapeutic work. Consequently, it may be helpful to assess the presence of mediators, which are "intervening variables that occur or change after application of a therapeutic agent or intervention and represent the potential mechanisms or causal agents by which a treatment affects outcomes" (Labus, 2007, p703). Measuring outcomes on the basis of psychological mechanisms may capture important information.

Pragmatic approaches: Some measures are adapted to capture what is considered important in specific clinical practice. Measures which have been adapted to be more practical in a specific population are very helpful, providing the adaptation is relevant throughout that population. The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was developed in order to detect anxiety and depression in service users with physical health conditions. As somatic symptoms are common in service users without anxiety and depression in this population, these items were specifically omitted. This is referred to as criterion contamination removal: irrelevant factors are removed in order to reduce systematic bias. Consequently the HADS (Zigmond & Snaith, 1983) is considered a useful tool for assessing mental health service users in a hospital setting. The difficulty here is that sometimes fatigue or insomnia is experienced due to mental rather than physical health problems, yet this is not captured. Furthermore, Carney and Freedland (2012) suggested that somatic symptoms of depression may be as good if not better predictors of cardiac events in service users with Coronary Heart Disease than cognitive symptoms. Therefore whilst pragmatic considerations are helpful, they must be applicable to all service users in order for outcome measure data to be useful at a service-level.

Whilst outcome measures based entirely on symptoms, theory or pragmatics may be helpful within population subgroups, they may miss important outcomes at a service-wide level.

Exploring these different types of measure suggests that other concepts, such as well-being and supportive relationships, are likely to be at least as important, if not more appropriate within a global outcome measure.

What measures are there?

In practice some measures may fit into two or more of those categories explored above. The BDI (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), for example, whilst theory-driven, is also symptom-focussed. Most AMH measures however are diagnosis specific; comparatively few are suitable across diagnoses. The high prevalence of AMH diagnosis-specific measures could suggest that services more commonly use measures to assess effectiveness at an individual rather than a service level. Table 1 illustrates some common diagnosis-specific measures. Most of these are symptom-focused, fewer are theory-driven, and fewer still are pragmatically adapted. This asymmetry suggests that AMH services predominantly focus on diagnoses rather than the therapy employed.

Table 1: Common mental health diagnoses and their accompanying outcome measures

Diagnosis	Example Measures
Depression	Beck Depression Inventory (BDI-II; Beck, Steer, Ball, Ranieri, 1996)
	Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)
Obsessive Compulsive Disorder	Maudsley Obsessive Compulsive Inventory (MOCI; Hodgson & Rackman, 1977)
	Yale-Brown Obsessive Compulsive Scale (YBOCS; Goodman, Price, Rasmussen, Mazure, Fleischmann, Hill, Heninger & Charney, 1989)
Post-Traumatic Stress Disorder	Impact of Events Scale-Revised (IES-R; Weiss & Marmar, 1997)
	PTSD Checklist (Weathers, Litz, Herman, Huska, & Keane, 1993)
Agoraphobia	Mobility Inventory for Agoraphobia (Chambless, Caputo, Jasin, Gracely & Williams, 1985).
Social Anxiety	Fear of Negative Evaluation Scale (FNE; Watson & Friend, 1969)
	Liebowitz Social Anxiety Scale (LSAS; Liebowitz, 1987)

More recently measures have been developed which capture a range of concepts considered relevant across diagnostic groups. The CORE-OM was developed in order to measure psychotherapeutic outcomes generally, "regardless of the clinical settings, mode of therapy or specific problems of the patients" (Barkham et al, 1998, p35). The CORE-OM has four subscales: Well-being, Problems, Functioning and Risk. These concepts reflect the earlier discussion on symptom-focused outcome measures which suggested that well-being and functioning may be important outcomes in addition to symptoms.

Outcome measurement in Clinical Health Psychology (CHP)

What is CHP?

CHP services offer psychological interventions to service users diagnosed with physical health conditions. It seems that some overlap across CHP and AMH populations is likely, as both may experience mental health difficulties. So, both populations may benefit from similar interventions, such as stress management. However CHP interventions, such as pacing (Meeus, Nijs, Van Oosterwijck, Van Alsenov, & Truijen, 2010), may not be as relevant in AMH. This difference appears to be because the aims of interventions in each population are different. Latchford and Fielding (1999) proposed that these populations differ as the focus of AMH interventions is on the mental health problem, whereas in CHP, interventions are largely focussed on improving the management of physical conditions. Also, CHP interventions may be informed by or tailored according to different theoretical frameworks to those used in AMH, such as the Health Belief Model (Becker et al, 1977) or the Illness Representation Model (Leventhal et al, 1984). To sum up, whilst there appears to be overlap in psychological interventions used across CHP and AMH, there also appears to be differences. However, it is certainly possible that these differences may not manifest in practice.

According to the British Psychological Society (BPS; 2008), some of the main areas Clinical Health Psychologists (CHPs) work in include: cancer, chronic pain management, cardiology, renal medicine, orthopaedics and obesity. Due to medical advances, people are now living longer with these conditions (Kaplan, 2002); the majority of service users referred to CHP services have chronic physical health conditions (hereafter called chronic conditions). In addition to these conditions, CHP service users experience psychological difficulties which hinder their management of the chronic condition. Consequently, the treatment objective within CHP is to improve management of physical health conditions.

What to measure?

Whilst the main objective in CHP is improved management of the chronic condition, this may be captured in various ways. Earlier, aspects of process, in addition to symptom, theory and pragmatic-based outcome measurement were examined in the context of AMH services. This suggested that assessing superordinate symptoms, functioning, well-being, hope, supportive relationships, meaning and the therapeutic alliance may be important aspects of outcomes.

Process: Process may be a particularly important aspect of CHP work. As discussed, therapeutic alliance is an aspect of process, yet also appears to be related to outcomes. A good alliance has been found to be related to higher service user involvement in therapy (Reandeau & Wampold, 1991). Furthermore, Hirsh and colleagues (2005) explored service user satisfaction with chronic pain treatment; they found that a good therapeutic alliance predicted satisfaction with improvement, and that service users satisfied with improvement were also more compliant with treatment recommendations. The treatment objective in CHP is to support improved management of chronic conditions, which includes treatment adherence, therefore aspects of process may be important outcomes.

Symptom-focused measures: It may be valid to assess symptoms which are shared across conditions in CHP. Physical health symptoms should not be assessed, as they are not expected to change and it would be inappropriate to base measures on symptoms of mental health diagnoses, as these are not ubiquitously prevalent. Instead service users present with psychological difficulties related to chronic condition management. There may be unique difficulties associated with each chronic condition; however it seems intuitive that these overlap across chronic conditions. Perhaps rather than each condition having its own unique psychological profile, concepts are shared across conditions.

As in AMH, functioning may be a key concept in CHP. The Phase Model of Psychotherapy (Howard et al, 1996) suggested that improved functioning is an important outcome. Some chronic conditions permanently impact on functioning, thereby preventing a return to pre-morbid functioning. As functioning does not necessarily change, it would be unhelpful to assume that no change equates to a poor outcome. Perhaps satisfaction with functioning is more important than functioning per se.

Theory-driven measures: Theory-driven outcome measures are helpful because they may reflect psychological mechanisms related to therapeutic objectives. Typical presenting problems in CHP include: poor medication or treatment adherence, difficulties in making decisions regarding their condition, and unwanted side effects of treatment such as nausea. Altered

psychological mechanisms, such as the development of coping strategies, may support service users to better manage their condition over the long term.

Theories such as Locus of Control (LoC) can be used to explain how service users overcome psychological difficulties. It is likely that many psychological mechanisms and theories are pertinent in CHP, although it is unclear how to usefully measure these. For example, a CHP service user may not adequately adhere to their medication regime, partly due to an external LoC, as they may feel that their condition is controlled by factors which they cannot influence. It may seem that a good outcome would be the development of an internal health LoC: if the service user felt more in control of their condition, this may promote self-efficacy and consequently improved treatment adherence. However Burnish, Carey, Wallston, Stein, Jamieson and Lyles (1984) established that an internal LoC is not always helpful. They found that chemotherapy service users with a high external health LoC show less negative affect. Therefore whilst an internal LoC may improve some difficulties, such as treatment adherence, it may be detrimental in other ways for some service users. For example, negative affect may lead to withdrawing from social support and disengaging from activities. Perhaps an internal LoC is more important when the treatment is complex and requires more planning to adhere to. In summary, whilst LoC is an important concept in CHP, the type of LoC required to produce a good outcome varies. Consequently, measuring theories or psychological mechanisms in a clinically meaningful way is complicated.

Pragmatic approaches: A pragmatic outcome measure is one which is adapted so that it removes criterion contamination, making it more relevant for a given population. As discussed, some chronic conditions permanently impact on functioning, so perhaps for a measure to be pragmatic in CHP it should not assess functioning. One of the overarching concepts in CHP is Quality of Life (QoL), which appears to be defined in terms of well-being rather than functioning. There is some variation with regard to defining the key QoL concepts, but largely they are focussed on how a person feels within various domains of their life rather than what they can or cannot do: Flanagan (1978) suggested these are physical well-being, relationships, community involvement, personal development and recreation, whereas Felce and Perry (1995) suggested five domains: physical well-being, material well-being, social well-being, emotional well-being and development and activity. Adapting concepts so they only assess relevant aspects will make the outcome measure more pragmatic.

In summary, a range of concept types have been offered which may be relevant to a CHP population, as illustrated in Table 2. As in AMH, symptom-focused measures fail to capture important outcomes in CHP. Alternatively, superordinate concepts regarding psychological

management of symptoms and satisfaction with functioning may be more appropriate. Furthermore, concepts such as hope, supportive relationships, empowerment and finding meaning, as featured in the Recovery Approach, may be relevant. Capturing psychological mechanisms and theories, such as LoC, may also be very important, although items should be worded so that they can be interpreted in a way that is most appropriate for the service user. Finally, in terms of pragmatics, a CHP outcome measure should not assess aspects which are unachievable, such as a change in functioning per se; rather, it may be more appropriate to assess concepts such as well-being. Perhaps a CHP outcome measure which assesses concepts within these categories will be more relevant.

Table 2: Relevant CHP concepts

Therapeutic alliance	Hope	Supportive relationships
Psychological mechanisms	Empowerment	Superordinate concepts
Well-being	Meaning	Satisfaction with functioning

What measures are there?

Many measures have been developed to assess psychological change in specific health conditions, as illustrated in Table 3. Measures in this table were selected on the basis of local availability, rather than an attempt to encompass the main health conditions which present in CHP. As local CHP departments are some of the largest in the UK covering a wide range of specialties, they may be representative of the most common chronic conditions in the UK. Furthermore in some areas, such as pain, there are many measures of a wide range of facets.

Table 3: Common CHP clinical areas and their accompanying outcome measures

Clinical Area	Outcome Measure
Cancer	Mental Adjustment to Cancer Scale (Watson et al, 1988; MACS)
Diabetes	Perceived Control of Insulin-Dependent Diabetes (PCIDD; Bradley, Brewin, Gamsu & Moses, 1984)
Obesity	The Obesity Adjustment Survey (OAS; Butler, Vallis, Perey, Veldhuyzen Van Zanten, MacDonald & Konok, 1999)
Pain	Pain Self-Efficacy Questionnaire (PSEQ; Nicholas, 1989)
	Patient Comfort Assessment Guide (McCorkle & Young, 1978)
Prosthesis	Trinity Amputation and Prosthesis Experience Scales (TAPES; Gallagher, & MacLachlan, 2000)

As discussed, diagnosis-specific outcome measures cannot be used for service-level evaluation. However, these measures may tap into concepts which are relevant across conditions. Several CHP outcome measures have been specifically developed to assess concepts across conditions. Table 4 illustrates some of these condition-general measures. These capture one or a small range of concepts.

Table 4: Common CHP expected outcomes and their accompanying outcome measures

Expected Outcome	Outcome Measure
Acceptance	Acceptance of Illness Scale (AIS; Felton, Revenson, & Hinrichsen, 1984)
Well-being	The Well-Being Questionnaire (Pincus, Griffith, Isenberg & Pearce, 1997)
Social functioning	Community Integration Questionnaire (CIQ; Dijkers, 2000)

Acceptance: The Acceptance of Illness Scale (AIS; Felton, Revenson, & Hinrichsen, 1984) consists of items which describe negative consequences of ill-health. The process of acceptance is complex, but it is an important concept in CHP. Karademas, Tsagaraki and Lambrou (2009) found that in service users hospitalised with chronic conditions, acceptance negatively correlated with psychological symptoms and positively correlated with self-rated health. It may be helpful to further explore what acceptance is.

Acceptance may refer to many different things. Thompson, Arnkoff and Glass (2011) reviewed the concept of acceptance and found some definitions, as follows. Follette, Palm and Hall (2004) suggested that acceptance involves three processes: observing psychological events, letting go of the desire to alter these events and seeing actual events as separate from psychological experiences. Whereas Hayes (2004) offered another definition: "openly embracing experience in the here and now and acknowledging reality in a non-judgmental manner" (Thompson, Arnkoff & Glass, 2011, p222). Adding further weight to the diverse interpretations of acceptance, the review acknowledged that the psychological conceptualisation is different from the everyday interpretation, which equates it with positive evaluation (Robins, Schmidt & Linehan, 2004). This suggests that the concept of acceptance may mean something different to service users and CHPs.

Well-Being: The Well-Being Questionnaire (Pincus, Griffith, Isenberg & Pearce, 1997) consists of three subscales: negative well-being, energy and positive well-being. This concept features in the Phase Model of Psychotherapy (Howard et al, 1996). Several studies have attempted to deconstruct the concept of well-being. Ryff and Keyes (1995) proposed a six factor model, including autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self-acceptance. This suggests that well-being is an overarching concept made up of several components.

Social Functioning: The Community Integration Questionnaire (CIQ; Dijkers, 2000) was developed for people recovering from traumatic brain injury. It contains specific items, such as "Do you have a best friend with whom you confide?" This supports the importance of social functioning in CHP and suggests related concepts are also relevant, such as emotional support.

This brief review of three condition-general measures suggests that important concepts may comprise several components and be interpreted in various ways. There are also CHP condition-general measures which capture a broader array of concepts. The Short Form-36 (SF-36; Ware, & Sherbourne, 1992) is used across physical health diagnoses and it assesses both physical and mental health, as illustrated in Figure 1.
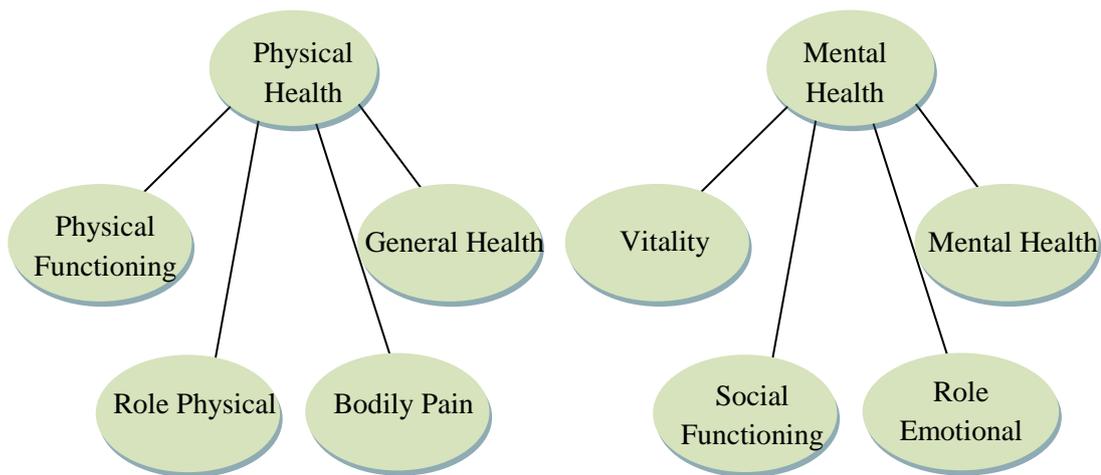
Figure 1: The scales and higher order clusters within the SF-36 (Adapted from Ware, Kosinski, Keller, 1994).

There is substantial evidence in support of the SF-36 being a good measure. On a conceptual level it fits in with some of the criteria discussed, as it assesses superordinate concepts and functioning. It is claimed to be a better measure than the Nottingham Health Profile as it detects positive in addition to negative health symptoms (Brazier, Harper, Jones, O'Cathain, Thomas, Usherwood, & Westlake, 1992); which the Recovery Approach suggests is important. Moreover, it has been well-validated in a range of health conditions, including: asthma (Bousquet, Knani, Dhivert, Richard, Chicoye, Ware & Michel, 1994), traumatic brain injury (Guilfoyle, Seeley, Harkin, Richards & Hutchinson, 2009), cystic fibrosis (Gee, Abbott, Conway, Etherington, & Webb, 2002) and endometriosis (Stull, Wasiak, Kreif, Colligs, Seitz & Gerlinger, 2009). Examining the literature suggests that the SF-36 is a widely used, popular measure in CHP.

However, there are significant shortcomings to this measure. The SF-36 was developed for use in a Medical Outcomes Study for RAND Corporation health insurance (Ware & Sherbourne, 1992): the aim was to assess when service users were recovered from their health condition and able to return to work. The implication here is that service users will make a physical recovery from their condition. However, this is not the aim of psychological therapy with CHP service users. In CHP, the emphasis is on psychological and social aspects, which this measure scarcely covers.

Additionally some items have been operationalized poorly. The items "Does your health limit you in your ability to do vigorous activities, such as sports, running, lifting heavy objects?" and "Does your health limit your ability to walk a mile?" fail to account for individual differences inherent in service users' pre-morbid level of functioning (Hunt & McKenna, 1993). As

discussed, functioning is likely to vary significantly across individuals; but what seems more important, and universally applicable, is satisfaction with functioning. Moreover, this focus in the items obscures the impact of psychological mechanisms, such as those involved in the Dual Process Model (DPM; Brandtstädter & Rothermund, 2002b). The DPM suggests that whilst service users sometimes assimilate when contemplating activities, meaning they keep their goals and adapt their circumstances, at other times they accommodate, meaning they adapt their goals to make them more achievable. At times accommodation may be a healthy adaptation, but this is not captured by the SF-36.

In summary, similar categories of outcome measure may be helpful in CHP as in AMH. However these concepts may need to be operationalised differently due to the differences between these groups both diagnostically and in terms of the type of psychological intervention that is helpful. Intuitively these aspects suggest that different outcomes should be expected across AMH and CHP. Unfortunately it appears that there are no outcome measures which adequately assess a broad array of relevant concepts, such as psychological mechanisms, across health conditions.

Developing a new measure in CHP

A new measure is required to accurately capture outcomes in CHP. Currently CHP outcome measures assess specific conditions or a limited range of concepts across conditions. Whilst the CORE assesses a comprehensive range of constructs in AMH, the exclusive focus on mental health symptoms makes it unsuitable for routine use in CHP. A CHP alternative is the SF-36, as this is well-validated and can be used across conditions. Yet this measure is based on physical rather than psychological symptoms or theories. It would be useful to explore the possibilities of developing a new measure in CHP which could be used across chronic conditions to evaluate service effectiveness.

The Development of Existing Measures

Appraising how existing measures were developed will provide a useful guide for developing a new CHP global outcome measure. Below is a critical appraisal of one of the main measures used in CHP, the SF-36, and one of the main measures used in AMH, the CORE-OM. As this appraisal suggests that construction of the SF-36 was relatively poor, the literature was searched for examples of how other CHP measures have been constructed. Of these, one measure stood out as being well constructed: the Quality of Life for Chronic Diseases (QoL-CD) measure. An

appraisal of the development of the QoL-CD therefore is also offered, to illustrate a comparison of robustness of measure construction.

SF-36: This measure was constructed more as a conglomerate of other measures available at the time than a current reflection of stakeholders' key issues. Originally "the authors chose to represent health concepts most frequently included in widely-used health surveys (physical, social and role functioning, mental health, and general health perceptions) along with two additional concepts that are strongly supported by empirical study (bodily pain and vitality)" (Ware & Sherbourne, 1992; p474). There are risks associated with using concepts directly from existing measures: depending on how old the measures are, they may not be currently culturally valid. Concepts may have been more relevant if they were appraised and subsequently revised immediately prior to forming them into items Furthermore, as discussed the aim of the SF-36 was to assess when service users were recovered from their health condition and able to return to work. Regardless of how relevant the concepts listed above are to CHP, the process of transforming these concepts into items in alignment with this aim is likely to have diminished their relevance in CHP. For example, "role functioning" may be important in CHP, yet the aim in CHP is not necessarily to support service users to return to work. Therefore if the measure were tailored to CHP the item informed by the "role functioning" concept may have reflected satisfaction with role functioning. This study essentially only used one methodology to construct the SF-36 and therefore was vulnerable to bias. Triangulating by combining several research methodologies helps to overcome sources of bias and increases the validity of results. Consequently, there are several potential weaknesses to the way in which the SF-36 was designed.

Quality of Life for Chronic Diseases (QoL-CD): This CHP outcome measure used a more comprehensive method of construction. Wan, Tu, Messing, Li, Yang, Zhao, Gao, Yang, Pan & Zhou (2011) recently commenced the development of a system of Quality of Life Instruments for Chronic Diseases, starting with a General Module. Initially a focus group comprising physicians, researchers and a medical educator discussed which domains should be represented within the measure. Representation from a range of stakeholders at this stage may have ensured that a more comprehensive set of domains were generated and therefore improved the measure's validity. A nominal group comprising a similar professional membership reviewed existing measures and proposed items for each of the postulated domains. Members of each group ranked the importance of each item, discussed these rankings and eliminated the lowest ranked items. As discussed within the SF-36 appraisal, there are risks associated with using concepts from existing measures. However, this systematic method of ranking items may have helped to make it more culturally valid at the time of construction. However, omitting items prior to

consultation with service users was rash as there may have been differences of opinion across the two groups; not consulting service users privileged professionals' opinions and may have biased the item set. A sample of 10 service users and 10 clinicians were interviewed, after which items were modified and refined. 86 participants, including service users with chronic diseases and nominal group members scored the importance of each item, resulting in a preliminary scale of 38 items rated most important. Whilst this shows that service users were only involved in the later stages of measure construction, it appears this occurred in a meaningful way, as considerable amendments were made following their involvement. Involving service users is crucial for ensuring the measure is culturally relevant and more likely to be acceptable to the service users to whom the measure will be administered in practice. Furthermore, this study triangulated several methods, including consultation with a range of relevant stakeholders, thereby increasing the validity of their results. This method of construction appears to be innovative and consisted of a range of advantages, as a range of stakeholders were consulted, service users were involved and several methods were used, which all supported the development of a more valid, less biased measure.

CORE: The CORE system of outcome measurement (Barkham et al, 1998) was planned over four years and involved several stages, making it a comprehensively constructed measure. Initially a stakeholder survey was conducted: both AMH service providers and purchasers were sent questionnaires to assess a wide range of information, including: aspects of service users' problems considered useful at both pre- and post-treatment stages, the measures used to assess these, and exceptions and barriers to routinely measuring outcomes (Mellor-Clark, Barkham, Connell and Evans, 1999). By specifically asking participants about a range of aspects related to service user outcomes, they helped to ensure that the resulting data would be comprehensive. Purchaser questionnaires were sent to chief executives at Family Health Service Authorities (FHSAs). Provider questionnaires were sent to clinical directors, directorate managers, senior consultants, directorate nurses and service managers responsible for mental health services, in addition to all members of the UK chapter of the Society of Psychotherapy Research. In total, 246 questionnaires were returned, representing 19% of those originally sent out. Whilst many participants were recruited, it appears all participants either had a high level of experience, as in clinical directors, or a specific interest in research, as in those from the Society of Psychotherapy Research. These clinicians may have been chosen on the grounds they were more likely to be interested and therefore participate in this study, or because they had more experience in outcome measurement. However, this may have contributed to systematic bias, due to participant homogeneity. Furthermore, these participants may have engaged in less direct clinical work at the time of the study, due to engaging in more research or management duties.

This could be improved by also recruiting clinicians who definitely carry a clinical caseload. Gathering information in this way ensured that the CORE reflected what was viewed as important in current clinical practice by a specific group of clinicians.

Existing measures were then assessed. Providers reported using the following measures the most: the Beck Depression Inventory (BDI; Beck et al, 1961), Hospital Anxiety and Depression Scale (HADS; Zigmund & Snaith, 1983), Symptom Checklist (SCL-90-R; Derogatis et al, 1973), the General Health Questionnaire (Goldberg, 1978), the Rosenberg Self-Esteem Inventory (Rosenberg, 1965) and the Inventory of Interpersonal Problems (IIP; Horowitz, Rosenberg, Baer, Ureño, Villaseñor, 1988). A team of researchers, including CPs, psychiatrists and a non-clinician, reviewed items in these measures. A further group of therapists, researchers and lay-people also reviewed items, to ensure representation from a broad array of psychological approaches, including psychoanalytic/dynamic, interpersonal, humanist, cognitive/cognitive-behavioural and systemic. This ensured that items chosen were relevant to service users accessing a range of approaches. Consequently, 45 people reviewed 638 items. They included items from the following measures to ensure coverage of under-represented items: Beck Anxiety Inventory (BAI; Beck et al, 1988), Borderline Symptom Index (Conte, Plutchik, Karasu et al, 1980), the Irritability, Depression and Anxiety Inventory (Snaith et al, 1978) and the Personality Diagnostic Questionnaire (PDQ-R; Hyler & Rieder, 1987). All items were then rated according to whether it might be; biased by demographic factors, cause offence, addressed subjective well-being, symptoms/problems, life functioning and whether it appeared suitable for a core self-report measure. The core team of researchers formulated a set of 40 items, including those with a positive focus, to ensure items were not exclusively problem-focused. As discussed, although there are risks associated with using items from existing measures, these appear to have been mitigated here. By consulting a large range of stakeholders on service user aspects prior to this stage, they ensured the measure would be based on a range of domains that were currently culturally relevant. Furthermore, items from these previous measures were thoroughly reviewed by a range of stakeholders, which again likely improved its cultural relevance. Finally, there was a quality control check. A wider group of therapists, researchers and lay people, specifically including those from ethnic minorities, were consulted for qualitative feedback on this item pool. Feedback was used to amend item wording and condense the pool down to 34 items. Psychometric properties were gained by administering this measure to 2000 respondents, including 55% lay people and 45% counselling and psychotherapy service users. Whilst the presence of non-clinicians in the development of the measure may have supported inclusion of a more comprehensive range of items, service users were not involved at any point in the construction of this measure. Lack of service user consultation risks the final measure

being considered unacceptable in terms of item wording or incomplete in terms of concepts represented, by the service users to whom the measure will be administered in practice.

The process of developing a measure

There is significant variability in terms of how outcome measures are developed. However, there are some key learning points from the critical appraisal of these three measures regarding how best to construct an outcome measure. Firstly, consulting a range of stakeholders helps to reduce systematic bias. Secondly, ensuring that existing measures are examined separately to stakeholder feedback, rather than purely consulting stakeholders on data from existing measures, helps to mitigate risks around the measure not being currently culturally relevant or valid. Thirdly, consulting service users helps to ensure the measure is acceptable to them and reflects what is important to them, and therefore improves its' validity. Fourthly, conducting quality control checks, such as a further group of stakeholders reviewing the item pool, ensures that research data obtained from earlier stages is of high quality. Implementing these points may support a more robust construction of an outcome measure.

Aims

Measures used in CHP are either suitable for specific health conditions or specific concepts which apply across conditions. No currently used measures appear to capture the full range of concepts relevant to CHP service users' outcomes. Therefore, the aims of this research were to: (1) seek consensus from people working in CHP regarding which are the most relevant psychological concepts across health conditions and (2) generate items which may inform a global outcome measure in CHP.

Methodology

Design

This research consisted of two stages, as illustrated in Figure 2. In Stage A, a systematic literature review and clinician telephone interviews were conducted, in order to generate concepts relevant to outcome measurement in CHP. These concepts were formed into themes, which were compared to categories highlighted as potentially important in the introduction, henceforth referred to as 'previously highlighted concepts'. This was in order to provide a quality control check regarding the themes' relevance. This was an inherently subjective process and themes could be relevant to more than one previously highlighted concept. No items were formed from previously highlighted concepts. Themes, from literature and interview data, were then formed into items in accordance with an agreed set of criteria.

In Stage B, a Delphi Group composed of clinicians working in CHP developed and refined the item pool generated from Stage A. The aim of this stage was to facilitate consensus regarding which items were the most relevant.
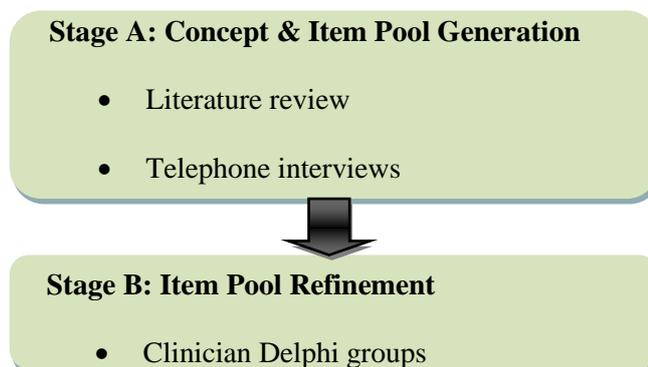
Figure 2: Flow chart illustrating methodological stages of the research

Participants

There were two groups of participants: Group 1 was a small sample of clinicians working in CHP and Group 2 was a large sample of clinicians working in.

Group 1 inclusion criteria

This comprised clinicians working in CHP at Leeds General Infirmary (LGI), St. James' University Hospital (SJUH) in Leeds, St. Luke's Hospital in Bradford, Royal Victoria Infirmary

(RVI) in Newcastle and Newcastle Freeman Hospital. These represent the largest CHP services in the North East of England, and some of the largest of such services in the UK. Only clinicians who currently held a clinical caseload in CHP were included. A recruitment email was sent to the head of seven CHP departments, who were asked to cascade this to all CHP staff. Clinicians were offered an interview slot at a convenient time for them. Interview slots continued to be offered whilst interviews were being conducted; no further interviews were arranged at the point when data saturation was reached. Data saturation was defined as the point when concepts proposed in interviews were very similar to those proposed in previous interviews.

Group 2 inclusion criteria

Clinicians were recruited through personal e-mail and a posting on the discussion lists of the British Psychological Society (BPS) Division of Clinical Psychology Faculty of CHPs (FacCHP). Most participants currently held a clinical caseload in CHP, but the researchers also selected experts who were not practicing clinicians in CHP whom it was felt would extend the range of expertise. This comprised of both clinical academics and active clinicians, including Liaison Psychiatrists, Health Psychologists and Specialist Counsellors whom the researcher felt had an advanced understanding of CHP issues.

Procedure and Data Analysis

Stage A: Concept & Item Pool Generation

Literature Review: A literature review was conducted in order to gain a preliminary understanding of the important concepts in CHP relevant to service user outcomes. This builds upon work already carried out, looking at example outcome measures. The purpose of this review was to identify a comprehensive range of concepts that are relevant in CHP, including those already captured within CHP or AMH outcome measures and those not yet addressed. The scope of the review was such that it included studies exploring concepts in CHP, in addition to current measures in CHP and possible related measures in AMH. The inclusion of AMH measures was to determine whether there were additional concepts relevant to CHP.

A specific procedure was devised to search the literature. Literature was searched within the following search engines: AMED, Embase, Ovid MEDLINE, PsycARTICLES and PsycINFO. The following search terms were used: "outcome or concept or construct" and "psych*". A basic preliminary search was completed to determine the most appropriate search terms in addition to these. Initially, "clinical", "health" and "psychology" were chosen, however this

search yielded only 36 hits. The literature was searched again using the terms "cancer or pain or cardio* or renal or orthopaed* or obes* or plastic*".These search terms were chosen as they capture the main chronic conditions which present in CHP (BPS, 2008). This search yielded 259 hits and therefore these terms were selected for the final literature search. The advantage of these search terms is that they elicited hits which were specifically relevant to CHP; the disadvantage is that they narrowed the focus of those hits to particular conditions. The search was restricted to articles published in the last 20 years, in order to ensure the review was of a manageable size.

Articles which did not meet certain criteria were excluded. A framework was devised in order to appraise the quality of the articles. This framework stipulated the following should have featured in each study: A clear hypothesis, an appropriate research design, an appropriate recruitment strategy, a clear report of how data was collected and analysed, and conclusions justified. Those articles which did not meet these criteria were omitted. Of the remaining articles, those which met the following criteria were excluded: participants who do not have chronic conditions; participants who were under 18 years old; exclusive focus on physical, rather than psychological aspects of chronic conditions. The remaining articles were reviewed for psychological concepts or outcome measures and recorded. The type of chronic conditions investigated in each article was also recorded (Appendix A).

Concepts which met a set of exclusion criteria were omitted. These criteria were developed to increase the likelihood of items being relevant to a broad range of chronic conditions. The criteria were as follows: specific to one type of chronic conditions (e.g. body image), impracticable to capture directly in an item (e.g. somatisation), unclear meaning of terms (e.g. morphologic).

In terms of data analysis, a list of concepts was compiled from the literature review. Concepts referred to either explicitly or implicitly in the outcome measures used in these studies were also included in this list. Analysis was loosely based on Thematic Analysis (Braun and Clarke, 2006): whilst concepts were not assigned codes, they were organised into themes. Each theme was defined by allocating a name to it. Themes were kept narrow and specific so as to minimise loss of detail. In this study, 'theme' refers only to those overarching conceptual units generated by thematic analysis.

Clinician telephone interviews: Participants were interviewed using a schedule (Appendix B). The aim of this interview was to ascertain which concepts were considered important in CHP. The main question was loosely based on ideas from Personal Construct Theory (PCT; Kelly, 1955). Kelly used a methodology of triads for eliciting constructs; an instruction often given is

to say that constructs are "a way in which two objects are alike and so different from a third" (Butt (2008, p70). This is thought to enable participants to think more about how constructs are related and facilitates the emergence of similarities and differences, therefore a deeper understanding of the constructs themselves. These principles were used to support participants to consider concepts relevant to CHP outcomes in more depth. These principles were adapted so it was more feasible to explore by telephone. CHPs were asked to hold in mind two service users they had seen recently: one who had significantly improved and another who had not. Participants were asked to consider which concepts were relevant to improved outcomes using their experience of these two service users. The intention was to facilitate more consideration of which concepts are unique to good outcomes.

Interviews were audio recorded and transcribed. Due to technical difficulties, one of the interviews was not recorded, therefore notes were taken instead. Each transcription was reviewed for psychological concepts and each instance of a concept was assigned a two figure code. The first figure corresponded to the interview number and the second figure corresponded to the line number within the interview transcription. Data was analysed using the same method as that used for the literature review.

Item Pool Generation: Themes elicited from the telephone interviews and the literature review were compiled into a list. All themes were recorded in a grid: each theme was recorded in its own row, unless two themes were very similar (e.g. Anxiety Symptoms and Worry) in which case they were recorded next to each other on the same row: interview and literature themes were not merged with each other. Themes were formed into items (Appendix C) whilst taking into account the factors listed in Text Box 1. Some items were formed from more than one theme, where themes were related; this was done to help the items make more sense, as certain themes had more meaning when combined with other themes.

- All items were worded in the present tense
- Item wording was considered accessible to a wide range of service users
- Items did not explicitly contain value judgments
- Items were written from the perspective of how service users *felt*, in addition to their *ability* to do activities, where appropriate, due to the restrictive nature of some conditions.
- Item phrasings were not based on therapeutic modalities
- Items were phrased to facilitate positive scoring, in order to simplify scoring

Text Box 1: Factors considered in forming concepts into items

The resulting items were reviewed and revised with SM and GL to ensure they made grammatical and semantic sense, and accurately reflected psychological concepts.

As discussed by Rust and Golombok (1989), prior to assessing a measure's psychometric properties, initially there should be approximately double the number of items than in the final measure. The aim was to produce a pilot measure and therefore to terminate at the point at which the outcome measure may be administered to service users to elicit its psychometric properties. The CORE has 34 items and the SF-36 has 36 items; the average number of items across these measures is 35. Consequently the aim was to produce a measure consisting of approximately 70 items.

Stage B: Item Pool Refinement

Clinician Delphi Groups: The Delphi Method is a systematic technique for gaining and refining feedback from a large panel of experts (Keeney, McKenna & Hasson, 2010). Online format enables all participants to remain anonymous. Participants are asked to comment on a topic in an initial online survey. Responses are refined by the researcher and fed back into a second round. This is repeated until consensus is reached. Some advantages of the Delphi Method are that it eliminates the influence of group dynamics and participant conformity to the facilitator's perspective and it may be conducted with a very large group of participants.

This stage consisted of an online survey (Appendix D), hosted by Bristol Online Survey (BOS) which comprised three iterative rounds. At the beginning of each round, participants were asked to indicate their professional background (i.e. CHP, Liaison Psychiatry, Health Psychology, Specialist Counselling or Other), their clinical specialism (i.e. Cardiac, Chronic Pain, Cystic Fibrosis etc.) and the number of years they had been qualified in their profession.

In each round participants rated items' relevance on a 5-point scale from "Extremely relevant" to "Irrelevant". At the end of each round items were arranged in order of their relevancy scores, according to the procedure illustrated in Text Box 2.

- Each participant's item rating was replaced with a score e.g. "Extremely relevant" was replaced with a "4" and "Irrelevant" was replaced with a "0"

- For each item the sum of participants' ratings was divided by the number of ratings, to produce a mean score

- Items were reorganised using this mean score, with those items assigned the highest score placed at the top of the list

Text Box 2: Procedure for Arranging Items According to Relevancy Scores

Participants were invited to comment on each item specifically and the item pool in general. Comments were used to amend item wording or to create new items. Comments on specific items were only considered for that item and therefore no data analysis was carried out on these comments between the rounds. Specific comments were reviewed as a whole upon completion of Stage B to consider any themes in the data. Comments which featured similar words were considered in context and their potential meaning interpreted.

General comments on the item pool were analysed. Suggestions for additional items were discussed with SM and GL to consider the extent to which they were relevant to CHP; if they were relevant, they were added to the item pool in the following round (Appendices E, F & G). Upon completion of Stage B, general comments across the three rounds were thematically analysed (Braun & Clarke, 2006). Comments were read several times to allow familiarisation of the data. Codes were generated by identifying features within the data that were relevant to CHP concepts, therefore the analysis was deductive. These codes were formed into themes and allocated names. Largely the data was analysed at a semantic level, as relatively surface level meanings were interpreted along with the significance of these meanings in relation to previous literature.

At the end of each round, items were rearranged according to their relevancy score, amended and new items added as described above. This item list was reviewed and revised, with GL and/or SM, to ensure they made grammatical sense, and accurately reflected psychological concepts. This list was then disseminated in the next round.

Ethical Aspects

The BPS's Code of Ethics and Conduct (2009) was consulted in order to assess the ethical implications of conducting this research. Accordingly, participants were provided with a comprehensive rationale, describing the aims of the research, when they were asked to participate. They were invited to ask further clarifying questions about any aspect of the research as and when they saw fit. Ethical approval was gained from the University of Leeds Faculty of Medicine and Health Ethical Review Panel for all three stages of this research (Appendix K).

Results

Stage A: Concept & Item Pool Generation

Literature Review

A literature review was conducted to gather relevant concepts in CHP. The database search yielded 259 articles. After removing duplicates, this left 129 articles (Appendix A). As illustrated in Figure 3, full articles were accessible for 62 references, and abstracts were accessible for 60 references. In total, 68 of these articles passed the exclusion criteria and therefore were relevant.
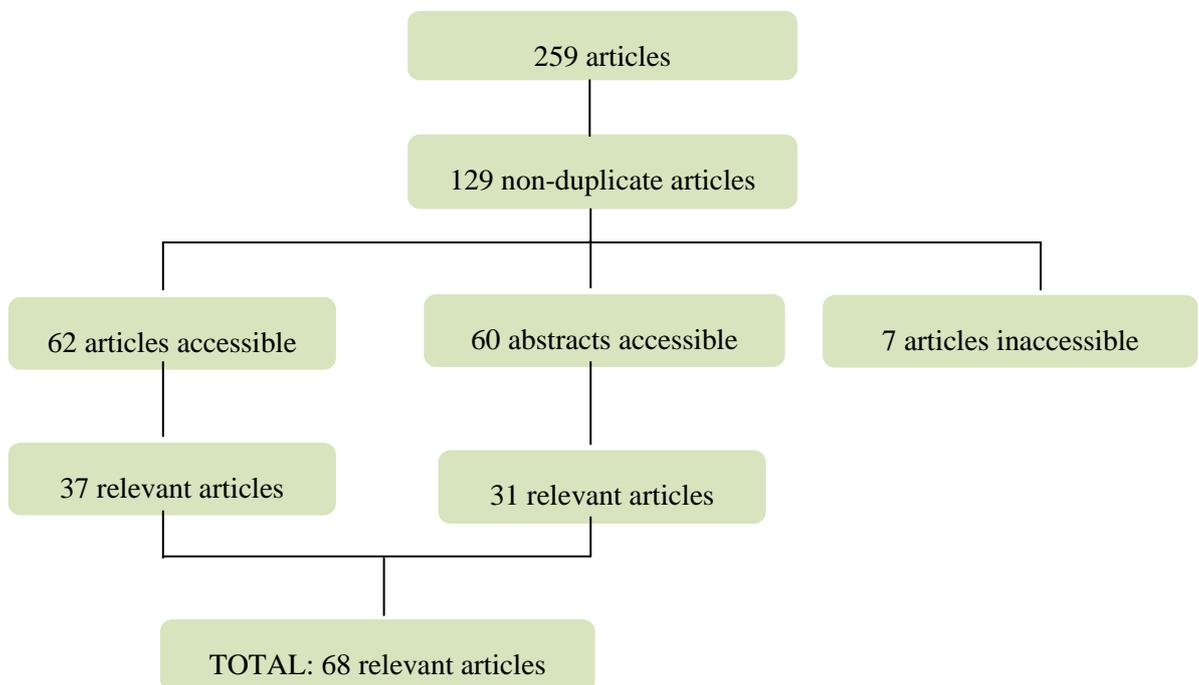
Figure 3: A flow chart of article accessibility and relevance

The 68 relevant articles were reviewed for psychological concepts and chronic conditions. This process resulted in 63 final articles, which described at least one psychological concept or used at least one outcome measure. Most were focussed on specific chronic conditions. Table 5 illustrates the number of articles focussed on each chronic condition. This shows that 98% were focussed on a chronic condition, and 78% were focussed on either cancer or pain.

Table 5: Frequency of articles focussed on each health condition

Chronic Condition	Number of Articles
Cancer	31
Pain	18
Obesity	4
Cardiac	4
Renal	2
Surgery	2
Musculoskeletal	1
None	1

Concepts were extracted from outcome measures referred to in this literature. Each measure was recorded, and where possible, concepts within these were noted. 52 outcome measures were used across the studies; the frequencies of themes represented in the outcome measures are illustrated in Table 6.

Table 6: Frequencies of outcome measure themes present in the literature

Outcome Measure Theme		Number of outcome measures
Mental Health	General Psychopathology	1
	Anxiety/Depression	17
	Self-esteem	1
	Personality	2
Adjustment		7
Trauma		5
Quality of Life		5
Physical Symptoms		5
Condition-Specific	Pain	10
	Appearance	3
	Spinal	1
	Obesity	1
	Cancer	1
Other*		9

Other: Hopelessness, Cognitive functioning, mental well-being, Interpersonal, Affect, Coping, Compliance, Outcome Perceptions, Alexithymia

Final themes from the literature, including themes from outcome measures, are illustrated in Table 7.

Table 7: Themes elicited from the literature

Depression	General activities
Worry	Work functioning
Condition-related distress	Social support
Illness intrusiveness/ Trauma	Close Relationship functioning
Self-esteem	Positive relations with others
Coping: Optimism/ Discouragement about the future	Well-being: Environmental mastery/ Sense of control over life
Helplessness Identity/ Personality	Well-being: Autonomy
Hopeless	Well-being: Purpose in life/ Meaning
Assertiveness	Belief in ability to adhere to treatment regimen
Adjustment	Participate in decisions
Acceptance of self	Helpfulness of information
Personal growth	

Telephone interviews

Nine clinicians participated in telephone interviews in which they were asked which concepts they felt were relevant to outcomes in CHP. A further two clinicians agreed to participate in this stage, but as this was outside the interview time frame and it was felt data saturation had been reached, they were not interviewed. Table 8 illustrates the 17 themes and 44 subthemes from the interviews.

Table 8: Themes (and subthemes) from the interviews

Acceptance (Life, Condition, Limitations)

Understanding (Emotions, Limitations, by others, Condition)

Positive affect (Confidence, General, Self-compassion)

Mood/Anxiety (Symptom reduction, management)

Identity (Meaning, positive)

Functioning (Social, school/work, relationships, sexual, personal leisure)

Management/ Coping (Coping, management of condition, decision-making)

Control (Of the condition)

Goals (Set & achieve, recalibrate, realistic expectations)

Self-Efficacy

Thinking (Differently, intrusions)

Communication (In general, expressing needs, about the condition, about emotions)

Information (Coping, finding)

Adherence (In general, medication)

Health System (Understanding, relationship, management, involved, attendance)

Engaged (Life)

Proactive (In general)

Some concepts elicited from the literature review and interviews are similar to previously highlighted concepts. Table 9 illustrates which concepts elicited map onto those categories outlined earlier. This shows that 16 of 24 themes from the literature review (67%) and 14 of the 17 themes from the interviews (82%) overlapped with previously highlighted concepts.

Table 9: Literature and interview concepts mapped onto previously highlighted concepts (PHC)

PHC	Literature	Interviews
Therapeutic alliance	Participate in decisions	Communication; Health system; Engaged; Proactive; Management/ Coping
Psychological mechanisms	Coping: Optimism/ Discouragement about the future; Belief in ability to adhere to treatment regimen	Management/Coping; Goals; Control; Thinking; Acceptance
Well-being	Well-being: Autonomy; Environmental mastery/ Sense of control over life; Personal growth	Positive affect; Control
Meaning	Identity/ Personality; Well-being: Purpose in life/ Meaning	Identity
Supportive relationships	Close Relationship functioning; Positive relations with others; Social support	Functioning; Understanding
Hope	Hopeless	Positive affect; Thinking
Empowerment	Self-confidence/ Self-esteem; Assertiveness	Self-Efficacy; Communication; Health System
Satisfaction with functioning		Acceptance
Superordinate concepts	Acceptance of self; Condition-related distress	Acceptance; Identity; Communication

Item Pool Generation

Themes from the literature review and telephone interviews were converted into an item pool which consisted of 50 items. 17 items were supported by both literature and interview data, 8 items were supported by just the literature and 25 items were supported by just the interview data. Concepts were recorded along with the origin (literature review or interview) and the resulting item (Appendix C).

Stage B: Item Pool Refinement

This stage consisted of a three round online Delphi survey. Figure 4 illustrates participant attrition across the three rounds.

Round One: 47 participants

Round Two: 35 participants

Round Three: 27 participants
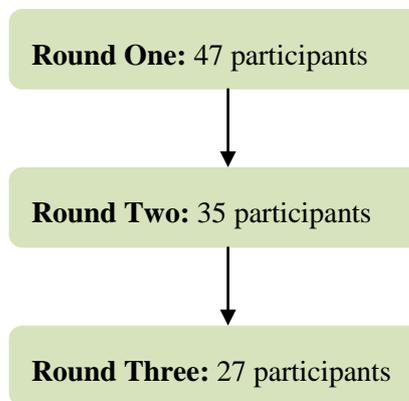
Figure 4: A flow chart of participant attrition over the Delphi surveys

Participation dropped by 26% from Round 1 to Round 2, and by 23% from Round 2 to Round 3. Participation dropped by 43% from Round 1 to Round 3.

Demographic Data

At the start of each round, participants were asked to answer basic demographic questions, as displayed in Table 10.

Table 10: Participants' demographic data

Demographics		Round 1	Round 2	Round 3
Male: Female*		12:34	10:25	4:16
Experience within Profession (years)	1 to 4	5 (11%)	4 (11%)	2 (7%)
	5 to 9	14 (30%)	10 (29%)	7 (26%)
	10+	28 (60%)	21 (60%)	18 (67%)
Professional Background	Clinical Health Psychology	39 (83%)	29 (83%)	23 (85%)
	Liaison Psychiatry	2 (4%)	1 (3%)	0 (0%)
	Health Psychology	3 (6%)	1 (3%)	2 (7%)
	Other**	3 (6%)	4 (11%)	2 (7%)
Primary Clinical Area	Chronic Pain	12 (26%)	8 (23%)	5 (19%)
	Neuropsychology	5 (11%)	3 (9%)	1 (4%)
	Cancer	4 (9%)	3 (9%)	2 (7%)
	Diabetes	3 (6%)	1 (3%)	1 (4%)
	Plastic Surgery	3 (6%)	1 (3%)	2 (7%)
	Respiratory	3 (6%)	2 (6%)	2 (7%)
	Other***	17 (36%)	16 (46%)	14 (52%)

* Participants were asked to submit an email address to participate in the following round; sex was deduced from the name within this.

**Other: Clinical Neuropsychology, Clinical Psychology

** *Other: Cardiology, Cardiopulmonary transplantation, Chronic Fatigue Syndrome, Cystic Fibrosis, Immunology, HIV/AIDS, Palliative, Renal, Spinal

Table 10 illustrates that participants varied along several demographic domains, both within and between each round. In terms of similarities, across the three rounds participation was at least: 71% female, 60% had over 10 years of experience in the profession, 83% had a CHP background and 19% worked primarily in Chronic Pain. In terms of variation between rounds, male participation dropped from 29% to 20% and there was no participation from Liaison

Psychiatry by the third round. There was variation within each round, mostly in terms of participants' Primary Clinical Area.

Descriptive Statistics

Basic data regarding the items across the three rounds are illustrated in Table 11, including the number of comments, the number of items commented upon, and the number of items changed or added following Round 1. These aspects declined gradually across the three rounds.

Table 11: Basic item data across the 3 rounds

	Round 1	**Round 2**	**Round 3**
Number of items	50	62	61
Items commented on *(%)*	50 *(100%)*	55 *(89%)*	43 *(70%)*
Comments made *(mean)*	251 *(5.0)*	140 *(2.3)*	87 *(1.4)*
Items changed *(%)*	38 *(76%)*	40 *(65%)*	26*(43%)*
New items	12 added	1 omitted	1 omitted

Two items were omitted because it was felt they were too similar to others in the item pool. The item "I feel involved in the decision-making process with health care staff" was omitted following Round Two, as there were 3 other items about health care staff and one item about decision-making. The item "I am satisfied with my ability to manage my condition" was omitted following Round Three, as a participant fed back that it was very similar to another item, "I am able to cope with my condition".

Item Movement

Participants rated the relevance of items within each round. After each round items were arranged in descending order of their mean rating, in preparation for the next round. Appendix I illustrates the number of spaces items moved between Rounds 1 and 2 and Rounds 2 and 3, thus illustrating the volatility of items' relevance. Item movement is important for demonstrating consensus: a large amount of item movement demonstrates that participants' opinions have changed considerably between rounds regarding how relevant the item is, whereas a small amount of item movement suggests that participants have rated its' relevance similarly across rounds. Table 12 summarises the range and average of this movement. It illustrates that the range of movement decreased, which could suggest the emergence of consensus, whilst the mean item movement remained similar, which could suggest a lack of consensus. However,

Appendix I illustrates that some items moved far more than other items; this may indicate that a different degree of consensus emerged for each item.

Table 12: Range and mean item movement

	Round 1 to Round 2 Movement	**Round 2 to Round 3 Movement**
Range	0-45	0-32
Mean number of spaces moved	11	12

Specific Item Qualitative Feedback

Participants contributed qualitative feedback at the end of each round, both in terms of suggestions for changes to specific items and general feedback on the item pool. In terms of specific feedback, as illustrated in Table 11, 478 comments were made on the items across the three rounds, which is too many to detail here. Examples will be used to illustrate how one item's wording was changed, how contradictory feedback was used and participants' criticisms of items that were not recovery-focused.

One item's wording changes: Item feedback included comments on the clarity of wording, definitions of terms and concepts represented. The process used to decide which feedback was implemented is clarified in this example of one item's wording changes across the three rounds, as outlined in Table 13.

Table 13: Wording change for an item

Round 1	**Round 2**	**Round 3**	**Post-Round 3**
I have come to terms with my condition	I have accepted my condition/s at the moment	I have accepted my condition	I have accepted my condition

Initially, the item was "I have come to terms with my condition" and it was intended that this would reflect the concept: "acceptance of condition". Participants made eight comments on this item during Round 1. Four of these comments suggested that "come to terms with" was a poor choice of phrasing; reasons included that it seemed vague, difficult to understand or implied surrender. Two comments suggested alternative phrasings: one comment suggested "I accept" and another suggested "learned to live with" or "I have found a helpful way to understand my

condition". A further comment reflected that service users may come to terms with their condition at one stage, but not another and therefore suggested the suffix "at the moment". In terms of implementing this feedback, it was agreed that "come to terms with" would be changed, as several participants suggested this was unhelpful. As this item was originally intended to reflect "acceptance of condition", the item prefix was changed to "I accept" rather than "learned to live with" or "found a helpful way to understand". The other two alternative prefixes were not chosen because they appeared to reflect slightly different concepts, such as understanding, which featured in other items. There was no reason to disregard the comment about adding "at the moment", therefore this was also added. Furthermore there was general feedback on the item pool that CHP service users often have multiple conditions and therefore items should reflect this. Consequently, this item was amended to "I have accepted my condition/s at the moment" and this formed part of the next round.

Participants made four comments on this item during Round 2. One participant commented that "at the moment" should be removed, as it was suggested that the timeframe was implied. Three comments reflected that "acceptance" of the condition is not necessary for a good outcome or the term is unclear; this debate is explored further in the following section. General comments were made that items should be about one condition rather than "condition/s", as service users' ratings of these items may vary with each condition. In terms of implementing this feedback, "at the moment" was removed. It was decided to keep "accept" in the item, as no alternative phrasings were offered. Consequently, this item was amended to "I have accepted my condition" and formed part of the next round. No participants commented on this item during Round 3.

Contradictory feedback: Whilst feedback was considered when revising items, it was impossible to implement all feedback as some of it was contradictory. For example, across the three rounds there were recommendations for eight items to be amended to include "I accept" replacing item prefixes, such as "I feel content", "I recognise" and "I can manage" (One item in Round 1, three items in Round 2 and four items in Round 3). However, in response to the revised item "I have accepted my condition/s at the moment", two participants suggested that the word "accepted" was unhelpful, one because some service users "see themselves resisting/fighting it" and another because "sometimes people can live well whilst not accepting the condition"; a third suggested that acceptance is "a bit woolly".

Recovery Focus: Some feedback suggested recovery-focussed alternatives to the items. In Round 2, a participant commented that the item "I accept the extent to which I am able to carry out everyday activities" does "not sound rehabilitation-focussed". This appears to reflect the

impression that the item was illness-focussed and implied that this is less helpful than an item focussed on well-being. A participant commented on the item "I follow recommendations made by health care staff" by highlighting that "patient empowerment is about finding out what's important to the patient and staff suggest things that may or may not then be implemented with /without support". Empowerment is a concept related to the Recovery Approach. Further, this comment suggests that the item privileged medical expertise over service users' judgement.

In Round 3, a participant commented on the item "I feel able to accept any limitations caused by my condition" by pointing out that "the Social Model of Disability would suggest that many limitations are social/ cultural/ prejudicial and should not be accepted, so maybe change to 'I can deal with limitations'". This feedback was used and the item was changed to "I can deal with the limitations caused by my condition". A participant also commented on the item "I attend health care appointments" with "where relevant and/or where they are helpful - some clinical interactions are not". These comments appear to reflect a preference for a person-centred focus over medical expertise. This is consistent with the philosophical approach inherent in the Recovery Approach.

General Qualitative Feedback

General feedback was inspected across all three rounds and two themes emerged: Practical and Conceptual. Table 14 illustrates the eight subthemes within the Practical theme and Table 15 illustrates the five subthemes within the Conceptual theme.

Table 14: Participants' comments regarding subthemes within the practical theme

Theme	Subtheme	Number	Comment
Practical	Number of items	3	The item pool is too large; "half as many would be good"
	Positive phrasing	1	A balance of positively and negatively phrased items would be better, as "the impact of rating self against all this positivity, which scant few can claim… doing this form may be quite a strain."
	Time frame	3	Queries whether SUs should hold in mind the present situation and over how many weeks.
	Response scale	2	A need for a 'response scale'; doubt regarding the appropriateness of one scale for all items.
	Active voice	1	Use an 'active voice' within items.
	Concrete language	1	Use 'concrete language' within items.
	Multiple conditions	1	Many SUs present with 'multiple conditions', so they may be unclear about how to respond to items.
	Ambiguity	1	"If I thought the questions were unclear, ambiguous etc., then I rated them as unsure".

Table 15: Participants' comments regarding subthemes within the conceptual theme

Theme	Subtheme	Number	Comment
Conceptual	Over-inclusivity	1	The item pool seems "over-inclusive and repetitive".
	Reasonable-ness	1	Some items imply unrealistic expectations, "suggesting that a place to aim for is no feelings of helplessness".
	Psychologist assumptions	1	Some items are "based on Psychologist assumptions about what is 'best' for people".
	Process vs. outcome	3	Items reflect both process and outcome; more items are focussed on process, as they are "dominated by feelings and not performance".
	Symptom management	1	Items regarding management, tolerance and coping are most useful.

Outcome Measure Construction

The final item pool was formed into a pilot outcome measure (Appendix J). For the purposes of this study, the measure was named 'CORE for Health', which reflects that it is intended to be a global outcome measure that is relevant for people with health conditions. Forming it into an outcome measure required the construction of an introductory section and response scale. In terms of the introductory section, four participants commented that service users may experience confusion regarding what time frame to hold in mind and whether to answer items regarding one or multiple conditions. It was decided that the measure's introductory section should guide service users to respond to items with regard to the condition/s for which they are currently seeking CHP support. Further, it was decided to direct service users to hold in mind the previous week, as per the CORE-OM (Barkham et al, 1998). The introductory section was constructed as follows:

*"Please read each statement and rate how much you have felt that way **over the last week.** Please hold in mind the condition or conditions for which you are currently seeking support".*

Two participants commented on the need for a response scale. One further participant suggested that some items implied unrealistic expectations, which is further evidence that a response scale with graded options may be important. Figure 5 illustrates the response scale that was selected.

Not at all	Only occasionally	Sometimes	Often	Most or all of the time

Figure 5: Response scale (Taken from CORE-OM; Barkham et al, 1998)

Discussion

Summary

This study gained consensus regarding the most relevant concepts in CHP by conducting a literature review and interviews. Concepts were formed into items using a set of principles to ensure they were accessible and relevant to a broad range of service users. The item pool was compared to previously highlighted concepts, to check how relevant it was. This item pool was refined, both conceptually and linguistically, using participant feedback over three iterations of an online Delphi survey. At this stage a degree of consensus was reached. This final item pool was formed into a pilot global outcome measure for use in CHP.

Relevance

The first aim of this study was to seek consensus from people working in CHP regarding which are the most relevant psychological concepts across chronic conditions. The first aspect of this is the relevance of concepts elicited. Concept relevance was demonstrated by the agreement between those concepts elicited in the study and previously highlighted concepts. Most themes from the literature review (67%) and interviews (82%) overlapped with previously highlighted concepts. Perhaps a lower proportion of themes from the literature review overlapped with previously highlighted concepts because some of these studies may have consisted of participants who do not work clinically in CHP, whereas all interviewees held a current clinical caseload. Working clinically at the present time may support a more up-to-date, culturally relevant understanding of concepts which are relevant to CHP service users. Some Delphi participant comments on how to revise items were consistent with previously highlighted concepts, such as recommending a focus on satisfaction with functioning rather than functioning itself. This provides further evidence for the validity of previously highlighted concepts.

Relevance of Previously Highlighted Concepts

It seemed to emerge over this study that previously highlighted concepts are very relevant to CHP. This group of concepts was constructed by critically appraising the type of outcomes that appear to be assessed in CHP and AMH, and then revising them. For example, some outcome measures in AMH, such as CORE-OM (Barkham et al, 1998), assess symptoms and functioning, yet in CHP, service users are not necessarily expected to fully recover previous functioning. Therefore it was considered that satisfaction with functioning may be a more relevant concept. In this way, the previously highlighted concepts are subtly, yet perhaps significantly, different

from concepts in existing CHP and AMH outcome measures. As discussed, concepts represented in the "CORE for Health" seem to overlap with previously highlighted concepts. As this measure was formed from concepts elicited from both the literature and CHP clinicians, this provides evidence of their validity from these sources.

Consensus

The second aspect of this first aim considers the extent to which consensus was reached. Consensus in this study relates to the convergence of concepts represented in the item pool. Initially 34%, or 17 of 50 items, were supported by both concepts from the literature and interviews. Evidence for emerging consensus was provided in the form of item movement, comments and changes in Stage B. Progressing from the first to the final round in the Delphi study, fewer comments were made, fewer items were commented on, changed or added and the range of movement reduced. Collectively these reductions indicate increased participant satisfaction with the items and therefore consensus. However, mean item movement remained constant and by the final round 70% of items were commented on, which suggests that agreement was not unanimous. A greater degree of consensus may have been reached, had there been a fourth iteration of the Delphi survey. However, given the rate of participant attrition over the first three rounds and the lack of representation from some demographic groups such as Liaison Psychiatry, it was likely that the final sample would have been small and homogenous, and therefore any consensus may have reflected opinions of specific groups of clinicians and therefore less relevant as a global CHP outcome measure.

Whilst some consensus was reached, unanimity was not, and it is doubtful that it should realistically be expected in a large group of experts. The lack of complete agreement may be due to divergent opinions of concepts' relevance, or different interpretations of the language used to convey the concepts.

Opinions of Concepts' Relevance

The lack of unanimity may be due to participant disagreement about items' relevance. This may have been due to differences in service users' presentations, perhaps according to their specific chronic condition, or differences in concepts identified by participants.

In terms of differences in service user presentations, it was hypothesised that rather than each chronic condition having its own unique psychological profile, many concepts are shared across conditions. There is evidence for and against this hypothesis; the consensus achieved suggests some concepts are shared across chronic conditions, whilst the lack of unanimity could suggest that other concepts are differentially relevant.

Alternatively, the lack of unanimity could be due to the different aspects of service users' presentations that participants attend to. Due to factors such as previous training, a CHP may more readily identify concepts around expectations, a CP may identify concepts around compassion and a Liaison Psychiatrist may identify concepts around functioning. There may be a similar impact in other areas of difference, such as participants' primary clinical area. Perhaps all elicited concepts are relevant to CHP service users, but recognised as such to different extents by participants. Data from participants within each round was amalgamated; therefore which feedback was related to each area of difference could not be determined. Consequently, the extent to which participants' relevance ratings were a product of differences in their experiences of individual service users' presentations is unknown. This may be explored further by comparing specialist participants' ratings with those of participants who carry a generic CHP caseload, or by administering the outcome measure to service users with different chronic conditions and comparing their results. To sum up, in terms of the data elicited in this study, items may be relevant despite a lack of unanimity.

Interpretations of Language

The lack of unanimity may also be due to participants' different interpretations of the language used to convey concepts. As discussed, some concepts, such as 'acceptance', have many interpretations attributed to them both amongst clinicians and between clinicians and service users (Hayes, 2004; Thompson, Arnkoff & Glass, 2011; Robins et al, 2004). Indeed, in Stage B whilst recommendations were made for eight items to be amended to include "I accept" rather than other item prefixes, other participants suggested that acceptance is irrelevant or unclear. Detailed exploration of concept definitions was beyond the scope of this study, however different interpretations may well have impacted on participants' relevance ratings, and also how service users may answer items. Consequently, the lack of unanimity may be partially due to different interpretations of language used.

Item Construction

The second aim of the study was to generate items which may form a global outcome measure in CHP. This involved forming the elicited concepts into items. A set of guidelines was produced to facilitate this construction; however, several issues affected on item construction in regard to subjective judgements within item phrasing and item pool revisions.

Item Phrasing

Subjective judgment was used to determine how items were phrased, both in terms of applying themes to practice and utilising feedback on specific items. Themes could have been operationalized into items in several ways. For example, the item "I feel content with the control I have over my condition" was formed from the concepts: "Well-being: autonomy" and "Control (Of the condition)". Autonomy broadly means independence and freedom; therefore an item based on this theme alone may have been "I am able to independently manage my condition". Literature around the importance of social support suggests this item does not relate to a desirable outcome and may even imply a lack of treatment adherence. The original item mostly reflects the theme, "Control (Of the condition)", with the "Well-being: autonomy" theme influencing the type of control i.e. internal.

In terms of utilising feedback, for some items several alternative phrasings were suggested and subjective judgement was used to determine the most appropriate. For example, in the first round of Stage B, 11 participants commented on the item "I feel content in my ability to engage in sex"; six of these comments were alternative phrasings, such as "I am not troubled by sexual difficulties". The feedback was discussed and used to consider the most appropriate revision, but the specific alternative phrasings were not always used. However, each revision was then checked for relevance in the subsequent iteration of the Delphi survey, therefore precision may not have had a substantial impact on the final items.

Item Pool Revisions

One of the subthemes in the general qualitative feedback was straightforward to implement, as it was consistent with the previously highlighted concept 'psychological mechanisms', and therefore enhanced the item pool's relevance. The comment within the subtheme 'symptom management' was that items which focussed on management, tolerance or coping were more useful than symptoms per se. As such, further items were added on distress, low mood, anger and anxiety, in terms of their management.

Some general qualitative feedback in Stage B was clear yet unsuitable to implement. Revisions took into account the item phrasing guidelines: feedback was not implemented if it contradicted these. For example, although participants commented that certain items would be clearer if they were negatively phrased, positive phrasing was used throughout to allow ease of scoring of the final outcome measure by clinicians. Other participants fed back that the item pool was over-inclusive. It was decided to retain similar items in Stage B, in the event that certain nuances prove important when the outcome measure is administered to service users.

Several participants also commented that the item pool was too large and half as many items would be better. However, the intention was to produce double the number of items required for the final measure by the end of Round 3 (Rust & Golombok, 1989).

Some general qualitative feedback in Stage B related to complex issues, such as the subtheme 'process vs. outcome'. This reflects an observation that items were a mixture of both process and outcome with a trend towards more process items by the final round. Prior to data collection, the issue regarding defining process and outcome had been considered. These concepts may be separated on a broad level; indeed, within the NHS Outcomes Framework (DoH, 2010), quality of life and recovery are offered as separate domains to patient experience, which may tap into process issues. Perhaps these domains are more easily separated in medical settings, whereby, for example service users' experience of healthcare staff has a lesser impact on the healing of a broken bone than the treatment itself, such as the use of a cast. However, in psychological therapy settings, research suggests that process issues can significantly impact upon outcomes. Here it may be appropriate to combine process and outcome items in a measure. It was unclear which items were felt to be reflective of process, as this was general feedback on the item pool. Process may relate to items which assess the relationship service users have with the healthcare team or appointment attendance. This seems appropriate in CHP, as service users are likely to access services continuously or intermittently, and therefore good condition management may relate to their use of services.

Appraisal of Construction Method

Earlier, the methods used to construct three outcome measures were appraised and four key learning points were derived. Briefly, these were: consulting a broad range of stakeholders; examining existing measures separately to stakeholder feedback; consulting service users; and conducting quality control checks. This may be used as a framework for considering how the 'CORE for Health' compares to existing measures. As part of this measure's construction: a broad range of stakeholders were consulted through the Delphi survey; existing measures were examined within the literature review, and concepts elicited here did not influence the interview data; and a basic quality control check took place, as Stage A themes were checked against previously highlighted concepts. In these ways, this measure was well constructed and comparable to the robust aspects of other measures' construction. Some aspects of this measure's construction were different to these learning points, however as the measure is not yet complete, there remains scope for these to be addressed. Firstly, service users were not

consulted. Whilst very few items were omitted, thus facilitating service users to contribute considerably to the refinement of the measure, this remains a disadvantage as service users may not be able to contribute to the extent that clinicians did. Secondly, a substantial quality control check was not conducted; however again, this may be achieved at a later date. These were not completed as they were beyond the scope of this study. Possibly the biggest shortcoming of this measure's construction in accordance with these learning points is that a broader range of stakeholders did not participate. The Delphi participants were demographically diverse, such as in terms of professional backgrounds. However, the low participation rate and consequent attrition throughout the rounds meant that representation from some groups was small. To sum up, comparing this measure to the key learning points derived earlier, the 'CORE for Health' was well constructed, and most of the ways in which it did not follow these learning points may be addressed following this study.

Limitations

There are at least four key limitations in this study. One of these is a methodological limitation: Stage B data was amalgamated, meaning that it was impossible to distinguish between data from different professional groups. The other three limitations relate to choices made about the study design: the measure was designed for chronic rather than acute conditions; service users were not directly consulted; and item wording may be confusing to service users, leading to misleading data.

Lack of Data Discrimination

A methodological flaw in this study is that Stage B data was not separated according to professional background or any other criteria, and therefore it was impossible to determine the extent that item ratings and comments differed according to these factors. It was hypothesised that many concepts are shared across chronic conditions; whilst some support was found for this, analysing data from clinicians who specialise in these different conditions separately may have lent further support to this hypothesis.

Acute Conditions

This outcome measure may not be as relevant for certain groups of service users, since it has been developed to assess service users with chronic, rather than acute, conditions. It was decided to limit the study to service users with chronic conditions, including episodic, recurrent and deteriorating conditions. This was because literature suggests that these form the largest

proportion of service users who are currently seen in CHP. However, many CHP service users have acute conditions, and the measure may not be valid in this population.

Service User Involvement

The most significant limitation of this study is that it did not consult service users. Other outcome measures (CORE-OM, Barkham et al, 1998; SF-36, Ware, & Sherbourne, 1992) were criticised for their lack of service user involvement at the construction stage. It was decided that there would be another stage following this research, where service users would be consulted. As this is a global outcome measure, in order to find concepts that are relevant to service users with many different chronic conditions, a broad range of service users would have needed to be consulted. This would have been a large undertaking, possibly equivalent to the size of this study.

Whilst it was decided not to consult service users at this stage, it can be shown that they were held in mind to a greater extent than in the construction of other outcome measures. There are several key differences in the construction of this outcome measure compared to the CORE-OM and SF-36. Whilst only professionals were consulted in this study, the type and therefore biases of these professionals differed from those consulted in the construction of the CORE-OM and SF-36. The CORE-OM consulted service purchasers and service providers who work at a high level, such as clinical directors; in this study people who work directly with service users were consulted. The SF-36 was constructed by its two authors surveying current outcome measures and literature, but no clinicians were surveyed and therefore it potentially failed to measure what was currently important for service users. The largest component of the present study was Stage B, where currently practicing clinicians were asked which concepts are relevant, and therefore elicited concepts that may be currently important for service users.

An attempt was made to consider CHP concepts from service users' perspectives. Clinicians were asked in the Stage A interviews to hold in mind service users they had seen, rather than just to consider relevant concepts. As discussed, many of the concepts elicited from these interviews and the literature coincided with the previously highlighted concepts, and more than half of the previously highlighted concepts originated from the service user endorsed Recovery Approach. Furthermore some of the Stage B feedback suggested item revisions which were in line with Recovery Approach concepts, such as empowerment, thus demonstrating the final outcome measure's relevance to service users.

Administration

A final limitation is that whilst this outcome measure may be easy for clinicians to score, the wording may be difficult for service users to answer. Although some clinicians suggested in Stage B that positive wording was at times confusing, and negative wording may be clearer, it was decided to retain positive wording. However, if service users do find this wording confusing, then their responses may not reflect their intent, they may omit items or they may not complete the outcome measure at all. These are significant concerns. However, as will be discussed, it is intended that the next stage of this research should involve service user consultation, at which point they will have an opportunity to express whether items are confusing and the wording may be altered prior to finalising the measure.

Strengths

A strength of the current research is its relevance, which has culminated in a practical tool that may lead to more effective outcome measurement in CHP. Its strengths as an effective measure lie in its reflection of what clinicians feel is relevant, inclusion of recovery-focussed items and items reflecting psychological theories.

Unlike other measures, the construction of this measure involved extensive input from diverse CHP staff with a current clinical caseload. Consequently this outcome measure appears to capture a wide range of concepts in CHP which appear to be relevant to many chronic conditions; such a range of concepts have not been captured in one measure previously. This research has demonstrated that there are many more CHP concepts which are important to assess in addition to symptoms; for example, this outcome measure contains items which reflect concepts associated with the Recovery Approach and so may be culturally relevant.

The current attempt to capture relevant psychological mechanisms enables service users to interpret items in a way that is appropriate for them, rather than imposing a set standard. For example, LoC is an important theory in CHP. Whereas a perception of too little control may lead to poor treatment adherence, an entirely internal LoC may also be unhelpful (Burnish et al, 1984); therefore items which ask how much control the service user thinks they have are unhelpful. This measure assesses LoC with the items: "I am satisfied with the control I have over my life" and "I accept how much control I have over my condition". These items assess two significant aspects of control; rather than dictating what kind of control is best, they allow the service user to determine this for themselves.

An important theory-driven model in CHP is the Dual Process Model (DPM; Brandtstädter & Rothermund, 2002b), which suggests that sometimes it is most helpful for service users to keep their goals and adapt their circumstances, and at others it is best to adapt goals to make them more achievable. The previously discussed SF-36 item, "Does your health limit your ability to walk a mile?" fails to capture these important processes. Equivalent items in this measure are "I think that my expectations and goals are realistic" and "I am able to do the things that I enjoy". These items may more accurately account for assimilation and accommodation, as per the DPM.

Validity

Bias

Concepts represented in the items may have been biased by those relevant to specific chronic conditions. Most articles in the literature review were focussed on pain or cancer, and in Stage B more participants worked in chronic pain than any other specialty. It was hypothesised that rather than each chronic condition having its own unique psychological profile, concepts are shared across conditions. However, if this is not true, then the over-representation of certain chronic conditions may have biased the items. There were very few articles which did not focus on a specific chronic condition or participants in Stage B who worked generically. Also, the sample was not large enough to exclude articles or participants working within a particular primary clinical area.

Content Validity

As discussed, the overlap between elicited concepts from the literature and interview data and previously highlighted concepts provides initial support for the content validity of the item pool. Further support comes from participants' endorsement by commenting on fewer items throughout the rounds in Stage B.

External Validity

The methodology used helped to improve the external validity of the item pool. As the Delphi Method and BOS questionnaire are not limited in size, they surveyed a wide range of opinions. In both stages, clinicians participated from several CHP departments across the UK and therefore were not skewed by locally relevant issues.

Recommendations

Whilst this research has made a contribution to the development of a new global outcome measure in CHP, this is not yet complete. A pilot measure has been produced and therefore further steps are necessary before this measure can be administered in routine clinical practice. These steps include service user consultation and validation by examining its psychometric properties.

Service User Consultation

The next stage in the development of this outcome measure should involve consulting CHP service users to ascertain the extent to which they think items are relevant and whether further items are needed. It is recommended that a Delphi survey is conducted. This is an appropriate method for gaining feedback on such a large item pool. This survey could ask service users to rate the items, using the same scale as was used in the present study. This could ask for feedback regarding item wordings and concepts represented, in addition to asking for recommendations for further items. It is important that service users with a broad range of chronic conditions are surveyed, so that concepts relevant to all conditions are represented. It may also be important to survey service users who have completed a course of psychological therapy recently; surveying those who have not completed therapy may not have achieved the expected outcomes, and surveying those who completed therapy a long time ago may struggle to remember which outcomes were related to completing therapy. It may be important to ascertain in the survey whether participants feel they achieved a good, neutral or poor outcome: service users who did not achieve a good outcome may have insight into what would have been helpful.

Psychometric Properties

Once service users have been consulted, the pilot outcome measure should be administered to a large group of current CHP service users to explore its psychometric properties. Participants with a wide range of chronic conditions should be surveyed, who are currently seeing a CHP. It may be useful to administer the measure to service users with acute conditions, to determine whether it is also an effective measure in that population, and analyse this data separately. The measure should be administered at the start and end of therapy; a 6 month follow-up may also be desirable.

The item pool will be refined in this stage: approximately half of the items will be selected for inclusion in the final version of the outcome measure, using Principal Components Analysis (PCA). PCA is a statistical method used to understand the underlying structure of data. It does

this by finding factors within the data set and how much variance each factor accounts for. The set of factors which account for the most variance are then selected. If several items are consistently rated very similarly by participants then one item may be selected and the other items omitted.

Once the final item pool has been selected, the reliability and validity of the measure will be inspected. Test-retest reliability is an appropriate method for determining variation in measurement. This will involve administering the measure to service users once and then a second time a week later. As the data should not change over this time, similarity across the data sets would signify reliability of measurement. The measure's validity could be determined by administering it to service users concurrently with measures thought to assess similar concepts. Two of the most similar measures presently available are the SF-36 and CORE-OM, so these would be the most appropriate choices to administer it with. Similar data across these measures would provide evidence of the new measure's construct validity.

Conclusion

The aims of this research were largely achieved as concepts elicited appear to be relevant, some consensus was reached from CHP clinicians and a pilot global CHP outcome measure was constructed. This pilot measure is made up of items which represent a range of psychological concepts which appear to be relevant across different chronic conditions. As such, it may facilitate more accurate measurement of outcomes in CHP; given the current drive to measure outcomes, this measure could support CHP services to provide more accurate evidence of their effectiveness. This research has also attempted to identify the main principles that are important for constructing a new measure and contributed an alternative method of outcome measure construction based on these principles: unlike existing measures, the development of the 'CORE for Health' started at a more basic, conceptual level. This research represents the first stage of developing a measure, as further work is required to develop it into a validated, reliable outcome measure.

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Meeus, M., Nijs, J., Van Oosterwijck, J., Van Alsenov, V., & Truijen, S. (2010). Pain physiology education improves pain beliefs in patients with chronic fatigue syndrome compared with pacing and self-management education: a double-blind randomized controlled trial. *Archives of Physical Medicine & Rehabilitation, 91(8),*1153-1159.

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Repper, J. & Perkins, R. (2006) *Social Inclusion and Recovery: A Model for Mental Health Practice.* Bailliere Tindall, UK.

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Wan, C., Tu, X., Messing, S., Li, X., Yang, Z., Zhao, X., Gao, L., Yang, Y., Pan, J., & Zhou, Z. (2011). Development and validation of the general module of the system of quality of life instruments for chronic diseases and its comparison with SF-36 . *Journal of Pain and Symptom Management, 42 (1),* 93-104.

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Weathers, F., Litz, B., Herman, D., Huska, J., & Keane, T. (October 1993). *The PTSD Checklist (PCL): Reliability, Validity, and Diagnostic Utility*. Paper presented at the Annual Convention of the International Society for Traumatic Stress Studies, San Antonio, TX.

Weiss, D. S., & Marmar, C.R. (1997). *The impact of event scale – revised*. In J.P. Wilson & T.M. Keane (Eds.). Assessing Psychological Trauma & PTSD: A Handbook for Practitioners (p399-411). New York: Guildford Press.

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Zigmond, A. S. & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica, 67 (6),* 361-370.

Appendix A: Literature review articles

Reference	Accessible	Clinical specialism
Harris, N.J. Robson, M.J. Simpson S. & Mehta, B.H. (1997). A prospective evaluation of both outcome and psychological status in 100 patients with mechanical lower back pain. *Journal of Back and Musculoskeletal Rehabilitation,* 9(1), 39-41.	Abstract only	Pain
Trovato, G.M., Martines, G.F., Trovato, F.M., Pace, P., Pirri, C., Tonzuso, A. & Catalano. D. (2012). *Psychological determinants of dietary adherence and intervention outcome in obesity: Self-efficacy, dietary and physical exercise counseling.* Conference: Experimental Biology 2012, EB San Diego, CA United States	Abstract only	Obesity
Rudol, G., Rambani, R., Saleem, M.S. & Okafor, B. (2012). *Psychological distress screen as a predictor of outcome of epidural injection in chronic lower back pain.* European Spine Journal. Conference: Annual Meeting of the British Association of Spine Surgeons, BASS: Britspine 2012 Newcastle United Kingdom. 21 (pp S234),	Abstract only	Pain
Abbott, A.D., Tyni-Lenne, R. & Hedlund, R. (2011). Leg pain and psychological variables predict outcome 2-3 years after lumbar fusion surgery. *European Spine Journal,* 20 (10), 1626-1634.	Yes	Surgery
Beale, M., Cella, M. & Williams, A.C. (2011). Comparing patients' and clinician-researchers' outcome choice for psychological treatment of chronic pain. *Pain*, 152(10), 2283-6.	Yes	Pain
Goerling, U., Foerg, A., Sander, S., Schramm, N. & Schlag, P.M. (2011). The impact of short-term psycho-oncological interventions on the psychological outcome of cancer patients of a surgical-oncology department - A randomised controlled study. *European Journal of Cancer,* 47 (13), 2009-2014.	Yes	Cancer
Vodermaier, A., Caspari, C., Wang, L., Koehm, J., Ditsch, N. & Untch, M. (2011). How and For Whom Are Decision Aids Effective? Long-Term Psychological Outcome of a Randomized Controlled Trial in Women With Newly Diagnosed Breast Cancer. *Health Psychology,* 30 (1), 12-19.	Yes	Cancer
Yeoman, T.F.M. & Wigderowitz, C.A. (2011). *The effect of psychological status on pain and surgical outcome in patients requiring arthroscopic subacromial decompression.* International Journal of Surgery. Conference: National Undergraduate General Surgery Conference, NUGSC 2011 England United Kingdom. 9 (5) (pp 369)	Abstract Only	Surgery
Kanel, R.V., Hari, R., Schmid, J.-P., Saner, H. & Begre, S. (2011). *Psychological distress perceived during myocardial infarction as a predictor of poor Cardiovascular outcome.* Psychosomatic Medicine. Conference: 69th Annual Meeting of the American Psychosomatic Society San Antonio, TX United States. 73 (3) (pp A21)	Abstract Only	Cardiac
Torer, N., Nursal, T.Z., Cahskan, K., Ezer, A., Colakoglu, T., Moray, G. & Haberal, M. (2010). The effect of the psychological status of breast cancer patients on the short-term clinical outcome after mastectomy. *Acta Chirurgica Belgica,* 110 (4), 467-	Abstract Only	Cancer

470.		
Gordon, D.B., Polomano, R.C., Pellino, T.A., Turk, D.C., McCracken, L.M., Sherwood, G., Paice, J.A. Wallace, M.S., Strassels, S.A. & Farrar, J.T. (2010). Revised american pain society patient outcome questionnaire (aps-poq-r) for quality improvement of pain management in hospitalized adults: Preliminary psychometric evaluation. *Journal of Pain,* 11 (11), 1172-1186.	Yes	Pain
Luckett, T., Butow, P.N., King, M.T., Oguchi, M., Heading, G., Hackl, N.A., Rankin, N. & Price, M.A. (2010). A review and recommendations for optimal outcome measures of anxiety, depression and general distress in studies evaluating psychosocial interventions for english-speaking adults with heterogeneous cancer diagnoses. *Supportive Care in Cancer,* 18 (10), 1241-1262.	Abstract only	Cancer
Pessin, H., Rosenfeld, B., Breitbart, W., Kolva, E. & Radomski, J. (2010). *The utility of the Hopelessness Assessment in Illness (HAI) as a psychotherapy intervention outcome measure in advanced cancer.* Psycho-Oncology. Conference: IPOS 12th World Congress of Psycho-Oncology Quebec City, QC Canada. 19 (pp S139).	Abstract only	Cancer
Leboeuf-Yde, C., Rosenbaum, A., Axen, I., Lovgren, P.W., Jorgensen, K., Halasz, L., Eklund, A. ^ Wedderkopp, N. (2009). The Nordic Subpopulation Research Programme: Prediction of treatment outcome in patients with low back pain treated by chiropractors - does the psychological profile matter? *Chiropractic and Osteopathy,* 17	Abstract only	Pain
Blaine, B.E. (2009). Obesity, binge eating, and psychological distress: The moderating role of self-concept disturbance. *Current Psychiatry Reviews,* 5 (3), 175-181.	Abstract only	Obesity
Moss, T.P. & Harris, D.L. (2009). Psychological change after aesthetic plastic surgery: A prospective controlled outcome study. Psychology, *Health and Medicine,* 14 (5), 567-572.	Yes	Surgery
Goldzweig, G., Hubert, A., Walach, N., Brenner, B., Perry, S., Andritsch, E. & Baider, L. (2009). Gender and psychological distress among middle- and older-aged colorectal cancer patients and their spouses: An unexpected outcome. *Critical Reviews in Oncology/Hematology,* 70 (1), 71-82.	Yes	Cancer
Serpentini, S., Alducci, E., Del Bianco, P., Zotti, P., Belluco, G., Bernini, D., De Salvo, G., Toppan, P. & Pucciarelli, S. (2009). *A prospective multicenter study: Psychological well-being outcome related to multimodal treatment in locally advanced rectal cancer patients.* Psycho-Oncology. Conference: 11th World Congress of Psycho-Oncology of the International Psycho-Oncology Society, IPOS Vienna Austria. 18 (pp S94)	Yes	Cancer
Keller, M., Jost, R., Haunstetter, C.M., Sattel, H., Schroeter, C., Bertsch, U., Cremer, F., Kienle, P., Tariverdian, M., Kloor, M., Gebert, J. & Brechtel, A. (2008). Psychosocial outcome following genetic risk counselling for familial colorectal cancer. A comparison of affected patients and family members. *Clinical Genetics,* 74 (5), 414-424.	Yes	Cancer
Falagas, M.E., Zarkadoulia, E.A., Ioannidou, E.N., Peppas, G., Christodoulou, C. & Rafailidis, P.I. (2007). The effect of	Yes	Cancer

psychosocial factors on breast cancer outcome: A systematic review. *Breast Cancer Research,* 9 (4)		
Kissane, D.W., Grabsch, B., Clarke, D.M., Smith, G.C., Love, A.W., Bloch, S., Snyder, R.D. & Li, Y. (2007). Supportive-expressive group therapy for women with metastatic breast cancer: Survival and psychosocial outcome from a randomized controlled trial. *Psycho-Oncology,* 16 (4), 277-286.	Yes	Cancer
Yu, Z.-H. & Yang, J.-H. (2006). Effect of psychological factors on the genesis, development and outcome of cancer. *Chinese Journal of Clinical Rehabilitation,* 10 (30), 137-139.	Abstract only	Cancer
Buddeberg-Fischer, B., Klaghofer, R., Krug, L., Buddeberg, C., Muller, M.K., Schoeb, O. & Weber, M. (2006). Physical and psychosocial outcome in morbidly obese patients with and without bariatric surgery: A 41/2-year follow-up. *Obesity Surgery,* 16 (3), 321-330.	Abstract only	Obesity
Derby, R., Lettice, J.J., Kula, T.A., Lee, S.H., Seo, K.S. & Kim, B.J. (2005). Single-level lumbar fusion in chronic discogenic low-back pain: psychological and emotional status as a predictor of outcome measured using the 36-item Short Form. Journal of neurosurgery. *Spine,* 3 (4), 255-261.	Yes	Pain
Nano, M.T., Gill, P.G., Kollias, J., Bochner, M.A., Malycha, P. & Winefield, H.R. (2005). Psychological impact and cosmetic outcome of surgical breast cancer strategies. *ANZ Journal of Surgery*, 75 (11), 940-947.	Yes	Cancer
Hassanein, K.A.-A.M., Musgrove, B.T. & Bradbury, E. (2005). Psychological outcome of patients following treatment of oral cancer and its relation with functional status and coping mechanisms. *Journal of Cranio-Maxillofacial Surgery,* 33 (6), 404-409.	Yes	Cancer
Cole, B.S. (2005). Spiritually-focused psychotherapy for people diagnosed with cancer: A pilot outcome study. *Mental Health, Religion and Culture,* 8 (3), 217-226.	Abstract only	Cancer
Van der Hulst, M., Vollenbroek-Hutten, M. M.R. & IJzerman, M. J. (2005) A Systematic Review of Sociodemographic, Physical, and Psychological Predictors of Multidisciplinary Rehabilitation— or, Back School Treatment Outcome in Patients With Chronic Low Back Pain. *SPINE,* 30 (7), 813–825.	Yes	Cardiac
Rothenhausler, H.-B., Grieser, B., Nollert, G., Reichart, B., Schelling, G. & Kapfhammer, H.-P. (2005). Psychiatric and psychosocial outcome of cardiac surgery with cardiopulmonary bypass: A prospective 12-month follow-up study. *General Hospital Psychiatry,* 27 (1), 18-28.	Yes	Cardiac
Buddeberg-Fiseher, B., Klaghofer, R., Sigrist, S. & Buddeberg, C. (2004). Impact of psychosocial stress and symptoms on indication for bariatric surgery and outcome in morbidly obese patients. *Obesity Surgery*, 14 (3), 361-369.	Abstract only	Obesity
Rehse, B. & Pukrop, R. (2003). Effects of psychosocial interventions on quality of life in adult cancer patients: Meta-analysis of 37 published controlled outcome studies. *Patient Education and Counseling,* 50 (2), 179-186.	Yes	Cancer
Karlsson, J., Taft, C., Sjostrom, L., Torgerson, J.S. & Sullivan, M. (2003). Psychosocial functioning in the obese before and	Yes	Obesity

after weight reduction: Construct validity and responsiveness of the Obesity-related Problems scale. *International Journal of Obesity,* 27 (5), 617-630.		
Di Gallo, A., Amsler, F., Gwerder, C. & Burgin, D. (2003). The years after: A concept of the psychological integration of childhood cancer. *Supportive Care in Cancer,* 11 (10), 666-673.	Abstract only	Cancer
Bolton, J.E. & Humphreys, B.K. (2002). The Bournemouth Questionnaire: a short-form comprehensive outcome measure. II. Psychometric properties in neck pain patients. *Journal of Manipulative and Physiological Therapeutics*, 25(3), 141-8.	Yes	Pain
Gellrich, N.-C., Schimming, R., Schramm, A., Schmalohr, D., Bremerich, A. & Kugler, J. (2002). Pain, function, and psychologic outcome before, during, and after intraoral tumor resection. *Journal of Oral and Maxillofacial Surgery,* 60 (7), 772-777.	Yes	Cancer
Malmgren-Olsson, E.-B., Armelius, B.-A. & Armelius, K. (2001). A comparative outcome study of body awareness therapy, feldenkrais, and conventional physiotherapy for patients with nonspecific musculoskeletal disorders: Changes in psychological symptoms, pain, and self-image. *Physiotherapy Theory and Practice,* 17 (2), 77-95.	Yes	Musculoskeletal
Hutten, M.M.R., Hermens, H.J. & Zilvold, G. (2001). Differences in treatment outcome between subgroups of patients with chronic low back pain using lumbar dynamometry and psychological aspects. *Clinical Rehabilitation*, 15 (5), 479-488.	Yes	Pain
Zlot, S.I., Herrmann, M., Hofer-Mayer, T., Adler, M. & Adler, R.H. (2001). A comparison of self-concept and personality disorders in women with pain accounted for by psychological factors, women with major depression, and healthy controls. *International Journal of Psychiatry in Medicine,* 31 (1), 61-71.	Abstract only	Pain
Butow, P.N., Brown, J.E., Coates, A.S. & Dunn, S.M. (2001). Psychosocial predictors of outcome IV: Patients with early-stage breast cancer. *Breast,* 10 (SUPPL. 3), 182-189.	Abstract only	Cancer
Hoskins, C.N. & Budin, W.C. (2000). Measurement of psychosocial adjustment to breast cancer: a unidimensional or multidimensional construct? *Psychological Reports,* 87 (2), 649-663.	Abstract only	Cancer
Schochat, T., Rehberg, W., Von Kempis, J., Stucki, G. & Jackel, W.H. (2000). The North American Spine Society Lumbar Spine Outcome Assessment Instrument: Translation and psychometric analysis of the German version in rehabilitation patients with chronic back pain. *Zeitschrift fur Rheumatologie,* 59 (5), 303-313.	Abstract only	Pain
Monsen, K. & Monsen, J.T. (2000). Chronic pain and psychodynamic body therapy: A controlled outcome study. *Psychotherapy,* 37 (3), 257-269.	Yes	Pain
Vendrig, A.A., Derksen, J.J.L. & De Mey, H.R. (2000). MMPI-2 Personality Psychopathology Five (PSY-5) and prediction of treatment outcome for patients with chronic back pain. *Journal of Personality Assessment,* 74 (3), 423-438.	Abstract only	Pain
Al-Ghazal, S.K., Fallowfield, L. & Blamey, R.W. (1999). Does cosmetic outcome from treatment of primary breast cancer influence psychosocial morbidity? *European Journal of Surgical Oncology,* 25 (6), 571-573.	Yes	Cancer

Bolton, J.E. & Breen, A.C. (1999). The Bournemouth Questionnaire: a short-form comprehensive outcome measure. I. Psychometric properties in back pain patients. *Journal of Manipulative and Physiological Therapeutics*, 22(8), 503-10.	Yes	Pain
Nordin, K., Berglund, G., Terje, I. & Glimelius, B. (1999). The mental adjustment to cancer scale - A psychometric analysis and the concept of coping. *Psycho-Oncology,* 8 (3), 250-259.	Yes	Cancer
Cole, J.D. (1998). Psychotherapy with the chronic pain patient using coping skills development: outcome study. *Journal of Occupational Health Psychology,* 3 (3), 217-226.	Yes	Pain
Devins, G.M., Beanlands, H., Mandin, H. & Paul, L.C. (1997). Psychosocial impact of illness intrusiveness moderated by self-concept and age in end-stage renal disease. *Health Psychology,* 16 (6), 529-538.	Yes	Renal
Huether, G., Doering, S., Ruger, U., Ruther, E. & Schussler, G. (1996). Psychical stress and neuronal plasticity: An extended neurobiological model of the stress-reaction-process as a novel concept for the understanding of adaptation processes in the brain. *Zeitschrift fur Psychosomatische Medizin und Psychoanalyse,* 42 (2), 107-127.	Abstract only	-
Gatchel, R.J., Polatin, P.B. & Kinney, R.K. (1995). Predicting outcome of chronic back pain using clinical predictors of psychopathology: a prospective analysis. *Health Psychology*, 14 (5), 415-420.	Yes	Pain
Bremer, B.A., Haffly, D., Foxx, R.M. & Weaver, A. (1995). Patients' perceived control over their health care: an outcome assessment of their psychological adjustment to renal failure. *American journal of medical quality: the official journal of the American College of Medical Quality,* 10 (3), 149-154.	Abstract only	Renal
Moorey, S., Greer, S., Watson, M., Baruch, J.D.R., Robertson, B.M., Mason, A., Rowden, L., Tunmore, R., Law, M. & Bliss, J.M. (1994). Adjuvant psychological therapy for patients with cancer: Outcome at one year. *Psycho-Oncology,* 3 (1), 39-46.	Yes	Cancer
Talo, S., Puukka, P., Rytokoski, U., Ronnemaa, T. & Kallio, V. (1994). Can treatment outcome of chronic low back pain be predicted? Psychological disease consequences clarifying the issue. *Clinical Journal of Pain,* 10 (2), 107-121.	Yes	Pain
Alexander, P.J., Dinesh, N. & Vidyasagar, M.S. (1993). Psychiatric morbidity among cancer patients and its relationship with awareness of illness and expectations about treatment outcome. *Acta Oncologica,* 32 (6), 623-626.	Yes	Cancer
Omne-Ponten, M., Holmberg, L., Burns, T., Adami, H.O. & Bergstrom, R. (1992). Determinants of the psycho-social outcome after operation for breast cancer. Results of a prospective comparative interview study following mastectomy and breast conservation. *European Journal of Cancer Part A: General Topics,* 28 (6-7), 1062-1067.	Abstract only	Cancer
Hoffmann, A., Pfiffner, D., Hornung, R. & Niederhauser, H. (1995). Psychosocial factors predict medical outcome following a first myocardial infarction. Working Group on Cardiac Rehabilitation of the Swiss Society of Cardiology. *Coronary Artery Disease,* 6(2), 147-52.	Yes	Cardiac
van der Mei, S. F., Dijkers, M. P. J. M. & Heerkens, Y. F. (2011). Participation as an outcome measure in psychosocial oncology: Content of cancer-specific health-related quality of life instruments. *Quality of Life Research: An International*	Yes	Cancer

Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation, 20(10), 1617-1627.		
Weingart, K. (2012). The effects of preferred and non-preferred partner support on psychosocial outcome in breast cancer patients. *Dissertation Abstracts International: Section B: The Sciences and Engineering,* 72(9-B),5583.	Abstract only	Cancer
Jensen, S. E. (2011). Psychoneuroimmunologic predictors of post-surgical outcome in women with endometrial cancer. *Dissertation Abstracts International: Section B: The Sciences and Engineering,* 72(3-B),1797.	Abstract only	Cancer
Allen, J. L. (2011). The effectiveness of group music psychotherapy in improving the self-concept of breast cancer survivors. *Dissertation Abstracts International Section A: Humanities and Social Sciences,* 71(11-A),3837.	Abstract only	Cancer
Gomez-Perez, L. & Lopez-Martinez, A. E. (2008). Psychological variables related to treatment outcome perception in chronic pain patients. *Revista Mexicana de Psicologia,* 25(2), 283-293.	Abstract only	Pain
Ogrodniczuk, J. S., Piper, W. E. & Joyce, A. S. (2008). Impact of pain on the outcome of group psychotherapy. *International Journal of Clinical and Health Psychology,* 8(2), 399-409.	Abstract only	Pain
Fernandes, S. & McIntyre, T. (2002). Outcome evaluation of a brief psychological intervention program for women with breast cancer. *Psicologia: Teoria, Investigacao e Pratica,* 7(2), 353-372.	Abstract only	Cancer
Maurischat, C., Harter, M. & Bengel, J. (2002). The Freiburg Questionnaire - Stages of Chronic Pain Management (FQ-STAPM): Factorial structure, psychometric properties and construct validation. *Diagnostica,* 48(4), 190-199.	Abstract only	Pain
Cole, B. S. (2000). The integration of spirituality and psychotherapy for people confronting cancer: An outcome study. *Dissertation Abstracts International: Section B: The Sciences and Engineering,* 61(2-B), 1075.	Abstract only	Cancer
Hendrickson, R. (1995). Chronic pain and outcome in a pain clinic population: The relationship between etiology and psychological functioning. *Dissertation Abstracts International: Section B: The Sciences and Engineering,* 55(9-B), 4121.	Abstract only	Pain
Morris, T., Pettingale, K. & Haybittle, J. (1992). Psychological response to cancer diagnosis and disease outcome in patients with breast cancer and lymphoma. *Psycho-Oncology,* 1(2), 105-114.	Yes	Cancer

Appendix B: Clinician interview forms

Dear all,

Generation of Items for a Clinical Health Psychology Global Outcome Measure

I would like to invite you, as a Clinical Heath Psychologist (CHP), to participate in my DClinPsychol research project. I am eager to draw from your clinical experience which outcomes you feel are important for patients accessing CHP services by the end of treatment.

I have attached two documents: these are an information sheet which explains the research in more detail, and a consent form. If, after you have read the information sheet, you are happy to participate, then please complete the consent form and return to me either by email or post.

If you have any questions, please feel free to get in touch.

I look forward to receiving your response.

Many thanks,

Krystel Shelmerdine

Psychologist in Clinical Training at the University of Leeds

UNIVERSITY OF LEEDS

Doctor of Clinical Psychology Training Programme
Clinical Health Psychologist Participant Information Sheet

Why am I being asked to participate in this project?
All Clinical Health Psychologists who have held an active clinical caseload for at least five years are being asked to participate.

What is the purpose of the research project?
At present none of the outcome measures in Clinical Health Psychology (CHP) are of the same standard as in Adult Mental Health: most are either suitable only for specific health conditions or specific aspects which apply across conditions. At present there does not appear to be any outcome measures which can be used across different health conditions seen within CHP, which captures the main aspects relevant to patients' improved outcomes. The aim of this research is to explore which are the most relevant psychological concepts across health conditions, and generate items which may later be used to construct a global outcome measure in CHP. The project will form part of a Doctorate degree in Clinical Psychology at Leeds University.

Do I have to take part?
It is up to you to decide whether to take part or not. If you decide to participate you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are free to withdraw without giving a reason. If you are interested in taking part I will answer any questions you may have.

What will I have to do if I take part?
Initially you will be asked to participate in a brief telephone interview. You will be contacted by email to arrange a convenient time for this. During the interview you will be asked to hold in mind patients you have recently seen and completed therapy with, and consider how they improved. The interview will be conducted by Krystel Shelmerdine, a PICT at the University of Leeds.

Secondly you will be asked to participate in a Delphi group. This is an online survey, comprising three phases, where you will have the opportunity to consider and refine your opinion regarding which outcomes are important in CHP.

Are there any benefits or risks involved in participating in this project?
Participating will take an amount of your time, but this time can be planned by you to suit your commitments.

What happens to the information about me and to the case study?
All information you provide will be kept anonymous when it is written up. Hard copies of data will be stored in a locked filing cabinet and electronic copies will be stored on a personal drive on the university server. The interview will be audio recorded, and quotes from this may be used in the final report and presentation, but you will not be personally identified. If you are unhappy with extracts from your interview being used, you are welcome to ask for these to be omitted. At the end of the project I will prepare a report of what I have found, which will be submitted as my doctoral thesis. This may also be presented at a national conference and published in a journal. If you would like this or any other information about the project then please contact me at the address below.

Krystel Shelmerdine, Room G.04, Charles Thackrah Building,
University of Leeds, 101 Clarendon Road, Leeds, LS2 9LJ
Tel: 0113 343 2732
If you are concerned about this project, you may contact Professor Stephen Morley, Course Director, or Dr Gary Latchford, Research Director of the Doctoral programme, at the address above

Doctor of Clinical Psychology Training Programme

CHP Participant Consent Form

_____

Please tick as applicable

I have read the participant information sheet. ☐

I have had the opportunity to ask questions and discuss the project. ☐

I am satisfied with the answers to my questions. ☐

I have received enough information about this project. ☐

I understand that I am free to withdraw from the project without giving a reason. ☐

I agree to take part in the telephone interview stage of this project. ☐

I understand that all data will be anonymised and I agree to extracts from
my contributions being used in the subsequent report ☐

I understand that if I am uneasy about part of my data being used as an extract, I
may ask for it to be omitted from the report. ☐

I would like to participate in the telephone interview ☐

I would like to participate in the online survey ☐

Email address...

Signature..

Name..

Date..

UNIVERSITY OF LEEDS

Doctor of Clinical Psychology Training Programme

Clinical Health Psychologist Participant Telephone Interview Guide

Introduction: Thank you for agreeing to participate in my research, I appreciate you taking the time to talk to me about this. The aim of this research is to explore which are the most relevant psychological concepts across health conditions, and generate items which may later be used to construct a global outcome measure in Clinical Health Psychology. I have a few questions to ask you, which should take around half an hour. I'd like to record this phone call, so that I can focus on talking to you, rather than writing everything down. Could I please ask whether I have your consent to record this call? The other reason for recording is that I may later choose to include quotes from this interview in my report. Is it ok if I do this?

To help understand which outcomes are important, throughout this interview I'd like you to hold in patients you've completed therapy with, whom you've seen recently.

1. *What did you notice changed as a result of your intervention?*

   a. *Did you notice any differences in the patient's behaviours?*

   b. *Did you notice any differences in the processes that occurred with your patient?*

Keeping in mind patients you've completed therapy with, whom you've seen recently, I'd like you to consider one patient who has improved and another who has not improved (I'll give you a moment to think).

2. *What differences did you observe in the patient who improved compared to the patient who did not improve? (in terms of what you saw rather than what you did)*

   a. *In terms of behaviours?*

   b. *In terms of processes?*

3. *If you were designing a Clinical Health Psychology outcome measure, what would you measure?*

   a. *Would you divide these into categories?*

4. *Which outcome measures do you currently use?*

That's all and thank you for taking part.

Appendix C: Initial item pool and concepts

No.	Construct	Origin	Item
1	Acceptance (Condition)	Interview	I have come to terms with my condition
2	Acceptance (Life), Acceptance of self	Interview; Literature	I have come to terms with who I am
3	Acceptance (Limitations of condition)	Interview	I have come to terms with how my condition affects me
4	Understanding (Condition)	Interview	I understand my condition and how it affects me
5	Understanding (Emotions)	Interview	I understand my feelings about my condition
6	Understanding (By others)	Interview	I am satisfied with others' understanding of my condition
7	Understanding (Emotions); Condition-related distress; Personal growth	Interview, Literature	I am aware of how I feel and behave as a consequence of my condition
8	Positive affect (General)	Interview	I am able to enjoy my life
9	Positive affect (Self-compassion); Self -efficacy	Interview	I take good care of myself
10	Coping – optimism; Discouragement about the future	Literature	I feel optimistic about my life
11	Mood (Symptoms); Depression	Interview; Literature	I do not feel depressed or low in mood
12	Mood (Management)	Interview	I am able to manage any feelings of low mood and depression
13	Anxiety (Symptoms); Worry	Interview; Literature	I do not feel anxious
14	Anxiety Management	Interview	I am able to manage any feelings of anxiety and worry
15	Condition-related distress	Literature	I feel able to tolerate feelings of distress about my condition
16	Thinking (intrusions about condition)	Interview	I do not have intrusive thoughts about my condition
17	Illness intrusiveness	Literature	I feel able to tolerate intrusive thoughts about my condition
18	Positive affect (Confidence); Self-esteem	Interview; Literature	I have confidence in myself
19	Identity (Positive); Identity/Personality	Interview; Literature	I feel content with who I am
20	Engaged (Life); Functioning	Interview	I feel able to focus on and value things in my life other than my condition
21	Management/Coping (management of condition)	Interview	I feel able to manage my condition
22	Social support; Communication (about emotions)	Interview; Literature	I feel emotionally supported in a way that is helpful to me

23	Functioning (relationships); Close Relationship functioning	Interview; Literature	I feel content in my ability to form and maintain close relationships
24	Sexual functioning	Interview	I feel content in my ability to engage in sex
25	Functioning (Social); Positive relations with others	Interview; Literature	I feel content in my ability to engage socially
26	Functioning (School/work); Work functioning	Interview; Literature	I feel content in my ability to work
27	General activities	Literature	I feel content in my ability to do day to day activities
28	Functioning (Personal leisure)	Interview	I feel content in my ability to do activities that I enjoy
29	Proactive (In general); Thinking (Differently); Functioning (personal leisure)	Interview	I feel able to let go of those activities I am no longer able to do
30	Management/ Coping (Coping)	Interview	I feel able to cope with my condition
31	Understanding of limitations	Interview	I feel able to recognise my limitations
32	Control (Of the condition); Well-being: autonomy	Interview; Literature	I feel content with the control I have over my condition
33	Well-being - environmental mastery; Sense of control over life	Literature	I feel content with the control I have over my life
34	Goals (Recalibrate; Realistic expectations); Personal growth	Interview; Literature	I feel my expectations and goals for myself are realistic
35	Adjustment	Literature	I am able to make the changes I need to
36	Management/ Coping (Decision-making); Health System (Involved); Participate in decisions	Interview; Literature	I am able to make, or be involved in, decisions regarding my condition
37	Information (Finding)	Interview	I feel content with the amount of information I have on my condition
38	Information (Coping); Helpfulness of information	Interview; Literature	I feel able to take on board and cope with new information about my condition
39	Communication (About the condition)	Interview	I feel comfortable to talk to others about my condition
40	Communication (Expressing needs); Assertiveness	Interview; Literature	I am able to clearly express my own needs
41	Communication (In general)	Interview	I feel listened to
42	Adherence (Medication); Belief in ability to adhere to	Interview; Literature	I take all medications relevant to my condition

	treatment regimen		
43	Adherence (In general); Health system (Attendance)	Interview	I attend all health care appointments relevant to my condition
44	Health system (Understanding)	Interview	I understand what I can expect from health care staff
45	Health system (Relationship)	Interview	I feel confident to communicate with health care staff
46	Health system (Management); Management/ Coping (Decision-making)	Interview	I feel part of the decision-making process with health care staff
47	Goals (Set & achieve)	Interview	I feel able to achieve the things I want to
48	Well-being - purpose in life; Identity (Meaning)	Interview, Literature	I feel I have a purpose in life
49	Helplessness	Literature	I do not feel helpless
50	Hopeless	Literature	I do not feel hopeless

Appendix D: Delphi email and survey

Email 1:

Hello,

Many thanks for participating in the **1st of 3 online surveys** as part of my research on generating items for inclusion in a **new global outcome measure in Clinical Health Psychology.**
We had a large number of respondents offering helpful comments on the items as well as ideas for changing them and new items. Some respondents were very generous with their time and made some really helpful comments about the concepts behind items and suggested new concepts that we might tap into. **This led to the revision of most items and the addition of 12 new items. This has all enriched the project immensely and I'm very grateful.**
This email is about the next step in the Delphi study. This is where I send out a revised version of the items based on all of your feedback in an attempt to further refine it so we end up with a measure that best reflects all of our opinions.
The 2nd online survey will remain live for a fortnight, until Tuesday 27th November. Please feel free to get in touch if you have any questions about this.

Thanks again & looking forward to hearing more from you,
Krystel Shelmerdine
Psychologist in Clinical Training
University of Leeds

Email 2:

Hello,

Many thanks for participating in the **2nd of 3 online surveys** as part of my research on generating items for inclusion in a new global outcome measure in Clinical Health Psychology. Again, we were very pleased to gain so much helpful feedback on the items. More than half of the items were revised, which has substantially enriched the project and for this I'm very grateful.

This email is about the next round in the Delphi study. This is where I send out a revised version of the items based on your feedback, to further refine it so we end up with a measure that best reflects all of our opinions.

I would be grateful if you could now complete the **3rd and final online survey**. This will remain live for a fortnight, until Monday 24th December. Please feel free to get in touch if you have any questions about this.

https://www.survey.leeds.ac.uk/chp3/

Thanks again & looking forward to hearing more from you,
Krystel Shelmerdine
Psychologist in Clinical Training
University of Leeds

Welcome

Thank you for taking the time to participate in this research.
Please complete this survey by **Wednesday 17th October**. It will not available after this date.
The survey is completed anonymously, can be saved part way through and takes around 10 minutes to complete.
All data collected in this survey will be held anonymously and securely. No personal data is asked for or retained, other than your email address.
Cookies, personal data stored by your Web browser, are not used in this survey.
Note that once you have clicked on the CONTINUE button at the bottom of each page you cannot return to review or amend that page

Participant Information

Why am I being asked to participate in this project?
Psychologists and Mental Health professionals working in physical health who currently hold an adult clinical caseload are being asked to participate.
What is the purpose of the research project?
At present there is no consensus on suitable outcome measures to be used in Clinical Health Psychology (CHP): those most widely used are generally either suitable only for specific health conditions or specific aspects which apply across conditions. Arguably none of the measures currently used are ideal in having a utility across the different health conditions seen within CHP, and in capturing the main aspects relevant to patients' improved outcomes. The aim of this research is to explore which are the most relevant psychological concepts across health conditions, and generate items which may later be used to construct a global outcome measure in CHP. The project will form part of a Doctorate degree in Clinical Psychology at Leeds University.
Do I have to take part?
It is up to you to decide whether to take part or not. If you decide to take part you are free to withdraw without giving a reason. If you are interested in taking part you may contact me using the details below and I will answer any questions you may have.
What will I have to do if I take part?
This is an online survey, comprising three phases, where you will have the opportunity to consider and refine your opinion regarding which outcomes are important in CHP.
Are there any benefits or risks involved in participating in this project?
Participating will take an amount of your time, but this time can be planned by you to suit your commitments.
What happens to the information about me and to the case study?
All information you provide will be kept anonymous when it is written up. Hard copies of data will be stored in a locked filing cabinet and electronic copies will be stored on a personal drive on the university server. At the end of the project I will prepare a report of what I have found, which will be submitted as my doctoral thesis. This may also be presented at a national conference and published in a journal. If you would like this or any other information about the project then please contact me at the address below.

Krystel Shelmerdine, Room G.04, Charles Thackrah Building, University of Leeds, 101 Clarendon Road, Leeds, LS2 9LJ
Email: umks@leeds.ac.uk
Tel: 0113 343 2732
If you are concerned about this project, you may contact Professor Stephen Morley, Course Director, or Dr Gary Latchford, Research Director of the Doctoral programme, at the address above

Consent

Please read the statements below:

I have read the participant information.

I have had the opportunity to ask questions and discuss the project.

I am satisfied with the answers to my questions.

I have received enough information about this project.

I understand that I am free to withdraw from the project without giving a reason.

I agree to take part in this survey

I understand that all data will be anonymised

I agree to my anonymised contributions during this survey being used in the subsequent survey

By clicking *continue* you are agreeing to all of these statements.

Items

The aim of this research is to decide which items should be included in a Clinical Health Psychology global outcome measure. Specifically, this is for **adult** patients with **chronic conditions**, including episodic recurrent and deteriorating conditions.

Our preliminary research included a systematic literature review, which yielded 130 articles, and 9 interviews with clinicians working in Clinical Health Psychology. Relevant concepts were extracted and formed into the items on this page. Consequently they are all thought to be relevant for patients seen in Clinical Health Psychology.

Please read the items below and for each one, rate the extent to which you feel the item is relevant. Please use the text box next to each item for any comments you would like to make, including revisions of item wording.

Note that once you have clicked on the CONTINUE button your answers are submitted and you cannot return to review or amend that page.

Clinical Specialism

1. Please select your professional background

If you selected Other, please specify:

If you selected Other, please specify:

2. Please select a description of the primary clinical area you work in

If you selected Other, please specify:

 If you also work in another clinical area, please write this below. *(Optional)*

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3. Please select the number of years since you qualified in your profession

Items

4. Please rate how relevant you feel each of the items below are for patients seen in Clinical Health Psychology.

	Extremely relevant	**Moderately relevant**	**Slightly relevant**	**Unsure**	**Irrelevant**	**Comment or suggested rewording**
a. I have come to terms with my condition	○	○	○	○	○	
b. I have come to terms with who I am	○	○	○	○	○	
c. I have come to terms with how my condition affects me	○	○	○	○	○	
d. I understand my condition and how it affects me	○	○	○	○	○	
e. I understand my feelings about my condition	○	○	○	○	○	
f. I am satisfied with others' understanding of my condition	○	○	○	○	○	
g. I am aware of how I feel and behave as a consequence of my condition	○	○	○	○	○	
h. I am able to enjoy my life	○	○	○	○	○	

i. I take good care of myself	○	○	○	○	○	
j. I feel optimistic about my life	○	○	○	○	○	
k. I do not feel depressed or low in mood	○	○	○	○	○	
l. I am able to manage any feelings of low mood and depression	○	○	○	○	○	
m. I do not feel anxious	○	○	○	○	○	
n. I am able to manage any feelings of anxiety and worry	○	○	○	○	○	
o. I feel able to tolerate feelings of distress about my condition	○	○	○	○	○	
p. I do not have intrusive thoughts about my condition	○	○	○	○	○	
q. I feel able to tolerate intrusive thoughts about my condition	○	○	○	○	○	
r. I have confidence in myself	○	○	○	○	○	
s. I feel content with who I am	○	○	○	○	○	
t. I feel able to focus on and value things in my life other than my condition	○	○	○	○	○	

u. I feel able to manage my condition	○	○	○	○	○	
v. I feel emotionally supported in a way that is helpful to me	○	○	○	○	○	
w. I feel content in my ability to form and maintain close relationships	○	○	○	○	○	
x. I feel content in my ability to engage in sex	○	○	○	○	○	
y. I feel content in my ability to engage socially	○	○	○	○	○	
z. I feel content in my ability to work	○	○	○	○	○	
aa. I feel content in my ability to do day to day activities	○	○	○	○	○	
ab. I feel content in my ability to do activities that I enjoy	○	○	○	○	○	
ac. I feel able to let go of those activities I am no longer able to do	○	○	○	○	○	
ad. I feel able to cope with my condition	○	○	○	○	○	
ae. I feel able to recognise my limitations	○	○	○	○	○	

	○	○	○	○	○	
af. I feel content with the control I have over my condition	○	○	○	○	○	
ag. I feel content with the control I have over my life	○	○	○	○	○	
ah. I feel my expectations and goals for myself are realistic	○	○	○	○	○	
ai. I am able to make the changes I need to	○	○	○	○	○	
aj. I am able to make, or be involved in, decisions regarding my condition	○	○	○	○	○	
ak. I feel content with the amount of information I have on my condition	○	○	○	○	○	
al. I feel able to take on board and cope with new information about my condition	○	○	○	○	○	
am. I feel comfortable to talk to others about my condition	○	○	○	○	○	
an. I am able to clearly express my own needs	○	○	○	○	○	
ao. I feel listened to	○	○	○	○	○	

ap. I take all medications relevant to my condition	○	○	○	○	○	
aq. I attend all health care appointments relevant to my condition	○	○	○	○	○	
ar. I understand what I can expect from health care staff	○	○	○	○	○	
as. I feel confident to communicate with health care staff	○	○	○	○	○	
at. I feel part of the decision-making process with health care staff	○	○	○	○	○	
au. I feel able to achieve the things I want to	○	○	○	○	○	
av. I feel I have a purpose in life	○	○	○	○	○	
aw. I do not feel helpless	○	○	○	○	○	
ax. I do not feel hopeless	○	○	○	○	○	

5. Please write below any other items you feel should also be included *(Optional)*

Contact details

6. Please enter your email address so that you may be contacted for the 2nd stage of this online survey

Thank you

Many thanks for taking the time to complete this survey.

The second stage of this survey will be sent to you on **Monday 29th October**, and again will be available for 2 weeks.

Appendix E: Round 1 items and comments

Original Item	No. of Comments	Concepts in comments	Replacement item	New?
I am able to enjoy my life	3	-Generally/ condition specific -Meaningful life	I am able to enjoy my life	N
I understand my condition and how it affects me	3	-affects which part? -2 distinct questions	I understand my condition/s	Y
I feel able to focus on and value things in my life other than my condition	1	-condition/visible difference	I feel able to focus on and value things in my life other than my condition/s	Y
I feel able to manage my condition	3	-To a reasonable extent? -Process or outcome?	I feel able to manage my condition/s to a reasonable extent	Y
I feel able to cope with my condition	2	-I am able…	I am able to cope with my condition/s	Y
I am able to make, or be involved in, decisions regarding my condition	3	-get involved in... -make or contribute to decisions...?	I am able to make, or contribute to, decisions regarding my condition/s	Y
I take good care of myself	3	-Lacks specificity - I follow a healthy lifestyle? -highly subjective	I take good care of myself	N
I feel I have a purpose in life	4	-vague -I feel that my life is meaningful?	I feel that my life is meaningful	Y
I do not feel hopeless	5	-I do not struggle with feelings of hopelessness -I feel hopeful	I feel hopeful	Y
I have come to terms with my condition	8	-more fluid: can adjust to one stage, then struggle with a new stage, maybe could say, "at the moment"? - acceptance better -prefer "cope with" - learned to live with or I have found a helpful way to understand my condition	I have accepted my condition/s at the moment	Y

I am able to manage any feelings of anxiety and worry	5	-...about my condition -2 questions	I am able to manage feelings of anxiety or worry about my condition/s	Y
I have come to terms with how my condition affects me	6	- more about managing to handle the condition rather than passive acceptance - I have come to terms with how my condition affects who I am; I have come to terms with how my condition affects what I can do in life	I have come to terms with how my condition/s affects what I can do in life	Y
I am able to manage any feelings of low mood and depression	4	- low mood or depression - two questions	I am able to manage any feelings of low mood or depression	Y
I do not feel helpless	5	- I do not struggle with feelings of helplessness -try reversing	I do not feel helpless	N
I feel able to tolerate feelings of distress about my condition	5	- NONSENSE to patients! - my own feelings or the feelings of those around me?	I feel able to tolerate any feelings of distress about my condition/s	Y
I feel content in my ability to do day to day activities	3	- I accept the extent to which I am able to carry out everyday activities? -"content" is problematic	I accept the extent to which I am able to carry out everyday activities	Y
I feel part of the decision-making process with health care staff	4	-I view myself as involved in..	I feel involved in the decision-making process with health care staff	Y
I feel emotionally supported in a way that is helpful to me	2	-people still do ok if not supported by others?	I feel emotionally supported in a way that is helpful to me	N
I feel content in my ability to engage socially	5	-I am able to socialise to a reasonable extent? -wouldn't use word engage -I feel able to engage socially	I feel able to socialise	Y
I feel confident to communicate with health care staff	3	-I feel confident about my ability to communicate...?	I feel confident to communicate with health care staff	N
I feel content in my ability to do activities that I enjoy	5	-the word "content" is problematic - I am able to do activities that I enjoy to a reasonable extent?	I am able to do activities that I enjoy	Y
I feel listened to	8	- specify by whom	I feel listened to by important people in	Y

			my life	
I have confidence in myself	4	- unclear - too general - perhaps confidence in taking care of myself, or confidence in being around others, or confidence to follow my treatment....	I have confidence in myself	N
I am able to clearly express my own needs	4	-with respect to my condition or in general -I clearly...	I clearly express my own needs	Y
I feel my expectations and goals for myself are realistic	3	- I think that my...?	I think that my expectations and goals for myself are realistic	N
I feel able to recognise my limitations	7	- I feel able to accept the limitations caused by my condition AND I feel content with the way society is organised to minimise limitations associated with my condition; I feel able to accept the limitations that others have in understanding my situation	I feel able to accept the limitations caused by my condition/s	Y
I feel content with the amount of information I have on my condition	3	-I am satisfied with the amount of...?	I am satisfied with the amount of information I have on my condition/s	Y
I feel optimistic about my life	6	-I feel able to face whatever the future might bring	I feel able to face whatever the future might bring	Y
I am able to make the changes I need to	7	- a bit vague and broad - as a result of my condition	I am able to make the changes I need to, as a result of my condition/s	Y
I feel able to achieve the things I want to	3	- I can - a bit vague	I can achieve the things I want to	Y
I feel content in my ability to form and maintain close relationships	5	- use confident instead of content - I am satisfied with	I am satisfied with my ability to form and maintain close relationships	Y
I feel content in my ability to engage in sex	11	- sexual relationships - I am distressed by issues around sexual feelings/sexual activity - not sure about word 'content'	I am satisfied with my ability to engage in sexual activity	Y
I do not feel depressed or low in mood	7	- two questions here	I do not feel depressed or low in mood	N

		- Maybe some kind of time statement e.g. 'normally' or 'in general' needed		
I feel able to tolerate intrusive thoughts about my condition	5	- I feel able to tolerate any intrusive thoughts I have about my condition - am able to let go of sudden reminders of my condition	I am able to let go of any sudden reminders about my condition/s	Y
I feel able to let go of those activities I am no longer able to do	6	- I accept that I am no longer able to do some things	I accept that I am no longer able to do some things	Y
I feel content with the control I have over my condition	4	- I am satisfied with the control	I am satisfied with the control I have over my condition/s	Y
I feel content in my ability to work	7	- I am not significantly troubled by employment issues - my condition doesn't affect my ability to work - to work or contribute in other ways - should include work around the house/ chores if someone not in employment	I feel content in my ability to work I feel fulfilled with what I do during the day	N
I understand my feelings about my condition	6	- vague - how I feel about	I understand how I feel about my condition/s	Y
I feel able to take on board and cope with new information about my condition	3	- I can... - maybe separate out different others: colleagues, friends, family, health care professionals, benefits advisers	I can handle new information about my condition/s	Y
I am aware of how I feel and behave as a consequence of my condition	10	- just behave - and ..I understand the ways my thoughts, emotions and actions have an impact on my condition - I am aware of how my condition affects how I feel and behave - too complicated	I am aware of how my condition/s affects how I feel and behave	Y

I feel comfortable to talk to others about my condition	4	- comfortable talking to others - I feel able to talk to others about my condition if the need arises	I feel able to talk to others about my condition/s	Y
I do not feel anxious	7	-I feel calm	I feel calm	Y
I feel content with who I am	2	- are you asking about acceptance? If so, needs to be asked!	I feel content with who I am	N
I am satisfied with others' understanding of my condition	7	- how other people understand - significant others (friends, partners etc) - close members of my family have a helpful understanding of my condition	People who are important to me have a helpful understanding of my condition/s	Y
I feel content with the control I have over my life	6	- I am satisfied…	I am satisfied with the control I have over my life	Y
I understand what I can expect from health care staff	4	- this has two parts - extent of understanding and variability in expectations - might know exactly what to expect but that might be bad or good	I understand what I can expect from health care staff	N
I attend all health care appointments relevant to my condition	5	- may also capture those that overuse services/attend through anxiety /other needs	I attend health care appointments	Y
I take all medications relevant to my condition	7	- as prescribed - how would they answer if they take most -I take the medications prescribed for my condition	I take the medications prescribed for my condition/s	Y
I do not have intrusive thoughts about my condition	10	- Isn't it about coping with these thoughts, rather than whether they are experienced or not? - might not understand what an intrusive thought is - 'I don't find myself thinking about my	I don't have troublesome thoughts about my condition/s	Y

		condition when I don't want to' - Worrying/troublesome thoughts		
I have come to terms with who I am	8	- 'I feel that I know who I am'	I have come to terms with who I am	N

General Comments	Concepts/ Specific suggestions	New item
All items appear very important and difficult to separate	-	-
Can cope with the future (perception of threat) Something about perception of autonomy	-Cope with the future -Perception of autonomy	-
having a collaborative and mutually respectful relationship with healthcare team(s)	-Collaborative and mutually respectful relationship with healthcare team(s)	I have a mutually respectful relationship with my healthcare team(s)
I can manage the reactions of other people to my condition. I can deal with questions and comments about my condition. I can manage teasing and bulling about my condition. I can manage staring. I can make decisions about surgery.	-I can manage the reactions of other people to my condition. -I can deal with questions and comments about my condition. -I can manage teasing and bulling about my condition. -I can manage staring. -I can make decisions about surgery.	I can manage the reactions of other people to my condition/s I can deal with questions and comments about my condition/s
I can see that you are trying to phrase these items as positive goal statements, however think of the impact of rating self against all this positivity, which scant few can claim, and you can see that doing this form may be quite a strain. You may wish to mix positive with negative phrasings to balance it out. also put something in about suffering from guilt, on getting the condition or for not	- suffering from guilt, on getting the condition or for not being strong enough in one's response	I do not feel guilty about my condition/s

being strong enough in one's response etc. good effort, glad to trial		
I feel able to deal with questioning, staring or comments about my condition/visible/speech difference.	- I feel able to deal with questioning, staring or comments about my condition/visible/speech difference.	-
I feel ashamed about my condition or I try to hide the extent of my condition from others (this is very common in the area I work)	-I feel ashamed about my condition -I try to hide the extent of my condition from others	I do not feel ashamed about my condition/s
I follow all recommendations made by health care staff	- I follow all recommendations made by health care staff	I follow recommendations made by health care staff
I presume the questions refer to where somebody is in terms of their health at present? It may be important to stipulate this as people can have difficulties at certain times and not others with their condition or some aspects of treatment and not others and I am not sure these questions pick that up.		
I understand how my mood affects my ability to cope with my condition or something around having good support from family and friends	- I understand how my mood affects my ability to cope with my condition -something around having good support from family and friends	I understand how my mood affects my ability to cope
I'll probably think of something just after I've clicked "continue"!		
It seems a bit over inclusive and repetitive and there are existential items (who am I) as well as condition specific ones (I can cope with it). Need to be clear about which angle you are going for in this proposed measure or include two different scales or scores on it.		
Just a comment: I find a lot of confusion between what I would call process and outcome in the items above		
Maybe something about being able to swap between coping styles i.e. facing problems/uncertain future when need to and putting it aside when need to- i.e. flexibility of coping strategies? Maybe	- being able to swap between coping styles i.e. facing problems/uncertain	-

that is more to do with process not outcome though.	future when need to and putting it aside when need to- i.e. flexibility of coping strategies?	
perceived manageability appraisals - threat, challenge, overwhelmed, negative predictions		
These are nearly all subjective. In Neuropsychology, pt perceptions may be distorted by illness. Npsy is always in need of outcome measures which measure functional abilities and actual behaviour and objective relationships. Perhaps your survey should have relative/carer's version?		
There seem like some good questions, but a lot of them (e.g. "I do not feel helpless") seem like they are suggesting that a place to aim for is no feelings of helplessness, which, in the context of chronic health difficulties, seems unrealistic. I like the questions that have a sense of someone being able to "manage" or "tolerate" or "cope with" the best. Outcome measures that look at a person's ability to cope with what's happened to them are the ones that I find most useful - other ones I feel are a bit quasi-diagnostic.		
They all feel relevant. I wondered whether some items are more enduring and less likely to change over time and therefore less useful in an outcome measure.		
Think about using active voice in the way questions are worded. How about addressing understanding the ways that emotions/behaviours affect/amplify my symptoms and I have confidence in managing to plan/pace my activities -I'm thinking of the work we do with people with troublesome or unexplained symptoms questions about self-management of symptoms (breathlessness/fatigue/nausea/insomnia//coping with pain etc.). Perhaps a question about engagement in self-management of condition. Understanding the impacts of emotions on physical signs. Questions about ability to direct self towards meaningful activity in spite of condition. My comments are to take or leave and rather hastily added here. Good luck with this - a potentially very helpful project for us all	- understanding the ways that emotions/behaviours affect/amplify my symptoms -I have confidence in managing to plan/pace my activities - engagement in self-management of condition - Understanding the impacts of emotions on physical signs. - ability to direct self towards meaningful activity in spite of condition	I am able to balance rest and activity

Wording perhaps needs to take into account that most people with long term conditions have more than one condition.. So they may wonder which aspect of their condition to focus on with each answer? I feel that my life has meaning I can be creative in my life I am able to help and support others I have plenty of laughter in my life i am able to get enough sleep at night I feel constantly exhausted I am able to get regular exercise I am able to eat a healthy diet I can make meaningful contributions to the world my condition is all that others seem to notice about me I am able to have fun in life I do not feel angry I feel able to manage my anger about my life I feel worried about having enough money I feel worried about my housing situation. I am at risk of being bullied by others I feel that others patronise or belittle me because of my condition I can appreciate the good things in life I feel that I am still progressing and developing as life goes on Life is worth living for me	- more than one condition I feel that my life has meaning -I can be creative in my life -I am able to help and support others -I have plenty of laughter in my life -I am able to get enough sleep at night -I feel constantly exhausted -I am able to get regular exercise -I am able to eat a healthy diet -I can make meaningful contributions to the world -my condition is all that others seem to notice about me -I am able to have fun in life -I do not feel angry -I feel able to manage my anger about my life -I feel worried about having enough money -I feel worried about my housing situation. -I am at risk of being bullied by others -I feel that others patronise or belittle me because of my condition -I can appreciate the good things in life -I feel that I am still progressing and developing as life goes on -Life is worth living for me	I do not feel angry I feel able to manage angry feelings I have Life is worth living for me
You ask how relevant these questions are so I've rated them for relevance. But if I thought the	-	

questions were unclear, ambiguous etc., then I rated them as unsure, because an ambiguous question can't be relevant. In order to judge the questions properly, I'd need to see the response scale I'm not sure if it is possible to have one scale that is relevant across conditions - although I can see the attraction of having one Similarly, there are so many aspects to good and poor outcome, that I am not sure it is possible to construct a scale that combines them all. If you administered it and factor analysed it, wouldn't it come out in its component parts - e.g. satisfaction with treatment, emotional response, life satisfaction etc.?		

Appendix F: Round 2 items and comments

Original Item	No. of Comments	Concepts in comments	Replacement item	New?
I am able to enjoy my life	1	-lack of enjoyment may be attributable to other life factors vs. physical health difficulties per se - this needs to be considered otherwise it will be a misleading scale	I am able to enjoy my life	No
Life is worth living for me	1	- My life is worth living	My life is worth living	Yes
I am able to do activities that I enjoy	1	- 'Activities' is misleading - why not 'the things that I enjoy'?	I am able to do the things that I enjoy	Yes
I understand my condition/s	3	- may understand one condition and not another -Better to write condition and put a footnote - to the degree that they WANT to	I understand my condition	Yes
I feel able to focus on and value things in my life other than my condition/s	3	- 2 concepts - only focus on OR value	I feel able to value things in my life other than my condition	Yes
I am able to cope with my condition/s	2	- Needs to be more specific?	I am able to cope with my condition	Yes
I feel confident to communicate with health care staff	1	- feel confident IN communicating	I feel confident in communicating with health care staff	Yes
I feel fulfilled with what I do during the day	0		I feel fulfilled with what I do during the day	No
I feel that my life is meaningful	0		I feel that my life is meaningful	No
I feel listened to by important people in my life	1	- by those who are important to me in my life	I feel listened to by those who are important to me	Yes
I am able to manage feelings of anxiety or worry about my condition/s	3	- relating to or concerning my condition. - I feel able?	I feel able to cope with worries or anxiety about my condition	Yes

		- manage/ 'cope with' better		
I am satisfied with my ability to form and maintain close relationships	1	- 'ability' is v unclear	I am able to form and maintain close relationships	Yes
People who are important to me have a helpful understanding of my condition/s	0		People who are important to me have a helpful understanding of my condition.	No
I feel able to manage my condition/s to a reasonable extent	3	-"satisfactory" rather than "reasonable"? - Too vague	I am satisfied with my ability to manage my condition.	Yes
I am satisfied with the amount of information I have on my condition/s	0		I am satisfied with the amount of information I have on my condition.	Yes
I am able to balance rest and activity	1	- ...to a reasonable extent?	I am able to balance rest and activity	No
I am able to make, or contribute to, decisions regarding my condition/s	2	- complex wording - only to the extent that the individual WANTS/chooses to	I am able to make decisions about my condition	Yes
I feel emotionally supported in a way that is helpful to me	2	-around my condition - do you need "in a way that is helpful to me"?	I feel emotionally supported in a way that is helpful to me	No
I have confidence in myself	1	- self vs. body - may have confidence in self but not in body	I have confidence in myself	No
I am satisfied with my ability to engage in sexual activity	3	-'ability' is v unclear - sexual intimacy, not activity -intimacy and sex	I am satisfied with my ability to engage in intimacy and sex	Yes
I have come to terms with how my condition/s affects what I can do in life	3	- how is this different to item 10?	I have come to terms with how my condition affects what I can do in life	Yes
I am satisfied with the control I have over my condition/s	2	- suggest "satisfied" is too much of a positive emotion about not having control -vague	I am satisfied with the control I have over my condition	Yes
I am aware of how my condition/s affects how	1	-break down into 2 qs	I am aware of how my condition	Yes

I feel and behave			affects me	
I feel able to talk to others about my condition/s	1	- assuming people WANT to talk to others	I feel able to talk to others about my condition	Yes
I feel able to manage angry feelings I have	3	- ...any angry feelings I have	I feel able to manage any angry feelings I have	Yes
I am able to manage any feelings of low mood or depression	5	- "any" sounds difficult to achieve - I feel able? - is it helpful to distinguish between that which is due to the condition/situation and more pervasive low mood?	I am able to manage feelings of low mood or depression	Yes
I take good care of myself	0		I take good care of myself	No
I feel able to tolerate any feelings of distress about my condition/s	2	-don't use 'tolerate' - take out "any"	I feel able to tolerate feelings of distress about my condition	Yes
I clearly express my own needs	2	- I am able to clearly express my own needs - I can clearly express my needs	I can clearly express my needs	Yes
I am able to make the changes I need to, as a result of my condition/s	2	- too inclusive e.g. might be able to make practical changes needed but not the emotional adjustment -bit wordy	I am able to make the changes I need to, because of my condition	Yes
I feel content with who I am	1	- very general	I feel content with who I am	No
I do not feel ashamed about my condition/s	1	-may not understand/acknowledge complex feelings	I do not feel ashamed about my condition	Yes
I feel hopeful	3	- I feel realistically hopeful - not feeling hopeful does not necessarily mean one feels hopeless - What if they are dying?	I feel hopeful	No
I understand how my mood affects my ability to cope	0		I understand how my mood affects my ability to cope	No
I have accepted my condition/s at the moment	4	- Some of my pts see accepting condition as a bad	I have accepted my condition	Yes

		thing (as they see themselves resisting/fighting it) - Too vague - take out "at the moment" -this is a bit woolly		
I do not feel helpless	3	- better to say "I feel hopeful" - "I can manage feelings of helplessness"	I do not feel helpless	No
I feel involved in the decision-making process with health care staff	2	- only where patients WANT to		OMIT
I think that my expectations and goals for myself are realistic	1	- very subjective	I think that my expectations and goals are realistic	
I feel able to accept any limitations caused by my condition/s	3	- "tolerate" rather than "accept" - feels repetitive to previous items	I feel able to accept any limitations caused by my condition	No
I do not feel depressed or low in mood	1	- Suggest not using "I do not" wording	I do not feel depressed or low in mood	No
I am satisfied with the control I have over my life	3	- "satisfied" is not a great word here - over life or over their condition?	I am satisfied with the control I have over my life	No
I do not feel guilty about my condition/s	2	- may not understand /acknowledge complex feelings - suggest "I feel guilty" rather than "I do not feel guilty"	I do not feel guilty about my condition	Yes
I can manage the reactions of other people to my condition/s	2	- I can accept the reactions of others... - I can deal with the reactions...	I can deal with the reactions of other people to my condition	Yes
I can deal with questions and comments about my condition/s	0		I can deal with questions and comments about my condition	Yes
I accept the extent to which I am able to carry out everyday activities	6	- bit complex wording? - "I am able to tolerate the limitations to my everyday activities"? - i am able to carry out everyday activities - hard to separate what impairment from acceptance of it	I can accept the limitations on the things that I am able to do	Yes

		- Doesn't sound very rehabilitation focused		
I accept that I am no longer able to do some things	5	- as a result of my condition - suggest "tolerate" rather than accept - Has the patient given up and accepting a lower level of function than they should or are they realistically accepting.	I accept that I am no longer able to do some things	No
I feel able to face whatever the future might bring	4	- Don't really see what this will tell you - I feel prepared to… - I feel ready to... - separate out health and other life events	I feel ready to face whatever the future might bring	Yes
I feel content in my ability to work	3	- many can't work or have retired	I feel content in my ability to work	No
I understand how I feel about my condition/s	2	- assuming that people need to understand how they feel	I understand how I feel about my condition	Yes
I attend health care appointments	3	- I do not avoid attending health care appointments - is it about the right amount of health care appts	I attend health care appointments	No
I feel able to socialise	3	- assuming everyone WANTS to	I feel able to socialise when I want to	Yes
I can achieve the things I want to	1	- assuming people WANT to	I can achieve the things I want to	No
I can handle new information about my condition/s	2	- I feel I can... - 'handle' - unclear	I can handle new information about my condition	Yes
I understand what I can expect from health care staff	2	- my expectations are met - I understand the role of the health care staff involved in my care	I understand the role of the health care staff involved in my care	Yes
I take the medications prescribed for my condition/s	4	- I consistently take the medications - many prescribed medications may be unhelpful and cause symptoms for otherwise asymptomatic conditions	I follow the treatment for my condition	Yes

		- This can be misleading, often people don't because of terrible side effects		
I have a mutually respectful relationship with my healthcare team/s	3	- the wording of this may be a bit complex for some?	I have a respectful relationship with my healthcare team	Yes
I don't have troublesome thoughts about my condition/s	5	- ...too many troublesome thoughts...? -disturbing - not keen on negative way round of the wording	I don't have troublesome thoughts about my condition	Yes
I follow recommendations made by health care staff	4	- about managing my condition - advice or guidance - patient empowerment is about finding out what's important to the patient and staff suggest things that may or may not then be implemented with /without support	I follow recommendations made by health care staff	No
I have come to terms with who I am	5	- very vague - have any of us??!!	I have come to terms with who I am	No
I am able to let go of any sudden reminders about my condition/s	6	- "I am not unduly upset by sudden (or unexpected?) reminders about my condition" or "I am able to let go and return to normal when faced with sudden reminders about my condition" - suggest "mostly let go" - assumes that 'letting go' of thoughts is a good thing - sometimes a sudden reminder of condition is a reminder e.g. to take treatment - thinking things through and a degree of rumination may be helpful for some people	I spend a lot of time thinking about my condition	Yes
I feel calm	3	- assuming this is a good thing - why not invigorated/excited/energetic? - calm about what?	I feel able to relax	Yes
I do not feel angry	3	- being angry may be helpful/motivating - negative wording is confusing - to do with condition or other factors	I do not feel angry	No

General Comments	Concepts/ Specific suggestions	New item
relevance on assumption that there would be a time frame for all Qs i.e. how feeling now/over last week etc., and also that response would be on some sort of scale, (not yes/ no/na etc.)		
As an overall comment I think it is best to stick to more specific questions, than general statements		
coming together nicely		
I feel able to relax?	I feel able to relax	I feel able to relax
I think there are too many items, ideally half as many would be good!		
I think this is a significant improvement on the first version and now covers all important areas. A short version would be helpful - but perhaps not easy to achieve! Results of factor analysis would be very interesting.		
I wondered if you had asked any patients to do the survey? We have some very useful volunteers here who might be willing if you have ethics for that		
Maybe something specific about finance / benefits	finance / benefits	
My condition makes me feel defective or second rate. i worry that if i had children they would have the same condition. I am in control of the amount of time I spend looking or checking my condition	My condition makes me feel defective or second rate. I worry that if I had children they would have the same condition. I am in control of the amount of time I spend looking or checking my condition	
Possibly items about symptom management, health anxiety, avoidance of activity because of impact of condition, a body image question. I've mostly rated the items as moderately relevant - they won't all be relevant to everyone, but I do think that these are important items	symptom management, health anxiety, avoidance of activity because of impact of condition, a body image question	
see my comments above re the ambiguity of some of the questions		

Too many items focused on thoughts and feelings! A mix of process and outcome, if you ask me. A definition or model of outcome needed so that we can fit this content to that. "outcome" is too broad a concept.		
You haven't added anything in about dealing with the potential economic limitations or on dealing with the benefits system? e.g. maybe I feel supported by health care staff in dealing with the benefits system (this is currently such a big pre-occupation for my clients. Or, I feel helped in dealing with any financial implications of my condition/s	economic limitations or on dealing with the benefits system	

Appendix G: Round 3 items and comments

Original Item	No. of Comments	Concepts in comments	Replacement item	New?
I am able to enjoy my life	1	-ability to have interest or pleasure in life is important	I am able to enjoy my life	N
My life is worth living	0		My life is worth living	N
I am able to do the things that I enjoy	1	-I am able to do things that I enjoy	I am able to do things that I enjoy	Y
I understand my condition	0		I understand my condition	N
I feel able to value things in my life other than my condition	3	-I feel able to value things in my life -I feel able to value things in life despite my condition	I feel able to value things in my life	Y
I am able to cope with my condition	0		I am able to cope with my condition	N
I feel confident in communicating with health care staff	0		I feel confident in communicating with health care staff	N
I feel fulfilled with what I do during the day	2	-What I do during the day fulfils me	What I do during the day fulfils me	Y
I feel that my life is meaningful	0		I feel that my life is meaningful	N
I feel listened to by those who are important to me	2	-not always important to the individual -I can get myself heard when it matters?"	I feel heard by those who are important to me	Y
I feel able to cope with worries or anxiety about my condition	0		I feel able to cope with worries or anxiety about my condition	N
I am able to form and maintain close relationships	2	-make close relationships and keep them -can't assume everyone wants this	I am able to make close relationships and keep them	Y
People who are important to me have a helpful understanding of my condition	1	-only if relevant to the individual	People who are important to me have a helpful understanding of my condition	Y
I am satisfied with my ability to manage my	1	-repeat of "I am able to cope with my		OMIT

condition		condition"?		
I am satisfied with the amount of information I have on my condition	1	-repeat of "I understand my condition"?	I am satisfied with the amount of information I have on my condition	N
I am able to balance rest and activity	1	-"manage the balance between rest and activity" otherwise sounds like "I am able to balance"	I am able to manage the balance between rest and activity	Y
I am able to make decisions about my condition	2	-'when I choose to' -may be more about FEELING able to make decisions	I feel able to make decisions about my condition, when I choose to	Y
I feel emotionally supported in a way that is helpful to me	1	-academic phrasing	I feel emotionally supported in a way that is helpful to me	N
I have confidence in myself	1	-Define confidence!	I have confidence in myself	N
I am satisfied with my ability to engage in intimacy and sex	3	-accepting rather than satisfied -where relevant to the individual	I accept my ability to engage in intimacy and sex	Y
I have come to terms with how my condition affects what I can do in life	2	-accept -prefer wording of "I have accepted my condition" item	I have accepted how my condition affects what I can do in life	Y
I am satisfied with the control I have over my condition	4	-"..with how much control I have over my condition" -'level' of control -accepting rather than satisfied -"I am at peace with..." or "I can live with..."	I accept how much control I have over my condition	Y
I am aware of how my condition affects me	1	- I like the wording, but repeat of "I understand my condition" & "I am satisfied with the amount of information I have on my condition"?	I am aware of how my condition affects me	N
I feel able to talk to others about my condition	2	-I am satisfied with the amount I talk to others about my condition -people may not want/like doing this	I am satisfied with my ability to talk to others about my condition	Y

I feel able to manage any angry feelings I have	1	-It depends on what you mean by manage	I feel able to manage any angry feelings I have	N
I am able to manage feelings of low mood or depression	0		I am able to manage feelings of low mood or depression	N
I take good care of myself	2	-I take care of myself as well as I can -I take good enough care of myself	I take care of myself	Y
I feel able to tolerate feelings of distress about my condition	3	-don't use 'tolerate' -person's own or those of others?	I feel able to manage feelings of distress about my condition	Y
I can clearly express my needs	2	-'when i need to' -"clearly" implies a higher level of satisfaction than the wording for most other items	I can express my needs when I need to	Y
I am able to make the changes I need to, because of my condition	4	-I am able to make the changes I need to make due to my condition -phrasing is hard to understand	I am able to make the changes I need to make due to my condition	Y
I feel content with who I am	0		I feel content with who I am	N
I do not feel ashamed about my condition	1	-Dislike negative phrasing	I do not feel ashamed about my condition	N
I feel hopeful	3	-I have hopes for the future -'hope' as a construct is complex & not necessarily ubiquitous across populations. Suggest 'hopeless' (depression) is more relevant	I have hopes for the future	Y
I understand how my mood affects my ability to cope	2	-too academic & abstract -I understand how my mood can affect my ability to cope	I understand how my mood can affect my ability to cope	Y
I have accepted my condition	0		I have accepted my condition	N
I do not feel helpless	2	-dislike phrasing -like wording of "I feel fulfilled with what I do during the day", "I feel that my life is meaningful" and "I am able to make decisions	I do not feel helpless	N

		about my condition" more		
I think that my expectations and goals are realistic	0		I think that my expectations and goals are realistic	N
I feel able to accept any limitations caused by my condition	1	-the social model of disability would suggest that many limitations are social/ cultural/ prejudicial and should not be accepted, so maybe change to I can deal with limitations	I can deal with the limitations caused by my condition	Y
I do not feel depressed or low in mood	2	-dislike negative phrasing	I do not feel depressed or low in mood	N
I am satisfied with the control I have over my life	0		I am satisfied with the control I have over my life	N
I do not feel guilty about my condition	2	-a degree of guilt may be helpful -dislike negative phrasing	I do not feel guilty about my condition	N
I can deal with the reactions of other people to my condition	0		I can deal with the reactions of other people to my condition	N
I can deal with questions and comments about my condition	0		I can deal with questions and comments about my condition	N
I can accept the limitations on the things that I am able to do	0		I can accept the limitations on the things that I am able to do	N
I accept that I am no longer able to do some things	0		I accept that I am no longer able to do some things	N
I feel ready to face whatever the future might bring	2	- don't think this tells you much - who does?	I feel ready to face whatever the future might bring	N
I feel content in my ability to work	6	- Define 'work' - dislike phrasing "content" - I am able to accept the extent to which I am able to work? - accept rather than content	I am able to accept the extent to which I am able to work	Y
I understand how I feel about my condition	0		I understand how I feel about my	N

			condition	
I attend health care appointments	2	- where relevant and/or where they are helpful - some clinical interactions are NOT	I attend health care appointments	Y
I feel able to socialise when I want to	1	- as much as I want to?	I feel able to socialise as much as I want to	Y
I can achieve the things I want to	1	- I can achieve enough of the things I want to?	I can achieve the things I want to	N
I can handle new information about my condition	1	- 'handle'?	I can manage new information about my condition	Y
I understand the role of the health care staff involved in my care	0		I understand the role of the health care staff involved in my care	N
I follow the treatment for my condition	1	- not necessarily a good outcome - for e.g. people with diabetes who may stop metformin due to side effects and request an alternative; who adjust insulin dose to manage side effects etc.	I follow the treatment for my condition as appropriate	Y
I have a respectful relationship with my healthcare team	1	- I understand how to get the best from my health care team	I understand how to get the best from my health care team	Y
I don't have troublesome thoughts about my condition	4	- dislike negative phrasing - I am not disturbed by troublesome thoughts about my condition? - "Thinking about my condition doesn't bother me" - some are expected/relevant even	Thinking about my condition doesn't bother me	Y
I follow recommendations made by health care staff	2	- what about when recommendations from different team members are conflicting	I follow recommendations made by health care staff	N
I have come to terms with who I am	4	- has anyone??! - Come to terms implies who I am has something wrong with it. I accept who I am might be better?	I accept who I am	Y
I spend a lot of time thinking about my	2	- "more time than I would like"?	I do not spend too much thinking	Y

condition		- this may be good or bad	about my condition	
I feel able to relax	0		I feel able to relax	N
I do not feel angry	4	- anger can be motivating and may underpin a good sense of self - dislike negative phrasing - I do not feel angry about having my condition?	I do not feel angry about having my condition	Y

General Comments
Again, some items seem to be based on psychologist assumptions about what is 'best' for people - I don't think these should be included within a q'airre about outcomes across a health population
As before, I see any of these as process items and not outcome. Many of the items are dominated by feelings and not performance. I would personally make an outcome measure more about performance and less about feeling. This is a philosophical choice though. In a survey like this people may work from different background assumptions and that may cause confusion.
great concepts, but language and phrasing must be more accessible and concrete
I have difficulties with pain
I know how to deal with the benefits system?
Is still far too long to use clinically, especially for people with cognitive problems or fatigue

Appendix I: Item movement across the rounds

Final Position	Item	Round Movements	
		1 to 2	**2 to 3**
1	My life is worth living	-	+1
2	I am able to cope with my condition	-1	+4
3	I am able to enjoy my life	0	-2
4	I am able to do the things that I enjoy	+18	-1
5	I feel that my life is meaningful	-1	+4
6	I feel able to cope with worries or anxiety about my condition	0	+5
7	I take care of myself	-20	+20
8	I feel able to socialise as much as I want to	-32	+43
9	I understand my condition	-2	-5
10	I am satisfied with the amount of information I have on my condition	+12	+5
11	I am able to manage feelings of low mood or depression	-13	+15
12	I am able to make the changes I need to make due to my condition	-1	+18
13	I can deal with the reactions of other people to my condition	-	+30
14	I can achieve the things I want to	-22	+38
15	What I do during the day fulfils me	-	-7
16	I am satisfied with my ability to manage my condition (OMITTED)	-10	-2
17	I feel able to manage feelings of distress about my condition	-13	+11
18	I do not feel ashamed about my condition	-	+14
19	I understand how my mood can affect my ability to cope	-	+15
20	I think that my expectations and goals are realistic	-13	+18
21	I feel confident in communicating with health care staff	+13	-14
22	I am able to make decisions about my condition, when I choose to	-11	-5
23	I feel emotionally supported in a way that is helpful to me	0	-5
24	I have confidence in myself	+4	-5
25	I am aware of how my condition affects me	+17	-2
26	I am satisfied with my ability to talk to others about my condition	+17	-2
27	I feel able to manage any angry feelings I have	-	-2
28	I can accept the limitations on the things that I am able to do	-29	+17

29	I have accepted how my condition affects what I can do in life	-9	-8
30	I have hopes for the future	-24	+3
31	I am satisfied with the control I have over my life	+4	+10
32	I accept that I am no longer able to do some things	-11	+14
33	I feel able to relax	-19	+28
34	I feel able to value things in my life	-2	-29
35	I am able to make close relationships and keep them	+19	-23
36	People who are important to me have a helpful understanding of my condition	+31	-23
37	I do not feel depressed or low in mood	-7	+3
38	I feel content with who I am	+12	-7
39	I have accepted my condition	-25	-4
40	I do not feel helpless	-22	-4
41	I do not spend much time thinking about my condition	-26	+19
42	I accept my ability to engage in intimacy and sex	+12	-22
43	I accept how much control I have over my condition	+14	-21
44	I can deal with questions and comments about my condition	-	0
45	I am able to manage the balance between rest and activity	-	-29
46	I feel ready to face whatever the future might bring	-19	+1
47	I follow the treatment for my condition, as appropriate	-7	+8
48	Thinking about my condition doesn't bother me	-8	+9
49	I can clearly express my needs when I need to	-5	-20
50	I understand how I feel about my condition	-11	-1
51	I attend health care appointments	-3	-1
52	I understand how to get the best from my healthcare team	-	+4
53	I do not feel guilty about my condition	-	-11
54	I can manage new information about my condition	-14	-1
55	I feel heard by those who are important to me	+12	-45
56	I can deal with the limitations caused by my condition	-13	-17
57	I am able to accept the extent to which I am able to work	-11	-9
58	I accept who I am	-9	+1
59	I understand the role of the health care staff involved in my care	-8	-5
60	I follow recommendations made by health care staff	-	-2
61	I do not feel angry about having my condition	-	+1

Appendix J: Pilot outcome measure

CORE FOR HEALTH

Client ID: ……………………………..   Date: ……………………………..

Please read each statement and rate how much you have felt that way **over the last week**. Please hold in mind the condition or conditions for which you are currently seeking support.

	Not at all	Only occasionally	Sometimes	Often	Most or all of the time
1. My life is worth living					
2. I am able to cope with my condition					
3. I am able to enjoy my life					
4. I am able to do the things that I enjoy					
5. I feel that my life is meaningful					
6. I feel able to cope with worries or anxiety about my condition					
7. I take care of myself					
8. I feel able to socialise as much as I want to					
9. I understand my condition					
10. I am satisfied with the amount of information I have on my condition					
11. I am able to manage feelings of low mood or depression					
12. I am able to make the changes I need to make due to my condition					
13. I can deal with the reactions of other people to my condition					
14. I can achieve the things I want to					
15. What I do during the day fulfils me					
16. I feel able to manage feelings of distress about my condition					
17. I do not feel ashamed about my condition					
18. I understand how my mood can affect my ability to cope					
19. I think that my expectations and goals are realistic					

*Please rate how you have felt **over the last week**.*

	Not at all	Only occasionally	Sometimes	Often	Most or all of the time
20. I feel confident in communicating with health care staff					
21. I am able to make decisions about my condition, when I choose to					
22. I feel emotionally supported in a way that is helpful to me					
23. I have confidence in myself					
24. I am aware of how my condition affects me					
25. I am satisfied with my ability to talk to others about my condition					
26. I feel able to manage any angry feelings I have					
27. I can accept the limitations on the things that I am able to do					
28. I have accepted how my condition affects what I can do in life					
29. I have hopes for the future					
30. I am satisfied with the control I have over my life					
31. I accept that I am no longer able to do some things					
32. I feel able to relax					
33. I feel able to value things in my life					
34. I am able to make close relationships and keep them					
35. People who are important to me have a helpful understanding of my condition					
36. I do not feel depressed or low in mood					
37. I feel content with who I am					
38. I have accepted my condition					
39. I do not feel helpless					

*Please rate how you have felt **over the last week**.*

	Not at all	Only occasionally	Sometimes	Often	Most or all of the time
40. I do not spend much time thinking about my condition					
41. I accept my ability to engage in intimacy and sex					
42. I accept how much control I have over my condition					
43. I can deal with questions and comments about my condition					
44. I am able to manage the balance between rest and activity					
45. I feel ready to face whatever the future might bring					
46. I follow the treatment for my condition, as appropriate					
47. Thinking about my condition doesn't bother me					
48. I can express my needs when I need to					
49. I understand how I feel about my condition					
50. I attend health care appointments					
51. I understand how to get the best from my healthcare team					
52. I do not feel guilty about my condition					
53. I can manage new information about my condition					
54. I feel heard by those who are important to me					
55. I can deal with the limitations caused by my condition					
56. I am able to accept the extent to which I am able to work					
57. I accept who I am					
58. I understand the role of the health care staff involved in my care					
59. I follow recommendations made by health care staff					
60. I do not feel angry about having my condition					

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Miss Krystel Shelmerdine
Psychologist in Clinical Training
Institute of Health Sciences
Room G.04, Charles Thackrah Building
University of Leeds
Leeds LS2 9LJ

05 July 2012

Dear Krystel,

Re ref no: **HSLTLM/11/041**

Title: **Generation of an Item Pool to Inform a Global Outcome Measure in Clinical Health Psychology**

I am pleased to inform you that the above research application has been reviewed by the Leeds Institute of Health Sciences and Leeds Institute of Genetics, Health and Therapeutics and Leeds Institute of Molecular Medicine (LIHS/LIGHT/LIMM) joint ethics committee and following receipt of the amendments requested, I can confirm a favourable ethical opinion on the basis described in the application form, protocol and supporting documentation as submitted at date of this letter.

Please notify the committee if you intend to make any amendments to the original research as submitted at date of this approval. This includes recruitment methodology and all changes must be ethically approved prior to implementation. Please contact the Faculty Research Ethics and Governance Administrator for further information FMHUniEthics@leeds.ac.uk

Ethical approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I wish you every success with the project.

Yours sincerely

Professor Alastair Hay/Mrs Laura Stroud/Dr David Jayne
Chairs, LIHS/LIGHT/LIMM Joint REC

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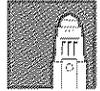
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12 February 2013

Miss Krystel Shelmerdine
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Room G.04, Charles Thackrah Building
101 Clarendon Road
University of Leeds LS2 9LJ

Dear Krystel

Re ref no: HSLTLM/12/034

Title: Generation of an Item Pool to Inform a Global Outcome Measure in Clinical Health Psychology

I am pleased to inform you that the above research application has been reviewed by the Leeds Institute of Health Sciences and Leeds Institute of Genetics, Health and Therapeutics and Leeds Institute of Molecular Medicine (LIHS/LIGHT/LIMM) joint ethics committee and I can confirm a favourable ethical opinion based on the documentation received at date of this letter.

Document	Version	Date
LIHS Ethics Application	1	28.01.13
Ethics Vs 2	1	04.02.13
Thesis Ethics Form	1	04.02.13

Please notify the committee if you intend to make any amendments to the original research as submitted at date of this approval.   This includes recruitment methodology and all changes must be ethically approved prior to implementation.   Please contact the Faculty Research Ethics Administrator for further information FMHUniEthics@leeds.ac.uk

Ethical approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds.   Nor does it imply any right of access to the premises of any other organisation, including clinical areas.   The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I wish you every success with the project.

Yours sincerely

Professor Darren Shickle
Acting Chair, LIHS/LIGHT/LIMM Joint REC
University of Leeds