The development and initiation of a stroke awareness campaign for ethnic minorities. A qualitative analysis of knowledge translation and utilization through social networks

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Abstract

Objectives

Social networks play a major role in health promotion, influencing knowledge dissemination and stakeholders' coordination. I studied a stroke awareness campaign for ethnic minorities to explore: characteristics of social networks relevant for the execution of campaign activities; information acquisition, management and dissemination; evidence generation and translation; network dynamics and mechanisms influencing campaign development and initial dissemination of campaign message.

Methods

I conducted a qualitative case study, specifically focussed on network interactions. I conducted interviews with the main actors of the campaign (N = 17) and non-participant observations of significant interactions (N = 25). I coded data using the constant comparative method, and produced network maps for significant interactions. Overarching themes were identified and analysed using a relational point of view.

Results

Key characteristics of activities accomplished through network interactions included: short-range, local dimension of exchanges between actors through the network; importance of gatekeepers; situational, unsystematic methods for collecting and sharing information and resources, mainly based on tacit knowledge and informal procedures; narrative, anecdotal re-elaboration of information and evidence, aimed at shared construction of meanings; frequent post-event justification of actions, linked with iterative sense-making procedures aimed at coping with unexpected or unknown situations. These characteristics were linked to weak central control on the campaign, and the lack of a global view by actors on the network and of shared context.

"Situational sense-making" emerged as an overarching theme, influencing the intervention along three axes (1) emergence of the campaign in the social space of the community through role negotiations and co-construction of the ethnic identity of the target; (2) unsystematic evidence generation/utilization and short-range, reactive information exchange; (3) localized mechanisms of involvement, judgement and decision making.

Conclusion

A network-oriented view of a community-based health promotion campaign may help process monitoring and understanding of factors contributing to its outcomes.

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List of abbreviations

BME   Black, minority and ethnic

CLAHRC   Collaboration for Leadership in Applied Health Research and Care

CBHP   Community-based health promotion

GP   General Practice

NHS   National Health Service

PCT   Primary Care Trust

RCT   Randomized controlled trial

TIA   Transient ischaemic attack

The daunting task that remains now is to show in detail how, in particular instances, narrative organizes the structure of human experience – how, in a word, "life" comes to imitate "art" and vice versa.

(Jerome Bruner, The narrative construction of reality, 1991)

Chapter 1 Introduction

1.1 Background

Community-based health promotion (CBHP) interventions are usually considered complex and difficult to plan, perform, and evaluate. As described in section 2.1.8, this is due to the high number of variables involved in the interventions, including complex behavioural factors, the influence of culture and norms operating in a community on health behaviours and often the simultaneous presence of several health promotion interventions. Consequently, current methods for planning both an intervention and the associated evaluation need improvement to cope with this complexity and help produce interventions which are effective, and whose effectiveness can be demonstrated. As shown in section 2.1.4, public health researchers are increasingly adopting analytical methods focussing on interactions and networks, both to clarify and to reach a better understanding of underlying mechanisms of action of health promotion interventions, and to improve their design and delivery. The present work applies a qualitative network analysis perspective to the study of a specific CBHP intervention to improve stroke awareness in the black, minority and ethnic (BME) community, in a large English metropolitan area. I used such an intervention as a case to study the complex dynamics of CBHP, on the assumption that in-depth analysis may lead to a better understanding of the mechanisms, which in turn may help improving the design and delivery of interventions. This section will outline the rationale for my study, the research question and objectives and the structure of the thesis. It starts with a clinical definition of stroke and the current best options for treatment, followed by a presentation of the importance of stroke awareness and the consequent justification for my study.

1.1.1 Definitions and public health importance of stroke

Stroke is a medical condition causing loss of cerebral function, itself triggered by brain ischemia (due to vessel occlusion) or haemorrhage. If ischaemic stroke symptoms last less than 24 hours, the event is usually referred to as a transient ischaemic attack (TIA) (Donnan et al. 2008). Ischaemic strokes account for about 80% of all strokes. As a result of a stroke event, patients experience one of more of the following symptoms: facial weakness, difficulties in moving or raising arms or limbs, especially on one side of the body, difficulties in speaking, seeing and understanding language and severe headache, alongside others (Ginsberg 2010, chap.11). Consequences of stroke are generally very serious: "about a quarter of stroke patients are dead within a month, about a third by 6 months, and a half by 1 year" (Donnan et al. 2008). Furthermore, stroke survivors often experience mild to severe disability or

impairment (for US data, see Go et al. 2013, p.e137). For example, in the US stroke was in 2005 the tenth major cause of disability, accounting for 2.4% of all disabilities (Centers for Disease Control and Prevention 2009).

Consequently, from a public health point of view, burden from stroke is large, both in terms of disease burden and health service costs. Despite reduced mortality in recent years, particularly in high income countries, the prevalence of stroke remains significant in both the developed and the developing world (Feigin et al. 2009). According to the World Health Organization (2011), stroke is the second cause of death in the world, accounting for 10.8% of total deaths in 2008. The disability burden from stroke is between 3 and 11% of the total disease burden (deaths and disability) (Moon et al. 2003). Therefore, health system costs resulting from stroke are high, between 2 and 4% of total health system costs (Moon et al. 2003; Donnan et al. 2008). The association of stroke with human ageing is an additional problem, given the current demographic trends (Truelsen et al. 2006); moreover, the economic and financial burden on society is also significant (Demaerschalk et al. 2010). Health inequalities are an additional source of concern about stroke. For example, since being members of an ethnic minority is often associated with living in difficult economic, social and cultural conditions, the burden and consequences of stroke are particularly heavy for members of ethnic groups, as Stansbury et al. (2005) showed for African-Americans.

The best current evidence suggests that stroke has to be treated as a medical emergency. On identification of stroke symptoms, the medical emergency service should be contacted immediately, in order to take the patient to the nearest stroke unit. After admission, a computerized tomography (CT) scan needs to be performed. If the stroke diagnosis is confirmed and the patient is eligible (e.g. in case of ischaemic and non-haemorrhagic stroke) - recombinant tissue plasminogen activator (rtPA) thrombolysis must be performed within a maximum of three hours from the onset of symptoms (National Institute for Health and Clinical Excellence 2007). While such treatment can significantly contribute to reduced severity of stroke and subsequent disability, further evidence suggests that also administering thrombolysis from three to four and a half hours after the onset of symptoms can reduce short-term disability (Hacke et al. 2008; Hacke et al. 2004). However, it is a fact that the sooner acute stroke patients reach the emergency unit, the better. Nonetheless, only a very small percentage of eligible patients receive the recommended treatment, the main reason being the delayed admission to hospital due to pre-hospital delays, i.e. delays occurring from the onset of symptoms to admission (Kleindorfer et al. 2009), or "time from symptom onset to arrival at the hospital or the emergency department" (Teuschl & Brainin 2010). Primary

prevention may be effective against stroke, since most risk factors can be controlled or reduced, blood pressure being one of the most prominent (Seshadri et al. 2006). However, since not all strokes can be prevented, secondary prevention[1] could play a very important role when the first symptoms appear. It therefore seems reasonable to assume that awareness of stroke symptoms and early signs, and of subsequent actions to take, might have a positive impact in obtaining the best possible treatment after a stroke or TIA has occurred, thus directly influencing the disease burden. Concerns about prevalence of stroke and its burden, together with the availability of new treatment options, have prompted a shift in guidelines and policy in several developed countries aimed at enhanced stroke service provision through tertiary prevention and hyper-acute care (see for example: Royal College of Physicians. Intercollegiate Stroke Working Party 2012; National Stroke Foundation (Australia) 2010; Haute Autorité de Santé 2009).

1.1.2   Understanding stroke awareness

Such arguments were taken into account when the UK Department of Health launched the National Stroke Strategy (Department of Health 2007), aimed at improving prevention and care of stroke. The first quality marker highlights the necessity that "members of the public and health and care staff are able to recognise and identify the main symptoms of stroke and know it needs to be treated as a medical emergency" (Department of Health 2007, p.5). However, stroke awareness improvement is a particularly complex challenge, as summarized in Figure 1.1.

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[1] "Secondary prevention involves actions to identify disease when it is at an early stage" (Department of Health 2007).
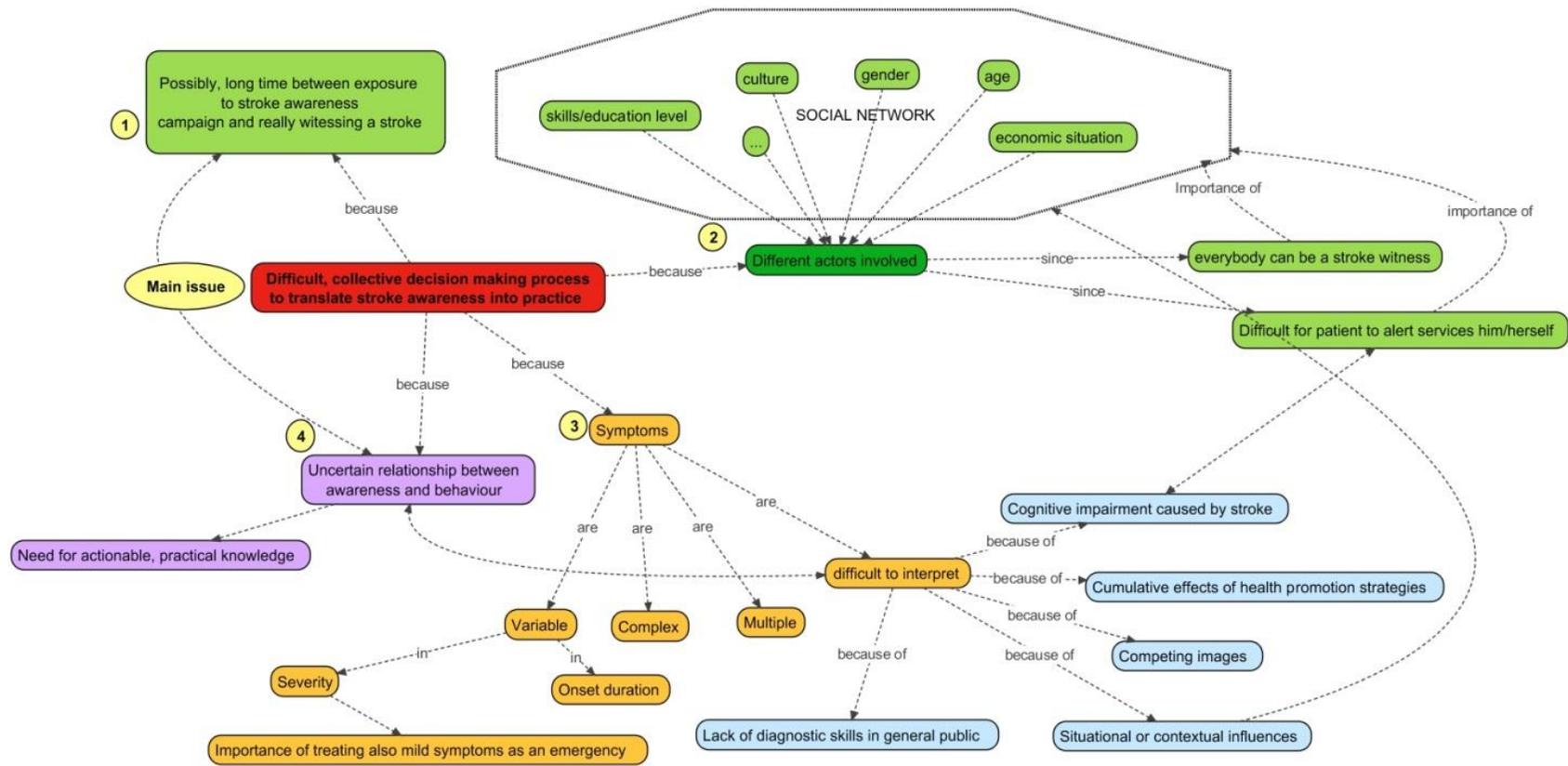
Figure 1.1 The complex nature of stroke awareness - related decision making

Firstly, the behaviour to address is in itself more complex than it can appear at first sight. Moloczij et al. (2008), in their study on factors influencing the decision to call emergency medical services (EMS) when witnessing a stroke, describe a complex decision making process, which includes recognition, interpretation and negotiation, influenced by four factors: making sense of symptoms, maintaining a sense of normality, presence and influence of another person and perception of medical services. Hence, deciding to call EMS when witnessing a stroke is a collective, network-mediated, community-based decision-making process. Consequently, simply broadcasting detailed information about stroke symptoms to the broadest possible audience does not seem to guarantee an immediate reduction in pre-hospital delays for stroke patients. Several actors interact in this process: "stroke patients usually do not activate emergency medical services themselves (…) due to impairment of language, motor function, and cognition" (Mullen Conley et al. 2010). As a result, it would be necessary to train almost everybody in a community to recognize stroke symptoms: this in turn confronts health promoters with the challenge of reaching different audiences effectively.

Awareness of stroke symptoms does not automatically translate into the ability to recognize such stroke symptoms in a patient:

> *"[p]eople's reaction to stroke depends mostly on their sociodemographic profile and their reaction to specific warning signs, independently of recognizing them as 'originating from stroke' "* (Moreira et al. 2011).

Stroke symptoms are multiple and complex, they vary between patients and are difficult to interpret, especially for non-health professionals, also due to situational and contextual influences (Jones et al. 2010; Lisabeth & Kleindorfer 2009; Sekoranja et al. 2009; Teuschl & Brainin 2010; Lecouturier, Murtagh, et al. 2010). Moreover, almost all research on stroke awareness relies on self-reported knowledge, attitudes, and behavioural intents, given the clear difficulty of assessing how a layperson operates when witnessing a stroke. In addition, the literature does not show any linear relationship between the level of stroke awareness in a community, the behavioural intent to call EMS when witnessing a stroke, and effective reduction of decision delays (Willey et al. 2009; Lecouturier, Murtagh, et al. 2010; Lecouturier, Rodgers, et al. 2010). This could be explained by several factors, the first being the lack of agreement on the basic elements of stroke awareness. Furthermore, different theories are used to plan stroke awareness interventions (see section 2.2.2.6 for examples), and educational interventions have very different durations and level of details. Finally, different learning styles of target audiences should be taken into account, along with the type of information supplied, and format and channels for delivery.

As a consequence, assessing stroke knowledge in a population sample is very difficult, since no generally acknowledged tool is available to assess such knowledge, its duration etc., although the Stroke Action Test (Billings-Gagliardi & Mazor 2005) has raised some interest. Finally, with the important exception of Mikulik et al. (2008), no studies define an acceptable level of knowledge prior to conducting an assessment. Unsurprisingly, therefore, Teuschl & Brainin (2010) found that educational initiatives improve stroke awareness, but reduced pre-hospital delays are not associated with better stroke awareness. Several variables influence the level of stroke awareness. However, since it is difficult to indicate an acceptable level of knowledge and awareness of stroke, the evidence is inconclusive and results are often contradictory within and between single studies. Variables often suggested include: ethnic group, cultural level, community/cultural issues, older age, prior stroke, socio-economic status (Lecouturier, Murtagh, et al. 2010; Jones et al. 2010; Teuschl & Brainin 2010). In addition, very few studies take into account retention and recall of stroke-awareness information after months, or even years. Teuschl & Brainin (2010) observe that a few studies show a persistence of knowledge gained through educational initiatives, but the span is only of some months. However, the persistence of knowledge is a vital concept, since the decision making process related to calling EMS when witnessing a stroke is a collective one, involving different actors who may have received stroke awareness information in very different time periods, and from very different sources, at times even competing with each other. The complex dynamics related to stroke awareness, and to the related task of improving awareness in ethnic minorities, make such a context an ideal one to study in-depth through a network-oriented perspective. This is even more important, because section 2.2 will show that these health promotion scenarios are particularly under-explored.

1.2 The research journey and the development of the research question and objectives

The purpose of this section is documenting the process through which the final research question and objectives were developed, revised and elaborated.

1.2.1 The research journey

I based my initial idea for a PhD on my previous experience and research interests. I am an information professional by background, and had previously researched the usage of biomedical digital libraries and users' information behaviour, from the perspective of evidence-based information practice and evidence-based medicine. The aim of my previous studies, however, was mostly practical, oriented towards improving the experience of library

users, and the approach was mostly quantitative (Gardois 2000; Gardois 2001; Gardois et al. 2002; Gardois et al. 2005).

During my experience as an MSc student in International Information Studies, I discovered the potential of qualitative research in studying the information behaviour of clinicians. My masters dissertation was based on fieldwork conducted using qualitative methods in a paediatric care unit in an Italian teaching hospital. In particular, I studied the collaborative information behaviour of clinicians and other personnel in the unit, through interviews and non-participant observations (Gardois 2011). Moreover, for the first time, I had the opportunity to study information-related behaviour outside the organizational context of a physical or digital library. Exploring, for example, how clinicians exchanged information and used it to diagnose diseases and manage patients, allowed obtaining valuable insights of the complexities and richness of information behaviour in the context of a hospital. Furthermore, I could appreciate the importance of interactions and networking to share information that represented the basis on which decisions were made and complex everyday activities were coordinated and carried out.

Consequently, as I considered taking on a PhD position, my initial research interest was oriented towards studying the importance of networks and information sharing in the context of a health-related organization. I was also particularly interested in the emergence of coordinated behaviour as a consequence of information sharing in networks of professionals. My first draft research proposal was titled "How does a stroke prevention team deliver evidence based care? A qualitative analysis of collaborative information behaviour". It was mainly concerned with exploring "the dynamics of information-related interactions, along with iterative cycles of acquisition, archiving, utilization and sharing of information". I also placed a particular focus on "the different roles and perspectives of actors and their information exchange with external players (their "gatekeeping" function)".

Eventually, however, the opportunity arose to study a health promotion campaign involving ethnic minorities. This obviously implied a major shift in focus – from studying the information behaviour of health professionals, to exploring the information dynamics in non-organizational situations, e.g., the interface contacts between health professionals, community gatekeepers and ethnic minority members. After careful consideration, I decided that this was a welcome possibility to apply my preferred research methods and the conceptual frameworks I had previously adopted to a new, more complex social situation. Hence, as the requirements of my involvement in the campaign as a researcher became progressively clearer, I started reviewing

the literature on several different topics, related to how the study of information- and network dynamics could influence the outcomes of CBHP campaigns (see section 2.1).

Meanwhile, the campaign had started, and the NHS commissioners stressed the importance of my role as a researcher in understanding the potential of the social marketing approach taken by the campaigners, and the dynamics involved in the co-production of campaign materials with the target communities. Hence, I initially focussed on the value of social marketing for the campaign, and the lessons learned that would be useful for the roll-out of the campaign to communities located in different cities in the region.

As reported in section 4.1, however, the focus of the campaign changed: only a limited number of target communities was selected after an exploratory phase, and long delays occurred due to organizational reasons. I experienced this period as particularly difficult, since I had started developing my research methods, and I expected to start testing them in the field, but I could not start until the campaigners went to the field again to start the pre- and co-production phases – and this happened only some months later. In the meantime, however, I was able to obtain ethical approval for my research, and to conduct some pilot interviews and observations. Nonetheless, this period of testing and reflection proved useful in refining the methodology. I decided to discard formal, quantitative network analysis, since both I and the supervisors realized that it was important to focus on the complexities of the setting and on exploring the richness of the information dynamics, rather than testing hypotheses or applying existing conceptual frameworks to a mostly under-researched social situation.

I subsequently observed a good number of sessions between campaigners, gatekeepers and communities, and the first round of collected data proved rich in details and meanings at a first, draft analysis. I then decided to stick to my research methodology, although the research question somewhat evolved. In fact, it became progressively clear that – given the time constraints of the PhD and the slow development of the campaign, it would not prove feasible to collect sufficient data from communities to assess the outcomes of the campaign in terms of information diffusion in the communities themselves. A decision then followed, to focus mostly on information exchanges based on networks that were activated at the level of interfaces between "organizational" actors on one hand (NHS managers, campaigners, and the like) and gatekeepers and community members on the other hand. Hence, I recruited these actors for my interviews, and observed all possible interactions between campaigners and gatekeepers/community during the final phase of the campaign. Once again, a decision that had been made in part for opportunistic reasons proved in fact fruitful, as it allowed studying a particularly under-researched phase of CBHP campaigns using an innovative point of view,

namely "qualitative network analysis" (see section 3.3). In summary, the research journey, although far from being easy, proved important in shaping both the research question and the specific objectives in a way that allowed both to preserve my original focus on networks and information sharing, and to make an original contribution to the field of study of CBHP. In the next section, I specifically outline how the research journey influenced the progressive development of my research question and objectives.

1.2.2   Initial research question and objectives

The initial research topic, as explored during the progression to MPhil, involved exploring the dynamics of knowledge translation of scientific evidence from campaigners for a social marketing campaign to the target communities. The study planned to focus on the effectiveness of the social marketing campaign in bridging the gaps between the best evidence for stroke awareness available in the literature and the practical, effective knowledge about such a topic in the community, as its message flows through the social networks of which the community is composed. The three related objectives included the understanding of the following elements:

(a) how the social marketing campaign message on stroke awareness flows through the social networks in the community;

(b) how and if evidence is translated into new knowledge in the community;

(c) how and if such new knowledge is actionable, i.e. might produce changes in the collective decision making processes which are needed when members of the community witness a stroke.

An instrumental objective linked to dimension (a) involved mapping the individuals and the community exposed to the social marketing campaign on stroke awareness in terms of social networks, describing actors (nodes) and relationships (links), as far as the information flow was concerned.

1.2.3   Changes to the initial research question and objectives

Objective factors mainly related to the change in focus of the campaign and the delays in its execution (see section 4.1) prompted a change in focus of the research objectives. In fact, one year later it became clear that the best way of capitalising on the opportunity provided by the campaign within the time frame afforded by the PhD was to collect data concerning the co-production of materials with communities and an initial, short phase of dissemination of materials and a limited number of health promotion events for small groups. The critical importance of network interactions also became clearer and therefore I revised the main

research question and objectives to focus on the development and initiation of the campaign rather than the spread of information from the social marketing campaign.

The revised research question focused on how social networks influenced information circulation and practical outcomes at different levels (commissioners, campaigners, gatekeepers, communities). Three specific objectives derived from this question.

(a) Describing and interpreting the different dimensions, meanings and impacts of social networks in the organization of the campaign, with a focus on the impact of information circulation in the execution of practical activities.

(b) Analysing how scientific evidence about stroke awareness had been translated into a message and its dissemination was initiated, in the context of the campaign.

(c) Analysing how social networks, interactions and social contexts influenced the way in which the campaign was developed and the initial dissemination of the stroke awareness message to the communities.

The research question and objectives were subsequently re-worded, with the intention of making them clearer and more explicitly related to the case study, but without changing the nature of the research project's overall aim and objectives.

1.3 Final version of the research question and objectives

The main research question is:

How did interactions happening in social networks influence the development and initiation of a health promotion campaign aimed at increasing stroke awareness in BME communities?

Social networks can be described under three main aspects. Firstly, their main characteristics in terms of structure, roles and identities involved. Secondly, how networks operate around an object, which in this case is the complex series of activities related to translating evidence and disseminating information about stroke awareness in a culturally appropriate way to ethnic communities. Thirdly, how networks operate with specific mechanisms or dynamics, which allow activities to progress over time. Consequently, the specific objectives are as follows.

1. To understand what elements and characteristics of social networks were relevant for the execution of activities related to the campaign, and why.

2. To analyse how evidence about stroke awareness was acquired, generated and translated and information was acquired, managed and disseminated, in the context of the campaign.

3. To analyse the key network dynamics and mechanisms through which the campaign was developed and the stroke awareness message was initially disseminated to the communities.

The evolution of the research question, objectives and global focus is also witness in the changes to the title of the study. The research proposal presented for the upgrade from MPhil was titled "Does a social marketing campaign enhance community capacity for collective decision making when a stroke is witnessed? A qualitative analysis of knowledge translation and utilization through social networks", reflecting the original research question and objectives. Eventually, the title evolved to its final form, reflecting the evolutionary process just described. However, at the time of ethical approval of the information sheets and consent forms the title was still in its original form, hence these materials as reproduced in the Appendixes display the initial title. Furthermore, the description of the research question and objectives in the same materials still reflects the original focus of the research. This aspect was not amended, however, since the shift in the research question and objectives only involved a narrower focus, but did not require significant changes in the wording of the research objectives, as far as research participants were concerned.

1.4 Structure of the thesis

Chapter 2 contains a literature review focussed on two main topics: a brief summary of the most important theoretical frameworks possibly useful to interpret the findings of this thesis and a systematic review about the state of the art of health promotion interventions aimed at raising awareness of stroke symptoms and related actions for members of ethnic minorities. Chapter 3 concerns the chosen methodology and methods, and in particular the justification of their appropriateness in answering the research question and objectives. Firstly, I briefly clarify my ontological and epistemological stances, and discuss the choice of qualitative network analysis as a methodology. Subsequently, I describe sampling, data collection and data analysis, and I conclude the chapter with a brief overview of the management of ethical and research governance issues. Chapters 4 to 7 present the findings of my research. In chapter 4, I present the stroke awareness intervention and its organizational context. Thereafter, I introduce the relational point of view, and outline the structure of the findings. Chapter 5 fulfils the first research objective, concerning the characteristics of social networks influencing the intervention, focussing on roles, identity and the emergence of the campaign as a temporary social space, along with the role played by social networks in the organization of the campaign. With chapter 6, I move to the second research objective, analysing how evidence and information are acquired, generated, translated and disseminated in network interactions. Chapter 7 is concerned with the third research objective, network dynamics and

mechanisms influencing the intervention. I analyse three main mechanisms of influence of networks: involvement, the forming of judgements and dynamics of decision making. Chapter 8 summarizes the main findings and presents the thematic network. I subsequently discuss the implications of the findings in the context of the literature, before outlining the strengths and limitations of the research, its implications for practice, policy and future research, and the conclusions.

Chapter 2   Literature review

The aim of this literature review is twofold. Firstly, I present the main theoretical frameworks that I considered useful to frame the complex issues arising from planning and delivering CBHP interventions. Secondly, I analyse the literature to understand what is already known about health promotion initiatives aiming at increasing awareness of stroke symptoms and related actions in ethnic minorities. Consequently, the first section of the chapter summarizes the theoretical frameworks I considered most relevant for CBHP, including network theories, planning and evaluation frameworks, community theories and models concerning information and evidence. The second section consists of a systematic review of literature concerning CBHP interventions aiming at increasing stroke awareness in BME communities.

2.1   Theories and frameworks contextualizing the analysis of community-based health promotion interventions

This section will outline some important theoretical frameworks, useful to consider as a background of the thesis, since they are often mentioned in the literature in the context of CBHP interventions.

2.1.1   The literature review: justification and chronology

The process of selection of theories and frameworks that I used to interpret and contextualize community-based health promotion interventions was strictly related to the research journey outlined in section 1.2 (see also section 4.1).

Consequently, different strands exist in the literature review, that were developed at different times during my research project, in response to the need of framing different aspects of the study. Moreover, I needed to review different sets of literature as my research questions evolved according to the shifting focus of the study. This section explains the building up of the literature review and its chronology, along with the justification for selecting some literatures and excluding others, according to the research question and objectives.

The first literature I reviewed concerned the conceptual frameworks of social marketing and co-production (section 2.1.6). I focussed on this literature because in the very beginning of the project the NHS stressed the importance of the innovative framework of social marketing adopted by the campaigners. Hence, it was necessary to understand the main conceptual tenets of this approach, and some possible criticisms. On one hand, as the research project took a different direction, I did not evaluate the effectiveness of this approach in relation with the campaign outcomes. On the other hand, however, taking this framework into account was

useful to contextualize and interpret the findings, especially about some critical issues related to the meaning of co-production.

The next set of literature I set out to review was focussed on community-based participatory models (section 2.1.7), as it was strictly related to the social marketing approach, and allowed understanding the basic elements underlying a health promotion approach geared towards communities and their empowerment – at least in theory. Although I did not use this set of literature in the final discussion of the findings, it was instrumental in developing my interpretation of the data, since it enabled me to add interpretive depth to the description of dynamics I had identified in the field. For example, section 5.4, concerning the importance of temporary events in real-life instances of CBHP, was at least implicitly developed in contrast with the concept of community development and its long temporal duration.

Subsequently, when I had already started the pilot phase of data collection, I decided to review two additional sets of literature. The first one concerned the importance of communities and networks in health promotion (sections 2.1.3 and 2.1.4). I had already in part taken into account the literature on communities and networks in my proposal for the upgrade from MPhil to PhD. However, once I started fieldwork, I realized I needed to develop further my understanding of networks and communities in the specific context of health promotion, since I thought this could contribute to understanding how campaigners approached communities, and made use of networks to advance the campaign. In fact, this literature sensitized me to the fact that communities and networks were complex, evolving social structures, and not stable entities. Consequently, the success of engaging with communities and their networks during a CBHP intervention is highly dependent on contextual and situational factors (see Chapter 5, Chapter 7 and section 8.2).

The second conceptual framework I engaged with during this phase related to the theory of diffusion of innovation. I first encountered the concept while reviewing the literature on the effects of networks in health promotion. This framework was often cited in works discussing the role of networks as barriers or facilitators in the adoption of healthy behaviours by individuals or communities targeted by health promotion campaigns. In my case study, however, this framework did not prove fruitful, partly because the dynamics of adoption were not linear and hence they were difficult to predict, but especially because I did not have sufficient time available to study the outcomes of the health promotion campaign on the daily behaviour of target communities.

The last literature I reviewed concerned the frameworks for planning and evaluation commonly used in CBHP. I already had a working knowledge of the main concepts of this area of study when I came to the final data analysis, but I felt I had to review the most important contributions related to "mainstream" practice in designing and assessing the effects of CBHP interventions, in order to provide a background against which my findings would be discussed. This set of literature turned out to be particularly interesting in establishing a comparison between situational management and strategic framework, and to discuss the need for both (Chapter 8).

I also had to exclude specific sets of literature from my review. The most important excluded literature concerned theories of information behaviour, especially the ones focussing on collaborative information acquisition and sharing. In fact, although useful in an organizational context, these theories did not seem particularly relevant for my need of studying the role of networks in understanding information-related dynamics at the interface between organizational and community-based actors.

In summary, the degree to which different sets of literature influenced the interpretation of my findings varied greatly. During data collection and analysis, however, I took into account all the literatures included in the review, either as sets of sensitising concepts, or as implicit or explicit terms of reference and discussion.

2.1.2 Introduction

Health promotion is mainly concerned with health-related attitudes, which can be described as properties of individuals, groups or communities. In other words, the main determinants of health act at different levels: from general dimensions related to the social, economic, cultural and environmental conditions, to specific living and working conditions, down to networks and communities, to end with lifestyle of individuals and biological and genetic factors characterizing individuals (Dahlgren & Whitehead 1991; see also: Lalonde 1981). Consequently, each level requires specific actions and strategies to promote health (World Health Organization & International Conference on Health Promotion 1986). Another similar conceptualization is the ecological perspective, described by Rimer & Glanz (2005, p. 10–12), which stresses the interdependence and causal influences between different levels and advocates for multilevel interventions. Within this framework, promoting behavioural change of individuals, groups and communities is one of the key objectives of health promotion, alongside interventions at the organizational, economic, political and legislation levels. Since behavioural change is a complex issue, involving several dimensions, different theories on behavioural change have been developed or used by health promoters in recent years (DeBarr

2004; Rimer & Glanz 2005; Abraham & Michie 2008). At the same time, researchers developed models and conceptual frameworks for planning health promotion interventions and for both formative and summative evaluation.

In this section, I will briefly recall the most important aspects of both theories and conceptual frameworks, as far as CBHP interventions are concerned. Following Rimer & Glanz (2005, p.4), I consider theory as an interconnected set of concepts and statements aiming at systematically understanding the main mechanisms of a health promotion intervention that can effect behavioural change – hence, possibly predicting their outcomes, at least to a degree. Such theories may be referred to behavioural change in the strict sense, are generally developed from a psychological perspective and concern individuals and small groups: examples include stages of change theory (Prochaska & DiClemente 1983), social cognitive theory (Bandura 1986), integrative model of behavioural prediction (Fishbein 2009, developed from the theory of planned behaviour). In addition, they may also include theories concerning communities or networks, hence developed from a social sciences perspective and taking into account a wider context in which behavioural change may take place. In reality, the two perspectives often intertwine; however, for clarity's sake and given the network-oriented approach of my work, I will mostly focus on theories trying to explain network- or community-level mechanisms influencing health-related behavioural change.

2.1.3 Communities and health promotion

In this section, I will introduce some topics related to the definition of communities for health promotion purposes and critically examine some major issues. According to a classic definition (Tönnies 2001, p.280), community involves social bonds related to "kinship, tradition, affinity, solidarity", and also beliefs and values: these relationships add up to confer on community an "unity of will", which in turn strengthens its cohesion. Frequently contrasted to the concept of community (or Gemeinschaft) is the concept of society (Gesellschaft), referring to more formal relationships between people, often motivated by rationally pursued self-interest (Tönnies 2001).

In a health promotion context, communities are defined according to different dimensions (Naidoo & Wills 2009, pp.155–7). Firstly, members of a community are thought to reside in a common physical environment – thus, a geographical criterion is adopted. Secondly, communities are believed to share a common culture, i.e. values, norms, and possibly religion, ethnic traits, etc. Finally, belonging to communities is also related to the position in society held by members, and the consequent fact that they share common interests related to particular social activities (work, leisure, etc.). Community members usually share an

emotional attachment and use social networks to communicate and keep in touch with each other and to share resources, such as mutual help (see also: Hubley & Copeman 2008, p.218; Nutbeam 1998). According to the emphasis given to specific traits of the above definition, it is possible to have both strong and weak communities in a health promotion context. As Israel and colleagues comment:

> *"a city (…) may be just an aggregate of nonconnected people, may include numerous communities, or may have little sense of communality. (…) the health educator needs to identify (…) contexts that already show some sense of community"* (Israel et al. 1994).

In addition, Thacker stresses the difference between connectivity and collectivity: while connectivity is defined as "a way of relating individuated units within a wide array of possible topological configurations", collectivity, while requiring "a minimum threshold of connectivity", happens only if "bodies are organized in some manner toward some agreed-upon action" (Thacker 2004a; Thacker 2004b). Furthermore, both networks and communities are defined in spatial terms, but the diachronic dimension is just as important, although underestimated: it is only in a time-related process that networks really operate, functioning as living organisms (Thacker 2004a; Thacker 2004b). Finally, Thacker also expresses the emergent behaviour of networks and communities, using the Deleuzian concept of intensity:

> *"Networks can intensify or de-intensify, depending on the quality, force, resiliency, and flexibility of the relations. Topology is not an extensive mapping, but is instead a topological intensification, culminating in a network affect."* (Thacker 2004a; Deleuze & Guattari 2004, chap.1).

The debate on the concept of communities in recent years has been particularly lively. In connection with social changes brought by globalization and the so-called "risk society" (Beck 1992) and "liquid modernity" (Bauman 2000), Bauman (2001) notes that belonging to a community is often perceived as a protection towards a very competitive social environment exerting threats on individuals, families and groups. Such belonging, however, increases the risk of losing autonomy and freedom, in strictly adhering to rigid social norms enforced by closed community with a strong identity. Further discussion is often focussed on social capital, described as "the social knowledge and connections that enable people to accomplish their goals and extend their influence" (Giddens & Sutton 2009, p.1132). The strong geographical connotation of communities, seems to have weakened nowadays, when global connectivity allows for contacts and sharing between people in distant geographical locations (Giddens & Sutton 2009, pp.815–27). These observations, for example, have lead sociologists such as

Putnam (1995) to theorize a decrease in social capital and in civic engagement in the USA. Others, however, appreciate that the concept of community has mainly changed its characteristics: new information technologies, such as the Internet, offer new possibilities to augment one's social capital by belonging to virtual communities all over the world. For example, Wellman has theorized that social groups have evolved towards "personal communities" by means of personalized networking, and "networked individualism" (Wellman et al. 1988; Wellman 2001; Wellman 2002).

Consequently, some main features of today's communities seem particularly relevant to health promotion practitioners. Firstly, stability over time is important: if either the turnover rate of community members, or the number of people living in the community only intermittently, are too high, it is even difficult to consider the community as a target for health promotion, not to mention seeing it as a resource or an agent (see section 2.1.7). Secondly, the consequences of secularization and social differentiation, immigration and liquid modernity play an important role. Bauman (2007), for example, states that

> *"in every city of a certain dimension, residents are characterized nowadays by an aggregate of differences related to ethnicity, religion and lifestyle, where the line separating insiders from outsiders is all but clear".*

Hence, the geographical dimension may considerably lose importance in the definition of communities, while communities are far less stable over time than they used to be. Moreover, the balance of power between individual and community has changed in favour of the former, whose possibilities of choice (in terms of connections / disconnection from communities) have substantially increased. Communities may be viewed less as a structural and stable property of groups inside society, and more as emergent properties of complex living networks (see section 2.1.4), which allow groups of people who share beliefs and values to temporarily converge on shared objectives.

2.1.4   Social networks and health promotion

As for communities, the fields of public health and health promotion have gradually exhibited over the last decade a growing interest in the workings of social networks (Luke & Harris 2007). According to Marin & Wellman (2011), "social networks are formally defined as a set of nodes (or network members) that are tied by one or more types of relations". Borgatti & Lopez-Kidwell (2011) specify that social network theories focus on two related issues: the architecture of networks, seen as structures with specific properties, and the flow of resources through networks, assimilated to pipes. Seeing networks as the environment for the flow of resources allows studying the exchange of such resources, and the influence of the position of

nodes and the global characteristics of a network on such a process. In this context, several popular network-related theories have been developed, including homophily (McPherson et al. 2001), strength of weak ties (Granovetter 1973) and related theories concerning social capital. From this perspective, dynamics of social capitalization are studied (i.e. how the flow of resources through nodes increases the social capital of nodes or groups) along with dynamics of social contagion, which are "the basis for most diffusion research" (Borgatti & Lopez-Kidwell 2011) – see section 2.1.5. From the network architecture perspective, the emphasis is not on the exchange of resources, but on the function of networks as coordinators of the activity of nodes. This happens mainly through nodes doing work on behalf of others, or by mobilizing knowledge available in one point of the network to be used elsewhere. A further topic of study concerns the dynamics of adaptation of nodes to their environment.

The available literature shows that social networks are a particularly important factor in health promotion interventions. Firstly, especially in CBHP, networks are vital to promote knowledge dissemination to communities, and of learning to practitioners and organizations; sometimes, however, they act as barriers to diffusion of innovation. Secondly, networks may help coordinate actors and actions in a health promotion campaign; depending on their structure, however, they may also represent a barrier to coordination. Thirdly, networks are known to contribute to an increase in social capital in communities targeted by health promotion interventions. This is a particular aspect of a more general influence of social capital and social support on health. Finally, networks can be optimized in health promotion interventions, to increase their effectiveness (Valente 2010, chap.11; Valente 2012; Luke & Harris 2007).

Here, I will look in more detail at the previous four points. As noted by Luke & Harris (2007), social network analysis was used in several studies in the last 50 years to understand how public health innovations were diffused. Such literature particularly stresses the importance of interpersonal communication and direct links with a source of health promotion information, in order to achieve effective outcomes. As an example, Valente & Fosados (2006) found that some network dynamics, such as the role of opinion leaders and of subgroups or cliques inside the network significantly influence the outcomes of HIV prevention programs, although acknowledging the need for further research on the real impact on social networks on campaign outcomes. Social networks are also used in public health to share knowledge and learning between practitioners (Luke & Harris 2007; Gibbons 2007). Furthermore, social support and social capital built through social networks were frequently found to have a significant positive impact on health and well-being, although the mechanisms through which this influence is exerted are often unclear (Cooper et al. 1999; Luke & Harris 2007, p.82;

Murayama et al. 2012). Considering health behaviour, however, the impact of participating in social networks and/or occupying a certain network position was related to particular health attitudes and behaviours (risk taking, smoking, and sexually transmitted diseases). However, social networks may exert either a positive or a negative influence, depending on the contexts (Luke & Harris 2007, pp.83–4).

Understanding how resources and information circulate through social networks may increase the understanding of the dynamics of health promotion interventions, and of barriers and facilitators influencing their outcomes. However, as Luke & Harris (2007, p. 86) note, we still "know very little about how social networks shape health communication among family members, friends, health professionals, and community organizations", and further research on specific mechanisms of interactions in health promotion is warranted. Finally, in recent years specific interventions aimed at optimizing social networks to reach specific outcomes in health promotion have been experimented with. A useful summary of the characteristics of such interventions is provided by Valente (2012), although for a wider context than health promotion. According to the author, network interventions may adopt four different strategies to reach their outcomes. Firstly, individuals occupying specific network positions can be identified to act as champions, brokers or change agents, spreading information, influencing behaviour of network members, providing advice, etc. For example, Valente and colleagues have showed that selecting a community opinion leader to promote behaviour change may have positive effects in health promotion campaigns (Valente 2010, pp.198–9; Valente & Pumpuang 2007). Secondly, network segmentation may be performed, to identify specific subgroups or nodes occupying particular roles that an intervention may target. Thirdly, interventions with a more complex design may aim at influencing network dynamics, by inducing cascades in information sharing across the whole network, through word-of-mouth or snowballing methods. Finally, the whole network structure may be altered, by adding or deleting nodes in particular positions, adding or deleting links between actors in a network, or changing the nature of specific links between nodes. This is obviously an approach focussing on system dynamics, which implies a thorough knowledge and understanding of target networks, but is also likely to be very resource-intensive and time-consuming. The author concludes, however, that research on network intervention dynamics is still at its early stages, and that it seems "unclear which network interventions work best under what conditions" (Valente 2012).

Having briefly described the main features of social networks studied so far in health promotion, I conclude by briefly outlining the relationships between communities and social

networks. Similarities and differences between communities and networks include the following. On the one hand, communities both host several networks and belong to different networks. For example, Palla et al. (2005) have defined communities as parts of a network "in which the nodes (units) are more highly connected to each other than to the rest of the network. The sets of such nodes are usually called clusters, communities, cohesive groups or modules". Moreover, information, beliefs, attitudes and behaviours seem to flow through networks in a given community. On the other hand, however, networks seem to contribute to the erosion of the same concept of traditional community. In a network society, networks seem increasingly centred on the individual, who can ever more easily connect and disconnect from several networks in relatively brief periods. In other words, in the horizon of liquid modernity,

> *"with networks, the fact of belonging is not previous to identity, but seems to follow from it. Belonging, referred to a network (…), tends to become an extension of an ever-changing identity, following (…) re-negotiations and redefinitions of identity itself"* (Bauman 2007).

Consequently, weak ties assume increasing importance in the organization of society. Weak ties were equated by Granovetter to an individual's acquaintances, as opposed to close friends (strong ties) (Granovetter 1973; Granovetter 1983). The importance of weak ties resides in the possibility of creating contacts between an individual and remote parts of the social system, otherwise inaccessible through the relatively closed worlds of friends, or strong ties. Arguably, the network society has multiplied the possibility of establishing weak ties. This corresponds to Bauman's statement about the multiplicity of networks in which an individual tends to be involved.

2.1.5   Diffusion of innovations

One of the most widely adopted community-level theories in health promotion is diffusion of innovations (Rogers 2003). Diffusion is a temporal process through which an innovative idea, product, technology, method, etc. spreads through specific channels to reach the members of a social system. According to Rogers, five perceived attributes of innovation influence its rate of adoption. The first is relative advantage (the fact that an innovation is perceived as better than the standard practice), followed by compatibility (the degree to which the innovation is perceived as compatible with the value system of potential adopters) and complexity ("the degree to which an innovation is perceived as difficult to understand and use"). The final attributes are trialability (how much the innovation can be experimented with on a small scale before adoption) and observability (how easy it is to see concrete results of an innovation).

Different communication channels may be used for adoption. The author stresses the importance of communication between peers and of role models; social structure influences the process, through opinion leadership, norms, etc. Furthermore, adoption happens through a process with five steps: knowledge, persuasion, decision, implementation and confirmation. Finally, Rogers describes as innovativeness a characteristic of the unit of adoption (individual, organization, etc.) responsible for the earlier or later adoption of innovation. According to innovativeness, adopters can be classified as innovators, early adopters, early majority, late majority, laggards. Finally, Rogers explicitly acknowledges the role of network dynamics in diffusion of innovations, especially with the concepts of critical mass and thresholds of adoption of innovations.

This theory seems particularly fit for understanding the dynamics involved in health promotion interventions. Firstly, Rogers himself uses several public health and health promotion examples to illustrate diffusion of innovation. Secondly, a number of practical examples of health promotion interventions based on diffusion of innovations exist. Rimer & Glanz (2005, p. 28–9) show a hypothetical example of translation of diffusion of innovations theory in terms of a concrete health promotion intervention, while the literature includes real-world applications of the theory. Owen et al. (2006) examine the role of diffusion of innovations in the field of promotion of physical activity. They also cite examples of application of the theory in other health promotion sectors, either specific such as cancer control (Ellis et al. 2005), or more general as the experience with the diffusion of the Guide to Community Preventive Services (Briss et al. 2004). On the other hand, such a theory has not been immune from criticisms, concerning different issues. Particularly relevant is the fact that the theory tends to portray adopters as relatively passive terminals of a centralized process of diffusion (Schön 1973; cited in: Rogers 1986). Rogers tried to address this criticism by envisaging decentralized models of innovation diffusion and by integrating in his theory re-invention of innovations by users during the adoption process, and analysing issues related to sustainability over time of adopted innovations. In addition, the attention to network dynamics seems to moderate the linearity of the diffusion model. However, the concern with the active role of communities targeted by health promotion interventions has increased in the last decades. Therefore, I will analyse two further important theoretical frameworks in health promotion: social marketing and community-based participatory approaches. The final section will describe some planning and evaluation models that are widely applied in CBHP.

2.1.6 Social marketing

Definitions of social marketing in a health promotion context include the following key elements (Andreasen 2002; Bryant et al. 2009; Gordon et al. 2006; Kotler & Zaltman 1971). The main *objective* of a social marketing program in health promotion is to promote a voluntary, health-related behaviour change in a target population; the outcomes related to such a change need to be specific and measurable; the well-being of the target is thus the main objective, and this is what distinguishes social marketing from profit-oriented commercial marketing. Moreover, the central idea of social marketing is the management of an *exchange* process between two parties. An example is as follows: a public agency investing public funds to stimulate behaviour change, and a target public audience investing time, physical and psychic energy and possibly money to adopt a new health-related behaviour. The optimization of the exchange process acts so that marketing techniques represent a catalyst or a bridge "between the simple possession of knowledge and the socially useful implementation of what that knowledge allows" (Kotler & Zaltman 1971, p.5), or between evidence and implementation. To establish a successful exchange, four factors need integration in an intervention. The first is product, a definite, specific object, definable as "the benefits customers gain by adopting the proposed behaviour or practice" (Bryant et al. 2009, p.335). A product can "turn motivation into action" (Kotler & Zaltman 1971) and it is often contrasted with generic appeals or blame- or fear-based prevention. It is possible to distinguish further between:

- actual product (the change in behaviour proposed by the social marketing initiative);
- core product, i.e. "the benefit gained by adopting the actual product" (Kotler & Zaltman 1971);
- augmented product, i.e. services, initiatives etc. which can help with the adoption of the core product and enhance its benefits (Grier & Bryant 2005).

The second factor is promotion, or "the communication-persuasion strategy and tactics that will make the product familiar, acceptable and even desirable to the audience" (Kotler & Zaltman 1971); promotion includes advertising, but has a wider scope, including all the promotional activities that aim at facilitating adoption of the proposed behaviour. Thirdly, place represents the availability of a channel, location and physical or metaphorical space enabling people to act in order to adopt the product; managing the "place" category in social marketing allows for adequate and compatible conditions allowing the target audience to perform the exchange, including "locations or distribution points (…) intermediaries (…) response channels" (Lefebvre & Flora 1988). Finally, price indicates the material or immaterial resources the audience needs to spend in order to adopt the behaviour. It would be advisable

to manage in integration the four Ps (the so-called *marketing mix*): a good intervention should allow people to choose a highly desirable product by means of cost-effective and targeted promotion strategies, at an affordable price and through a variety of convenient distribution channels.

Social marketing should be customer-oriented (Lefebvre & Flora 1988): instead of adopting an exclusively top-down approach to health promotion, needs and wants of the target audience should inform an effective marketing mix and thus an effective intervention. Hence, segmentation and targeting of the audience should be performed, to tailor the components of the marketing mix in order to achieve cost-effective results. Additionally, formative research should be conducted both prior to the intervention, and throughout its duration, from pre-testing to evaluation to roll-out to different targets. This allows constantly monitoring and receiving feedback on the suitability of the intervention for the needs of the audience, and constantly integrating and correcting the intervention accordingly. The literature should support the process in order to avoid duplication and allow for re-formulation and adaptation of previous initiatives. Finally, social marketing understands that competitive products – i.e. alternative behaviours – are available to the target audience. Consequently, interventions need to optimize the four Ps to compete with alternative products, including the current behaviour and habits of the target.

2.1.6.1   Limitations and open questions

Critical perspectives have produced useful contributions to social marketing theory. Bloom & Novelli (1981) cite several differences between the challenges that commercial marketers and social marketers need to face, in all phases of a campaign. Social marketers in general have smaller budgets. They generally "sell" products not particularly attractive to target audiences, and often consisting in complex behaviours to be maintained over time, instead of relatively simple and rewarding products, which can be easily bought. Additionally, social marketers have little knowledge of psychological costs and relative prices associated with the products they try to sell, since changing health behaviour often involves complex psychological attitudes, difficult to measure. They also "have less flexibility in shaping their products or offering" (Bloom & Novelli 1981), although they can try to augment the positive perception of their products – especially taking into account that the target of the campaigns are often people who have a negative attitude towards the product. Formative research is also hard to conduct, since participants are sometimes reticent to speak about sensitive and controversial topics such as health. Finally, some communication strategies simply cannot be adopted, due to budget constraints or to the fact that quick, actionable messages are simply difficult to

convey in some cases (e.g. awareness of complex behaviours). The evaluation of social marketing campaigns tends to be difficult, amongst other reasons, because it is often challenging to distinguish the unique effects of a campaign from other, parallel efforts of different health agencies in the same field.

McLeroy et al. (1987) analyse ethical issues related to marketing health promotion: in particular, they ask: "If behaviors are only probabilistically related to health status, are we selling services, behavior change, lifestyle, risk reduction, or health?". Further, health promotion marketing campaigns advertise behaviours which can have side effects, especially if not properly understood. Finally, "with few exceptions, the efficacy of health promotion programs in reducing subsequent mortality and morbidity is not well established" (McLeroy et al. 1987) – an issue still present now, as Stead & Gordon (2010) have recently pointed out in their review of challenges in evaluating social marketing interventions. Furthermore, communication strategies should respect the autonomy of individuals, and so they should not tend to blame the victim, or be manipulative or coercive. Particular attention should also be paid to

> *"the cumulative effects of health promotion messages (…) What is the public to make of all these risks? It is not clear whether or not the public will eventually develop resistance to additional health risk messages"* (McLeroy et al. 1987).

An example of such a resistance is the fact that in road safety messages, fear arousal is not always an effective technique in discouraging risky behaviour in target groups (Lewis et al. 2007). The last observation adds an ethical dimension to the information-related and economic dimensions of overlapping health promotion messages by health agencies. Similar worries are addressed as well by Brenkert 2002). Dolenko (1997), in a more comprehensive critique of social marketing, points out that social marketing campaigns tend to be based on rationalist approaches to individual and group behaviour. The risk lies in abstracting social products from social environments; such a problem concerns also communication strategies, if exclusively targeted at individuals, overlooking broader social environments. Furthermore, social marketing products are often negative products (i.e.: non-smoking) or "conceptual rather than tangible" products (Dolenko 1997, p. 49). Hence, sometimes the message and the product almost entirely overlap, thus challenging the specificity of the exchange/product metaphor, inherent to social marketing. Consequently, "without a physical presence, it is difficult to give a product a distinct identity in the minds of consumers" (Dolenko 1997, p. 51). Finally, power relations in the target communities should be taken into account, as I will outline in the next section.

2.1.7 Community development and community-based participatory models

As outlined, communities can be – and have been – incorporated in health promotion interventions to various extents, namely as a setting, target, resource, or agent (Wendel et al. 2009, p. 278). Communities can also be considered as *catalysts* for change, in an ecological or systemic perspective involving the "interdependence of people, institutions, services and the broader social and political environment" (Wendel et al. 2009, p. 278). Hence, Community capacity can represent both an input to health promotion programmes, and an outcome. At a basic level, many health promotion strategies are based in communities considered as settings, and aimed at individuals inside the community. However, more ambitious intervention models may aim at involving, developing and strengthening communities as a means to improve health, but also and more generally the quality of life of the community itself. The latter model is often inspired the community development perspective, developed since the 1970s (Ledwith 2005; Gilchrist 2004). Its main tenets are the following. Firstly, health promotion initiatives inspired by community development should act on the basis of needs and priorities identified by community members; hence, community involvement is a vital prerequisite. Secondly, instead of narrowly focussing on specific health outcomes, broader actions would help increasing health and quality of life at community level. More specifically, the global aim seems to relate to empowering the community so that it can increase its capacity to analyse health needs, establish priorities, take part in decision making and evaluation of health-related initiatives taking place within its boundaries (Wendel et al. 2009).

Health promoters using a community development model often carry out community profiling, aim at increase the community capacity, try to optimize networking with key players in the community and to negotiate and manage conflicts. In fact community development tends to see a community as a complex scenario, with tensions and role conflicts (Naidoo & Wills 2009, chap. 10). The main contribution of community development to health promotion seems to reside in focussing on real causes of ill health, in its inclusive approach and the importance it attributes to transfer health-related skills and learning within the community. However, such an approach seems very time consuming, and it often struggles to secure continuity of funding due to difficulty in showing clear outcomes in evaluations. Furthermore, health promoters may experience role conflicts, since often the needs of communities and of their own organizations diverge. Finally, community development is often attacked from different parts of the political spectrum, since it may appear too radical, but also a sort of excuse for the state to retreat from direct intervention in welfare (Naidoo & Wills 2009, chap. 10). In summary, community development and community-based approaches to health promotion have acquired an increasing importance over the past decades. Although specific approaches may struggle to

demonstrate tangible outcomes, it seems an established fact that most health promotion initiatives should take into account at least some of the dimensions of community capacity development described by the literature (see for example Wendel et al. 2009, p. 286–7).

2.1.8   Planning and evaluation frameworks

From the brief discussion of the most important issues related to health promotion in community settings, it seems clear that such interventions are difficult to plan, implement and evaluate, due to several factors. Firstly, even small-range health promotion programs often involve complex variables related to different aspects. For example, behavioural change and education are complex processes (Victora et al. 2004). Further, it is difficult to univocally define "health", and hence to demonstrate that a health promotion program has been globally successful (Thorogood & Coombes 2010, pp.28–30). Moreover, Naidoo & Wills (2009, chap. 10, 15) highlight the presence of stakeholders with different perspectives and objectives and financial barriers to design, implementation and evaluation of health promotion interventions. As a result, several planning and evaluation frameworks have been developed for health promotion, which tend to be widely adopted in the field. In this section, I will attempt only a brief summary of the main elements and issues involved in planning and evaluation, in order to complete the description of the main elements of CBHP. Firstly, as showed by Rimer & Glanz (2005, pp.5–7), theories are often incorporated in planning and evaluation, as they outline possible mechanisms and dynamics of interventions and, consequently, assumptions about how an ideal intervention should work. However, theories are not enough to design and plan a health promotion intervention: a considerable number of practical tools and techniques are often adopted in planning models to help health promoters move from theory to practice.

My brief review is based on the presentation of such models in health promotion textbooks (Naidoo & Wills 2009, chap.19–20; Hubley & Copeman 2008, chap.16–17; Scriven 2010, chap.5). I have also taken into account specific contributions describing widely adopted and/or comprehensive planning and evaluation framework, such as the PRECEDE-PROCEED model (Green & Kreuter 2005), the intervention mapping model (Bartholomew et al. 2011), and a general textbook on health promotion evaluation (Thorogood & Coombes 2010). Here, I will only present the main issues concerning the topic, while I will discuss limitations and possible integrations in various subsections of Chapter 8.

Generally, health promotion planning models present a linear sequence of procedures, although frequently the sequence needs iteration to develop a new cycle using as a basis the results of the previous one. The first step in designing a health promotion intervention is often considered a health needs analysis, to be performed using both hard evidence and the

involvement of communities and target individuals. Theories at different levels need then to be taken into account to devise how to respond to identified needs, leading in turn to develop "SMART" objectives (i.e., specific, measurable, achievable, realistic, time-bound). Next, risks and barriers to implementation should be detected and appropriate actions taken to address them. The subsequent stage involves identification of methods and resources to reach the objectives, and finally, the specification of evaluation methods matching both the objectives and the techniques adopted by the intervention. Both objectives and evaluation may concern different time scales, i.e. immediate impact or long-term outcomes. Once taken into account all these issues, a detailed action plan is usually designed, involving specific activities and the roles and actors in charge to carrying them out, with appropriate support of standard project management tools. Quality assurance may help ensuring that – where agreed procedures exist – they are uniformly followed.

Evaluation should be explicitly built in programs from the start and endowed with appropriate resources. It may serve different purposes. For example, it may assess the short- or long-term efficacy, effectiveness or efficiency of an intervention. It may focus exclusively on outcomes, or be also directed at evaluating the process and contextual factors through which outcomes are achieved. Furthermore, some evaluation approaches focus on checking the correct implementation of the intervention – e.g. that it has reached the target groups and it has been acceptable for them, it has been thoroughly performed and may be replicated in analogous situations. Evaluation should also ensure wide stakeholder participation and involve different disciplines, perspective and methods (e.g., both the medical and the social and educational perspectives on public health; both quantitative and qualitative methods of evaluation, etc.). Moreover, evaluation should be appropriate to the size and objectives of the intervention and aim at building capacity in view of further interventions.

2.2 Systematic review of the literature concerning community-based health promotion interventions for increasing stroke awareness in ethnic minorities

2.2.1 Background

I introduced the key background elements about stroke in section 1.1, where I also explored the key elements of the complex construct of stroke awareness. Evidence from surveys and systematic reviews suggests that the majority of people have relatively little knowledge of stroke symptoms and the appropriate response. A systematic review summarizing the results of 39 surveys conducted in different countries prior to 2008 (Jones et al. 2010) found that

"levels of knowledge about recognising and preventing stroke were poor". Another systematic review concerning 11 studies about response to stroke symptoms in the UK (Lecouturier, Murtagh, et al. 2010) states that "people who experience or witness stroke symptoms frequently do not call emergency services". Literature published after those reviews (between 2010 and 2012) seems to confirm these findings. Surveys conducted in several countries, belonging to different continents, confirm that stroke awareness is suboptimal, although it may be increased by specific health promotion initiatives (Cossi et al. 2012; Hickey et al. 2012; Kim et al. 2012; Lambert et al. 2012; Lundelin et al. 2012; Mata et al. 2012; Miyamatsu et al. 2012; Morren & Salgado 2012; Spark et al. 2011; Sun et al. 2011; Wiszniewska et al. 2012; Worthmann et al. 2013).

As a consequence, in recent years media interventions such as the FAST campaign in the UK (NHS Choices 2010)have targeted regions or local communities at particularly high risk. Their common goal is to reduce pre-hospital delays in presentation of a stroke patient so that timely administration of thrombolysis is possible, if indicated. As summarized in section 1.1, health-related inequalities have further influence on the level of stroke awareness of particular subgroups of the population, including BME populations in Western countries. As a response to these worrying data, several countries have invested on educational interventions for increasing stroke awareness in the general population, especially through media campaigns (Teuschl & Brainin 2010; Lecouturier, Rodgers, et al. 2010), although often with mixed results.

Ethnic communities in the UK are a particularly important target for stroke awareness campaigns: they both include a high concentration of individuals at risk, and present particular barriers to the uptake of stroke awareness messages. The National Audit Office (2010, p.44) therefore states that "The Department [of Health] (…) should consider particularly how to engage with groups at higher risk of stroke, such as people of Afro-Caribbean and South Asian ethnicity". Nonetheless, increasing stroke awareness in ethnic communities is particularly difficult. In recent years, there is a growing recognition that specific, community-based and culturally tailored health promotion interventions are needed to improve stroke awareness (Skolarus et al. 2011; Morren & Salgado 2012). One of the reasons is that the effect of mass media campaigns such as FAST on BME community members seems to be limited (Bietzk et al. 2012; Robinson et al. 2013; Department of Health 2010). Even beyond the context of stroke awareness, recognition of the importance of cultural tailoring of health promotion and health care research has been growing. Recent contributions have tried to shed light on this complex topic, by defining cultural appropriateness of interventions and main principles for conducting research on ethnicity and health (Beach et al. 2005; Netto et al. 2010; Mir et al. 2012). Given

these premises, it seems critical to understand which health promotion interventions have been carried out to increase awareness of stroke symptoms and response in BME communities, and whether there is evidence to demonstrate their effectiveness. Consequently, I decided to review the literature to establish the main characteristics of health promotion interventions directed towards increasing awareness of stroke symptoms and appropriate response in BME communities. Additionally, I assessed the existing evidence of their effectiveness. Answering such a question will also help to obtain useful elements to interpret my findings, emerging from the analysis of an intervention with similar targets and methods.

2.2.2   Methods

Having established that a recent literature review on this topic did not currently exist, I undertook a systematic review. My intention was to identify all studies describing health promotion interventions aimed at increasing awareness of stroke symptoms and appropriate response in BME communities, to map the main themes of these studies and to identify any evidence of effectiveness of these interventions. The present section will describe the search strategy, inclusion and exclusion criteria for identified articles, the process of article selection and the process of data analysis and synthesis.

A systematic review is a synthesis of literature that attempts at answering a specific research question by systematically retrieving the available empirical evidence, developing specific inclusion criteria, assessing the validity of the identified evidence and systematically presenting the results of the included studies (Higgins & Green 2011; see also: University of York. NHS Centre for Reviews and Dissemination 2009). Although systematic reviews were widely applied above all in clinical and experimental medicine and were mainly concerned with the meta-analysis of quantitative evidence, in recent years the method has spread to the social sciences (Petticrew & Roberts 2006). Systematic reviews have also begun including the objective of synthesizing qualitative evidence, in addition to quantitative evidence (Dixon-Woods 2006; Dixon-Woods et al. 2007; Thomas & Harden 2008). The present study aimed at producing a review according to the following objectives:

- identifying the best published evidence available;
- selecting the included studies according to rigorous inclusion and exclusion criteria;
- synthesizing the main themes present in the included studies;
- identifying evidence of the effectiveness of interventions.

2.2.2.1 Search, screening and selection strategy

As a first step, I conducted a systematic search on the four most important health sciences databases: Pubmed MEDLINE, EMBASE, CINAHL, and PsycInfo. I performed the searches on 17/01/2012, with the search string described in Table 2.1.

No.	Search string
1	("Stroke"[Mesh] AND (knowledge OR ("warning sign" OR "warning signs") OR recognition OR awareness) Limits: Humans, English, Publication Date from 1996)
2	(stroke AND (knowledge OR ("warning sign" OR "warning signs") OR recognition OR awareness) AND ("2011/07/15"[Date - Entrez] : "3000"[Date - Entrez]))
3	1 OR 2

Table 2.1 Search strings used in the Pubmed database

The string matched the inclusion and exclusion criteria described in section 2.2.2.2, and it was selected in agreement with the supervisors, after trying a number of pilot searches with combination of different terms. The second step in the search strategy is directed at identifying articles included in the database in the six months prior to the search, which would not include terms from the MeSH thesaurus and would therefore be lost if using only the first step in the strategy. I performed the same search, with the necessary adaptations, in the other three databases. The PRISMA 2009 flow diagram reported in Figure 2.1 (Moher et al. 2009) describes the process of selection and identification of articles.

PRISMA 2009 Flow Diagram
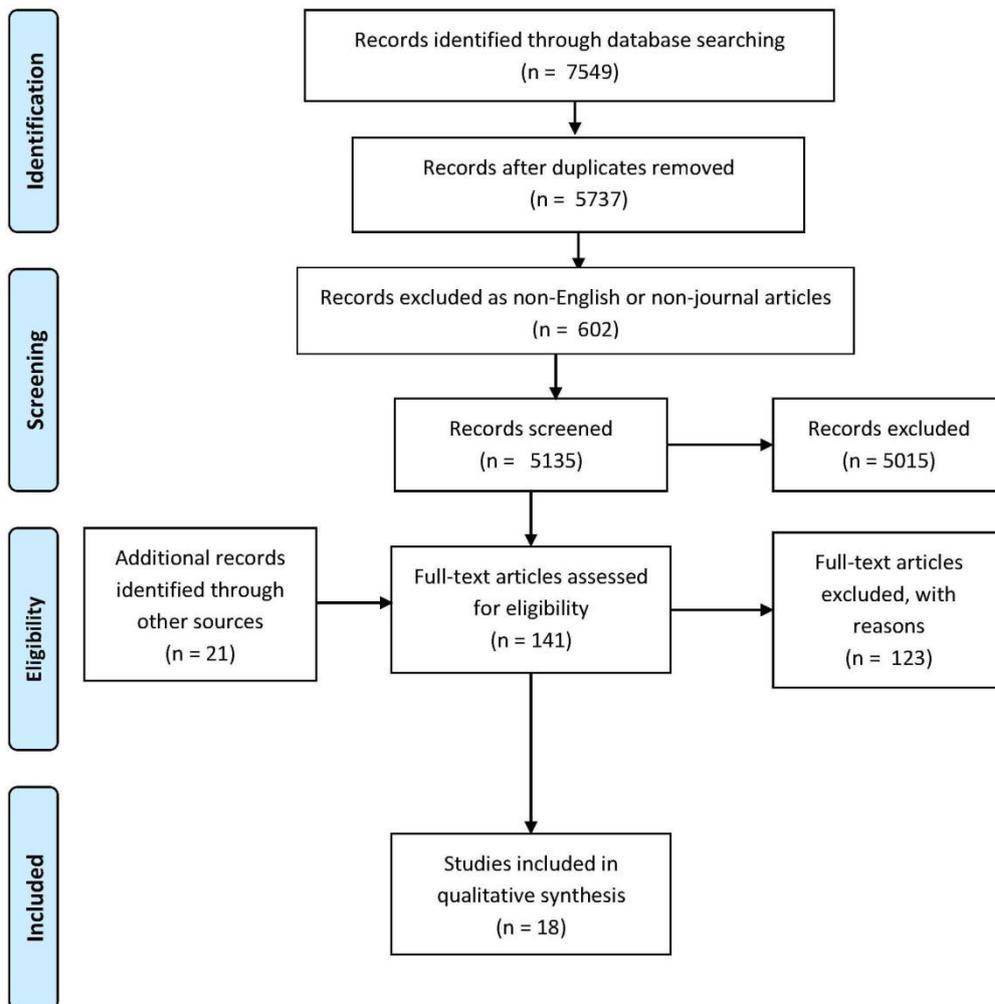
Figure 2.1 PRISMA 2009 flow diagram

The searches in the four databases yielded 7549 references. All references were included in a database in the reference management software Endnote X2 (Thomson Reuters 2008). Thereafter I performed automatic deduplication of results, followed by a manual check of all remaining references: I identified 1812 items as duplicates, while the remaining 5737 articles represented the initial dataset on which I performed the selection. According to selection criteria, I subsequently excluded 602 references, as they were not journal articles or were published in languages other than English. I therefore conducted the screening on 5135 references. In this phase, I screened the title of each reference to verify if it could possibly match the inclusion criteria; in case of uncertainty, I took into account the abstract, if available.

I resolved doubts and interpretive difficulties by discussing specific cases and criteria with all three supervisors.

To validate the process, each of two supervisors, in blind and with the same method, screened 515 randomly selected references (10% of the dataset). Using this method, 20% of the dataset was screened by at least two researchers: the results showed a uniform application of the screening methods. At the end of the screening process, 5015 articles were excluded, according to exclusion and inclusion criteria. Consequently, I thoroughly assessed for eligibility 120 articles, using the abstract and, in case of uncertainty, the full text. For each review identified during the eligibility assessment process, I checked all relevant references, and included them in the articles to check for eligibility if they had not been identified by the search strategy. Furthermore, I also checked for inclusion all citations from the included articles. This step allowed for the inclusion of 21 articles. In total, therefore, I assessed for eligibility 141 articles. Eighteen matched the inclusion and exclusion criteria and were therefore included in the review (Boden-Albala et al. 2010; Chan et al. 2008; Covington et al. 2010; Dromerick et al. 2011; Duraski 2003; Duraski 2006; Duraski 2007; Frank & Grubbs 2008; Gonzales et al. 2007; Kalenderian et al. 2009; Kleindorfer et al. 2008; Miller & Spilker 2003; Morgenstern et al. 2007; Mullen Conley et al. 2010; Villablanca et al. 2009; Williams & Noble 2008; Williams et al. 2012; Williamson & Kautz 2009). However, in some cases, more than one article reported the results of the same study, at different points in time. An intervention named "KIDS – Kids identifying and defeating stroke" was reported in three articles (Gonzales et al. 2007; Morgenstern et al. 2007; Mullen Conley et al. 2010); additionally, a stroke prevention and awareness intervention for the Hispanic community in the Chicago area was reported in two articles (Duraski 2003; Duraski 2006). An exception was represented by "Hip-hop stroke", which was the topic of two articles (Williams & Noble 2008; Williams et al. 2012), describing two entirely distinct phases of the intervention, targeted at different segments of the community and administered by different actors: in this case, for the review, they were considered as two different interventions. Hence, the total number of interventions found in the literature amounts to 15, reported in 18 articles. Search and selection results also confirmed that no review was available on the topic: consequently, I classified all included articles as primary studies.

2.2.2.2 *Inclusion and exclusion criteria*

Only studies describing one or more health promotion interventions aimed at increasing awareness of stroke symptoms, warning signs and appropriate response in BME communities were included. For this purpose, any intervention whose target audience was composed of at

least 50% BME community members was included. Any health promotion technique was included, whether or not it was based on a behavioural change theory. I did not exclude any article because of the study design. However, I included only articles published in a peer reviewed journal, while I excluded any other scientific contribution (e.g. books, conference proceedings, dissertations, etc.). I included interventions if they targeted either the general population or specific subcategories (e.g. students, parents, the elderly), or more specifically, stroke survivors. I instead excluded articles if the health promotion intervention was aimed at health professionals (including health champions, advisers, etc.). I only included articles in English for practical reasons relating to non-availability of translation services. In addition, I considered for inclusion only articles published from 1996 on, since the first trial showing effectiveness and safety of rtPA for stroke treatment if administered within three hours of onset of symptoms was published in December 1995 (The National Institute of Neurological Disorders and Stroke rt-PA Stroke Study Group 1995). It is therefore assumed that its content has had an impact on most educational interventions from such a date on. I also included studies if stroke awareness was not the sole aim of the reported interventions: for example, some articles related to interventions concerning stroke risk factors in addition to stroke awareness, while others concerned knowledge of cardiovascular diseases or diabetes alongside stroke awareness itself. I excluded studies identifying barriers, facilitators, or specific attitudes and needs of potential targets of stroke awareness interventions, as well as studies identifying theoretical issues not related to data directly emerging from specific health promotion interventions.

2.2.2.3   Data analysis and synthesis

After a first scan reading of the included articles, I developed a coding sheet (Cooper 1998), using MS Excel 2010 (Microsoft 2010a). The sheet was refined during the in-depth reading of the articles and through discussion with supervisors. In its final form, it included the columns now divided between Table 2.2, Table 2.3 and Table 2.4. I then populated the sheet with data extracted from studies reporting on individual interventions. In the case of multiple articles for a single intervention, I coded only the article reporting the most recent information on the study, adding information from the other articles if relevant.

2.2.2.4   Results

Results of the analysis are described in three synoptic tables, organized according to the P.I.C.O. framework, often used in systematic reviews of medical literature (Armstrong 1999). The acronym outlines the four main dimension of a clinical question – population, intervention, comparison and outcome. Here, I did not consider comparison, since a number of

interventions did not use specific comparators: accordingly, the three tables contain a synoptic description of items referring to population, intervention and outcomes. In the tables, studies are identified by the name of the first author followed by the publication year. The complete reference is available in the final references. Two rows contain more than one study, since I aggregated the results of more than one article, since they reported on the same intervention (see section 2.1.2.1).

2.2.2.5 Study populations

ID	Study	Target ethnic groups	Intervention level	Population	Population size
1	Boden-Albala 2010	Hispanics ; African Americans	Groups	Survivors (stroke and TIA)	736 enrolled at 2/2010; about a half to be randomized to the intervention arm
2	Chan 2008	African Americans	Individuals	General population	98 participants in intervention group, 100 in control group; follow-up data on 39% of them
3	Covington 2010	African Americans	Groups	General population	16 community members involved in the evaluation; 140 health champions trained 2007-2009.
4	Dromerick 2011	African Americans	Individuals	Survivors (stroke and TIA)	250 patients, in two arms of a RCT (only about a half will undergo the intervention)
5	Duraski 2006 ; Duraski 2003	Hispanics	Groups	General population	177
6	Duraski 2007	Hispanics	Groups	Children and young adults (aged 9-26)	32
7	Frank 2008	African Americans	Groups	Parishioners of African-American churches	120
8	Kalenderian 2009	African Americans ; Hispanics	Groups	Individuals taking part in church activities	Unknown number of participants: "(...) 1499 surveys were returned from 29 (7.5%) of the 388 SYH churches (...). Participation varied (…) from a few congregants to close to 2000".
9	Kleindorfer 2008	African Americans	Individuals	Women	"383 surveys (…) obtained at baseline, 354 were completed at the 6-week follow-up, and 318 were completed at the follow-up 5 months after".
10	Miller 2003	African Americans	Individuals	Patients at risk for stroke	60 patients divided in 3 groups: 20 received the intervention, 20 were used as a control and 20 received "simple advice".
11	Morgenstern 2007 ; Gonzales 2007 ; Mullen Conley 2010	Mexican Americans	Groups	Middle school students and their parents	194 students in control group, 168 in intervention. 121 completed post-test in control, 128 in intervention. 179 parents enrolled in control, 165 in intervention. 32 completed post-test in control group, 45 in intervention
12	Villablanca 2009	African Americans ; Hispanics	Groups	Women aged > 40 years	1052 enrolled ; follow up on 423 women
13	Williams 2008	Hispanics ; African Americans	Groups	Students aged 9-11	582
14	Williams 2012	African Americans ; Hispanics	Individuals	Parents of primary school children	101
15	Williamson 2009	African Americans	Groups	Members of an Afro-American church	Of 325 members, most involved in at least one activity, although not all on stroke symptoms

Table 2.2 Characteristics of populations of included studies

Since all interventions took place in the US (see section 2.2.2.6), the most represented ethnic group were the African Americans, who were targeted by 80% of interventions, followed by Hispanics (in one instance more specifically described as Mexican Americans), who were the target of 53% of interventions. No other ethnic group was represented; hence, no data are available for ethnic groups relevant for my study, i.e. for example Asians or Africans. Most

interventions were targeted at groups, while one third was delivered to individuals. However, a clear distinction is sometimes difficult to establish, since in some group interventions individuals received considerable attention (e.g. by screening, individual counselling after the session, etc.), and conversely participants in individual-level interventions were occasionally involved in group activities. No intervention targeted communities as a whole, nor specific social networks within communities. Even when sizeable groups were targeted, the main objective was still increasing the knowledge of individuals within the groups, without consideration for community or social network dynamics.

As for the specific population within the target ethnic groups, only three interventions were targeted at either stroke or TIA patients or patients at risk for stroke. Another fifth of the interventions was delivered to the general population of a specific geographical area or community, while the majority of interventions (60%) were targeted at specific subgroups, such as church members, women, students and parents. Generally, no age restrictions were imposed on participants, except in very few instances. Finally, population size was on several occasions very difficult to calculate. To obtain a rough estimate, I classified the intervention as small if it involved less than 100 participants, medium if 101-500 participants were involved, and large in case of more than 500 participants. According to this criterion, eight interventions were medium, three small and three large, while for one the size was unknown. However, evaluation may have concerned a smaller number of participants for each intervention, since not all enrolled individuals have in fact taken part in the evaluation.

2.2.2.6 Interventions

ID	Study	Intervention type	Focus	Duration of intervention	Setting	Administered by	Theories	Cultural adaptation
1	Boden-Albala 2010	"2 session stroke educational strategy"	Awareness	2 brief sessions within 3 weeks of stroke/TIA onset	Hospital or home	2 health educators and 1 physician or nurse	Social Cognitive Theory; motivational interviewing	"a) Bilingual materials with translation by community health worker; b) visuals integrating community places and promoting recognition of familiar surroundings (...); c) film footage of community stroke survivors recalling stroke experiences in their own language; and d) integration and instructions for current community resources (...)". "Conversations cover barriers such as mistrust of the health care system"; community committee evaluated cultural appropriateness of the intervention. Involvement of local stroke support group
2	Chan 2008	Stroke education program (video)	Awareness	12 minutes	Emergency department	African American actors instructed by Stroke Association	None	"The American Heart Association produced the video, and employed African-American actors"
3	Covington 2010	PowerPoint presentation; "educational materials to take to (…) families, (…) blood pressure screening and referral "	Equal focus	Single, brief session (duration not specified)	"Churches, group homes, community centers, and community organizations"	Trained college students acting as health champions	Social Cognitive Theory; Stages of change	Generic mention that the presentations were "culturally sensitive".
4	Dromerick 2011	Stroke navigators visiting patients at home and by phone calls	Equal focus	Advice sessions distributed over one year	Home	Lay community health workers	Theory of Reasoned Action; Theory of Planned Behaviour	Usage of American Heart Association "tailored AHA educational materials" ; provision of "tailored health education"
5	Duraski 2006 ; Duraski 2003	Short slide presentation, followed by stroke risk assessment screening and advice/discussion.	Equal focus	1 to 2 hours	Community centres and community organizations	Research nurse	None	"Presentation (...) developed for the Hispanic culture. Emphasis (...) on those risk factors that affect the Hispanic community (...). Information was not literally translated (…) to Spanish (...)". Verbal/written educational materials in Spanish about stroke warning signs/symptoms. Focus groups with communities to ensure that presentation was appropriate
6	Duraski 2007	Focus group session with slide presentation and interactive question/answers	Awareness	30 to 60 minutes	Unknown	Research nurse	None	Option offered to have focus groups in Spanish or English. Culturally sensitive information, not simply translated from English to Spanish
7	Frank 2008	Cardiovascular diseases and stroke education and screening integrated with Bible study, individual counselling, healthy food	Prevention/risk factors	About 2 hours for each intervention	African-American churches	Nurse researchers and nursing students	None	No

#	Study	Intervention description	Focus	Duration/delivery	Setting	Deliverers	Theory/model	Cultural adaptation
8	Kalenderian 2009	Educational sessions, distribution of educational package to "ambassadors", who then organized educational activities in churches, with "brochures, videos, posters and other standardized supplies"	Prevention/risk factors	Various, depending on specific interventions	Faith-based institutions, churches	Trained ambassadors	None	No
9	Kleindorfer 2008	Trained beauticians "educated their clientele": distribution of study packets ("brochures describing stroke, (....) wallet cards with the warning signs (...) visual depictions of the stroke symptoms (...) list of stroke symptoms"	Awareness	The intervention was delivered during a session at the beauty salon	Beauty salons	Trained beauticians	None	No
10	Miller 2003	Education about knowledge of stroke symptoms and modifiable stroke risk factors.	Equal focus	1-hour initial educational intervention plus 15' follow-up face-to-face meeting after 4-6 weeks	Medical practice (some follow-ups done at home)	Neuroscience nurses	Stages of change ; motivational interviewing	No
11	Morgenstern 2007 ; Gonzales 2007 ; Mullen Conley 2010	Children: lessons "about stroke signs and symptoms and [to] improve skills, self-efficacy, and outcome expectations related to (...) calling 911". Parents: taught about stroke by their children as homework assignment	Awareness	"Four 50-minute classes each year during the sixth, seventh, and eighth grades" plus homework with parents at home.	School and home	Educator, stroke neurologist, data manager, science/health teachers, KIDS project health professionals	Social Cognitive Theory	Culturally sensitive strategy developed through a focus group with parents, students and teachers. "Familism" and "multigenerational contact" taken into account in design. Inclusion of Mexican American health professionals in design; focus groups with local students, parents and teachers; aspects of Mexican-American culture included. Bilingual materials; role play scenarios reflecting Mexican American culture
12	Villablanca 2009	"Clinical lectures, health demonstrations, video presentations, personal testimonies, and other heart healthy activities (…) Medical screenings"	Prevention/risk factors	12-14 counselling sessions, only a minority of these on stroke awareness	Various faith-based, academic and non-academic sites	Site leaders, "cardiologists, endocrinologists, nurses, dietitians, physical exercise and other health professionals"	Stages of change	"Culturally appropriate, gender-specific health education curriculum, site leaders' guide, educational materials, and other culturally relevant materials and activities by each site were (…) tools in generating small group discussions, subject participation in exercise sessions and program activities, and encouraged group cohesiveness and empowerment"
13	Williams 2008	"Culturally and age-appropriate music and dance to enhance an interactive didactic curriculum including the FAST mnemonic"	Awareness	1-hour sessions over 3 consecutive days	School	"2 stroke education professionals and 2 community health professionals"	Theory of reasoned action ; social cognitive theory (self-efficacy)	Rap and hip-hop
14	Williams 2012	"Child-mediated stroke communication intervention" ; shared completion of stroke-related homework between children and parents	Equal focus	Short (not quantified)	Home	Children administered the intervention	None	Rap and hip hop (songs and dance)
15	Williamson 2009	"Educational sessions, health screenings, and weight watchers program", integrated by faith-based activities (e.g. prayers and hymns)	Prevention/risk factors	Interventions delivered over two years	A rural African American church	Nurses and nursing students	None	No

Table 2.3 Elements of interventions described in included studies

Firstly, I did not include a column for the country in which the intervention took place, since all interventions were carried out in the US. Consequently, all data concern a specific context, and no data on other relevant areas such as Europe, the Far East or Australia is available. All interventions included at least a part concerning awareness of stroke symptoms and related actions. In detail, 40% were mostly focussed on awareness, for 33% the focus was shared between awareness and prevention or risk factors, while the remaining 27% were focussed on prevention or risk factors, with only a small part concerning awareness of symptoms and actions. The interventions were delivered using very different techniques; also, in different interventions, sessions had a different level of standardization, ranging from an educational video to very informal, one-to-one advice sessions. In the included studies, there is a prevalence of educational sessions, either in the form of lessons, slide presentations or classroom lectures; often, such lessons were interactive, allowing for the exchange of questions and answers between health promoters and the audience, and occasionally role-plays. A certain number of interventions also included distribution of informative materials about stroke, occasionally to be shared with families and friends.

Single sessions were generally brief, most of them lasting between 30 minutes and 2 hours. However, in some interventions such sessions were repeated over time (weeks, months or even years), frequently covering a number of different stroke-related topics for the same audience. Interventions were delivered in a range of different settings. Unsurprisingly, interventions aimed at patients were held either at their homes, or in hospitals or medical practices. Interventions designed for the general population or specific subgroups were generally held in places where the subgroups used to meet: churches for church members, schools for students, community centres and organizations, hospital and medical practices, and in one instance even beauty salons. In addition, the actors designing and delivering the interventions varied widely in different interventions. Multiple professional profiles were involved in the delivery of most of the interventions, the ones delivered by a single professional category being an exception. Health professionals, in most cases with an academic affiliation, generally took the initiative of organizing and designing the interventions.

Roles most involved in the delivery of interventions were nurses (including research nurses and nursing students), trained community members acting as health champions or ambassadors (students, church members, beauticians), health educators and other community health workers, physicians. Finally, I enquired to what degree such interventions were theory-based, and whether they provided clear definitions of cultural adaptation. The majority of studies (53%) did not mention the utilization of any theory to design and evaluate the intervention.

Few of the other studies can be defined theory-based, since theories were only briefly mentioned, and no clear link with the factual content of the health promotion program was established. Mentioned theories include social cognitive theory (Bandura 1986), motivational interviewing (Miller & Rollnick 2002), stages of change (Prochaska & DiClemente 1983), theory of reasoned action (Fishbein 1980; see also Fishbein 2009), theory of planned behaviour (Ajzen 1991). All are individual-level, psychology-informed theoretical frameworks. Further, in most cases, campaigners used theories as a general reference to plan the interventions, and only very rarely to address and improve the awareness of stroke symptoms and related actions. As for cultural adaptation of interventions, as many as one third of the studies did not mention any specific strategy; two more studies just generically referred to cultural tailoring, cultural sensitivity. Of the remaining studies, four only reported one or two specific, practical facts related to cultural adaptation (e.g., using African-American actors for a video, translating materials and session contents, use of rap and hip-hop music). Consequently, only a minority of studies (27%) reported in some detail their cultural adaptation strategy. These included a number of different tactics, such as employing stroke testimonials from the community, incorporating community venues in materials, submitting the designed intervention to focus groups or community committees to obtain their opinion before the pilot phase, inclusion of specific traits of Hispanic or African-American culture, etc. However, none of these studies referred to general frameworks or models of cultural adaptation, theories of ethnicity, and the like, the approach being mostly practical. Consequently, no common definition of cultural competence or adaptation emerged from the included studies.

2.2.2.7 Outcomes

ID	Study	Study design	Evaluation method	Reported effectiveness
1	Boden Albala 2010	Randomized controlled trial (RCT)	Article reports only on protocol and baseline	Article reports only on protocol and baseline
2	Chan 2008	RCT	Pre-post test	Yes
3	Covington 2010	Case study	None	Not applicable
4	Dromerick 2011	RCT	Article reports only on protocol and baseline	Article reports only on protocol and baseline
5	Duraski 2006 ; Duraski 2003	Case study	Pre-post test	Yes
6	Duraski 2007	Case study	None	Not applicable
7	Frank 2008	Case study	Pre-post test	No
8	Kalenderian 2009	Case study	None	Not applicable
9	Kleindorfer 2008	Case study	Pre-post test	Yes
10	Miller 2003	Case study (repeated measures design with 3 groups)	Pre-post test	No effectiveness for treatment seeking behaviour (call EMS) ; unknown effectiveness for knowledge of stroke symptoms
11	Morgenstern 2007 ; Gonzales 2007 ; Mullen Conley 2010	RCT	Pre-post test	Yes for children ; unknown for parents
12	Villablanca 2009	Case study	None (only for outcomes other than stroke symptoms)	Not applicable
13	Williams 2008	Case study	Pre-post test	Yes
14	Williams 2012	Case study	Pre-post test	Yes
15	Williamson 2009	Case study	None	Not applicable

Table 2.4 Outcomes of included studies

No column was included concerning the intended outcome, since all interventions were aimed at increasing knowledge, except Morgenstern et al. (2007), aiming at addressing both knowledge and behavioural intention ("behavioral capability, self-efficacy, and outcome expectations"). Almost no intervention was therefore specifically designed to target behavioural change directed to call EMS when witnessing a stroke, and to evaluate such change. Sixty-six per cent of studies had an experimental design and provided some form of evaluation. However, only a minority (27%) was designed as a RCT, all the others being case studies. As for the evaluation method, eight used pre- and post-intervention tests, five did not evaluate the outcomes, and two studies were only preliminary reports, lacking evaluation data.

Of the eight studies providing evaluation results, six were case studies and two RCTs. Both study designs referred to very different populations, interventions and outcomes. Due to this

heterogeneity (which can be verified using the synoptic tables), no quantitative synthesis of results was possible. Hence, I will briefly comment on reported effectiveness. Two studies reported that the intervention was not effective. The six studies reporting effectiveness raise some methodological concerns. Morgenstern et al. (2007) found the intervention effective only for a subgroup of the target population (school children), while insufficient data were available to establish the effectiveness of the intervention for the other subgroup (parents). Additionally, the pre- and post-intervention test was not validated. In two cases (Chan et al. 2008; Duraski 2003; Duraski 2006), the difference between pre- and post-intervention test results was minimal, although statistically significant. Finally, Duraski's study had no control group. The lack of a control group characterizes also the other three studies claiming effectiveness for the described interventions (Kleindorfer et al. 2008; Williams & Noble 2008; Williams et al. 2012). Therefore, although evidence of effectiveness exists for specific outcomes on specific populations (e.g. a moderate increase in the knowledge of stroke symptoms maintained over a short time), no generalizable evidence of effectiveness exists for health promotion interventions aimed at improving knowledge of stroke symptoms and related actions in BME communities. Finally, all included studies used a quantitative methodology to evaluate the effectiveness of interventions.

2.2.3 Discussion

Interventions aimed at increasing awareness of stroke symptoms and appropriate response in BME communities share some common characteristics. Firstly, published literature on the topic only concerns African-American and Hispanic ethnic minorities in the US. No evidence was available for European countries, where minorities have different cultural and social characteristics directly influencing health-related attitudes. For example, Scheppers et al. (2006) show that ethnic minorities experience a number of barriers to accessing health services, frequently linked with particular cultural, religious or social traits. However, such traits are very different also between ethnic minorities: for example, UK Pakistanis and US African-Americans are likely to have very different perceptions of health, linked to religious views, level of integration in the country, etc. Moreover, as Scheppers et al. state (2006), the organization of health services in different countries plays an important role in shaping health-related attitudes of ethnic minorities. On a related note, studies concerning the definition of cultural competence often emphasize the importance of specific, contextual aspects, rather than abstract definitions of ethnicity, in order to successfully conduct health promotion and health care initiatives (Netto et al. 2010; Williamson & Harrison 2010). It is therefore reasonable to assume that specific key factors (perception of health and illness, language, available community resources, specific barriers and facilitators) greatly differ between

different ethnic minorities living in different countries. For all these reasons, it seems difficult to generalize any results from the included studies to the UK or European situation. In addition, included studies did not take into account the role of community networks and social support, with only two partial exceptions (Villablanca et al. 2009; Boden-Albala et al. 2010). In particular, no reported interventions targeted the communities by explicitly addressing their network dynamics, and the level of the interventions was generally focussed on individuals. Similarly, all theories - which informed a minority of the studies – concerned the individual level: neither network theories nor theories of social support were used to plan and deliver the interventions.

A further relevant point is that the interventions differed widely as to delivery methods, settings and populations. Hence, no general common characteristics could be identified, and this limits the usefulness of findings in contextualizing and interpreting the results of the thesis. Moreover, the theoretical basis of the interventions was generally absent or underspecified, especially as far as the definition of cultural adaptation is concerned. In fact, no common characteristics of cultural adaptation could be identified in the specific context. Finally, it seems difficult to assess whether evidence of effectiveness emerges from the included studies. As described in section 2.2.2.7, slightly more than half of the studies provided evaluation results, and only a minority of them included a control group. Therefore, current available evidence of the effectiveness of such interventions seems inconclusive. In addition, no qualitative study was available on such a topic area. While acknowledging the importance of quantitative evidence, it seems that integrating a qualitative approach would be appropriate for complex health promotion interventions. In fact, such interventions involve different variables such as ethnicity, knowledge and behaviour change, and - most importantly – their success seems to heavily depend on complex contextual factors, best considered within a holistic perspective (Tremblay & Richard 2011; Matheson et al. 2009). Hence, qualitative research is often advocated as an appropriate method in evaluating health promotion interventions (Naidoo & Wills 2009, pp.289–90; Hubley & Copeman 2008, pp.80–1).

2.2.3.1 Strengths and limitations

To the best of my knowledge, this was the first systematic review to date on the topic. The results outline the main characteristics of stroke awareness interventions for ethnic minorities in the US, alongside strength and limitations of both the interventions and the evaluation procedures. Review findings may therefore provide a useful starting point for academics and practitioners wishing to further analyse or plan similar health promotion initiatives in other parts of the world.

Limitations include the fact that searches excluded sources of particular types and languages. Although I searched the most relevant databases, broadening the search to supplementary sources and including more languages may increase the number of retrieved studies. The same results might be obtained by the inclusion of conference proceedings, dissertations, books, book chapters and grey literature results. Moreover, the analysis performed in the systematic review was mainly focussed on the evidence concerning health promotion initiatives similar to the one studied in my PhD. Different approaches and research questions may therefore imply more in-depth analysis of the same dataset, e.g. with a specific focus on cultural adaptation, evaluation methodologies, etc.

2.2.4 Conclusions

Results from the included studies were difficult to generalize outside the US context; hence, more research is needed on stroke awareness interventions for European ethnic minorities. Interventions widely differed in terms of specific target population, settings, delivery methods, contents and roles in charge of delivery, so that no common trends emerged. This provides a rationale for analysing the mechanisms, which contribute to design and delivery of stroke awareness campaigns for ethnic minorities. Behavioural theories were only marginally taken into account, and no higher-level conceptualization of cultural adaptation was available; hence, the analysis of such interventions has no predefined theoretical framework to draw upon. Finally, emerging evidence of effectiveness from quantitative evaluation of the interventions seems inconclusive. Therefore, research into dynamics and mechanisms contributing to delivery of effective interventions is warranted. As for the methods, qualitative research designs were absent in included studies: consequently, adopting a qualitative research perspective may contribute to a fresh understanding of the emerging issues. In conclusion, characteristics of included studies and the current gaps in knowledge suggest that research on the topic should be undertaken. In particular, the findings of the review do not seem to provide a robust evidence base to interpret and evaluate the results of the thesis. On the other hand, the lack of knowledge of network and community dynamics involved in planning and delivering such interventions provide a strong reason for undertaking the research reported in my thesis.

Chapter 3 Methods

3.1 Introduction

The present section outlines the methods used for the present research. After a quick clarification of my theoretical stance, mainly about ontology and epistemology, I justify the choice of a qualitative methodology. After that, I describe the methods adopted for sampling participants, collecting and analysing data, and I show their appropriateness for answering my research question and fulfil its objectives. Finally, I briefly report on the main ethics and research governance issues and processes, which informed the study methods.

3.2 Theoretical stance: ontology and epistemology

The section clarifies my perspectives and assumptions about ontology and epistemology. Firstly, I assume that the subject cannot entirely construct reality, neither as an individual nor as a member of social groups. There are external constraints transcending any constructive capacity of subjects and groups, operating on different levels (physical, biological, economic, social, etc.). Moreover, I adopt the view that both subjects and objects emerge as parts of relational processes, and are constantly modified by such processes. Consequently, relations are at the core of reality, and knowledge emerges as a shared construction carried out by subjects and groups, as they interact with each other and with the aforementioned external constraints. Knowledge is therefore the result of a range of formal and informal procedures operating inside a relational space, which includes both the subjects and the objects with whom they interact.

My point of view shares similarities with the context of relational sociology (see for example Donati 2011, chap.3). Moreover, my perspective is alike to systems theory (Maturana Romesin 2002), where reality is perceived as a system of interconnected processes - hence a system can be known and analysed by taking part in it. I also believe, in agreement with social constructionism (Burr 2003) that the interpreter is always internal to / involved in the processes constructing knowledge. In fact, some aspects of reality are better understood by using procedures emphasizing the differences between subject and object, and "pretending" that knowledge is referred to external objects. Such objects, in turn, can be studied by means of quantitative, highly standardized procedures (e.g. logics, mathematics, statistics, probability, etc.). Such knowledge is likely to produce explanations in the form of falsifiable theories (Mjøset 2001). It is unlikely, though, to be able to discover general laws in social systems, which are complex, conflicting and rapidly evolving (Mjøset 2001). Social reality, therefore, can

be better understood if the researcher is immersed in a situation and tries to interpret its main characteristics and dynamics in relational terms.

Knowledge produced by such an analysis is more likely to be based on abduction as the best possible form of generalization, according to a pragmatist point of view. Abduction is defined as inference to the best possible explanation, or "a fluid understanding that explicitly or tacitly recognizes the complexity and frailty of the generalizations we can make about human interrelationships" (Thomas 2010). Despite its limitations, pragmatist abduction can provide useful heuristics to obtain reliable generalizations, since the expectation is to obtain phronesis and not "scientific theories" (e.g. general laws). Phronesis is defined as "practical (…), craft knowledge (…) discernment or the ability to weigh up, to judge, to assess implicitly", always linked to a particular context and validated "through the connections and insights it offers between another's experience and one's own" (Thomas 2010). Finally, I share with social constructionism and ethnomethodology (Garfinkel 1967) the importance of the daily, negotiated and mutually agreed upon meanings of social practices in a given community or social context.

The described assumptions constitute the basis of a useful approach to my topic of study. Firstly, immersion in the field presupposes that the subjectivity of the researcher may contribute to construct the data and the "reality" to be analysed; however, this construction is objectively limited by what the researcher learns in the field, especially unforeseen and surprising events. Secondly, phronesis seems a relevant outcome for an under-researched and difficult to access field of study, where testing hypothesis would be impractical. Thirdly, directing attention towards daily, routine micro-dynamics may prove a powerful tool to understand complex situations where little or no specific orientation from the literature is available.

3.3   The choice of research methodology

The research question and objectives outlined in section 1.3, and the state of the art in the field of research on CBHP initiatives on stroke awareness imply the need for an in-depth exploration of a complex social context, emerging during and around a CBHP campaign. In addition, stroke awareness campaigns for ethnic minorities are a relatively under-researched topic area. Therefore, I could not formulate specific hypotheses, concerning the relationships between specific variables and the mechanisms operating in the setting.

In fact, my research aimed at discovering and understanding the main dynamics and mechanisms of the setting. In accordance with my assumptions on the relational nature of

social reality, the focus was on how networks of interacting actors shaped this specific social context and had an impact on a number of factors critical for the campaign. Firstly, it was important to explore the richness and complex internal articulation of single themes (e.g., information flows, evidence translation, etc.), and the particular ways in which themes interacted with each other. I also wanted to be open to the unexpected and therefore I needed as few assumptions as possible about how interactions of actors within social networks produced meanings and influenced actions. Consequently, it seemed appropriate to adopt a qualitative research approach to understanding network interactions, while taking into account both actors' experiences and my self-reflection. Additionally, the research methodology should allow focusing on relationships and interactions as much as on structures and substances.

Qualitative methodology is particularly suitable when it is necessary to understand what is happening in a given setting, and to obtain knowledge of the situation of the field directly from actors (Flick 2009; Silverman 2006). However, a wide array of qualitative research methods is available, inspired by different philosophical, sociological, anthropological and psychological traditions (Moriarty 2011, p.2; Denzin & Lincoln 2011). Further, most published qualitative research shows that even a single method of data collection or analysis may be applied in very different ways according to the researcher's point of view and research questions, provided some general principles of rigour be observed (see for example Mays & Pope 2000; Mays & Pope 1995; Flick 2009, chap.28–29). Consequently, for the present study, the research question and objectives drove the choice of methodology and specific research methods. The method more attuned to the needs of the present work seemed to be qualitative network analysis, which has already showed important applications in qualitative research (Hollstein 2011; Marin & Wellman 2011). According to Hollstein (2011) qualitative approaches to studying social networks usually aim at exploring meaning more than at producing measures; as such, they require open procedures in data collection, and interpretive methods of analysis. Hence, they seem particularly useful in exploring "new or yet unexplored forms of networks", or in understanding "the concrete acts, practices, interactions, and communication patterns in light of the respective contexts in which they occur – thus what actors actually do and how they network" (Hollstein 2011). In addition, such methods should be appropriate in understanding "actors' perceptions and assessments of the relationships and networks of which they are a part", how they are relevant for decision making and particular outcomes of a situation, and how and why networks evolve over time. This approach, sometimes defined as "qualitative network analysis" (Heath et al. 2009; Scheibelhofer 2011), is therefore similar to the one I adopted, and seems to represent the best fit for my research question and

objectives. In fact, it would allow understanding how networks had an impact on the campaign, in terms of their structure, how actors experienced their importance and the concrete practices of individuals and groups.

Furthermore, qualitative network analysis uses data collection methods such as interviews, non-participant observation, etc. which are widely used in qualitative health research. These can be well integrated with other non-network oriented qualitative research approaches. In order to increase the analytical power of my qualitative network analysis approach, I chose to structure my study as an exploratory qualitative case study (Baxter & Jack 2008; Yin 2008; Stake 1995) and to use thematic analysis in analysing the findings (especially in its variant called "thematic networks"). Firstly, to capture the widest possible range of events and experiences in the case study, I decided to avoid any a-priori assumptions about analytical categories before entering the field. The research question and objectives were the basis to build observation schedules and interview topic guides, subsequently integrated with further items as field research progressed and new problems and possible perspectives emerged. Reviewing the literature and reflecting on field experiences were used as tools to increase my sensitivity to what happened in the field, while avoiding to formulate hypotheses or to superimpose rigid structures on data collection (Corbin & Strauss 2008). Secondly, as it came to analysis, I chose coding as the basic step, alongside constant comparative analysis (Glaser 1965). The approach to identification of themes was inspired by thematic analysis (Braun & Clarke 2006) and the idea of thematic networks (Attride-Stirling 2001). Coding and the identification of thematic networks, however, integrated with network maps, as described in section 3.6. In summary, my approach allowed analysis to remain focussed on a relational point of view, while maintaining the depth of insight and the links between data and findings, a typical characteristic of qualitative case studies.

These elements of the three converging methodologies helped considering "as units of analysis […] the ecology of relations, not individuals or bodies" (Fox 2011), in a perspective linked to the work of Deleuze and Guattari (2004) and other social theorists (De Landa 2006; Lahire 2011; Latour 2005). Reconstructing and interpreting the ecology of relations in the context of a CBHP campaign, and understanding the main mechanisms and procedures emerging through the interactions between nodes in networks was in fact an essential aim of this case study. Hence, my method neither did aim to produce a substantive nor a formal theory (Glaser & Strauss 1967; Glaser 1978), but – as outlined – only inferences to the best possible explanations in a given context.

It is important to note that several other methods and concepts are available as guides to explore social networks in the context of health promotion initiatives. They range from formal, quantitative social network analysis (Hanneman & Riddle 2005; Valente 2010) to approaches emphasizing the role of networks as contributing to social capital or to social support for individuals, groups and communities. The chosen approach is different from those methods, for the following reasons. Firstly, social network analysis privileges quantitative approaches to data collection and analysis, with the main aim of understanding the structure of networks and the properties and characteristics of individuals and groups included in those networks. As such, social network analysis needs formal individuation of actors and clear, possibly univocal definitions of what constitutes a relationship. Therefore, it did not seem to meet the needs arising from my research question and objectives, requiring a qualitative, rich description of complex relationships and themes. In other words, I prioritized exploring the richness and complexity of different dimensions of networks experienced by actors, over establishing the structure of networks in which actors were involved and measuring specific parameters. Additionally, outlining the structure of far-reaching and complex networks such as ethnic communities or the NHS was beyond the scope of the research question and objectives and probably not feasible, given the time constraints of a PhD. On the other hand, I also chose not to focus on a specific definition of the role of networks before obtaining field data. Therefore, social support or social capital were discarded as concepts guiding data collection, as not appropriate to the research question and objectives. Establishing a priori that the main role of networks was related with social support or social capital would cause premature closure of the analysis, and prevent the exploration of other themes that may well emerge as more important from data.

3.4 Sampling and recruitment

The CBHP campaign described in section 4.1 involved a actors in different roles, interacting for the design and delivery of a health promotion intervention. It was therefore an ideal occasion to answer my research question and objectives, and met the requirements of the funding body, interested in facilitators and barriers for the future roll-out of the intervention to other areas. Hence, the campaign represented an ideal case to study for my research. Given the time constraints of the PhD project, however, it was not feasible to study other cases.

Once set to the campaign itself the *boundaries* of my data collection (Miles & Huberman 1994, p.27), the sampling of participants within the case study was driven primarily by the need to answer my evolving research question and objectives (see section1.2). Therefore, I looked for actors with a level of involvement in the campaign high enough to obtain from them

sufficiently relevant and rich perspectives on the intervention. As for interviews, I invited all actors with a role in organizing at least some aspects of the campaign. All agreed and were interviewed in the time I had available for data collection, except an illustrator, a NHS communication officer and the imam of a mosque. As for observations, I chose to collect data from the sessions in which there was an interaction between campaigners and community members, be it in the pre-production, co-production or delivery phase of the intervention. As a result, data about community members were mostly collected using this method. I therefore observed such interactions during the campaign, except two co-production sessions on which I obtained information from the campaigners. Consequently, data concerning community members came from direct observation, except for a group of elderly Pakistanis, who had been repeatedly involved in the campaign from the pre-production to the delivery phase. A limitation of my study is that it was not possible to interview other community members, since they were only involved in very brief sessions either in the pre- or co-production phases, or during the final events, and it was thus not possible to identify them individually and follow up with specific individual or group interviews.

Consequently, and given the relatively self-contained dimension of the campaign, sampling of participants did not represent an issue: in fact, I collected data from the vast majority of participants using either interviews or observations. A minor issue was that, for some participants, more than one interview would have been appropriate at different points in time, given their relevant role in the intervention. Examples would include actors belonging to the roles of campaigners, commissioners and community gatekeepers. Ideally, this would imply interviewing important actors three times – at the beginning, during and at the end of the intervention. However, both the unsteady and relatively unpredictable progress of the campaign, and the fact that a relevant number of those key participants had not been identified at the beginning of the campaign, but had been involved at the co-production or even at the delivery stage, made such a strategy impractical. However, I also took into account views from some of the key participants as they emerged during observations – in fact, the latter allowed for useful integration of the interviews. For example, I interviewed the campaigners after the co-production phase, but I obtained their perspectives and comments at later stages through observations as well.

 I decided to stop sampling and collecting data shortly after the last events in the campaign. This choice was dictated by the need to have enough time to analyse the data, but also and most importantly by the fact that I could not carry out further observations since the campaign was finished. On the other hand, I had been able to interview all the most relevant actors

during the campaign (see above), and therefore I did not need to perform further interviews in this time frame. In summary, the sampling strategies were successful in obtaining a sufficiently rich and varied dataset from a number of participants having taken an active role in the intervention. Hence, the sampling strategy turned out to produce relevant data, from situations in which the interactions I wanted to study appeared, and could be described in a way that was "true to real life" (Miles & Huberman 1994, p.34; see also: Curtis et al. 2000). The remaining part of this section will describe the strategies put in place to ensure both effective and ethical recruitment of participants.

3.4.1 Identification

Identification of potential interview participants differed according to roles of actors. By the time I started data collection, I had already made contact with commissioners and campaigners personally, by participation in committee meetings and through the Collaboration for Leadership in Applied Health Research and Care (CLAHRC). I identified additional participants through either commissioners or campaigners. Community gatekeepers agreeing to take part in my research helped identifying further gatekeepers or community members for interviews. As for observations, no previous identification of session participants was needed: I simply observed the interactions while informing participants of my role and aims (see section 3.7).

3.4.2 Approach

I approached in person almost all participants in interviews and follow-up was done by phone or email. At the first approach, I informed participants of the aims of the research project, the reasons why I had approached them and what contribution I expected from them.

3.4.3 Recruitment

After the first approach, I contacted participants again, to agree date and time for an interview, either directly, or through a gatekeeper or campaigner. Upon acceptance, I requested written informed consent, and once I obtained it, the interview took place. See Appendix B Appendix D and Appendix E for participant information sheets and the consent forms. For the observations, I showed an information sheet to participants in advance of sessions, so that every individual may raise issues or ask for further information before the observed sessions started. Participants had the right to ask me to withdraw from observation, if they felt uncomfortable, although this never happened.

3.5 Data collection

According to the chosen research methodologies, methods of data collection included the following.

3.5.1 Non-participant observation

Observation is a technique in qualitative research, usually adopted when it is necessary to gain a detailed, first-hand understanding of dynamics and practice in a particular situation (Flick 2009, chap.17; Patton 2002, chap.6). I took part in the pre- and co-production sessions and in the final delivery sessions of the campaign, trying to keep my interference to a minimum, and making field notes about interactions between actors, knowledge translation practices, possible misinterpretation and explicit or implicit conflicts, and, in general, facts and emerging related meanings. Hence, I adopted a non-participant attitude towards the observed events and settings. I also conducted observations during the distribution of leaflets and posters in community venues by campaigners. I reproduced observation schedules in Appendix A . The general guide for observations, based on the scheme proposed by Spradley (1980) and Fox (2008), has helped preventing some common shortcomings of observational methods. These include the failure to observe relevant interactions due to a lack of comprehension of the context by the researcher, and a lack of self-critical subjectivity in actually performing the observation (Fox 2008). The first observation session served as a pilot test in all contexts (pre-, co-production and delivery sessions, and materials distribution), in order to refine the methods of observation, the understanding of relevant contextual factors and the observation guide.

I did not perform any audio or video recordings. I transcribed field notes after the observations, taking care not to expand or interpret field-collected data at that stage; I recorded in memos the interpretations emerging during transcriptions. I took photographs during observations, orally asking for permission from bystanders. I used such photos exclusively as a memory aid during transcription and data analysis, and I never published them outside the context of the present thesis. In total, I performed 25 observations, between January 2011 and March 2012. I carried out observations during all phases of the intervention, with a prevalence of events observed during the delivery phase. A complete synopsis of observations is displayed in Appendix F.1. In summary, observations concerned about 200 community members and 15 community gatekeepers, as they interacted with campaigners and, on occasions, with a health professional. About a half of the community members belonged to the Somali community, while the others included members of the Yemeni and Pakistani community, alongside a very small number of members of other communities.

The typology of observed events varied, as shown in the table, including pre-, co-production and final sessions, and distribution of materials. On one occasion, the observation included a sort of "guided tour" through a community, accompanied by a community gatekeeper; this experience was somewhat similar to the "go-along interview" described by Garcia et al. (2012).

I carried out observations in different community venues, including community centres, mosques, pharmacies, libraries, cafes and restaurants. Each observation session lasted from a minimum of 40 to about 300 minutes. Before the first observation involving campaigners, I distributed to them an information sheet explaining the reason for my involvement. Additionally, before every structured session, I distributed an information sheet to participants to explain the reasons for my presence. I then answered any question asked by participants. None objected to my presence. Information sheets for non-participant observations are included in Appendix B .

3.5.2 Semi-structured interviews

Semi-structured interviews are commonly used in qualitative research, with the aim of understanding the meaning that participants attribute to social practices, and to achieve a rich description of specific, local practices in a particular context (Silverman 2006; Schostak 2006; Flick 2009; King 1994). Since the research question and objectives attempted to understand practices and interactions in a relatively new field of study, the structure of the interviews and the topic guide were open-ended, to allow flexibility in letting relevant experiences, practices and related meanings emerge. As suggested by Hollstein (2011), open-ended, in-depth interviews are particularly suitable to highlight the importance of actually existing ties in a social network and their impact on knowledge translation. However, interviews also aimed at understanding how a participant perceives the relative importance of different social ties in information and knowledge dynamics operating in his/her network (Marsden 1990).

The main principles followed in the interviews included non-direction (allowing the interviewee to express meanings and experiences with minimal interference by the interviewer), specificity (keeping the interview focused on the research topic), "range" ("The interview should maximize the range of evocative stimuli and responses reported by the subject") and "depth and personal context" (Merton & Kendall 1946; see also Bates 2004). Such techniques helped in reducing typical biases of interviewing methods, and in improving validity of the research data. I kept the length of the interview to the minimum necessary, to avoid distress to participants. I refined the interview guides after the first pilots, and adapted questions for different categories of research participants. For reproduced topic guides, see Appendix C . I completed 17 interviews, from July 2011 to March 2012. Participants with different roles were involved. I interviewed all organizational actors with a relevant role in commissioning, monitoring, delivering or evaluating the campaign. Exceptions included an NHS employee who moved away from the organization before the delivery phase and was not available for the interview within the timescale of the present work, and a member of the

campaign committee who was not interviewed because he was a member of my supervisory team.

Additionally, I interviewed all community gatekeepers with a significant role in the campaign, with the exception of two community leaders who did not respond despite repeated attempts. The only community members reachable within the timescale of this study were a group of Pakistanis. Interviews took place in venues chosen by the interviewee, where they could express their views while their privacy was respected. All participants agreed to audio recording of the interviews, which were then transcribed (Lapadat & Lindsay 1999; Bird 2005) by a specialized company, and subsequently reviewed by myself. The correspondence between the audio recording and the transcript was very high, with only a few gaps. Both parties used the software Express Scribe for listening to the recordings and transcribing. One interview was held through e-conference, using Skype 6 (Skype Technologies 2012) and MP3 Skype Recorder (Nikiforov 2012). Finally, all interviewees had the opportunity to discuss information in the information sheet with the interviewer before the interview started. A signed consent form was obtained for each of the interviewees. Information sheets for interviews in different languages are included in Appendix D , while consent forms are reproduced in Appendix E . Finally, Appendix F.2 contains a synoptic table of interview setting, phase and participants.

3.6 Data analysis

As frequently recommended in qualitative research, the analytical process started already during data collection (Corbin & Strauss 2008, pp.57–8). The first pilot interviews and observations were quickly analysed to identify emerging concepts, so that further interviews and observations could take these into account to verify emerging insights. The analytical process, inspired by qualitative network analysis, followed two integrated paths, connected by a common focus on networks and interactions as the primary unit of analysis: thematic qualitative analysis and relational analysis.

3.6.1 The coding process: generating themes from concepts

Following the research question and objectives, thematic qualitative analysis took as a primary object network relationships and interactions. Apart from that, no other assumption drove data analysis. The first analytical operation consisted in coding all transcripts of observations and interviews, using the qualitative data analysis software NVivo 10 (QSR International 2012). Coding consisted in assigning conceptual labels to portions of text of variable length (from single expressions to longer phrases). A portion of text could obviously be labelled with more than one code (and it frequently happened), while on the contrary some pieces of text without analytical interest were not coded (although this happened only rarely). Importantly, single

codes identified a conceptual characteristic of a fragment of text, that is a minimal unit of meaning assigned to it. Hence, coding was an interpretive operation from the beginning, not a merely descriptive one. When several concepts seemed to share some common characteristics or patterns, I grouped them into a common category, or theme. I eventually organized themes around a central theme, in relation to whom they became subthemes. However, the distinction between a descriptive and an interpretive level proved quite difficult to operationalize. Several attempts were necessary before managing to fine-tune the analysis to an acceptable level of interpretation. In fact, at the beginning, simply providing an accurate description putting together what seemed at first a disconnected series of observations or thoughts expressed by an interviewee seemed to me a useful (and difficult) interpretive act. However, as I progressed in the analysis, I eventually discovered that putting together several coded transcripts allowed identifying more complex and comprehensive patterns of meaning, thus leading to wider-scale interpretations.

Consequently, the coding process from data to descriptions to interpretations, in the case of my thesis proved very much related to a trial-and-error logic, constantly moving between and across different levels. I verified interpretations by returning to data and descriptions, while descriptions became more accurate in the light of more comprehensive interpretations, etc. The whole process, also, proved very time-consuming: insights did not come gradually, but they often materialized at the end of frustrating periods in which single interpretations struggled to find their place in a coherent picture. As a complicating factor, my approach was only instrumentally linked to thematic analysis: in fact, I needed to focus on relationships (both in the data and in the "reality" that the data contributed to construct). Hence, I did not aim at constructing a coherent picture of neatly interrelated "substances". On the contrary, I aimed at producing a network of themes in which ambiguities and conflicts could equally be represented.

As a guide for the analytical process, I employed several techniques suggested by the literature. Firstly, I used Saldana's book on coding (2009), with its description of a considerable number of possible approaches to coding qualitative research materials, to identify suitable approaches to my specific research problem. In particular, I used his suggestion of "reflect[ing] (…) about the possible networks (links, connections, overlaps, flows), among the codes, patterns, categories, themes and concepts" (Saldaña 2009, p.36). Furthermore, to ensure rigour to the coding process, I adopted the constant comparative method of analysis suggested by Glaser (1965): before assigning a code to a piece of text, I reviewed all existing codes to see if similar pieces of text had been assigned to one or more existing codes. This process was

greatly enhanced by the use of software, which allowed for rapid browsing of hierarchies of codes and for searching codes and text by keywords or more complex queries. Also, I used constant comparison as a tool to compare different situations, to understand different dimensions and properties of a code or a theme, as suggested by Corbin and Strauss (2008, pp.73–8). Moreover, I followed the suggestions by the same authors about different questions to ask from data. In particular, I aimed at taking into account the different meanings of words expressing important concepts. Furthermore, I tried to turn the same concepts " 'inside out' or 'upside down' to obtain a different perspective on a phrase or word (…) using [the researcher's] experiences to bring up other possibilities of meaning" (e.g. comparing the studied situations to others the researcher is familiar with) (Corbin & Strauss 2008, pp.78–80).

In addition, I periodically reviewed the structure of codes, merging similar codes in a single category; the same happened to similar categories. On the contrary, when a single code or category proved too heterogeneous, I split it into two or more codes or categories. Memos were produced and used at different moments. Memos were short annotations containing reflections on single topics emerging from data. I either produced them when checking transcripts of interviews, or when transcribing field notes or coding. Most memos were subsequently integrated in the interpretations of single themes or subthemes, since they represented an embryonic stage of reflections, which became more detailed later in the analytical process.

The single most difficult decision in data analysis concerned the end of the analytic process. I reached this point when "situational sense-making" emerged as a unifying theme for all other major subthemes. Having followed the very analytic and rigorous coding process described above, I was confident that I had not overlooked any important concept: hence, themes had been built in a robust way, and the interpretations they involved were directly linked to data. Consequently, when I aggregated the concepts into about ten major themes, I felt confident that they really represented salient aspects and dimensions of the phenomena I studied, and that each of them contributed to a rich understanding of the phenomena themselves. Moreover, no other concept emerging from the data could contribute a substantive answer to the research question and objectives[2]. Interestingly, along the way I had to discard some potentially interesting paths of analysis, as they were not strictly related to the research question and objectives. Examples include a possibly more detailed analysis of transitions in space and time experienced by actors during the campaign, an in-depth analysis of the role of

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[2] The slightly reworked main "candidate themes" are represented in Figure 8.1, alongside "situational sense-making".

community activists and a more complete exploration of the impact of turnover of actors on the campaign.

Although I thought that the data were rich and contributed to answering the research question and objectives, it was nonetheless difficult to decide which of the themes was able to unify all the other major emerging themes. In other words, after a detailed analytical work, I came to the point when I needed to consider the themes from a more "holistic", point of view: the task consisted in establishing their inter-relationships and the relative importance of each one in the bigger picture that was emerging. Furthermore, I wanted to make sure that the network of subthemes grouped around a major theme matched not only the data, but also my feelings and insights related to what "really mattered", gained through the prolonged immersion in the campaign. In fact, I think that insights and feelings contributed to determine the place of themes and subthemes in the final network. Since I valued the importance for the researcher of being immersed in the field (see section 3.2), I do not think this detracts from rigour of the analysis, but on the contrary it contributes to add richness and depth, exploiting the "situatedness" of my position.

In particular, the final coding structure showed the importance of narrative techniques used by actors, non-linear dynamics of relationships, difficulties for actors to adapt to unforeseen circumstances, local and short-range network interactions, and the like. It was only by carefully checking the relationships between these and other major themes and between the themes and the insights and feelings emerging from my involvement in the campaign that I finally identified the major topic of "situational sense-making". In fact, it was both emerging as the common feature unifying all other themes, and it matched also my experience that the most important issue faced by actors in the campaign was to continually make (and re-make) sense of specific, local situations to produce specific outcomes. Once I reached this point, I both felt and verified that the analytical process had been completed.

3.6.2   Relational analysis and the synthesis of results

I organized codes into a hierarchical structure of categories and subcategories. In its final version, this work produced about 430 single codes, eventually organized into eight main categories (each containing a number of subcategories), roughly corresponding to the eight main sections of my findings (Chapters 5-7). "Situational sense-making" provided the unifying concept to organize all these main subthemes. However, a hierarchical structure was not entirely appropriate to describe relational data. Hence, I adopted two strategies. Firstly, themes and subthemes were organized into a network structure (see Figure 8.1), which could easily display all horizontal interactions between subthemes, unlike a simple hierarchical

structure (Attride-Stirling 2001). More importantly, each subtheme could represent an entry point to the analysis, since subthemes are related to each other, and may be considered as specific lenses to read the whole analysis. The thematic network is therefore a horizontal more than a vertical structure, doing more justice to the relational focus of the thesis. Secondly, according to the qualitative network analysis perspective, I focussed both on the whole network and on single interactions – for example, on the egocentric[3] perspective of single actors emerging from interviews, and the interactions between specific categories of actors such as campaigners and community members in observations of sessions.

This analytical process was carried out mainly by two tools typically used in synthesizing results both in network analysis and in qualitative analysis: matrices and network diagrams (Miles & Huberman 1994, p.93). Additionally, social network analysts usually recur to the same analytical devices to organize information about networks, although often used for mathematical or statistical calculations out of the scope of the present work (Hanneman & Riddle 2005; Wasserman 1994). Consistently with these approaches, I produced three kinds of devices used both to explore data, and to display and summarize the findings. The first one consisted in network maps of situations, settings and interviews; the second in diagrams summarizing concepts and situations from a network- or interactional perspective; the third, was represented by matrixes showing the multiple relationships between a set of actors.

I used network maps to understand the position of actors in a network, and how their actions and perspectives were influenced by the way in which they took part in network relationships, and how in turn their actions influenced the network itself. Examples of such network maps employed in the findings section to illustrate information management by actors include Figure 6.4 to Figure 6.10. Network maps were valuable for data display, but – most importantly – they also contributed to outline themes and subthemes from a relational perspective. Some maps concerned properties of the whole network of actors – such as its structure, the relative position of actors and other properties: examples used in the findings include Figure 5.2 to Figure 5.4, Figure 5.6 to Figure 5.10 and Figure 7.1 to Figure 7.3.

Diagrams summarizing information from a network perspective include figures 4.1, 5.1, 5.5. They may be considered diagrams representing situations by locating actors, concepts and actions in the perspective of a network. Finally, I used matrixes to analyse and display multiple relationships between actors, especially in section 5.2. Relational and thematic qualitative analysis interacted in the analysis of data. Although rarely used together in general, these

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[3] Here, the word egocentric has a meaning related to social network analysis: an egocentric network is the network reconstructed from the perspectives of one of its nodes (ego).

methods helped integrating depth of insight and reflection with a relational perspective on data.

3.6.3 Software for qualitative network analysis

I used NVivo 10 (QSR International 2012) to store all transcripts and memos in a single space, to perform all the coding and to organize the hierarchical structure of codes. For the relational aspect of analysis and for linking concepts in network I used Visual Understanding Environment (VUE) 3.1.2 (Tufts University 2012). I produced with this software most of the network maps described in the previous paragraphs. Diagrams requiring more complex graphical devices were instead produced with Microsoft PowerPoint 2010 (Microsoft 2010b). Finally, for structural network mapping I used social network analysis software. UCINET 6 (Borgatti et al. 2013) was employed for network analysis, Netdraw 2 (Borgatti 2012) for network maps. Matrixes were generated using Microsoft Excel 2010 (Microsoft 2010a).

3.6.4 Quality, validity and rigour

I have described in the previous paragraphs on data collection and analysis the steps taken to ensure rigour in the research process. It is, however, difficult for a researcher working alone on a qualitative research project to maximize validity and rigour, while also striking a balance with time and resources available and the regulations concerning the conduct of a PhD. From a methodological point of view, the main challenge was the integration of different methods in analysing relationships instead of "substances". There was no single available method to apply, so I had, in some sense, to create my working tools at the same time as I did the analysis. However, as previously showed, I tried to apply as rigorously as possible and to illustrate most thoroughly the analytical techniques I used; whenever possible, I relied on well-known and well-developed methods and techniques for data exploration and display.

Triangulation of data collection methods (interviews and observation) allowed adding further depth and insight to the analysis. I looked for a richer understanding of data, rather than for confirmation of interview findings with observation, or vice-versa[4]. Furthermore, as for data analysis, the triangulation of different analytical techniques may have added depth and insights. As for reporting, I tried to adhere to best practices to report the results as clearly as possible (Sandelowski & Leeman 2012), also by making use of different visualization and diagramming techniques. Additionally, I reported words and actions of participants as often as possible, although I chose to use this technique sparingly both to improve the clarity and flow of argumentations, and to protect participants' privacy whenever needed. However, I always

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[4] I am indebted to Alicia O'Cathain for this important distinction about the meaning of triangulation, expressed during an informal PhD seminar in ScHARR in January 2011.

tried to back my statements in the findings with data, available for auditing. On the other hand, I learned from the research process that qualitative research often requires striking a balance between following procedural rules of analytical techniques as rigorously as possible to maximize rigour, and be creative and – to a degree – even able to break established analytical rules to maximize insight and depth. In fact, I directed my efforts towards this goal.

3.7 Ethics and research governance

I accomplished the research process in accordance with the research governance regulations of the main sponsor, the University of Sheffield. The research protocol obtained approval both from the University of Sheffield, and from the Research Ethics Committee and the Research and Development Office of the local NHS Primary Care Trust. I have covered issues related to selection of participants, approach, recruitment and informed consent in sections 3.4 and 3.5. In this section, I summarize the other key steps I have taken to ensure that my research adhered to the most rigorous ethical standards. Firstly, issues related to risks, burden and benefit for participants were analysed and informed the design of interviews. Additionally, I took standard measures of data protection to minimize risks of confidentiality breaches and protect the privacy of participants. All views expressed and actions observed remained and will remain anonymous in all analysis and reporting of the research. Individual participants did not receive any direct, personal benefit from taking part in the research. To ensure that data collected are useful to the community, research results will be disseminated as widely as possible. Participants will have the opportunity to ask to receive a copy of the final research report, and summaries of the research will be disseminated to the communities involved. Finally, no conflict of interest was identified, either for me, or for my academic supervisors.

Chapter 4   The campaign and its context. Introduction to findings

4.1   The campaign: timing, actors, activities

The campaign took place in a large metropolitan area in England. Two main actors were in charge of the campaign: the National Health Service Primary Care Trust (NHS PCT) of the main city in the area, and the NHS Regional Network working on stroke and cardiovascular diseases, which included representatives of PCTs, of patients and patient associations, and the local CLAHRC. The former will be named "PCT commissioners" in the thesis, while the latter will be referred to as the "Regional Network", and the main city in the area as "the city" (real names are not used for anonymization purposes). The Regional Network contributed to the project board with its Public and Patient Involvement manager, and with the Network director, who also coordinated the Network's internal stroke board, where decisions concerning the project were made. Therefore, when I use the term "project board", I refer to the steering committee created inside the PCT to manage the project locally, while "stroke board" refers to the Regional Network's organ in charge of making decisions concerning the campaign. Unless otherwise stated, in the findings "project board" jointly indicates PCT commissioners and Regional Network members involved in the board. Table 4.1summarizes the main phases of the campaign and the duration of my involvement.

	Period	Campaign phase	Main activities and events	Main roles involved
	9/2009 - 12/2009	Commissioning and selection	Tender published; company selected	PCT Commissioners, campaigners
	1/2010 - 6/2010	Insight phase	Campaigners collect data from different communities in the city (white affluent, white disadvantaged, BMEs, gypsies) and deliver first report to commissioners	Campaigners, community gatekeepers, community members, translators, PCT commissioners
	7/2010 - 11/2010	Steering committee re-definition and change of project focus	NHS PCT project leaders and many project board members leave; project board is re-designed; report submitted to Regional Network; decision to focus on Somalis, Yemenis and Pakistanis in the city	PCT Commissioners, Regional Network
	11/2010 - 6/2011	Pre-production phase	Campaigners back to selected communities to collect further data to produce materials and desing events	Campaigners, community gatekeepers, community members, translators
	7/2011 - 1/2012	Re-definition of delivery phase; completion, testing and printing of campaign materials	CLAHRC and Regional Network decide to fund final phase of campaign (branding and printing of leaflets/posters, distribution of materials, organization of final events)	Campaigners, community gatekeepers, community members, PCT commissioners, Regional Network, designers, translators
	1/2012 - 3/2012	Pilot delivery phase: distribution of materials and delivery of final events for communities	Stroke awareness events for communities; delivery of leaflets and posters	Campaigners, community gatekeepers, community members, translators, health professionals

Total campaign duration

Involvement of researcher

Table 4.1 Main phases of the campaign

The decision to commission a social marketing campaign for populations who had not benefited from the national FAST stroke campaign was made by the spring of 2009, by the PCT's public health lead, in collaboration with the Regional Network. PCT commissioners and the Regional Network identified the campaign as a pilot project, to be initially run in the city and whose learning points and implications would then be shared through the Regional Network. A project board including PCT and Regional Network representatives was formed, and subsequently a campaign brief was produced, with an invitation to present bids. After receiving applications, the selection took place in November 2009, and the winning company undertook activities in January 2010. Campaigners were subsequently co-opted on the project board. According to the brief, campaigners started an "insight phase" (see details in section 6.2.2.2) with BME communities, a gypsy community, a deprived white majority community and a control group (affluent white community) belonging to the same city, together with health workers and professionals. The aim was to obtain information on the level of stroke awareness and barriers and facilitators to health promotion and access to stroke services. Campaigners completed the insight phase in May 2010, with the presentation of a report including a qualitative analysis of focus groups with communities and interviews with health professionals and workers. By the summer, the project initiator and most project board members left, for reasons not related to the project. From June until October 2010 the project entered a stand-by phase, as the PCT and the Regional Network negotiated further developments according to revised priorities, and related funding decisions. Finally, it was decided that the campaigners would only carry out stroke awareness work with the Yemeni, Somali and Pakistani communities in the city, while funding for other parts of the project would go to other PCTs in the region willing to take part in the initiative (only one was interested). It was also agreed that campaigners would evaluate the work carried out by such a PCT, in addition to performing and evaluating the re-focussed project in the city. As a consequence, in November 2010 the campaign entered the "pre-production" phase, in which campaigners decided to collect more focussed data from the newly targeted communities, with methods and aims similar to the insight phase.

My involvement as a researcher in the campaign started in July 2010. Campaigners finalized pre-production in June 2011, and the results led to a short internal document recommending the production of multilingual stroke awareness leaflets and posters. After approval of recommendations by the project board, campaigners co-produced materials with communities and designers, between July and October. As it had become apparent by July 2011 that no plan was in place to print the materials and disseminate them to target communities, local CLAHRC and the Regional Network co-funded a further "initiation phase", in which campaigners were

entrusted with elaborating a dissemination plan, adding a logo to the materials and having them printed. Furthermore, funders requested that they organized the dissemination of leaflets and posters in target communities and a small number of stroke awareness events. Once completed, materials were signed-off by the project board in November, and were available in printed form in January 2012. The distribution of materials started at the end of January 2012, and the events were organized between February and the beginning of March 2012. From the initial decision to the initiation phase, the whole campaign lasted for slightly less than three years. My involvement in the campaign ended with the accomplishment of the initiation phase.

4.2 The context of the campaign: main properties and dimensions

4.2.1 How actors, roles, nodes and networks emerge from data: a relational point of view

In section 3.2, I described my approach as oriented towards a qualitative network analysis, emphasizing the importance of interactions between actors in the context of formal or informal networks. This implies interpreting field data using the lens of network relationships. The present section will explain the main characteristics of networks as emerging from the analysis of my dataset (see the overview presented in Figure 4.1).
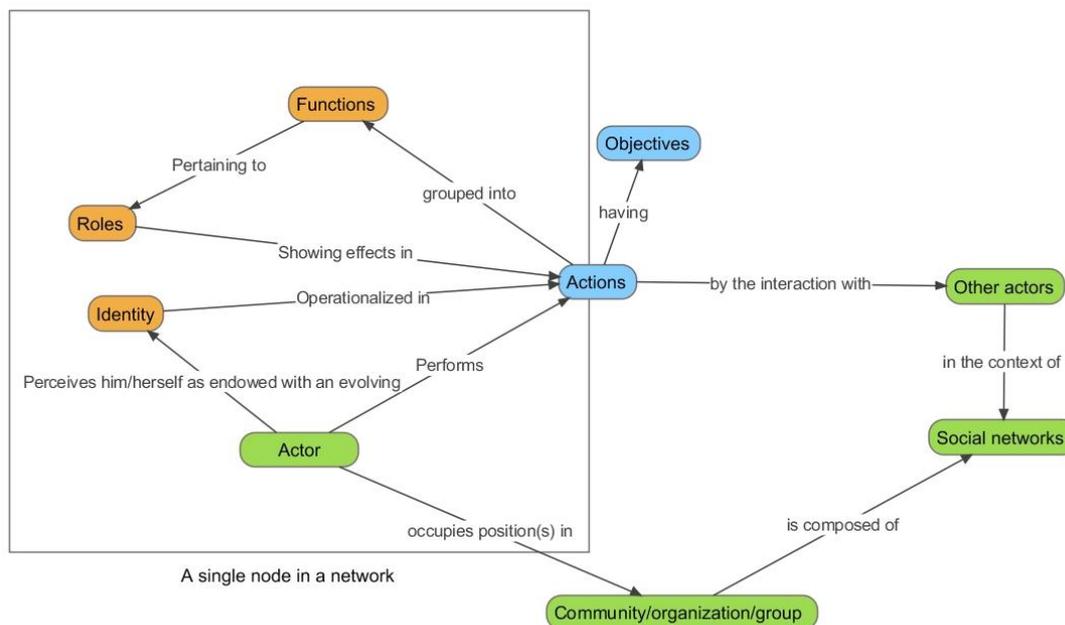
Figure 4.1 Main dimensions of an interacting node

Firstly, it is necessary to clarify the distinction between roles and actors, since their relationships in the data were complex and often ambiguous. An actor is any participant who carries out a relevant action for the campaign. Such actions are sometimes collected into

categories, called functions – e.g. commissioning the campaign, spreading lessons learned from the pilot project to the regional network, recruiting participants for sessions, etc. Each of those functions may group different subcategories, and each category or subcategory may include several actions. A role is a socially recognized pattern of behaviour. Roles primarily imply taking the responsibility (in theory or in practice) of one or more functions. For example, the role named "commissioner" implies being in charge of selecting which company will carry out the campaign, monitoring progress of the project, signing off the deliverables, evaluating the outcomes, etc.

As described in the previous section, the campaign took the traditional structure of a project, with a timeline, a steering committee, sign-off and control procedures, etc. Therefore, participants at all levels took on specific roles: this applies both to organizational actors, such as PCT commissioners, campaigners, Regional Network members, and to community members and gatekeepers. Roles were primarily the sum of functions related to actors taking part in the project. Hence, starting from a small numbers of roles, the deployment of the campaign *generated* new roles as it involved new actors, and modified the pre-existing ones through interactions and experiences of actors themselves.

Roles and actors do not exist in a void, however. Actors belong to one or more collective entities, such as communities, organizations, etc., in which they occupy more or less stable and clear positions: for example, project manager for a social marketing company, chair of the steering committee of the campaign, leader of a health promotion project in a community, head of a community centre, volunteer in a campaign, etc. Furthermore, actors show and act upon evolving identities, i.e. self-perceptions, linked to values, culture, groups, personal preferences, and the like. After that, actions have objectives, which in turn can be more or less clear, can evolve in the context of the campaign, and of course can be fulfilled completely, partially or not at all. The conceptualization of actors is influenced by the research question and objectives of the study. To understand how social networks influenced campaign deployment, actors are mainly characterized in terms of actions performed, concepts expressed, etc. I was less interested in identities, roles and functions as stable entities, and more in how roles and identities emerged and evolved in the context of interactions and relationships (see also section 3.2). Each actor can be represented as a node in a network. In the context of the campaign, all actions are performed in a relational context. Moreover, they can have an impact on the relational context even if they are not directly perceived as relational: expressed feelings, reported thoughts, impressions formed through the process are linked to other actions, actors, roles, etc. For the analysis, it does not count what an actor is, in

him/herself. What an actor is emerges from what he/she does in a relational context. In addition, it can emerge from what he/she thinks of being able to do, or should not do, or finally, might do only under certain conditions, etc. In turn, an action is not an abstract entity with given characteristics, but it can be equated with an interaction, in the context of a relationship.

I define this relational context as a social network, in which nodes are linked to other nodes through relationships. Therefore, nodes of a social network are not simply actors with some properties relevant for the interaction: the nodes are the assemblage of an actor, performing an action with an objective, fulfilling a function, acting according to a role, related to his/her identity. An actor can obviously fulfil completely, partially or not at all his/her function. Most importantly, all nodes undergo iterative modifications during sequences of interactions. Consequently, the campaign as a whole can be represented as the sum of myriads of interactions between nodes of a network. It exists only as far as nodes interacting with each other activate the networks. The meanings of the interactions and their relative importance, along with their reciprocal effects on nodes will be analysed.

4.2.2 Properties of the organizational context

Although networks are the main focus of analysis, a number of "non-network factors" (Valente 2012) play an important contextual role, and influence the way in which networks operate. In the case I studied, some key variables of the organizational context had a clear impact on the campaign. Firstly, interest for PCT commissioners and the Regional Network in the topic of how to increase stroke awareness for disadvantaged populations was high. This was due to the importance of stroke awareness for the National Stroke Strategy, and because there was a widespread perception that, locally, very few members of disadvantaged populations presented in time for thrombolysis. Additionally, there was a clear interest for the local NHS in targeting and reducing health inequalities in the city's population. The last point was also related to increasing use of health services by ethnic minorities and difficult-to-access populations. Interest in (and worries about) stroke were significantly high in the target population as well, thus making it a very suitable topic for a health promotion campaign. Secondly, the initiator of the project, and subsequently the whole project board were specifically interested in assessing the potential of the social marketing approach for health promotion, because it appeared as an innovative way to address traditional challenges posed by health promotion initiatives with specific methods and techniques. Thirdly, the involvement in the project board of the Regional Network and local CLAHRC meant that particular attention

was paid to dissemination of learning from the present project to other geographical areas and health topics.

The project was devised as a small-scale, pilot project. Moreover, it turned out to be particularly sensitive to changes and turnover at the level of PCT commissioners and the Regional Network: after the initiator left and a nationwide reform of public health started, the level of priority of the project significantly decreased, and its focus and range were restricted. Furthermore, the management style of the project was such that no tight control was exerted on schedules and specific objectives. While this allowed for greater flexibility in a constantly changing environment, it also made the campaign more liable to delays.

Finally, the environment in which the campaign took place (ethnic communities) was perceived as particularly difficult to access, and very few guidelines were available. In addition, delivery chains were long, involving actors with several different roles, both within organizations, and within communities.

4.3   Structure of findings

The brief diagram displayed here serves the purpose of helping the reader to navigate easily between the chapters that report the results of the study.
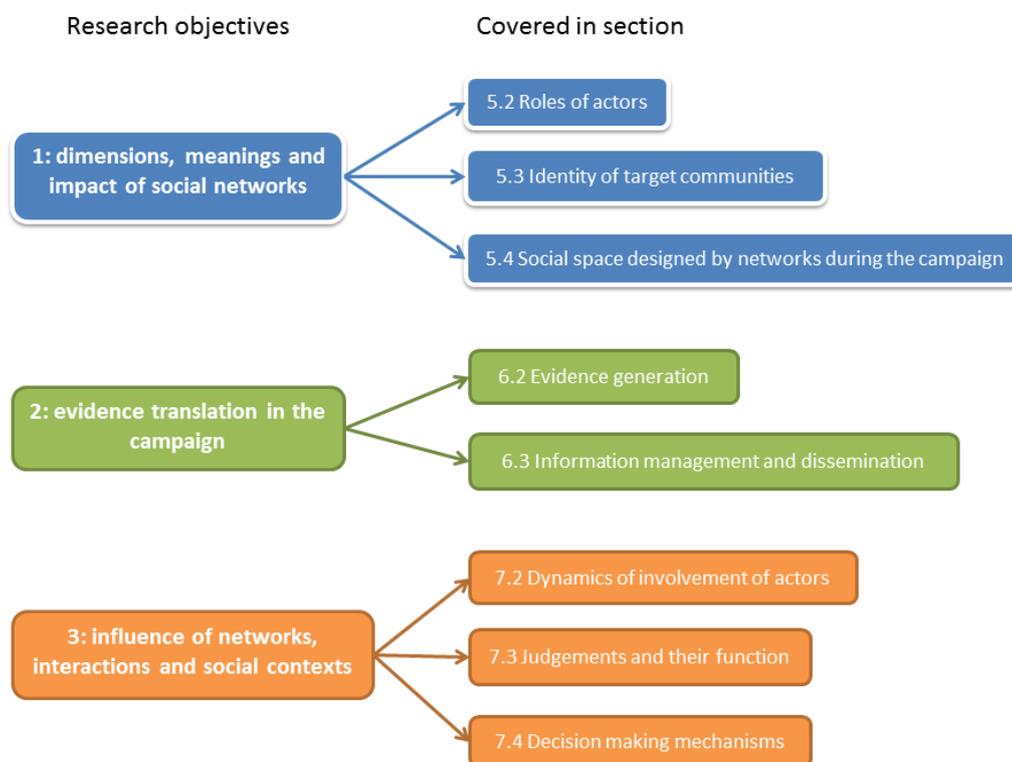
Figure 4.2 Research objectives and corresponding results sections

Chapter 5 Characteristics of social networks relevant for the campaign

5.1 Introduction

The chapter outlines the most important characteristics of social networks influencing the CBHP campaign. It contains the findings covering the first research objective, concerning the characteristics of social networks influencing the intervention. In the first section, I study roles of actors in the campaign, interpreting their perceptions, overlaps and evolution in relation to interactions happening in the social networks activated by the campaign. The second section is concerned with the co-construction of the identity of the target communities, jointly carried out by several interacting actors. Finally, the third section analyses the meaning of the emergence of the campaign as a temporary social space in the context of the target communities, and the role played by social networks as barriers and facilitators for the organization of the campaign.

While analysing the data, I aimed at identifying the main nodes, their relative position and importance, and the nature of resources flowing through the networks. In addition, I tried to understand how these multiple flows of impressions, information, etc. influenced each other, and how significant actions were accomplished. Particular attention was devoted to discovering the effects of networks on the perceptions of single actors considered as nodes in the network itself.

5.2 Influence of social networks on the roles of actors: perceptions, overlaps and evolution

As network interactions happen between nodes with specific roles (section 4.2.1), I will start by analysing the roles involved in the intervention. In this section, I will analyse how roles interacted with each other: hence, here the nodes involved in network interactions are roles, not single actors, unless otherwise stated. Consequently, I will generally use the term "role", with the meaning of "actors playing a given role", instead of the more generic "node".

5.2.1 Characteristics of roles as nodes in the network

Some roles were established from the beginning: PCT commissioners were the initiators and funders of the campaign, in charge of monitoring it, while campaigners were entrusted with designing and delivering the pilot phase. However, other roles eventually emerged at later stages, while yet others changed significantly during the campaign. Table 5.1 shows each role

involved in the campaign, the approximate number of actors and the phase in which a role began taking an active part in the intervention.

Roles	Actors	Main functions	Mainly involved from
PCT Commissioners	3	Commissioning and funding the campaign; monitoring progress and making decisions; signing off deliverables; evaluating outcomes	Commissioning and selection
Campaigners	3	Researching BME communities; co-producing campaign materials; recruiting gatekeepers and community members; outsourcing design and print of campaign materials; delivering materials; organizing events; holding events; evaluating campaign outcomes	Commissioning and selection
Regional Network members	4	High-level evaluation of the campaign; decisions on funding; support and monitoring of the campaign; spreading organizational learning to the network	Commissioning and selection
Community gatekeepers	15	Recruiting campaign participants; organizing pre- and co-production sessions; organizing final events; distributing campaign materials; raising stroke awareness in the community using existing settings and activities	Pre-production
Community members	200	Demonstrate their level of stroke awareness; share ideas to organize campaign; take part in final events; talk about stroke awareness to other community members; distributing materials in the community	Pre-production
Health professionals	1	Presenting, answering questions and measuring blood pressure at final events; validating campaign materials	Pilot delivery
Pharmacists, librarians, general practice (GP) managers	30	Making campaign materials available in their venues; starting conversations with BMEs using materials	Pilot delivery
Translators (language)	5	Translate into/from community language during co-production and final events; raising stroke awareness during sessions	Pre-production
Designers	2	Designing campaign materials; devising and agreeing licensing terms	Testing and production

Table 5.1 Synoptic description of roles in the campaign

I identified nine main roles within the network. Two of them (PCT commissioners and Regional Network) belonged to different sections of the commissioning organization (the NHS), while community members were the target of the campaign. Campaigners were the designated intermediaries to deliver the message of the campaign to communities, but to reach their objective they interacted with five other roles: four were auxiliary "interface roles"

(community gatekeepers, translators, health professionals, pharmacists/librarians/GP managers) while designers acted as technical intermediaries. Figure 5.1 shows role interactions.
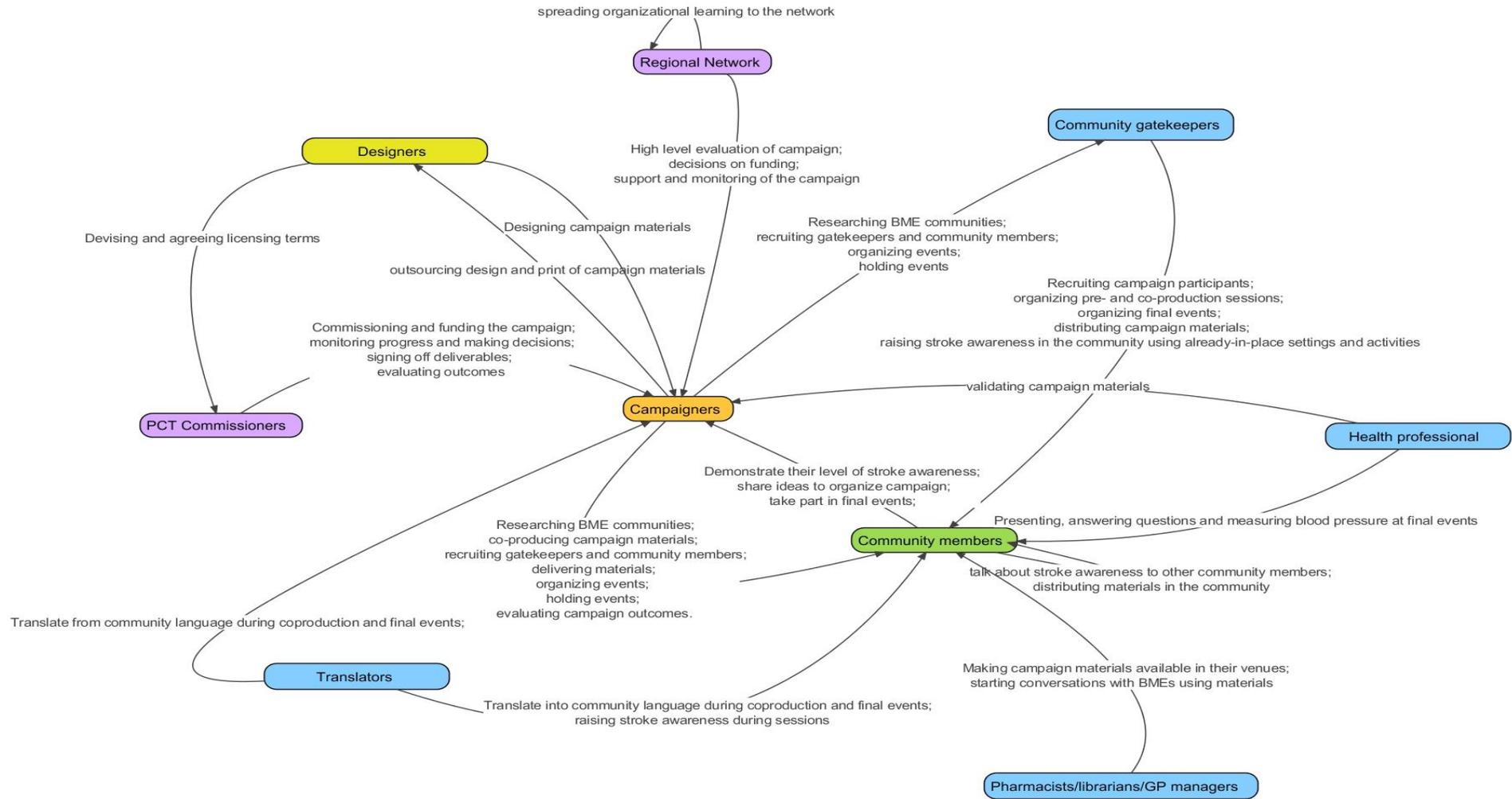
Figure 5.1 Main interactions between roles

The map shows how roles interacted with each other to fulfil a function. The main axes of reciprocal interaction are:

- between PCT Commissioners/Regional Network and campaigners, with interactions concerning funding, monitoring and evaluation;
- between campaigners and community members, often through community gatekeepers, with interactions concerning knowledge assessment, co-production and delivery of materials and events, and evaluation;
- between campaigners and auxiliary technical and interface roles – interactions concerning a variety of practical and conceptual activities (design, language translation, clinical expertise, etc.).

A simplified view of the network is therefore depicted in Figure 5.2.
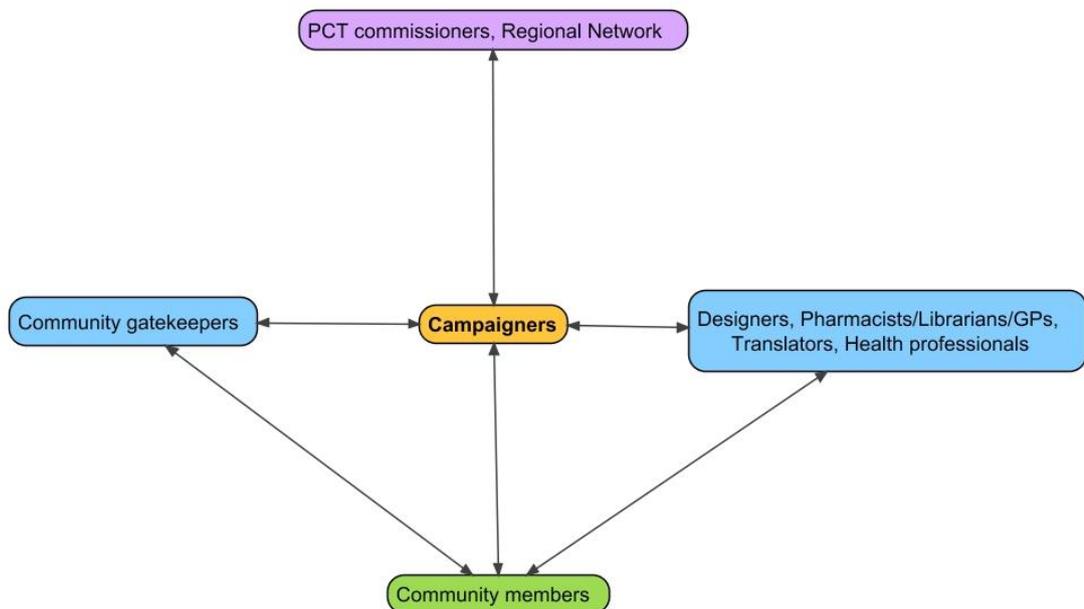
Figure 5.2 The basic structure of the network

Campaigners were the most central role in the network; if removed, the network becomes fragmented, and resource exchange through interaction is seldom able to happen. PCT commissioners and the Regional Network had very few direct interactions with other roles, except through campaigners. Community gatekeepers played a very important role in the interaction between campaigners and communities, as did also other auxiliary roles for specific issues. Fulfilling the first research objective, however, requires interpreting if and how those interactions happened, and the impact of interactions on single nodes, groups of nodes or the network as a whole.

5.2.2 Self-understanding and understanding of other actors' roles

In general, actors needed to understand their own and other roles to perform successfully a relevant action in the campaign. For example, when community members did not understand the campaigners' role correctly, the results of the interaction were less informative; when community gatekeepers did not exactly understand the aims of campaigners were less likely to become involved in organizing events; when there were misunderstandings between PCT commissioners and Regional Network roles, the project incurred delays and lost efficacy, etc.

Representations emerged from interviews and observations, as actors explained or justified their actions, acknowledged limitations and mistakes, criticized other actors' behaviour, etc. Therefore, this section explores if roles produced a representation of other roles, and to what degree the representation matched the role's self-representation. Firstly, it was possible to understand reciprocal perceptions only for interacting roles. Conversely, there were roles, which did not even perceive the existence of other roles, however relevant: for example, the health professional did not know the NHS office in charge of the campaign, while some community members thought that the campaign had been organized by the council. Hence, a biased understanding of the whole network structure followed. Secondly, some roles had supervisory duties (e.g. commissioners towards campaigners), while others were in charge of managing particular aspects of the campaign (e.g. campaigners managed the involvement of community gatekeepers and members in different phases). However, no one was in charge to ensure that each actor knew what to expect from each other, in different phases of the campaign. In other words, there were no formal role descriptions or processes by which different roles came into being. In addition, no one managed the roles. Noticeably, in such a situation, the network did *not* self-organize as a space for mutual understanding of actors' roles.

In fact, actors made sense "locally" and "situationally" of other roles during iterative interactions, and in different points of the network there were diverging understandings of the same roles. Furthermore, this "local understanding" remained largely tacit, and not shared between actors, with partial exceptions (see the construction of ethnicity). I will illustrate the point in detail, with examples of matching and non-matching role representations within the network.

5.2.2.1 Forming representations of other actors' roles

Firstly, I tried to discover the actors who had understood the role of other actors. "Understanding" means that an actor with a role has formed a representation of another role and its meaning; it does not imply that such an understanding is accurate. Using presence or

absence of understanding between roles, Figure 5.3 and Figure 5.4 show which roles formed an understanding of others during the campaign and which ones did not. Understanding is not necessarily mutual. Moreover, the two figures are symmetrical.
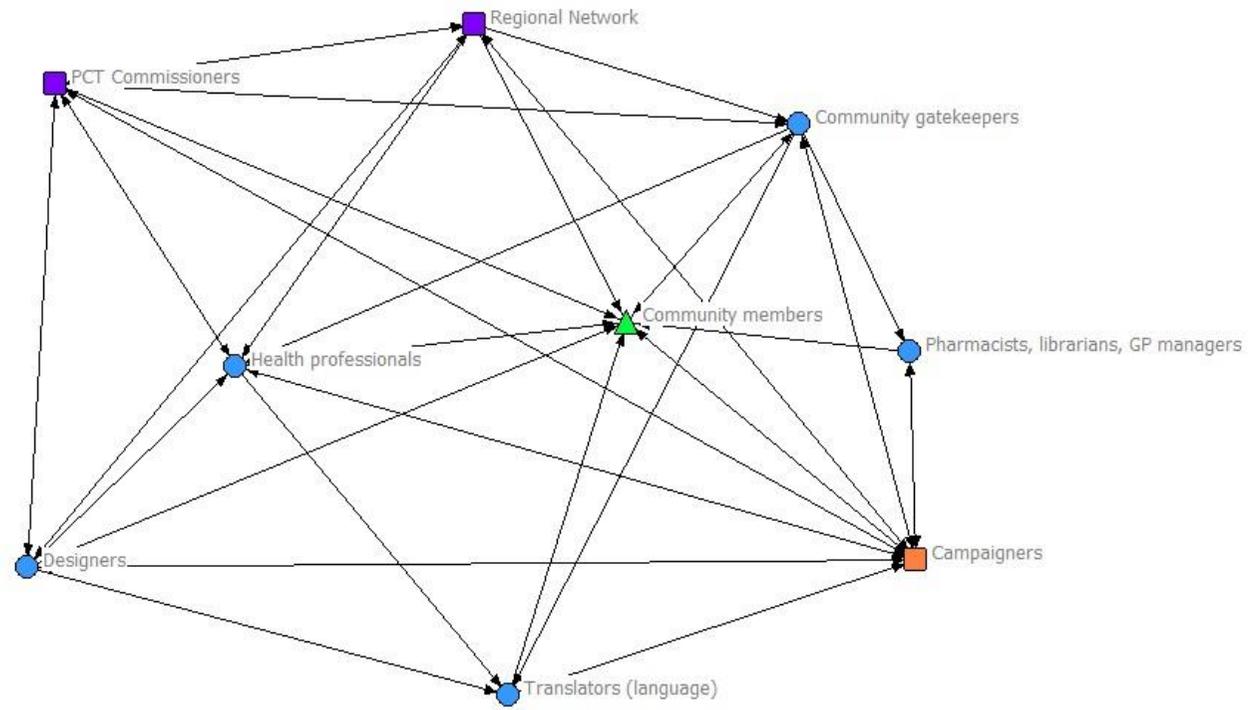
Figure 5.3 Roles with an understanding of other roles
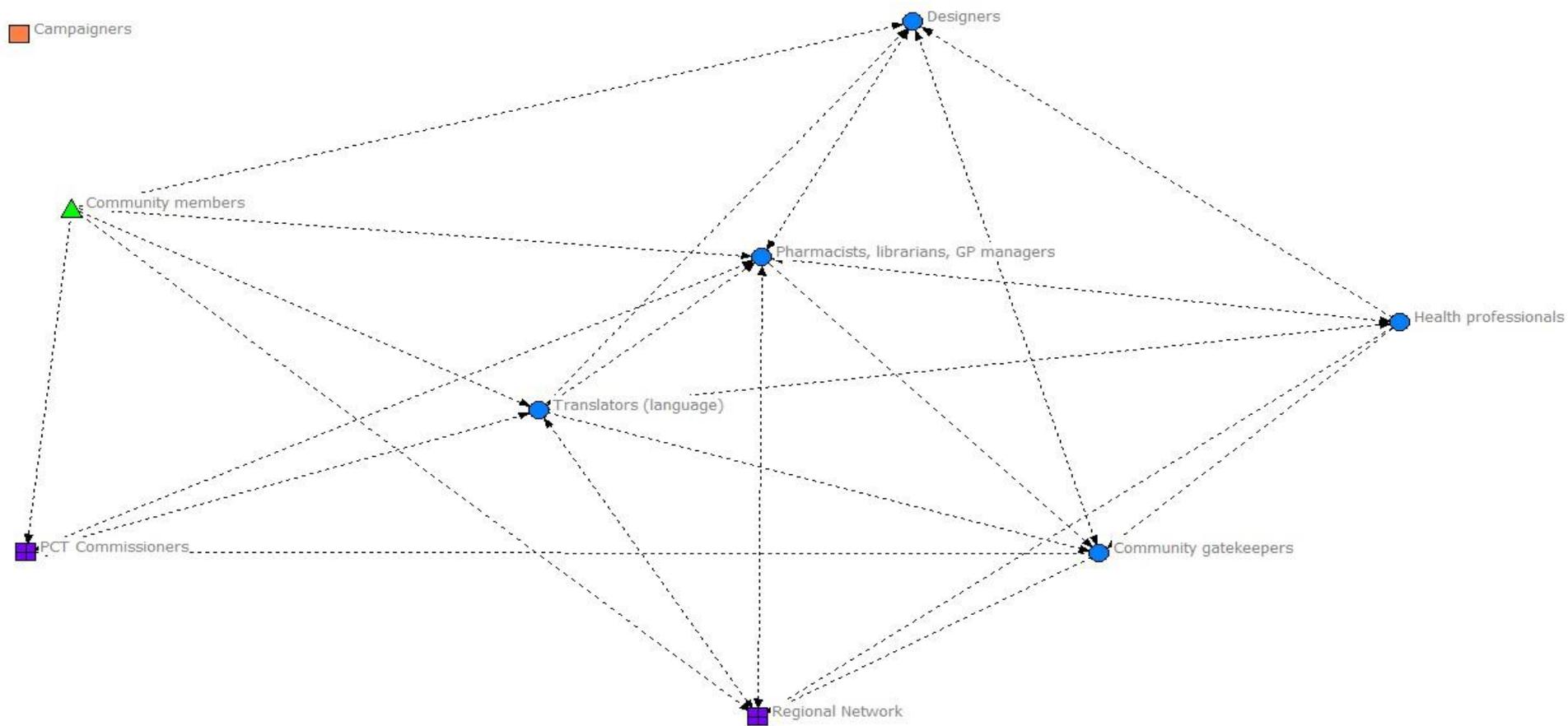
Figure 5.4 Roles without an understanding of other roles

As the most central role, campaigners "understood" all other roles, and were generally "understood" by others; community members, being the target of the campaign, were the only other role for which actors in all other roles formed a representation. The frequency of understanding of a role by others is not necessarily related to the frequency or intensity of its involvement in the campaign: for example, most roles formed a representation of health professionals, although the frequency of involvement of this role was very low. In general, peripheral, auxiliary roles were less likely to form a representation of others.

In some cases, the fact that roles did not form a representation of others has little relevance: for example, there seems to be a low need for designers to understand the role of pharmacists/librarians/GP managers. However, the lack of a clear understanding by community members and gatekeepers of the role of organizations in charge of the campaign is more worrying. Similarly, the lack of understanding of the role of Regional Network and community gatekeepers by the health professional involved has in fact caused problems, described in later sections. In addition, the lack of understanding of other roles involved in the campaign by pharmacists, librarians and GP managers implied that they only partially fulfilled their function.

5.2.2.2   *Understanding of other roles, and related mismatches*

As for roles with an understanding of others, it is important to see whether self-representation and representation by others coincided or diverged significantly. It is difficult to outline how actors represented their role or the role of others: consequently, I selected only the most important aspects of this understanding. Likewise, on the one hand, a role can be ambiguous for some actors, while clear for others. On the other hand, as a role is composed of different functions, some functions of a role may be perceived as generally clear, while others as unclear.

For example, it was clear for PCT commissioners/Regional Network and campaigners what to expect from each other (see Table 5.1), although there were important misunderstandings, on occasions: for example, campaigners expected a much stronger role by commissioners in the recruitment of gatekeepers and health professionals. Furthermore, campaigners knew what to expect from health champions and health professionals, although the former were never involved in the project and the latter's involvement was limited to a nurse presenting and measuring blood pressure at two final events. This last problem was probably caused by the fact that PCT Commissioners had no clear idea of the strategic importance of health professionals.

Furthermore, some roles remained unclear for the entire project, with an important influence on the co-production and delivery phases. For example, none seemed to know in detail what to expect from community gatekeepers or pharmacists/librarians/GP managers. Some actors, as community members, were not involved from the start, nor sat in any committee or board, as one interviewee noted. Their role was only broadly defined until the campaigners entered the field and started collecting data concerning attitudes towards health; even then, however, there was no systematic definition of the role of community members. Consequently, the view of target communities was incorporated only a-posteriori, and filtered through the reports produced by the campaigners. Further, it was unclear which role community members should play in the project: trainees, prospective lay health advisors, or simply communicators of the stroke awareness message through community networks? A similar issue arose about the involvement of health professionals. Although campaigners strongly suggested that they were involved from an early stage, this only happened in the delivery phase, and the nurse involved seemed to lack most of the context concerning the campaign. The lack of mutual and shared understanding of the characteristics of a role and the consequent impact on the campaign can be illustrated with reference to community gatekeepers (Table 5.2).

Role	Perceives community gatekeepers as	Role scope
PCT Commissioners / Regional Network	Points of contact within communities, to be used "just-in-case" for future health promotion	Wide, but vague
Campaigners	Sources of practical help in establishing trusted relationship with communities, organizing and translating sessions, etc.	Narrow, very focussed
Community gatekeepers	Recruiters of participants, organizers of sessions, directly involved in raising stroke awareness in communities, building on their established roles	Wide but tangible

Table 5.2 Different perceptions of the role of gatekeepers

Gatekeepers played a public, well-known role in the communities, such as activists, volunteers, leaders of community centres, etc. As such, they were involved in the project, but with different expectations. For the Regional Network and PCT commissioners, they were important as "channels" or points of contact to be used just-in-case, for subsequent projects. A Regional Network member comments:

"I did want (…) to build relationships with the communities for the future (…) for cardiac and other stroke work. (…) There's something about sustaining that relationship (…) then (…) when you do need to work with them again, you can pick it up (…) and you can create impetus very rapidly".

For campaigners, gatekeepers fulfilled more immediate practical needs (see Table 5.2). Gatekeepers generally fulfilled the role expected by campaigners, although with varying degrees of success. However, it seems difficult that they can act as stable gatekeepers for the NHS, since no direct contact occurred. Moreover, some gatekeepers represented their own role in markedly different terms. Especially Somali gatekeepers acted directly as event organizers, participant recruiters and stroke awareness champions. Hence, for a limited period, they took on a great part of the role of campaigners, leaving to "official" campaigners or health professionals only the function of presenting at meetings or events. Here, for example, a Somali community gatekeeper expresses the opinion that health promotion should be organized by community gatekeepers and members:

> *"The communities will negotiate their own time with people and will make it more flexible, they understand when people are available or no (…) and they also help each other with coming to the event, with organising, getting, engaging the event and it make them feel a sense that you're appreciating actually the community getting involved, so (…) you treat them as partners, not just as a participant".*

Some gatekeepers also felt that their role entailed direct action to raise stroke awareness in the community, starting conversations about stroke, distributing leaflets, etc. (section 5.2.3). In fact, recruiting participants, organizing formal and informal sessions, and delivering stroke awareness by starting conversations in the community were interpreted by gatekeepers as two parts of the same process. Relationships between role perceptions and self-perceptions were important, as they could lead to (or prevent) certain actions, or influence the style of actions. For example, if the project board had foreseen how gatekeepers perceived their role, they may have taken action to maximize its impact and reinforce community ownership for the campaign.

5.2.2.3 *Understanding of roles: a whole-network view*

After analysing examples of partial or mutually lacking understanding between roles, I will now try to show a whole-network view of mutual understanding between roles. I generated a matrix (Table 5.3) to summarize what actors expected from their involvement in the campaign and from the involvement of others. I represented self-perceptions as grey cells, while white cells record perceptions of a role by other roles.

Roles	PCT Commissioners	Campaigners	Regional Network	Community gatekeepers	Community members	Health professionals	Pharmacists, librarians, GP managers	Translators (language)	Designers
PCT Commissioners	Evaluators; decision makers; organizers of future health promotion	Relationship-builders with communities; people in charge of delivering stroke awareness message; campaign evaluators	Evaluators of their activity and campaign; decision makers for funding allocation; co-decision makers	Points of contact for communities, to be used "just-in-case" for future health promotion	Difficult-to-reach group. Target for increasing stroke awareness and for future health promotion	Collaborators in signing off the materials			Copyright owners, producers of materials to sign off
Campaigners	Evaluators; decision makers; organizers of future health promotion; potential providers of contacts to organize the campaign	Relationship-builders between communities - NHS; co-producers of campaign materials; delivering stroke awareness message; community trainers; campaign evaluators	Evaluators of their own activity; decision makers with funding allocation responsibilities	Sources of practical help in establishing trusted relationship with communities, organizing (translate) sessions, etc.	Difficult-to-reach group. Sources of information; materials co-producers. Potential trainees, target for increasing stroke awareness	Source of clinical information for sessions and materials; presenting & answering questions at sessions	Potentially delivering stroke awareness to their customers, starting from campaign materials	Translating exactly from/to community language during session and for campaign materials	Collaborators in translating on campaign materials the ideas emerging from community sessions
Regional Network	Commissioners in charge of the campaign and principal evaluators	Relationship-builders with communities; people in charge of delivering stroke awareness message; campaign evaluators	Network facilitators; brokers for knowledge emerging from campaign; evaluators of campaign; decision makers for funding allocation	Points of contact to communities, to be used "just-in-case" for future health promotion	Difficult-to-reach group. Target for increasing stroke awareness and for future health promotion	Collaborators in signing off the materials			Copyright owners, producers of materials to sign off
Community gatekeepers		Delivering stroke awareness message to communities		Participant recruiters, session organizers, directly raising stroke awareness in community, building on established roles	Target for increasing stroke awareness and for future health promotion; potential trainees	Trusted source of health information; presenters to community sessions	Potential help to deliver stroke awareness information to community	Doing both exact translation and addition of details to clarify message to community members	

Role									
Community members		People in charge of delivering stroke awareness message and materials to communities; people extracting knowledge for campaign from communities		Trusted gatekeepers for the community, delivering stroke awareness message and organizing event	Potential trainees, contributors of knowledge for campaign, target for stroke awareness message	Trusted source of health information; presenters to community sessions; source of advice for personal health			
Health professionals	Commissioners in charge of the campaign	Collaborators/ potential competitors in delivering stroke awareness message			Target for increasing stroke awareness and for future health promotion	Qualified community health promoter; sign-off of materials		Translating exactly from/to community language during session	
Pharmacists, librarians, GP managers		Delivering stroke awareness materials to communities			Target for increasing stroke awareness		Making materials available in their venues		
Translators (language)		Delivering stroke awareness materials to communities ; producing culturally-aware materials			Target for increasing stroke awareness			Doing both exact translation and addition of details to clarify message to community members	
Designers	Commissioners in charge of the campaign; evaluators of their own activity; sign-off providers	Delivering materials to communities; direct employers; collaborators providing community insights to translate into graphics; translators of clinical concepts into graphics	Commissioners in charge of the campaign; evaluators of their own activity; sign-off providers		Source of information on community attitudes to stroke message and of insights for materials; materials testers	Source of clinical sign-off for materials		Translating exactly from/to community language for campaign materials	Translators of clinical information into graphics; translators of community insights into culturally-sensitive stroke materials

Table 5.3 How do actors in one role perceive the meaning of other roles?

Some roles are clearly more "central", since they raise or express more role perceptions. Such centrality, however, should not always be equated with importance in the process. For example, health professionals were often perceived as having a potentially relevant role in the campaign, although their actual involvement was minimal. On the other hand, lack of centrality may sometimes be expected: for example, the role of the Regional Network implied that they were not involved directly in fieldwork for the campaign. Hence, their position was peripheral. Matrix columns identify roles with major differences between self-perception and perceptions by others, and important variations between the perceptions of a single role by different actors.

Firstly, role conflicts emerged between PCT commissioners and the Regional Network; both had an understanding that the other was effectively in charge of the campaign, with consequent delays and issues of fluctuating leadership. Campaigners perceived themselves as mainly committed to co-produce stroke campaign materials and events with communities, although with a view to generalizing results to possible future initiatives. However, the project board perceived the campaigners as gatekeepers between the NHS itself and the communities, with the role of building contacts potentially useful in the future. The only health professional involved in the delivery of events perceived the campaigners as collaborators in delivering events, but she also thought that qualified professionals would be more suited to explain health topics to community members and – especially – to answer their questions – a view shared by campaigners themselves.

Community members were uniformly perceived as difficult to reach. For PCT commissioners and the Regional Network they represented targets for future health initiatives. However, they perceived themselves as potential trainees in promoting stroke awareness as well, and this perception was shared by campaigners. Furthermore, for designers, campaigners and the project board, community members were also information providers on attitudes of the community towards health. As for pharmacists, librarians, GP managers targeted during the distribution phase, the perception of their role by campaigners (being proactive in delivering stroke awareness message to their customers) did not match their own perception (simply, making materials available in their venues). Translators as well played a sort of double role. In some cases, and by some actors, they were considered as sources of exact, verbatim translations; on the other hand, during sessions, some of them felt it was their duty to add details and convey to their audiences the "real" meaning of what the campaigners were saying.

Health professionals were uniformly recognised as authoritative in answering questions from community members; there were instead different views about the fact that stroke awareness messages delivered by non-health professionals may be comparably effective. Finally, designers perceived themselves as significantly contributing to the potential outcomes of the campaign, by translating complex clinical concepts into suitable, culturally adapted visual materials. However, they were mainly considered by the project board as copyright owners, to be engaged with mostly in order to obtain adequate copyright conditions.

The table contains only roles directly involved in the intervention. Hence, I excluded health champions, although they were perceived by commissioners and campaigners as potential collaborators in further health promotion initiatives. Additionally, some community gatekeepers thought that trained community members might become health champions themselves. I did not include my role either, since most actors considered me as a neutral observer. However, PCT commissioners and the Regional Network had expectations about the practical learning potentially emerging from my thesis. For campaigners and designers, since the local CLAHRC co-funded the last phase of the campaign as well as my research, I belonged to a body who commissioned their work. As a researcher in the field, at times I shared with campaigners the same potential participants, although my objectives (academic research) significantly differed from theirs (formative research focussed on production of materials and events). Furthermore, on occasions, session participants perceived me as a collaborator of the campaigners, since I usually observed sessions held by campaigners in the community.

In conclusion, roles seem largely constructed by actors during the process of the campaign, more than being formally defined at the outset of the campaign, and/or strictly adhered to by actors. At the same time, it was during interactions that actors understood how others perceived their role. Network interactions were therefore one of the main mechanisms through which transactions happened, and allowed organizing activities. Sometimes, however, perceptions were not shared directly, but were only collected and compared by myself. Reasons include politics and tactics of actors (in the case of the different, reciprocal role perceptions by the PCT and the Regional Network, or the different perceptions by/of health professionals and campaigners), or lack of direct access (e.g. PCT/Regional Network members and community gatekeepers).

No optimization of the understanding of roles occurred in the campaign, hence the existence of some roles was not even noticed by actors with other roles. Further, when an understanding of other roles was formed, it resulted from local network interactions, with related mismatches of perception having a significant impact on activities. In the intervention,

therefore, networks were essential in role perception. However, understanding of roles only happened locally, and networks as such did not represent an effective mechanism of coordination of understanding and expectations, since actors generally lacked a view of the whole network.

5.2.3   Description and meaning of role overlaps

During the implementation of the campaign, it became apparent that roles demonstrated some overlaps, already indicated in section 5.2.2. In some situations, one or more different roles performed actions typical of the function of a different role: I call this situation role overlap. Overlaps differ from role perceptions, as the former concern observed facts, while the latter are expressed also by reflections, feelings and expectations, observed directly or indirectly. After systematically analysing data for role overlaps, I built Table 5.4. Overlaps should be read starting from the row heading in the direction of a column heading. For example, in the first row, the role of PCT commissioners shows a medium overlap with the role of the Regional Network. Overlaps are not symmetrical: a role may perform actions pertaining to another role, but the reverse may well not happen.

Roles	PCT Commissioners	Campaigners	Regional Network	Community gatekeepers	Community members	Health professionals	Pharmacists, librarians, GP managers	Translators (language)
PCT Commissioners			Medium					
Campaigners						Low		
Regional Network	Medium							
Community gatekeepers		High			Low	Low	Low	High
Community members		Low				Low	Low	Low
Health professionals		Medium						
Pharmacists, librarians, GP managers		Low						
Translators (language)		Low		Low	Low	Low		

Table 5.4 Overlapping roles

Overlaps had both positive and negative consequences for the campaign. They revealed duplications of efforts, ambiguities and role confusion, but they also represented synergies: in the former instance, the network was inefficient in distributing effort across different roles, while in the latter it helped reinforcing positive outcomes of specific actions. A systematic description shows that the role of community gatekeepers was by far the most overlapping with others. This may reflect their centrality in the network, and their importance for establishing relationships between different actors. When community gatekeepers took an active role as information brokers for stroke awareness, they overlapped with both campaigners and health professionals. On the one hand, the overlap was positive, since conversations in the community about stroke probably reinforced the campaign momentum, for a period. On the other hand, negative effects may have arisen about information accuracy (see end of section).

Campaigners overlapped with few other roles[5]. They took on some functions of health champions – quite understandably, since the latter were not involved in the campaign. They also moderately overlapped with health professionals, since in some sessions they had to give clinical information at the request of participants. Additionally, community members' actions overlapped with those of several other actors, although with less important effects. Finally, translators often performed actions pertaining to different roles, although in the context of more limited interactions, like single sessions.

The columns in the table indicate the roles more influenced by overlaps with others. High presence of overlaps for a role indicates that either it was in high synergy with several different roles, or it was jeopardized or superseded by other roles. As health champions were not involved in the campaign, several other roles tried to occupy this empty space. However, no structured initiative was set in place for establishing a stable role for some actors to continue raising stroke awareness in the community after the end of the campaign. Therefore, partial overlap did not lead to a sustainable coverage for such a role. Another role with significant "incoming" overlaps was the campaigners', with implications more difficult to interpret. On the one hand, campaigners were central in the network, and had wide-ranging attributions. Hence, it was more likely that other roles overlapped with them. On the other

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[5] In addition to overlaps shown in the table, campaigners acted as researchers in the field, thus overlapping with my own role; however, research was performed with a marketers' and self-evaluator's attitude, without adopting an explicitly academic point of view. Especially during delivery, both campaigners and I required feedback from session participants. There was, therefore, an objective difficulty in accessing the participants without placing too much burden on community members. Secondly, since the sessions were very brief, time required to explain my presence and to distribute information sheets, and for campaigners to administer pre- and post-test questionnaires shortened the time available for actual session contents.

hand, it may raise some concerns that actors not qualified, and sometimes unaware of the context and objectives of the campaign (see section 5.2.2.2), acted continuously as campaigners. In fact, health professionals were involved in very few sessions. Community gatekeepers and members undertook several informal activities aiming at raising stroke awareness in the community. Both those roles then "replaced" health professionals in delivering clinical information and answering questions posed by community members – with room for possible misunderstandings and undue modifications of the message.

Finally, in community sessions the role of translators significantly overlapped with that of community gatekeepers: frequently, the same person who had recruited participants and collaborated to organize the session also translated session contents. They did not translate verbatim, but took a more active role, in line with their public role in the community, by adding details and adapting the session contents for their audiences – although perhaps involuntarily introducing biases in the message.

Another case where an overlap in roles led to suboptimal performances by both roles was the misunderstanding between the PCT and the Regional Network about who was in charge of coordinating the campaign (section 5.2.2.3): this not only raised conflicting expectations, but also produced decisions and actions, which sometimes hindered the progress of the campaign. Finally, I excluded designers from Table 5.4, since their role did not overlap with any other.

In summary, role overlaps emerged in the campaign, sometimes with significant consequences. Overlaps seem to be mainly caused by insufficient specification of roles and unpredictability of the environment. Organizational factors, such as small project size, high turnover and flexible management style were related to low role specification, and the absence of a tight, continuous monitoring on the process of the campaign (section 4.2.2). Role overlaps are also linked to the perceived difficulty of access to communities by campaigners and the NHS: when campaigners entered community settings, it was seldom the case that activities followed a predefined schedule. In fact, very often other actors (translators, community gatekeepers and members) overlapped with campaigners, and the settings where the campaign took place were rarely conducive to a rigid separation of roles.

I observed the same network dynamics both for role understanding and for role overlaps. On one hand, single actors could carry out activities only through network interactions; on the other hand, network interactions and the global structure of the network did not always help in coordinating actors. Mismatches in understanding or overlaps between roles could only be

managed locally, and solutions could not be generalized to the network, in absence of a stronger, global network management approach.

5.2.4 Evolution of roles during the campaign

Roles and related functions evolved as the campaign progressed. Therefore, the described role dynamics may also be interpreted diachronically, to show how roles evolved in relation with network interactions. Mechanisms underlying role evolution were strongly linked to organizational contextual factors (sections 4.2.2 and 5.2.3): turnover of actors, flexible management style and complexity of community environment. Role evolution, understandings and overlaps facilitated or hindered practical work, hence contributing to the campaign's outcomes. In Table 5.5, I describe evolutionary phases for three key roles – campaigners, community gatekeepers, community members. I chose them as examples because they showed important evolution over time. The table attempts to summarize several micro-processes, consequently the synthesis will not reflect all evolutionary dynamics. Noticeably, in this context evolution does not automatically mean progress. It is more likely that different aspects of a role take over in different phases of the project, and therefore there are different synergies/overlaps with different roles.

Roles & phases	Insight phase (2010)	Pre-, co-production (2011)	Delivery (2012)
Campaigners	Selecting community gatekeepers & making contacts; collecting data from communities; reporting to commissioners	Practical aspects: producing materials, recruiting participants, designing events	Focus on delivering: recruiting participants, involving gatekeepers, distributing materials
Community gatekeepers	Channels for initial contacts with communities	Channels for initial contacts with communities and sources of practical information for organizing events	Practical help to campaigners in organizing events; direct involvement in organizing & translating events and in delivering stroke awareness messages
Community members	Sources of knowledge for campaigners	Sources of knowledge for campaigners, expecting training	Targets for delivery

Table 5.5 Evolution over time of some "interface" role

Some common patterns emerge. Firstly, evolution of roles may or may not be predetermined. Some evolutions were scheduled: for example, the brief dictated that campaigners had to shift

from field researchers to co-producers of sessions and materials and finally to session presenters. Hence, this evolution responded to the internal logic of the campaign. A relevant number of role evolutions, however, happened mostly through iterative interactions between different actors, responding to evolving priorities and to the need of coping with unforeseen situations. For example, the role of campaigners evolved both according to the changing priorities of the commissioning board, and according to situations emerging in fieldwork (e.g., interest shown by communities in the campaign, more or less active role taken by gatekeepers, etc.). The decision of increasingly devolving the role of session organizers to community leaders was a reaction to practical difficulties met by the campaigners as outsiders in involving community members in initiatives. The expected evolution in the perception of community leaders as links between the NHS and communities for potential future events responded to a shift in focus of the new project board from the campaign-as-a-pilot to the campaign as an opportunity to establish links with communities for future health promotion.

However, role evolution happening through network interactions was not merely reactive, but was related to other factors as well. As an example, not all gatekeepers modified their role towards a direct involvement in delivering stroke awareness messages to the community. Such a decision was probably linked to the level of personal involvement in the campaign, their pre-existing experiences with stroke, their knowledge of the needs of the community, their understanding of the aims and objectives of the network carrying out the campaign, etc. In this case, such non-network factors were pre-conditions for a proactive role evolution.

5.2.4.1 Volunteering as an example of role evolution

Role evolution can be illustrated in connection with issues emerging about volunteering in the context of the campaign. Volunteering is best considered as a dimension added to the interpretation of a role by an actor, rather than as a role in itself. In fact, several actors interpreted their roles as "volunteers". However, the involvement of volunteers was not explicitly considered from the point of view of PCT commissioners or the Regional Network. This led to ambiguities, which in turn made some roles blurred or more complex, and/or caused them to evolve; volunteering was also occasionally the result of such an evolution.

First, the concept of volunteering implies both doing work for free and a willingness to spontaneously contribute to improving a social situation. A Somali community activist expresses the opposition:

> "This year I (…) took voluntary redundancy, so at the moment, I'm free of supporting whatever groups that I can work with on voluntary basis."

Community gatekeepers mainly acted as volunteers for the campaign, although on occasions they managed money for organizing events, or were involved as paid translators for materials and sessions. However, they volunteered for the campaign on several occasions as well – e.g. to organize events, distribute leaflets, recruit sessions participants.

Let us now compare the following statements from the field notes, referring to one community session.

> *"A participant asks [the campaigner] how much he is going to be paid for the session. [The campaigner] answers that he is actually volunteering, as he run out of budget time before."*

Here, volunteering is a consequence of inadequate budgeting, coupled with a genuine interest by the campaigner in doing work to help communities: in fact, in the last phase of the project campaigners worked longer hours than scheduled in the budget.

Finally, a similar dimension to volunteering was highlighted by organizational actors who did work that went beyond their established roles to move the project forward. A Regional Network interviewee, for example, says:

> *"On occasions I've stepped in and done things that (…) possibly shouldn't have done to move the project along."*

All these dimensions of volunteering are linked to flexibility, responsibility and trust[6]. A role can evolve to incorporate other roles during social interactions. This may happen as an actor tries to fulfil his/her initial expectations. Otherwise, one may start by being paid for work, but ends up undertaking part of it as a volunteer to maximize impact, for example. To summarize, role evolution during the campaign was only partly predictable. Sometimes it happened as scheduled. Other times it depended on a reactive approach to changing priorities and management styles. Still in other circumstances, it was linked with a proactive approach aimed at taking advantage of the possibility to improve community's stroke awareness. Once again, however, although role evolution had a considerable impact on the project, it only had local and limited effects. The effects were not generalized to the network as a whole, since the nature of the campaign as happening through a social network was not recognized.

5.2.5   Interpretation

Roles cannot be analysed in isolation. Dynamics related to roles in the CBHP campaign can only be understood in the context of network interactions, although non-network factors (values,

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[6] I will explore the link between volunteering and trust in section 7.2.3.

motivation, previous experiences, etc.) were relevant as well. As examples in the previous sections have shown, role understanding, overlaps and evolution were the effect of network interactions, and in turn contributed to modify the configuration of the network. Other factors contributed as well, such as level of control by management, priority of the project, management style, instability of the context and perceived "difference" of the target communities.

Firstly, actors in a role perceived themselves as endowed with certain functions; such self-perception may coincide to a degree with how actors in different roles perceived their role. However, there were always ambiguities and blurred boundaries for each role. Hence, significant misalignments in role perceptions may indicate criticalities or potentialities to explore in the evolution of the campaign. Secondly, roles overlapped with each other. This may indicate both the potential for synergies, and duplication of efforts and conflicts. A level of overlap between roles may be necessary for productive interactions to happen; significant overlap in critical roles may indicate serious issues. Finally, roles evolve over time, as actors interact in a network. The dynamics for role evolution may depend on project schedules, as much as on reactions to environmental changes and on proactive initiatives taken by actors.

The campaign, however, was not managed using a network point of view. Consequently, understanding, overlaps and evolution of roles were not managed in the context of a network. Their dynamics only produced local effects and could not be generalized to the whole network to improve the effectiveness of the campaign. In this context, network mechanisms did not produce self-regulation or optimization at a global level.

5.3 Construction of the ethnic identity of target communities through network interactions

In section 5.2 I studied how and why network interactions influenced single actors and the global network and what consequences they had on the campaign. Here I will inquire into the second essential dimension along which networks influenced the campaign: the construction of the ethnic dimension of the campaign target. This is relevant, because being an ethnic minority was not an objective fact. "Ethnicity" had different meanings for different actors. Furthermore, during social interactions, actors socially constructed meaning to reach specific goals: according to how ethnicity was emphasized, downplayed, simplified, etc. decisions were made, actions performed and outcomes generated.

The construction of the ethnic dimension of the target population starts with a brief produced by PCT commissioners, stating that stroke awareness needed to be raised "among deprived

and ethnic communities" and, more specifically, "communities that are known not to access services"[7]. Neither ethnic/cultural traits of interest for the campaign were specified in the brief, nor did any actor provide systematic definitions during the intervention. Exactly as roles had not been defined systematically or precisely, an operational definition of the ethnic dimension of the target population was missing. Therefore, it was unclear in what sense this specific stroke awareness campaign should be *different* from standard campaigns, aimed at the ethnic majority. My analysis revealed that several assumptions and perceptions about specific characteristics of those BME communities were developed through network interactions during the implementation of the campaign.

5.3.1 Language, word of mouth and community cohesion: perceptions of ethnic identity by different roles

Five roles offered most contributions to the construction of the ethnic identity of the target population. In the following subsections, I will outline how their network interactions contributed to define the specific ethnic dimension of the population, hence influencing the implementation and delivery of the campaign.

5.3.1.1 *PCT Commissioners and Regional Network*

In general, PCT commissioners and the Regional Network reported having some knowledge of ethnic communities, but they stress the limitations of the NHS in approaching them. They describe ethnic communities and the NHS as two different categories, with very crisp boundaries. For example, a Network member expected that the insight phase would produce

> *"new insight, new information about how these communities think, function, work together, [...] their beliefs, their value set".*

Such expectations concerned how cultural difference can influence stroke- (or health-) related behaviours in ethnic communities: barriers to service access, reason for specific modes of service usage, information utilization and sharing, "how they learn and how they transfer information and knowledge around their communities", communication habits. Practical information should then be used for further health promotion efforts directed towards similar targets: it's

> *"the nitty-gritty of what we've learnt by working with these communities that'll make a difference in terms of our approach and how we work with them in future"* (Regional Network member).

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[7] Bibliographic data of the brief cannot be cited as they contain names of commissioners and of organizations, thus compromising anonymization of results.

Therefore, commissioners and the Network shared some important initial assumptions and information needs about ethnicity. Firstly, based on either anecdotal evidence or statistical data, they perceived ethnic communities as different from the ethnic majority in access to services, health communication dynamics, etc. Moreover, communities were almost unknown – unknown because different, as well as different because unknown: a sort of "black box". Consequently, commissioners and the Regional Network wanted to know why they were different, and what to do in order to reach them: hence, campaigners needed to produce knowledge about a wide range of characteristics of ethnic communities. Such knowledge also had to be reported in a suitable form, to count as evidence for future health promotion initiatives aimed at similar ethnic communities. However, these broad and vague information needs left room for very different interpretations and constructions of ethnicity. Furthermore, the initial campaign brief provided no detailed description of qualitative methods for data collection or analysis. On one hand, practical, relevant and actionable knowledge was required; on the other hand, the brief contained no specific assumptions on the specific epistemological processes and methods that should be used to produce such knowledge. Campaigners elaborated on the initial stimulus provided by the campaign brief.

5.3.1.2 Campaigners

Campaigners collected data from the communities, according to the specifications contained in the brief. In the insight phase, campaigners held four focus groups with 24 participants overall, including Europeans, Asians and Africans, with a focus on Pakistanis and Yemenis. The main emerging themes included language problems (especially for newly arrived community members), difficulties with the interpretation of the FAST message (see section 2.2.1) and the fact that BME communities were "tightly knit". Moreover, "most of the [stroke] knowledge that people had was filtered down from other people or had spread through word of mouth", with the related problem of what the report defined "Chinese whispers"[8]. Finally, campaigners found a variable level of stroke knowledge, with the following barriers to immediate action in case of stroke: isolation, considering symptoms as transient and not serious, assumption that stroke only affects the elderly. Some of these themes are difficult to relate to any specific ethnic dimension. Others, like language, prevalence of word of mouth and tight community connections are difficult to attribute to specific ethnic groups, since participants came from very different ethnic backgrounds, the number of participants was low and data came only from short focus groups. Nonetheless, commissioners and the Network appreciated the insight report, both for the findings and for its qualitative methodology. Therefore, PCT

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[8] As for the brief, also bibliographic data of the report cannot be cited, as they contain names of commissioners, campaigners and organizations, thus compromising anonymization of results.

commissioners and Regional Network members uniformly considered the report as a good answer to their information needs.

A new iteration was necessary, however, since the project board decided that pre- and co-production phases needed to be more specifically focussed on the Yemeni, Somali and Pakistani communities. Consequently, the campaigners decided to collect more data from those three communities. Nonetheless, there was no significant change either in data collection methods or in the sample size. Further, no in-depth analysis was performed. As a result, initial assumptions about the importance of community languages, word of mouth and community cohesion were somewhat reinforced, although no further substantive evidence emerged from data – on occasions, even instances of conflicting evidence will emerge. Campaigners also tried to gauge stroke awareness of their sample of community members, and to collect practical information about strategies to promote stroke awareness within the target communities. Using the perceptions of ethnicity built until that point, campaigners moved to co-producing materials and co-designing sessions with a small sample of community gatekeepers and members of the same communities, and finally distributed materials and delivered stroke awareness events to Pakistani and Somali community members. Also during these last phases, construction of the ethnic identity of communities occurred within the context of the campaign. Hence, campaigners contributed to construct the ethnic identity on which the campaign was based, and acted according to such an identity, which was being built in several iterative network interactions.

As noted, identity was organized around three main themes – language, importance of personal communication and word of mouth, community cohesion. Campaigners perceived that language represented mostly a barrier: BMEs who could not properly speak and understand English would not benefit from stroke awareness information. Therefore, it was necessary to organize community stroke events and produce leaflets using languages spoken by community members. Translating stroke awareness information would be the main strategy adopted to ensure that the campaign could potentially reach every community member. Their perception was supported by data collected during pre- and co-production. In some sessions, there were participants with clear difficulties in understanding written and spoken English. Participants were also largely in favour of having sessions and leaflets translated in Urdu, Arabic and Somali. However, language was not only a barrier to overcome, but it may be considered an additional element of ethnic identity with a wider function – hence, a potential facilitator. In fact, communicating using a community language may open up further

possibilities for in-depth health promotion, using a different approach from translation. A community activist says, referring to a group of Somali women discussing about stroke:

"they're asking more, they were also explaining, expressing what they've been through, experienced the relatives dying of a stroke, friends or families and how they recognise so (…) they like to talk about it even more within (…) a group, because (…) when you interpret something for the community, the time is limited (…) but when they speak in their own language, they can express more, talk about more, ask questions about issues".

The example shows an important pattern in how network interactions have an impact on ethnicity construction and its practical consequences. Between the different possible dimensions of community language, campaigners focussed on the fact that it was a barrier, to overcome through translation. This happened because of the interplay between non-network-related factors and the network in which campaigners were involved. The former factors - vague, broad information requirements by commissioners, coupled with small financial resources and the need to "keep the project workable" (in the words of a campaigner) - led to focus on a limited number of ethnic characteristics without in-depth analysis. Network interactions reinforced such traits, and led to discarding possible alternatives.

The second aspect of the ethnic dimension perceived by campaigners was the importance of word of mouth and face-to-face communication in ethnic communities. The theme had a richer internal articulation. Firstly, according to a campaigner reporting his experiences of working with ethnic communities, although each individual might have his/her own small group of friends or acquaintances, such groups overlapped much more with each other, while ethnic majority networks are more segregated: "BME communities (…) once you do provide them with the knowledge, are natural communicators". He also referred to information sharing in the community as "an evolving flow of a discussion" which, once triggered on a topic, flows much more smoothly than in the ethnic majority. Verbal communication is therefore perceived as a characteristic of those communities, although it may well be shared with some segments of the ethnic majority, as another campaigner points out:

"although (…) [ethnic] communities (…) in [the city] (…) place a priority on verbal communication, there are some communities, and (…) older generations of (…) white British people as well, (…) that is still how they communicate actually".

The immediate, assumed consequence for the campaign was that – once you put health information in community networks, it would very soon spread to most of the community. The assumption is shared and reinforced by community gatekeepers and community members,

although with some important nuances and specifications which I will analyse in section 5.3.1.4. A related assumption is that BME communities heavily rely on personal stories to make sense of reality. According to a campaigner, "personal stories mean so much more to this community than anything else". This may however arise out of necessity more than desire, since older people in BME communities tend to have poor writing skills even in their own native language "although (…) the same can be said of older white British people", in the words of another campaigner. One of the PCT commissioners shared such a perception as well. I will show in section 5.3.1.3 that such an assumption was particularly important in shaping written stroke awareness materials. In the perception of campaigners, therefore, community information sharing is mainly verbal, flows naturally and its mechanism is a form of storytelling related to personal experience and opinions. In section 5.3.1.4 it will emerge that gatekeepers had a more nuanced perception of the topic.

The perceived enabling condition for this communication flow is community cohesion. Again, according to campaigners such a factor is related to communication more than to ideology, religion or social norms. In constructing the specific ethnic trait, campaigners relied on previous experience of work with ethnic communities and on interactions with the communities during the campaign. Hence, they selected the cultural traits, which seemed to promise a greater positive impact on the campaign. Noticeably, such traits were not – in themselves – positive or negative: they were interpreted as potentially positive, but it could have well been otherwise. For example, campaigners may have thought that verbal communication would promote what some interviewees referred to as "Chinese whispers", or the attitude of "natural communicators" would imply that small talk could overcome health information diffusion (see section 5.3.1.4). The selection mechanism shows the following pattern: an ethnic trait draws the attention of the observer; then, through successive network interactions, actors reinforce it and finally use it for performing concrete actions. In this case, between several possible ethnic traits, prevalence of verbal communication was linked by actors to reliance on stories and the image of community members as "natural communicators". These traits, in turn, become evidence on which campaigners and designers base the production of materials and events (see section 6.2.2.2). However, these are not simply decisions made by individuals according to their goals and agendas. The network is the environment where ethnicity-related information flows, hence its structure determines which actors and roles are involved, what information they share, and how.

The final selected ethnic trait was that, within a structured communication context, such as a session or event, BMEs communicate and behave differently from the ethnic majority.

Particularly some communities, such as the Somalis, show a "more relaxed attitude", according to a campaigner. He observes that they often speak all at once during sessions (although according to some kind of rules), tend to choose a spokesperson to communicate with outsiders and in general do not respect schedules. Time and dynamics inside a session are difficult to predict, thus requiring flexibility on the campaigners' side:

> "the ethnic communities (…) They're not as… English people particularly are quite rigid in their mode of communication. (…) some of the sessions (…) you might have 12 people talking at once (…) So you've got to be flexible, like they're flexible with how they communicate (…) otherwise we're not gonna get the information".

In this case, as well, it is difficult to establish whether usage of time and communication dynamics of community members may be rightfully established as a relevant ethnic trait. Surely, a contrast is patent. Campaigners, commissioners and designers, on one hand, work according to project plans, schedules and objectives. On the other hand, campaigners almost regularly met groups of community members coming late to meetings, talking to each other during sessions, and the like, and each new occurrence of such an attitude reinforced this "trait". However, several contextual factors that I will highlight in further sections may have contributed. These may include the fact that often gatekeepers recruited session participants on the spot, and therefore participants did not know exactly what to expect. Furthermore, they met in places where they regularly relaxed and had conversations with each other; finally, they had a low interest in the topic, or did not trust a stranger coming to their community, and so forth. There were also instances in which community members behaved in a much more "conventional" way during sessions. For example, they asked questions about "hard evidence" supporting a presenter's statements, or criticized the NHS because of specific facts and personal experiences. Additionally, community members on occasions also clearly analysed problems within the time available and produced practical, clear information on the organization of sessions and similar topics. In conclusion, data seem to support the claim that campaigners mainly constructed the ethnic dimension of the target community according to commissioners' expectations, time and resource constraints and perceptions arising during fieldwork, in a context of continuous network interactions.

5.3.1.3 Designers

Designers of leaflets and posters received the ethnic image of their target "market" from the campaigners. Consequently, they were sensitive to the importance of translating information in different languages and of the storytelling dimension of the leaflet, so that it could resonate with the storytelling attitude identified in the community by campaigners. The path followed

by the concept of storytelling through the network can therefore be traced. A perception of difference by commissioners/Network was specified by campaigners as a storytelling attitude, communicated to designers, and then fed back by designers in the form of a leaflet telling a story. When asked about her opinion on the leaflets, a PCT commissioner commented:

"there's something about it that tells the story in a different way and I think that's what it is that grabs me as being a good -, you can tell that it's been produced by the communities and I think that's important to hang onto because it's different, it's a different way".

In this case, therefore, the whole process was completed: from difference, to storytelling, to a story, to the story-dimension of the leaflet as a sign that the leaflets were perceived as positively different. Designers conceptualized communities as very "different" from their usual target markets. The chosen path was then related by actors to translation and simplification – concepts flowing through the network from campaigners to designers. Indeed, the whole co-production, as carried out by campaigners through the networks, implied the idea of translation, i.e. identifying scientific evidence and desired communication outcomes, then acquiring community views on how to perform the process, and finally, translating evidence and the communication process in a suitable form for the communities. As a result, when re-elaborated by designers, this translation/simplification process led to an emphasis on simplifying the message and avoiding usual inferences (related to shapes, colours, etc.) which could instead be valid for the ethnic majority. A designer comments:

"the use of shape and (…) of certain colours, (…) cross-culturally these things can have a big impact. (…) in China the colour red is a very lucky colour as opposed to certain other colours which are associated with death. So it's things like that, that you have to (…) be aware about".

In another instance, designers made efforts to keep design simple in response to a perceived "mysticism" possibly surrounding the approach to health and disease in BME communities, as opposed to a more rational approach in the ethnic majority. Further network patterns related to simplification will be analysed in section 6.3.1. On the other hand, designers also autonomously tried to conceptualize ethnicity – for example in the choice of combination of colours for different versions of the leaflet and poster. Designers then chose colours according to the national flag of the country of origin of each of the three communities. They assumed that the flag could be an important part of the identity of the ethnic groups – a more "theoretical approach" than the one of campaigners. Designers fed these concepts into the network, and the concepts contributed to development of materials: in this case, community

members did not express a particularly positive feedback when requested to, but campaigners decided to maintain the flag colours.

5.3.1.4 *Community gatekeepers*

Gatekeepers contributed to the network additional elements of the "picture" of ethnicity, and allowed to integrate or modify elements of this perception. In general, they shared the view that community members communicate effectively between each other, and once important health information is put in community networks, it will widely circulate. The community would consider information important if it touched a nerve, as it happened for stroke. However, gatekeepers often insisted on the internal articulation of the community according to age groups, religious orientation, gender, etc. Instead, such internal community articulation did not clearly emerge in the perception of commissioners/Network and – to a degree – of campaigners. Firstly, gatekeepers emphasized that some segments of the community are better at communicating: women would be more active in health information diffusion within their networks of acquaintances. The perception was uniform, although in the Pakistani community women were a particularly difficult group to access for campaigners. Secondly, the fact that the community is tightly linked often hides several internal lines of segmentation, which could well represent barriers to diffusion of health information. For example, gatekeepers represented the community as divided between a few keen activists and a vast majority of people difficult to involve. They also mentioned different religious opinions and presence of clans, able to hinder information diffusion. Furthermore, several gatekeepers underlined the divide between younger and older generations in terms of attitudes towards health and community cohesion. Noticeably, the campaigners were aware of such a possible segmentation as well, although it did not produce effects on the deliverables of the project. In this case, therefore, although gatekeepers fed important segmentation information into the network, it failed to produce results. In fact, campaigners could not use this information to differentiate campaign materials for different segments of the communities, because of time constraints and their approach to materials' production. This reveals an additional pattern: not all information or resources fed into the network are used, especially if they encounter barriers in the agendas and approach of key actors.

According to gatekeepers, another relevant cleavage within the community was related to job status: being jobless might negatively influence health attitudes and receptivity to health promotion messages. As for the contents of communication, a gatekeeper pointed out that small talk is often mixed in to health-related conversations. Therefore, information diffusion within a community of "natural communicators" could meet barriers (section 5.3.1.2), since

the message could be distorted and diluted within small talk. Mistrust of political initiatives also contributed a further element to the picture: gatekeepers on occasions mentioned that it was difficult to involve community members in health promotion since the community felt betrayed by past projects failing to deliver what community members had expected. Campaigners acknowledged such an attitude of ethnic communities as well, since they were aware of problems related to raising expectations in the community and not being able to satisfy them. They also fed back into the network such information to commissioners and Regional Network members, although, within the time frame of the campaign, this did not produce results. Finally, several Somali gatekeepers mentioned the existence of social practices such as chewing khat. Khat houses were identified both as elements of ethnic identity and as hubs for information circulation and exchange. However, gatekeepers mentioned the cultural trait too late in the campaign for the campaigners to profit from it in terms of organizing events or distribution activities. This draws attention to the fact that the timing of *when* information is fed into a network is crucial for its effective utilization – i.e. an ethnic trait not considered when campaign materials are being developed is unlikely to have an impact on the campaign.

5.3.1.5   Community members

The data I collected hardly contain any explicit reflections by community members on the meaning of their ethnicity. Therefore, the analysis of how they enact their own ethnicity comes mainly from my observations. During pre- and co-production sessions they stressed the importance of mosques for health information diffusion, thus adding a religious element to the picture of ethnic identity. They also uniformly considered women as more active in diffusion of information in the community, and community itself as a place where information easily circulates face-to-face. During observations in community venues, my impression was confirmed as many community members spent time talking and discussing on the streets and squares in their neighbourhoods, and gatekeepers frequently recruited potential session participants by contacting them in the streets. In addition, community members frequently reported basing their knowledge of stroke on personal experience, and often referred to personal stories about relatives or friends with stroke, thus reinforcing the campaigners' perception that personal stories are important in communication in an ethnic community. In addition, during sessions there were several instances of continuous flow of discussion with several participants talking at once. As for language, during the observed sessions there were several occasions when community members spoke Yemeni, Somali or Urdu languages with each other. However, this seemed to have different meanings according to specific actors and contexts. In some cases, speaking community languages was perhaps the only option for

people not particularly proficient with English; others, however, were equally skilled in both languages, and spoke Somali with other community members and English with the campaigners. In the second case, it was a specific choice to speak a community language, and the consequence was often to mark a cultural difference between insiders and outsiders. This happened especially in topic moments during sessions, e.g. questionnaire completion, or when the topics of the session were interesting for the community. On other occasions, however, community members used community language when they were not interested in the session, and seemed to mark their non-involvement by speaking to each other in a language that outsiders could not understand.

Such a use of language as related to cultural difference may reinforce the insight expressed by a community leader concerning the link between speaking a community language and the effective circulation of a health promotion message, as opposed to translation (see section 5.3.1.2). Moreover, on occasions, members of the Pakistani community expressed the view that an Urdu translation was unnecessary, since most Pakistanis understood English very well.

In the limited number of observed settings and contexts, I understood that community members selectively enacted their ethnic identity. There were circumstances when some traits became apparent – the use of language and the sustained importance of face-to-face communication during the campaign. However, the same dimensions proved less important in other contexts, while still other traits emerged but campaigners could not use them effectively– as it happened for religion or gender difference. Occasionally, community members seemed to be keen to emphasize difference through language or communication. In other circumstances, however, community members did not want to represent themselves as an ethnic minority – for example, by highlighting that stroke awareness should not be promoted only in ethnic communities but for the whole population, or by noticing that in a given community the level of English knowledge is so good that translation of health promotion materials is unnecessary. This seems to confirm that ethnicity is a construction happening through network interactions, carried out not only by outsiders (campaigners, designers, commissioners/Network), but also by community members. However, the assumption of ethnic difference was one of the basic background elements of the campaign. When involved in the network (through co-production, final sessions, distribution initiatives, etc.) community members knew they had been involved exactly as members of an ethnic minority. An "external" social entity had categorized them as a minority – although with the aim to promote health adopting a co-production approach. This had a clear effect on network dynamics: questions asked by campaigners were based on their own perception of the ethnic

identity. Group members reacted by either confirming or challenging such an identity, but generally remained within the limits of the categorization. It should also be considered that network interactions between community members and campaigners were superficial and generally brief, hence not representing ideal conditions for challenging stereotypes.

5.3.2 Impact of the network on ethnicity construction

Table 5.6 summarizes the main contributions of single roles to the construction of the ethnic identity of the campaign target.

Role	Perceptions of ethnic identity
PCT commissioners	Perceived difference and clear separation from ethnic majority; unknown difference and unclear reasons for difference
Campaigners	Difference in language, problems with English as barriers to overcome; tightly-knit communities; importance of word of mouth and personal stories; ethnic community members are natural communicators; BMEs communicate flexibly and informally, often talking all at once
Designers	Importance of national flag and culturally recognizable colours; mysticism of BMEs concerning health and disease
Community gatekeepers	Active role of women; lines of segmentation in the community (clans, gender, age, job status); word of mouth, community cohesion; mistrust of political initiatives; social practices (e.g.: chewing khat)
Community members	Speaking community language as a choice; face to face communication; personal stories; importance of mosques; active role of women

Table 5.6 Main contributions of each role to the construction of ethnic identity of the target population

As seen, however, such elements did not emerge in sequence, nor were isolated from each other. Their emergence followed a temporal line, but they consolidated images of ethnic identity through repeated interactions. Figure 5.5 shows the main sequence of network interactions that contributed to construct ethnic identity. An initial represents roles: "C" stands

for campaigners, "D" for designers, "G" for community gatekeepers, "M" for community members and "N" for commissioners/Network.
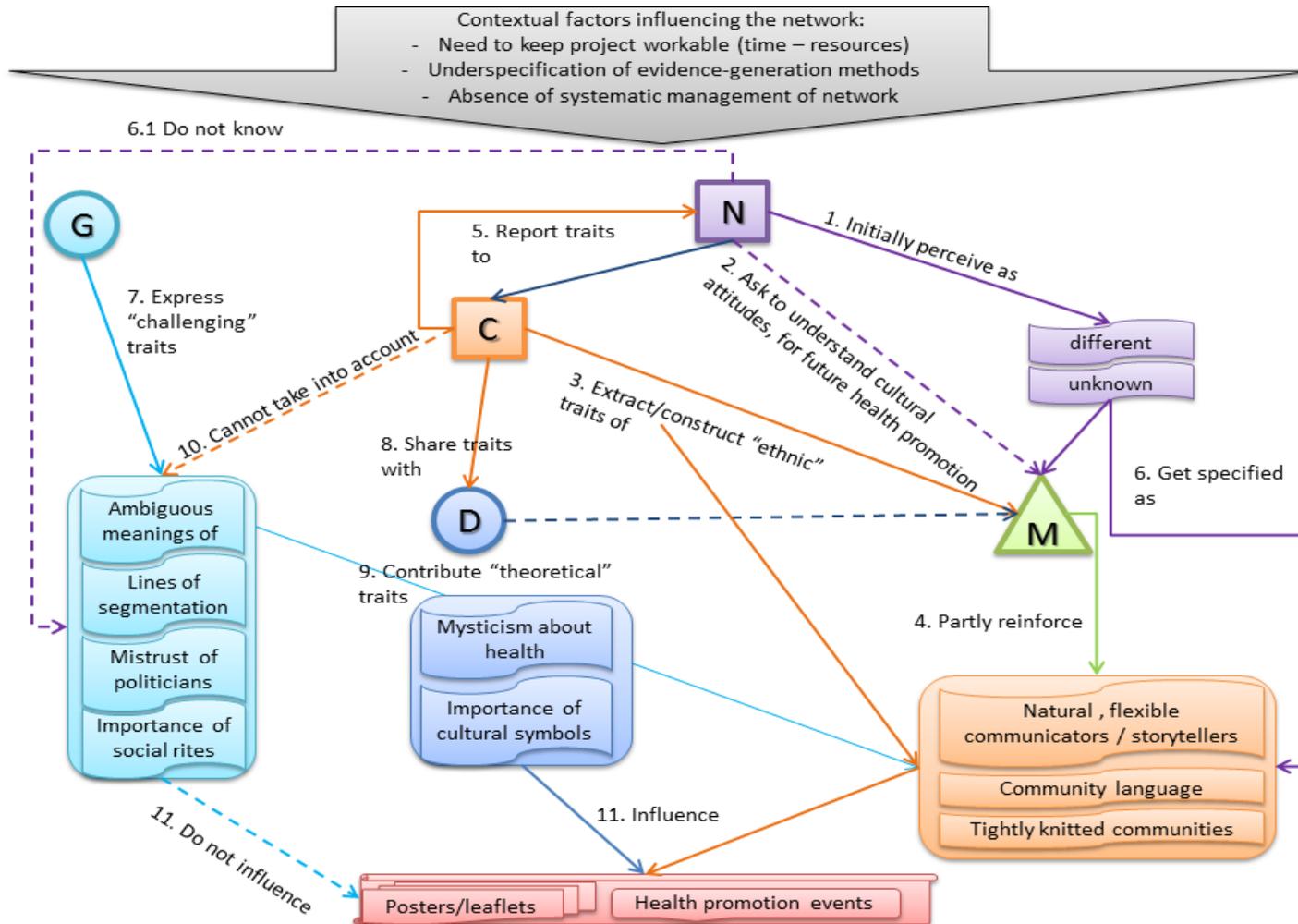
Figure 5.5 Sequence of network interactions influencing ethnicity construction

As noted in section 5.3.1, the network was a selection mechanism for cultural traits, together with non-network influences (outlined in the grey arrow in the top of the figure). Not all relevant cultural traits emerged during the pre- and co-production phase of the campaign. In addition, campaigners selected and interpreted some traits emerging in these phases partly according to their objectives. The whole selection process was not systematic, and some traits were not taken into account by either campaigners or designers, partly because they emerged only later, when I conducted interviews and analysed data.

Through this non-systematic process, ethnic identity was constructed by actors through iterative interactions, without any global management of these activities. Consequently, actors did not produce any general agreement on ethnic traits during interactions, nor did a shared reality emerge. As outlined also for section 5.2, due to the lack of "network management", there were different representations of ethnic identity in different points of the network. Local "solutions" were difficult to generalize and to understand systematically by actors in the networks. I, as a "neutral" researcher, was the only one who could reach a global view of the network, unlike any of the actors. Consequently, network interactions represented the only means to co-construct ethnic identity and use it for campaign implementation. However, the network was only partially and locally effective in reaching these goals.

5.4 Networks and the temporary emergence of the campaign in the social space of the community

So far, I have examined how actors used networks to make sense of roles, how such roles overlapped and evolved during network interactions, and how interacting actors co-constructed ethnic identity through a process of selection and reinforcement of ethnic traits. The third main theme was the contested emergence of the campaign as a temporary space within the wider boundaries of the community. In particular, I previously referred to local sense-making and local perspectives of actors in the context of a network. Here I will examine how actors used networks to make sense of "local" contexts and how, through their interactions, the campaign emerged in the community in the intermittent form of specific events. In particular, the campaign operated during relatively short time phases, interspersed with sometimes long intervals, and in specific places (mainly community venues). It is even questionable whether the campaign can be described as a whole, or instead as a series of interconnected but not necessarily continuous events. Consequently, this section analyses how the campaign managed to create its own space inside the wider social space of the community, through network interactions.

5.4.1 Qualitative network analysis of space sharing in the campaign

Ethnic communities are social spaces, i.e. physical and geographical locations where social interactions take place. Therefore, at the most basic level, network interactions happened in a specific place, which both constrained and enabled them. More precisely, the sum of interactions that produced the campaign happened in several, different spaces, geographically separated and with diverse functions. Observed or reported interactions between campaigners and PCT commissioners or Regional Network members mainly happened in NHS offices; campaigners and community gatekeepers met either in community venues (community centres, mosques, libraries, pharmacies etc.) or – much less frequently – in the campaigners' offices. Campaigners and community members usually met in community venues. A part of interactions happened either by email (mainly between campaigners and PCT commissioners or Regional Network) or on the phone (mainly between campaigners and community gatekeepers or PCT commissioners / Regional Network) – therefore not in a physical space, but in a (temporarily shared) virtual space.

The following network diagrams summarize the main interactions between roles, related to sharing a physical or virtual interaction space. I displayed roles as coloured nodes. Green represents community-roles, blue organizational ones. I did not include my role, as a non-participant observer. Edges (bidirectional arrows) show interaction between actors that I judged significant in a shared space during the campaign. Diagrams do not represent the duration or frequency of interactions, nor the campaign phase when they happened. Figure 5.6 shows roles interacting in community venues.
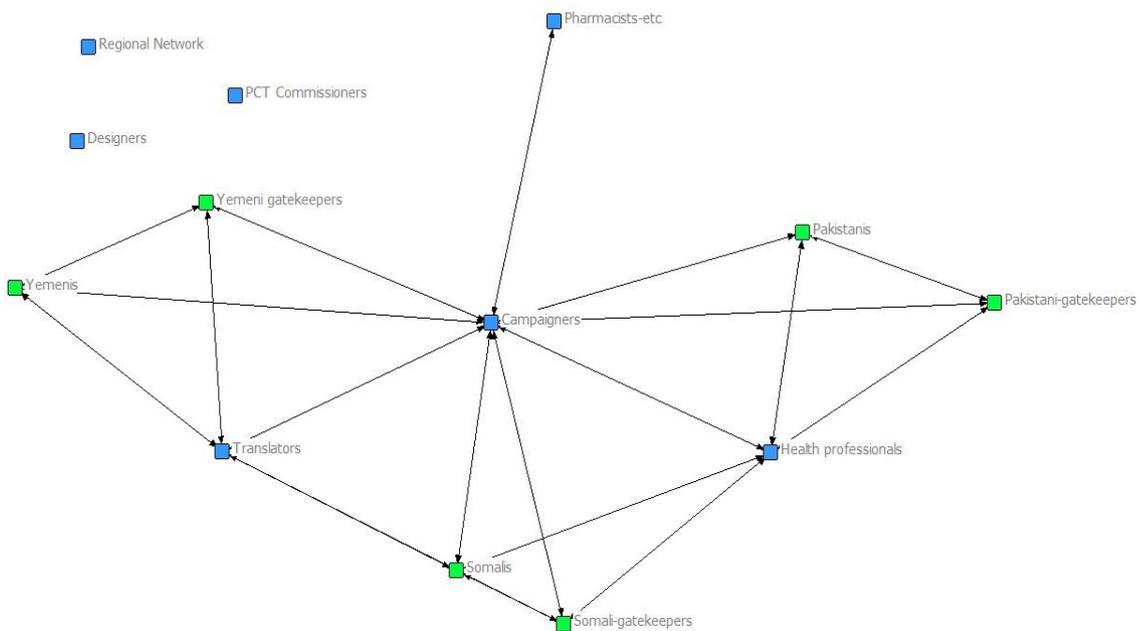
Figure 5.6 Roles interacting in community venues

Interactions in community venues concerned mainly campaigners (sometimes with health professionals and translators) with one community at a time. During both development and delivery, the campaign materialized a series of events localized in separate spaces, each belonging to a different community: communities did not generally establish contacts with each other during the campaign. Campaigners were clearly central between those distinct spaces, although they did not connect them directly – they could not put into practice their potential "bridge" role. Neither PCT commissioners nor Regional Network members ever interacted in a shared spatial context with community members or gatekeepers.

Figure 5.7 shows how actors with different roles interacted with each other using offices (either NHS or campaigners') as spatial contexts for interactions.
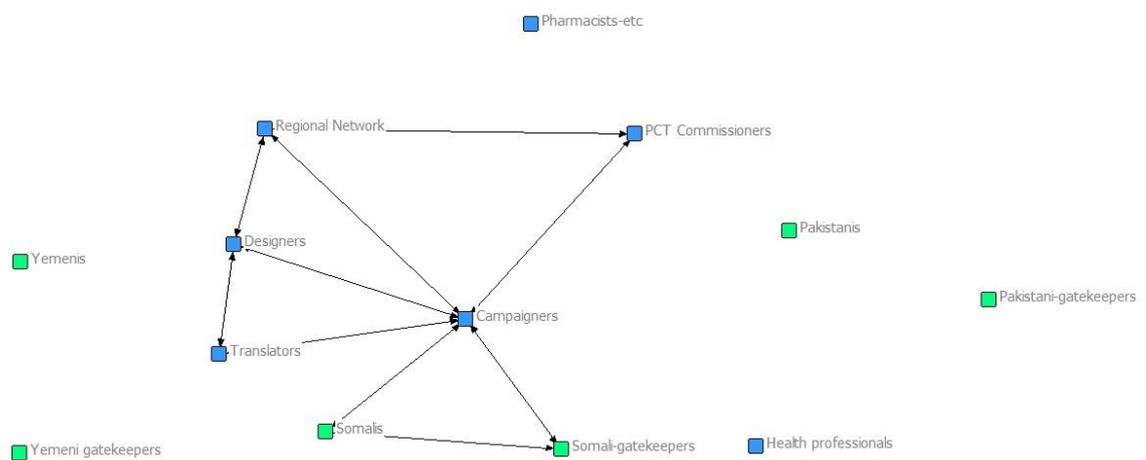
Figure 5.7 Roles interacting in offices

This figure is nearly the reverse of the previous one. Interactions in offices mainly concern organizational actors (with only one exception). Again, campaigners were the central node between all these spaces. Spaces where campaign organizers met to monitor progress, exchange ideas and evaluations or make decisions, were almost completely separate from the spaces in which the actions of the campaign took place.

In Figure 5.8, I show roles interacting in virtual spaces (phone or email).
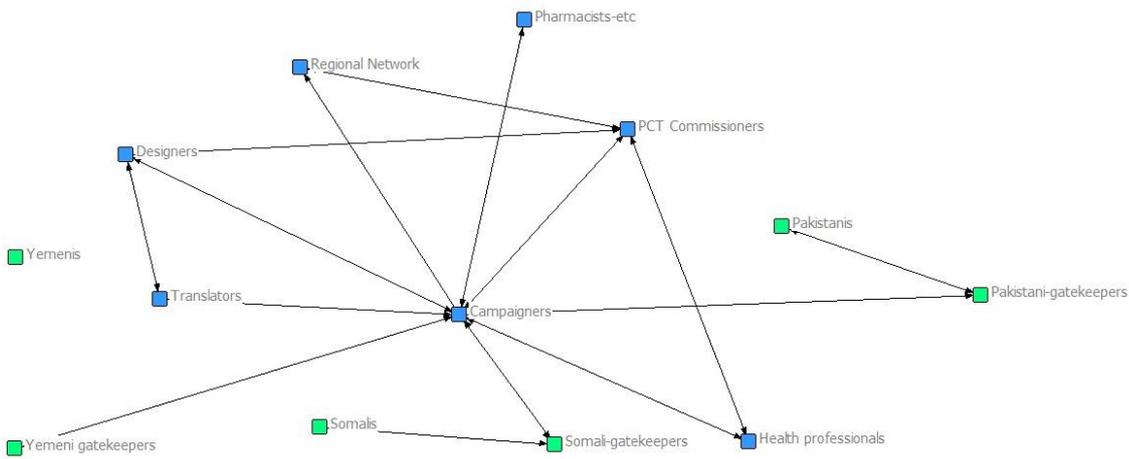
Figure 5.8 Roles interacting by phone or email

Interactions via phone or email were slightly more distributed across the network. Again, however, campaigners acted as a central point between distinct spaces, and no shared space emerged between roles.

Figure 5.9 maps all the interactions, happening in at least one of the three spaces identified.
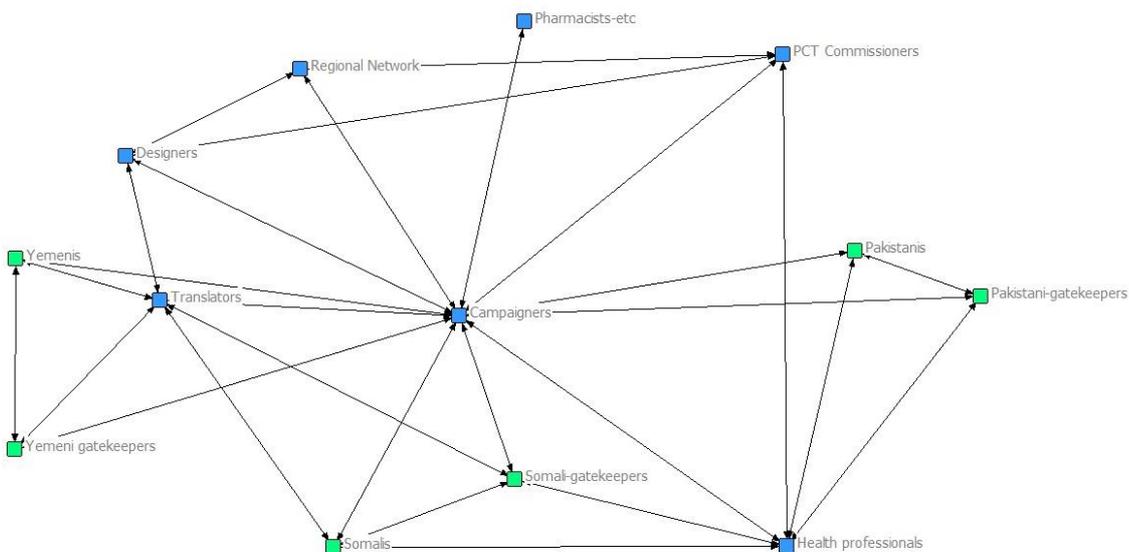
Figure 5.9 Roles interacting in at least one of the spaces

Organizational actors shared spaces mainly during one-to-one interactions with the campaigners. Interactions between communities and organizers were limited to individual community venues and happened through the intermediation of campaigners, translators, health professionals. No direct contact by means of shared spaces happened between different communities. Finally, Figure 5.10 shows how the spatial dimension of the campaign looks like without the role of campaigners – that is, if the main potential "bridge" is removed.
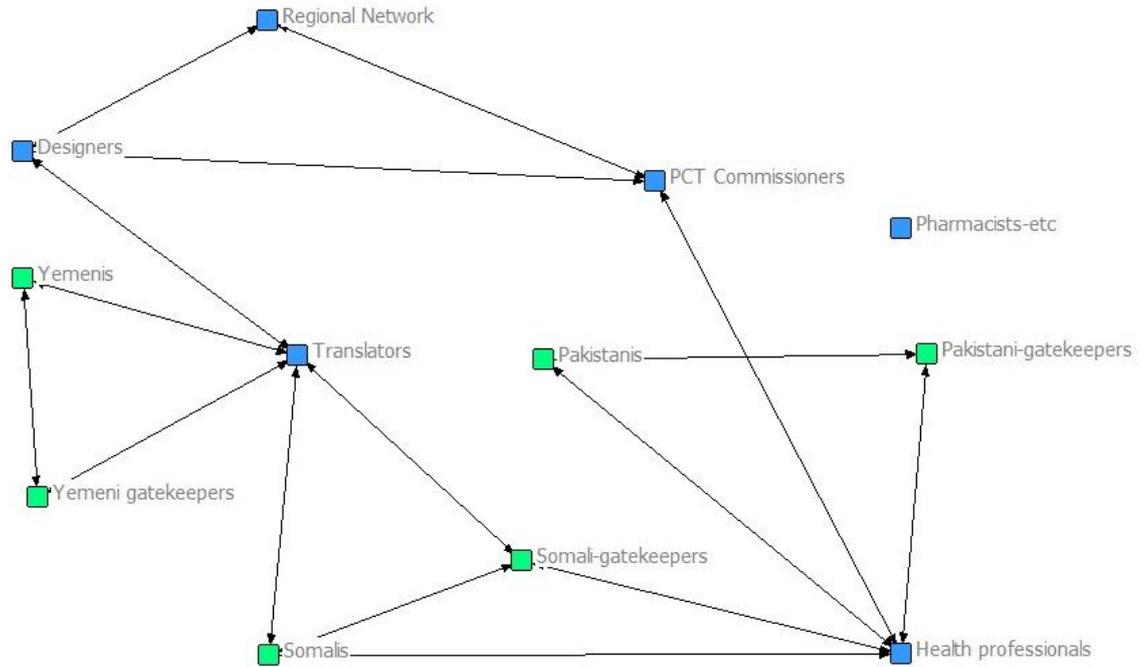
Figure 5.10 The campaign without campaigners: roles directly sharing spaces with each other, excluding campaigners

The three target communities did not interact with each other at all during the campaign. Only campaigners, translators and a health professional had contacts with more than one community. This confirms that there may be concerns about the sustainability of the project without the direct involvement of the campaigners.

5.4.2 Spaces and places: a qualitative analysis

Structural analysis of the spatial context of the campaign displays it as a series of semi-connected spaces, without strong interactions or continuity with each other. Hence, campaigners implemented the intervention in relatively isolated social spaces, without a marked continuity. Having defined the boundaries of the social space where the interactions happened, it is important to understand how actors perceived and constructed the qualities and meanings of the campaign as a specific, networked space. Firstly, community venues were widely perceived as important network hubs by community members. Such venues include community centres, mosques, informal meeting points such as cafes and restaurants and other shops, and the neighbourhoods' central streets and squares themselves, where community members often meet and discuss. The campaign took place also in pharmacies, GP surgeries and local libraries, which – although not specifically focussed on BMEs – were targeted by campaigners as venues for distributing stroke awareness leaflets and posters. These venues were locations where people acted (either agreeing or conflicting) according to rules, co-

constructed meanings and referred to partially shared values. As such, every typology of community space has particular characteristics, related to functions (a mosque serves a different purpose from a library or a GP surgery), roles involved and local culture. All this influenced how actors perceived and enacted the campaign.

A first common characteristic of community places influencing the campaign is their multi-functionality. Such places were either intrinsically multi-functional, or were used for a different function than usual. Obviously, no place exists in a community specifically aimed at discussions or events about health promotion. However, the fact that community members routinely used those places for different purposes had an important impact on the interactions. For example, community centres specifically exist to meet and exchange information, establish relationships, obtaining advice, etc. However, some gatekeepers and community members were particularly familiar with community centres – for example people regularly attending for playing cards, going to lunch clubs or discussion groups, etc. During observed sessions, those people generally kept on carrying out some of the "usual" activities: for example, they left in the middle of a session to brew coffee or tea, started discussions with each other about the news, left to greet a friend who had just arrived, etc. This behaviour may also have other motivations – e.g. not being interested in the content of the session. However, holding campaign events in community centres on the assumption that participants feel more comfortable may lead to "adverse effects" linked with an excess of familiarity with a place. Participants' behavioural dynamics were similar in mosques and cafes/restaurants: participants often kept on attending a place in the same usual way, and paid only peripheral attention to the health promotion event or the co-production session. Furthermore, community places were sometimes self-referential. By this, I mean I frequently observed that organizing co-production sessions in a community centre often resulted in participants suggesting the involvement of the centre itself and its regular attendants in final events and delivery of materials to communities. Hence, the portion of community considered relevant by participants seemed to coincide with the boundaries of the centre and the people attending it or being in contact with it. As evident from other sections, then, selecting a community place for developing the campaign may have important implications for the networks of people that can or cannot be reached when the campaign is delivered. One of the campaigners also confirmed this:

"I'm not (…) under any illusions that we've even probably reached 10 or 20% of the networks that exist, because… […] even […] if you went and lived with a Somali family in [the city], they would only have a certain number of networks that another Somali

family in [the city] would have, a totally different set of networks, […] their paths might never cross".

It seems, then, that the routine logic of the place – (its traditions, functions, culture) – through the mechanisms of multi-functionality and self-referentiality influenced the level of attention of participants and the selection of venues and participants for further health promotion activities. This happened to a lesser extent when community gatekeepers were more involved in organizing and carrying out the sessions, and consequently helped modify the logics of the place to help the campaign find its way to the participants, who were in turn more active. However, as noted in section 5.2.3, the intervention of gatekeepers was in turn never neutral towards session contents and participants behaviour. Something similar happened in pharmacies, libraries and GP practices as well with campaign materials (see end of section). Space was therefore never a neutral container. For example, materials' co-production and final events took place in "institutional" settings - community centres, community associations. Thus, both participants and campaigners had to go through several formal and informal levels and contexts, if they wanted to activate a rich and two-way communication. For example, campaigners had to understand the roles and attitudes towards the campaign of leaders of community centres, to adapt to a place either unknown or routinely used for different aims, to gauge how formal or informal the level of communication needed to be, etc. On the other hand, participants also needed to adapt to a different usage of space, understand the campaigners' objectives, become acquainted with their language, and the like.

5.4.2.1   *Making sense of the community space*

In general, boundaries and rules of a specific space represented constraints or limits within which the campaign struggled to emerge and reach its objectives. Even when the campaign succeeded, it can still be conceptualized as a relatively abstract "temporary space" with external actors and idiosyncratic rules, tending to disappear or lose momentum as soon as participants and campaigners left the venue. However, its existence may well continue in different forms – e.g. in occasional discussions in other community venues, as I will describe. Figure 5.11 summarizes the main dimensions of the interaction between community places and the campaign.
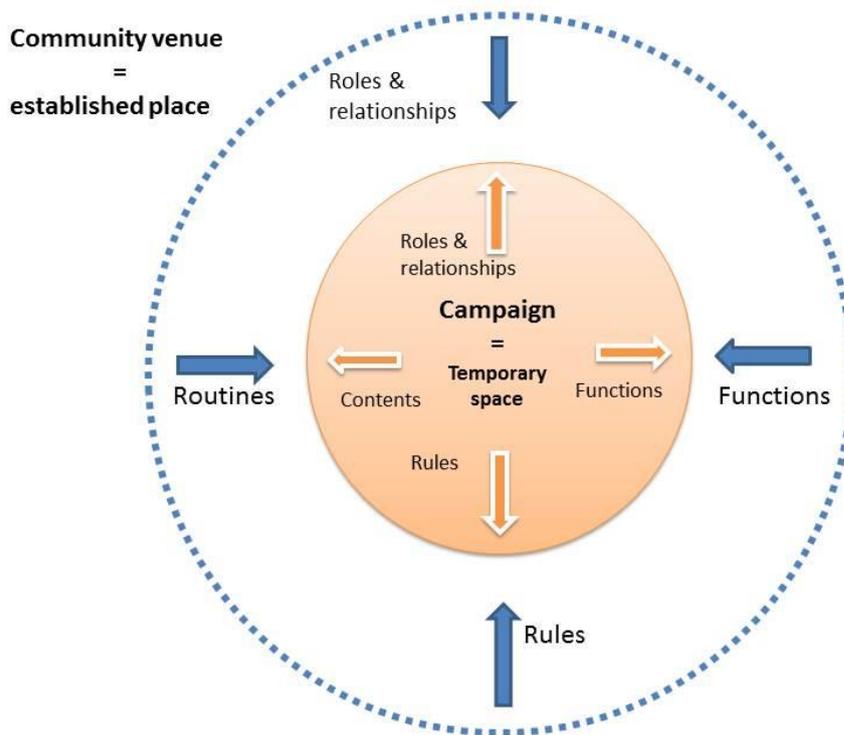
Figure 5.11 Interaction between community places and the campaign

The boundaries of this social space are somewhat "porous" and open: the space is multifunctional, it extends its influence beyond the physical space, and the membership is non-exclusive. However, although flexible, it exerts a considerable influence on anything happening inside its boundaries. By contrast, the campaign is a temporary space with crisp boundaries, whose internal logic struggles to emerge within the constraints of the host space. Community space has both a physical and a social dimension. For example, looking at the picture, it may be easy to understand the origin of a feeling of "us" and "them" arising during sessions, with community members on one side (experiencing a familiar place with established rules) and campaigners as outsiders on the other side (the campaign-space with tight schedules, crisp boundaries and explicit outcomes). By extension, the metaphor of the campaign struggling to emerge within a constraining environment may well apply beyond the limits of individual community venues, and be extended to the presence of the campaign as an "object" with precise boundaries within the wider and more vague boundaries of a whole ethnic community.

Firstly, it emerged from the observations that campaigners needed to make sense of the communities as a geographical space, both to distribute effectively leaflets and posters in relevant community venues, and to establish contacts and become acquainted with important

gatekeepers. A gatekeeper referred to this specific activity as "legwork", and he deemed it necessary to involve community members in health promotion initiatives:

> "once they're here, they enjoy and once they're here they benefit from the sessions, but there's a lot of legwork involved and a lot of reminders as well".

A campaigner expressed the importance of working in the field, visiting community venues and becoming familiar with places, when he commented during the distribution that it was far better simply to drive through the neighbourhoods, visit pharmacies and GP practices than drawing maps based on websites or wait to establish contacts through commissioners. In fact, a frequently observed dynamic was that campaigners tried repeatedly to establish contact with community groups, networks and organizations through the NHS or other organizational contacts from PCT commissioners. However, either no answer came from the NHS, or contacts did not lead to anything relevant during the campaign. Then, the campaigners went directly to community venues and tried to establish contacts directly. Such attempts tended to be more fruitful when supported by local gatekeepers (see Chapter 7). The feeling of the complex articulation of community space emerged when one campaigner commented, during the distribution of leaflets and posters:

> "just only to map all these [BME-related, community] networks which do not meet each other would be a very big project in itself".

This comment highlights another characteristic of the community space, as perceived by campaigners: its internal segmentation and compartmentalization. In the space of an ethnic community, several health-related initiatives happen simultaneously, often implemented by different organizations, with specific functions, objectives, strategies and style. Such networks may occasionally intersect each other, but seemed very difficult to coordinate and integrate, during the intervention. For instance, during the distribution of materials, two pharmacists asked the campaigners if the stroke awareness initiative was related with other PCT campaigns involving pharmacies. The fact that it was not, in the opinion of one pharmacist, explains why, in her pharmacy, both venue gatekeepers and the public perceived campaign materials as "just one between many things". Furthermore, campaigners established contacts with health champions and health trainers' coordinators, but it was not possible to integrate the campaign in their routine activities, since this would have taken too long. In fact, there were funding issues related to health champions, and they already had several scheduled activities, often linked to community centres. Therefore, as far as health promotion is concerned, several different, intersecting networks of actors populated community space, each with its own

agendas and priorities. As a further example, the co-presence of several health promotion activities in the community was clearly visible by the huge number of health promotion leaflets and posters in pharmacies and GP venues. Figure 5.12 and Figure 5.13 help visualizing an instance of this issue.

Figure 5.12 The campaign leaflet (marked in red) displayed alongside other health promotion leaflets in a GP surgery
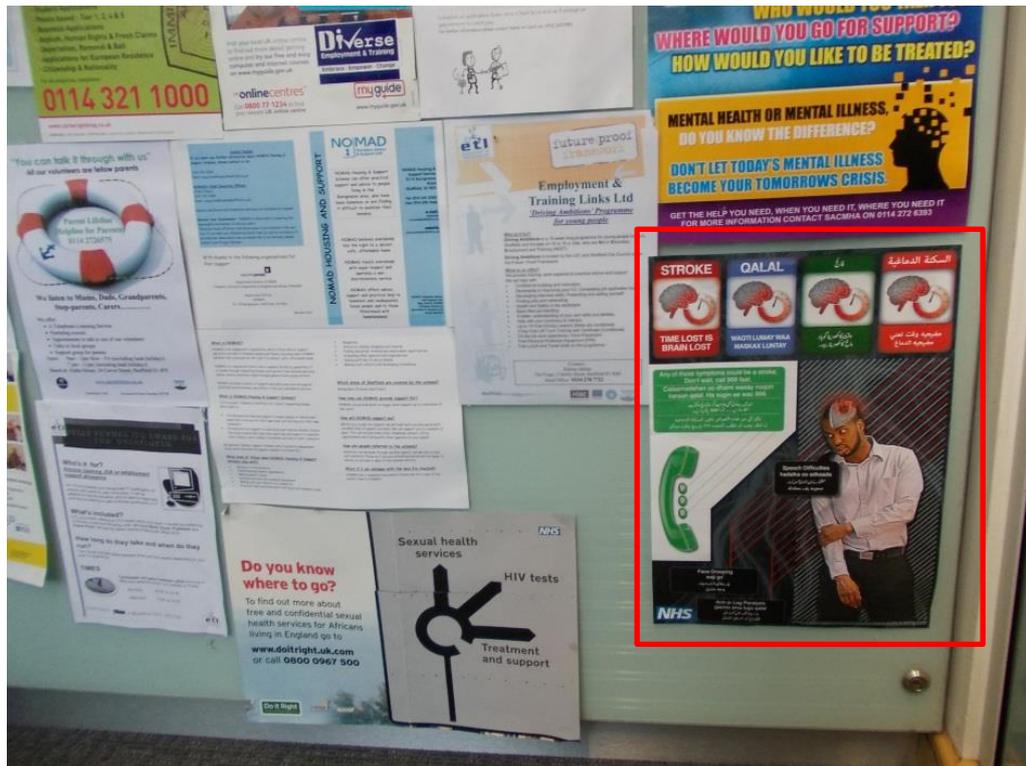
Figure 5.13 The campaign poster (marked in red) displayed alongside other health promotion posters in a GP surgery

In the context of the distribution, the pictures portray a relatively "good" example of materials displayed in community venues. In some other instances, materials were never displayed, and in one extreme case, the following interaction took place, which I report entirely from my field notes. In a GP surgery

"I notice that no leaflets have been displayed [after being distributed by campaigners two weeks before], [...]. I therefore ask the receptionist whether the leaflets had been displayed or not, but she does not seem to understand to which leaflets I am referring. We then both go round the practice, and she shows me two different leaflets about stroke (!), different from the ones of the campaign. One even has a face on, which corresponds to my description of the leaflets I was looking for!"

Figure 5.12 and Figure 5.13 show that campaign materials "struggle" to compete with several other similar materials, produced by different organizations. This may also represent the general situation of the campaign, competing against other similar initiatives within community spaces. Figure 5.14 portrays the competition and coexistence within a segmented community space between the campaign and other initiatives.
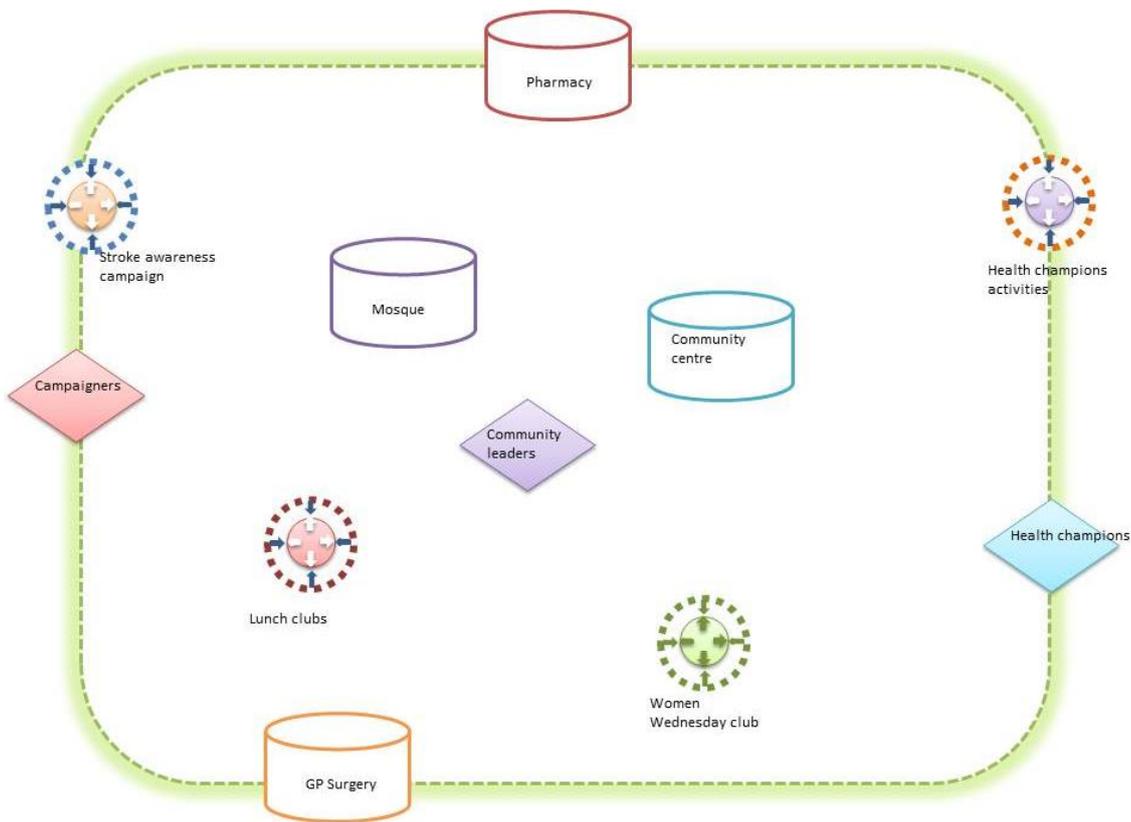
Figure 5.14 A simplified snapshot of the social space related to health promotion in a BME community

I have considerably simplified the structure of community space represented in Figure 5.14, by reducing the number of elements. However, I based the diagram on observations and interviews concerning the Somali and Pakistani communities. I represented the community space by a dotted line, since its boundaries are open and flexible: it is sometimes difficult to know whether an actor or activity is entirely located in a community space. Section 5.3 also showed that perceptions and self-perceptions of community boundaries are flexible and subjective, and vary with the perspectives of different actors. I portrayed example venues as containers; they refer to both physical and social spaces. Such venues may be more or less central to the community; some of them (e.g. GP practices and pharmacies) cross community boundaries, since they are not specifically targeted at community members. Some groups of actors (i.e. campaigners and health champions) occupy a similar peripheral position, while others are more central to the community (i.e. community leaders). In the same space, a series of health promotion activities are targeting the community: again, some are more exclusively aimed at community members, while others have a wider scope. This complex network of groups, venues and activities may be an acceptable approximation to the social space of the community. Between those roles, networks, venues and activities, complex forces exist, potentially promoting competition, integration or mutual indifference. Each of these elements is part of a complex environment, constantly modified by interactions at the local level. The

campaign was part of the network of interactions in a social space, and its main characteristics related both to its internal content and objectives, and to how it adapted to the external system of forces operating in such a space. I will describe concrete dynamics of adaptation in the sections about evidence translation, involvement, judgements and decision making.

5.4.3   Time perceptions and the places

"We now need to be equipping other people who have already got other existing communication channels, so that the message can come from all over the place and it becomes a normal message to be seen […] within those communities" (A campaigner).

"If we [had] done more -, if we had more time, we'd have got more people involved […] get all the gatekeepers involved as a stakeholder group and then ask them to roll the campaign in different places with different communities across the city […] focus in the Somali community as a whole across the city" (A community gatekeeper).

According to these two data extracts, both campaigners and gatekeepers had the clear objective of saturating community networks so that almost everyone received the message and stroke awareness could be sustained over time. Although campaigners and gatekeepers were also aware that this was not possible during the campaign, they thought the social space of the community needed to be "filled" by a pervasive stroke awareness message, and that fulfilling such an objective would need time. In fact, time was a key contextual element for the campaign. For example, delays affected campaign implementation, and had negative impact on the recruitment of participants. More generally, the intervention was not developed and delivered with a gradual and steady progression over time: there were very active but short phases, with sometimes long intervals when nothing happened. Hence, the campaign "happened" in a semi-connected space as much as it showed an intermittent intensity over time. My overall perception was based both on particular instances of data (organization of sessions, interactions between participants, etc.) and on a more holistic picture gradually forming. I felt that the campaign really "existed" only when networks were activated in specific moments of time; in other moments, the campaign seemed to be paused or temporarily inactive.

At a micro-level, perceptions and usage of time had a relevant impact in the context of individual sessions. Meetings and events needed to fit within the daily activities of community members. It was particularly important to avoid prayer times, for example, or late afternoon when parents had to fetch children from school, etc. In other instances, community sessions were organized within the time frame of routine activities, such as meetings, lunch clubs, etc. – again, imposing a constraint on the duration of sessions and consequently on communication

styles and the articulation of contents. As for the final events, for example, all actors involved agreed that available time was too short. Although campaigners could communicate the basics of stroke awareness, there was often no opportunity to ask further questions and sustain two-way communication between participants and campaigners. On a related note, as described in section 6.3 and Chapter 7, on occasions community members and gatekeepers raised and spread again the campaign message. For example, Somali community activists went to khat houses and other community venues to talk informally about stroke to community members not previously involved, thus reaching different points of the community network. From this point of view, figures presented in the previous section illustrate static snapshots of the campaign at a given moment in time. The campaign was indeed a process happening in, and shaped by a social space. Therefore, space and time were both inherent factors operating in the campaign, from the most abstract to the most concrete levels.

As a conclusion, within the period in which I could collect data, the linear progression of time in the campaign was not the norm: for example, networks had to be re-activated and relationships rebuilt several times. Therefore, I characterize the campaign as a temporary space, activated and inhabited only at specific, intermittent times. While the community social space was perceived as more permanent, and with relatively stable rules and recognizable patterns of interaction, the campaign struggled to affirm its existence, since it brought different rules, a different message, and proposed a different usage of familiar spaces and times. Moreover, sustained competition came from different, established and more central institutions and networks of actors. As a result, campaigners and community gatekeepers could not reach the saturation of networks with the stroke awareness message. Hence, networks were neither barriers nor facilitators for the intervention, but constituted the environment where it took place. Such an environment had both a spatial and a temporal dimension. Furthermore, campaigners and gatekeepers could not overlook its rules and culture if the campaign was to produce any specific effect.

5.5 General summary

Network interactions had a relevant impact on the whole campaign, and on specific aspects. In particular, it was through network interactions that actors negotiated roles and made them evolve. In addition, actors co-constructed the identity of the target community only through network interactions. Nothing like an objective identity of the community existed outside the interactions between community members and campaigners. Finally, as the campaign progressed, campaigners organized a series of health promotion events. By interacting with the community as a broader social space, actors created a temporary space, competing with

several different social forces within the community. Overall, network interactions between actors in the campaign had a disproportionate influence on the design, organization and delivery of the intervention.

Chapter 6 Evidence and information: acquisition, generation, translation, dissemination

6.1 Introduction

In this section, I will cover the second research objective, analysing how actors acquired, generated, translated and disseminated evidence and information in a series of complex, iterative network interactions. I am mostly interested in the interplay of practice and evidence in the design and initial delivery of the campaign and in the analysis of information-related behaviours of key actors.

6.2 Types of evidence and processes of evidence generation

6.2.1 Introduction

The general aim of the campaign was to communicate scientific and clinical evidence to specific target communities, in order to promote behavioural change. Its specific objective was to communicate to selected ethnic minority groups the need for stroke patients to present to emergency services as soon as possible after recognizing the onset of symptoms. Consequently, the type of evidence that campaigners had to share with target communities concerned scientific facts and behavioural prescriptions related to a specific health situation. However, the different objectives and points of view of actors with different roles bring to the foreground further conceptions of evidence. For example, community members related their knowledge of stroke to personal experiences or stories shared in the community. Campaigners collected and built evidence related to the specific ethnic dimension of a community (see section 5.3). Community gatekeepers often referred to evidence of the best strategies to involve members of community in health promotion activities, and related barriers and facilitators. PCT commissioners and the Regional Network expected to obtain evidence about how to create and sustain relationships between the NHS and ethnic communities. The list could be longer, and some examples will be analysed in more detail in the subsequent sections. It emerges, however, that different types of evidence were relevant for the intervention. Furthermore, actors built evidence and acted upon it through network relationships. Hence, I try to delve into the differences between conceptions of evidence and their relationships with particular roles, and the overall processes of evidence generation. In particular, I will describe the *types* of evidence relevant for the campaign, and actors' perspectives that caused them to interact with each other. I will also analyse who acquired and

generated evidence from whom (or what), i.e. which translations occurred between evidence and practice, in both directions.

6.2.2   Types of evidence and evidence generation

Two types of evidence strongly intertwined: scientific/clinical evidence, and practical evidence about how to carry out the health promotion campaign for target communities. The first type was definite and its boundaries clearly defined. The problem for campaigners, PCT commissioners, the Regional Network and related roles, such as designers and health professionals, was how to translate it adequately for a specific target. This task, in turn, needed to be carried out, if possible, according to an evidence base, indicating the best available practices. I illustrate in Figure 6.1 the initially agreed process between the project board and campaigners for evidence translation.
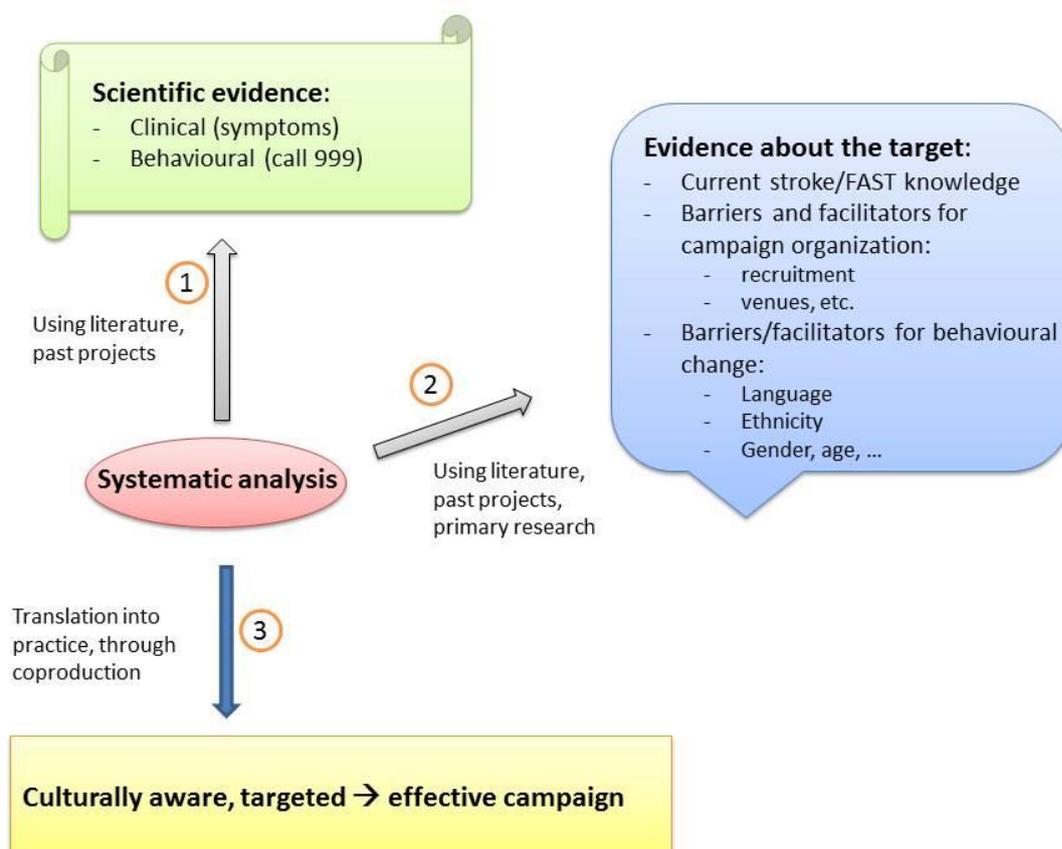
Figure 6.1 Initially agreed process of evidence translation into practice in the campaign

The process seems relatively linear. Researching the literature and taking into account past stroke awareness projects would allow identification of the main elements of the campaign content, from the clinical and behavioural point of view. After that, a systematic search and synthesis of the literature, conducted by the local CLAHRC, and primary research carried out by the campaigners following the brief specifications, would allow understanding best practices in

promoting stroke awareness, and specific barriers and facilitators. Finally, co-production was intended to drive the production of culturally-aware and community-tailored health promotion events and materials. The development of the campaign, however, showed a markedly different process.

6.2.2.1 Scientific and clinical evidence

Firstly, the division of labour between CLAHRC and the campaigners was not fully effective. CLAHRC investigators carried out a thorough search of the literature about stroke awareness promotion in ethnic minorities. They produced two reports during the campaign[9], both containing only a narrative synthesis of the literature, without clear answers concerning barriers and facilitators to stroke awareness promotion for ethnic minorities. CLAHRC investigators did not complete any systematic review of evidence before the end of the delivery phase. The two reports showed that most interventions had been carried out in different geographical areas and with very different communities. Therefore, no robust evidence about the effectiveness of stroke awareness interventions for ethnic minorities was available for campaigners.

Secondly, since campaigners had to co-produce materials and sessions with the communities, they did not conduct any initial systematic analysis of pre-existing materials for stroke awareness, although some were widely available (including FAST materials). However, when presentations for final sessions were developed, in fact the campaigners adapted pre-existing slides shared by email by one Regional Network member. No one clearly indicated the sources used in building presentations for the sessions and there was no formal justification or process for the selection of such sources. Finally, an important re-elaboration of the presentation of clinical evidence was involved in the creative process through which campaigners and designers produced leaflets and posters, integrating community-sourced indications and preferences.

According to a campaigner, stroke information materials should include a "multi-layered message": scientific and clinical facts should be integrated with a convincing narrative inviting the target to act immediately and in the right way when witnessing stroke symptoms. To reach this goal, designers integrated clinical evidence with their perception of the ethnic dimension of the target (see the example of the national flag, section 5.3.1.3) and with technical notions concerning shapes, colours and the importance of "shocking" the audience. Designers describe the process in the interview. Firstly, designers had several photographs taken with a volunteer

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[9] As described in notes 7 and 8, also for these reports I will not report the bibliographic data to protect anonymity of study participants.

in a fake clinical setting, to simulate stroke symptoms and related actions: this happened according to a plan about the type of desired images. Subsequently, designers sketched a first draft, and then revised it with the campaigner. The draft contained a graph, linking time after stroke and the growing number of damaged brain cells. The campaigner, however, thought that the figure seemed too complicated. Therefore, as a designer reports,

> *"the importance was highlighted again about the fact that these communities related to storytelling, which had been mentioned from the beginning. […] So then […] the three of us […] wrote this story, […] put down on paper […] the key messages […] to put across […] So the key messages were that you need to call 999 if you notice someone's had the symptoms, you need to do it fast, erm… if you do it, there will be somebody that can speak your language, so they can deal with your problem effectively, erm… and… the fact that it's free".*

Consequently, during a non-linear process in which different actors were involved, a story was built starting from clinical evidence and graphical concepts, and the reasons for a specified behaviour were integrated in the story (that is: "call 999 if you witness stroke, otherwise bad outcomes will happen"). This happened through several iterations and according to multiple inputs. Here is therefore another example of how actors transformed evidence to be communicated to an audience, through a process whose adequacy to a very complex goal is difficult to evaluate.

6.2.2.2 Evidence generated with the community

As for primary research, campaigners followed the specifications in the brief (see Chapter 4, together with section 5.3 for issues concerning ethnicity). They integrated it with a short review of the literature. They also attempted other searches that did not produce satisfactory results, so they primarily relied on evidence from fieldwork to make decisions about the campaign, as one campaigner confirms:

> *"We didn't really get too much secondary information; we mainly based it on our primary research".*

During the first round (called "insight phase"), data on stroke awareness, cultural and linguistic barriers and facilitators and community segmentation were collected from white deprived, gypsy and BME communities, along with health professionals and workers, using a white affluent community as a comparator. Campaigners summarized the main findings of this research in a report (see section 4.1). They identified barriers and facilitators for stroke awareness for each group, as well as recommendations for co-production of materials and events with the communities.

However, the process of production of such evidence proved problematic from several points of view. Firstly, requirements from the brief seemed very hard to fulfil in a short time scale, since commissioners expected that primary research by campaigners produced evidence related to a wide range of topics, including levels of stroke awareness, intake of FAST message, barriers and facilitators to stroke awareness. In addition, commissioners chose several different communities. However, campaigners could not explore topics in depth or with an adequate number of participants for each community. Fifty-one community members were involved; for 43 participants, campaigners collected data during single focus groups, whose duration was presumably short. Of these, 24 BMEs were involved, the other participants belonging to white communities. The only mentioned ethnic groups were Yemenis and Pakistanis, but probably other ethnicities were represented as well. In addition, campaigners interviewed eight stakeholders, but it is unclear how many of them were directly related to BME communities (probably no more than two). In summary, emerging evidence about stroke awareness, barriers and facilitators for health promotion and practical suggestions was therefore particularly weak: the sample was not directly linked to the target communities, and the interactions between campaigners and BME groups were probably too short to yield significant results. Noticeably, though, given the requirements of the brief and the short time available (less than four months) it would probably be difficult that campaigners could yield more significant data.

Once the steering committee decided to focus specifically on three BME communities, campaigners carried out a new round of data collection (see Chapter 4). Also in this circumstance, they held six focus groups, involving members of all three targeted communities. Questions concerned stroke knowledge and prospective and actual behaviour of community members when witnessing stroke symptoms. In addition, campaigners explored with participants potential methods for producing and delivering stroke-awareness information to the communities. I observed five out of six sessions, as the last one was for Pakistani women only and I was not allowed to participate. The sessions, held in community centres, lasted between 45 and 75 minutes each, involving 51 participants (seven to 14 per session; 19 women and 32 men; 22 Somali, 15 Yemeni, 14 Pakistani). Age groups varied, with a prevalence of elderly people. Campaigners reported holding the sixth session, of comparable length, in a community centre, involving five women. In a further report, campaigners summarized the evidence produced by these sessions, comparing stroke awareness/knowledge and behaviour between the three communities. Sessions were again very short, occasionally involving a considerable number of participants, so that people actually contributing were fewer than the total number of session participants (see also

Chapter 7). In addition, I observed that the campaigners usually established a contact with participants only just before the session: therefore, some time was devoted to setting the context for the meeting, including its specific objectives. No robust evidence about attitudes of BMEs towards stroke and related behaviours emerged from the sessions. Campaigners asked questions consistently between sessions, using the same topic guide. However, it was often hard to ascertain contributions of individual participants, and summarize the data accordingly, since it frequently happened that people talked all at once, and participants, reaching a sort of "consensus" during the session, summarized different points of view. Moreover, each main topic (knowledge, behaviour, practical information about organization of the campaign) could be explored only for 15 to 20 minutes in each session. This was probably too short an interval to explore such complex issues as BMEs' understanding of stroke, analysing the sources of stroke knowledge or the differences between actual and declared behaviour when witnessing a stroke. Another relevant point is the particular interest of campaigners in testing stroke awareness of community members. Indeed, campaigners used about one fifth of the time during community sessions (including the delivery phase) to check whether participants knew the symptoms of stroke, its causes and the optimal behaviour when a stroke is witnessed. This is understandable, because the campaigners wanted to make sure that their action was needed in the community; additionally, checking pre- and post-session stroke awareness proved a very quick way to show the effectiveness of the intervention on a short time scale, for evaluation purposes. The intention may also have consisted in trying to approach communities informally and to introduce the topic. However, there was the risk that particularly elderly male participants felt their knowledge and role in the community was challenged by outsiders trying to demonstrate that they knew less than expected.

I will report some examples of the interactions during the sessions that campaigners used to generate evidence. Firstly, the following excerpt from a meeting with Somali women illustrates a typical information exchange about stroke knowledge during a pre-production session:

> "The campaigner [C] asks who knows what a stroke is. […] One women raises her hand. Many women speak at the same time, to try to answer C's question. Answers include: when stroke happens people faint, seem to be frozen. It is linked to high blood pressure. Also heart disease and diabetes can cause stroke. C: what part of the body is affected? Participants indicate the head. C: are the heart, the brain or the lung affected by stroke? Someone answers that stroke starts from the brain, especially from its left side. Someone else answers that it does not start from the brain, but can affect the left side of the body. […] Someone else repeats that Stroke is caused by high blood pressure. C: how do you know that someone has a stroke? You have talked about hemiparesis: are there any other symptoms? Answers by participants: not being able to

speak; the tongue comes out; people lose control completely; loss of memory; complete paralysis of both sides of the body".

The observed interaction lasted for slightly less than 10 minutes, and involved 12 women. Participants expressed a mixture of correct, imprecise and wrong conceptions about stroke. It was very difficult to differentiate individual contributions, and most of all to establish a sort of "average" level of real stroke knowledge. The second excerpt concerns a discussion between a campaigner and an age-mixed group of Yemeni men:

> *"The campaigner [C] asks: what would you do if I had a stroke right now? Participants say: I would call the ambulance, emergency service, 999, doctor, hospital (they use single English words). C asks: would you take me to the hospital or to a doctor? Ps: I would take you to the GP if your symptoms were not so serious. C: how would you judge if the symptoms are severe or not? Ps: symptoms are severe if the brain stops working, if you cannot talk or feel, if you fall to the floor. [younger participants smile during the description]. C: how would you know exactly what the symptoms are? Most of participants agree that they have seen some people with stroke before, especially older people. Some of them also report having received a letter at home describing stroke symptoms. On TV, they say, there are always doctors explaining what it is better to do for health (exercise, etc.). [younger people laugh again]".*

Here, stroke-related behaviour is explored, and participants describe sources of stroke knowledge. Again, this interaction lasted well under 10 minutes. It is difficult to average the content of the declared behaviours concerning stroke symptoms. In addition, different levels of involvement are clearly visible. Elderly members of the group are more willing to talk (although struggling with their knowledge of English – the session included an interpreter), while younger people, in two instances, seem more interested in talking to each other and joking: therefore, not all participants expressed an opinion, and data produced during the session may come from just four participants, instead of eight. Under these circumstances, I could not draw any specific inference about general behaviour of community members. Finally, I will give an example of questions requiring much more time to be explored in details:

> *"Campaigner [C]: people in the community have a lack of knowledge about stroke, maybe. How would you help people in the community to become more knowledgeable? One of the oldest participants states that the first thing to do is to help community members with anger management, since stroke is caused by anger. According to another (younger) participant, people should first be informed by the media in the community (radio or TV). Only after this first step, will people take part in seminars. Another participant advocates the distribution of written materials in Somali language, their dissemination in places where people gather (e.g.: the mosque)".*

The sheer diversity of answers indicates how many different directions campaigners could have explored to gain a richer understanding of the dynamics of knowledge sharing in the

community context. Nonetheless, they could not explore the topics in detail due to lack of time. However weak, though, evidence constructed during the insight and the pre-production phases formed the basis on which decisions concerning the campaign were made by the project board after analysing the proposals by campaigners. Within the limits of the available time and resources, campaigners also managed to produce evidence generated with the contribution of community members and according to the requirements of the brief. However, campaigners and actors in related roles did not systematically produce and utilize the evidence, and therefore a quantity of important practical information was of limited value in actually designing campaign materials and events.

The process of interaction between campaigners and other roles during the campaign generated detailed outcomes partly analysed in section 5.2, and will be covered in section 6.3 and Chapter 7. There, I summarize dynamics of evidence generation in the interaction between campaigners and participants, which worked in a similar way also in receiving feedback from community members on campaign materials and final events. As for the practical knowledge about the best ways to produce events and materials for the campaign, other roles contributed to it, beyond campaigners and community members. Gatekeepers played a key role, particularly in organizing sessions, by relying on a different kind of evidence, related to their practical knowledge of community members' attitudes and behaviours that I will analyse in detail in Chapter 7.

6.2.2.3 *Evidence, PCT commissioners and Regional Network*

The final type of evidence that I will consider is linked to the role of PCT commissioners and Regional Network members. To begin with, such actors often cited evidence as a justification for the project. According to an interviewed Regional Network member, ethnic minorities are known not to "access services in the same way" as the ethnic majority, not just for stroke, but also for a variety of health issues. Consequently, this was the main strategic trigger for the campaign. The second type of evidence supporting the decision to commission the campaign was "negative". As reported in section 5.3.1.1, PCT commissioners and Regional Network members thought that NHS professionals had no significant knowledge about communities; therefore, one of the main expectations was to obtain practical knowledge about communities, as far as health-related issues are concerned. In expressing such a concept, one Regional Network member explicitly opposed quantitative evidence to evidence produced by means of a rich, qualitative understanding of communities. While acknowledging that

"grounding some elements of the project in evidence (…) in the current climate is really important", she also affirms that *"it's been the tiny detail hidden in the project that have been the eye openers for me. Not the bigger picture"*.

On a related note, another Regional Network member commented:

"what's coming out of [the project] is qualitative because you probably won't get much quantitative data out of this and what is evidence? It's equally valid to use qualitative data in the absence of that quantitative. So […] I suppose you could do some sort of randomised control trial, but it'd be very difficult for that group of people".

Another area of tension between "academic" and practical evidence concerned the evidence of effectiveness of the campaign. For example, the same interviewee clearly underlined the fact that grounding the project in evidence is usually a requirement by evaluators:

"in the current climate […] there's nothing surer at the moment - if it's not evidence based, it will get dismissed".

Qualitative evidence may triangulate, according to the interviewee, with quantitative evidence. This may resonate with the attitude of campaigners to evaluate the campaign through quantitative pre- and post-session questionnaires administered to community members, although campaigners integrated this data collection technique with short focus groups in which the same members could express their point of view on the campaign, as showed in section 7.4.

However, organizational actors expressed a third concept of evidence, beyond the clinical and the practical ones already analysed. They talk about evidence of effectiveness, and are aware of the difficulties in evaluating complex health promotion interventions, but also emphasize the value of generating this evidence so that programs can produce sustainable effects and best practices can be disseminated.

6.2.2.4   Evidence generation – a summary

Figure 6.2 shows the main interactions and processes involved in evidence generation in the context of the campaign.

Scientific evidence:
- Clinical (symptoms)
- Behavioural (call 999)

Evidence about/from target:
- Current stroke/FAST knowledge
- Barriers and facilitators for campaign organization:
- Barriers/facilitators for behavioural change

Reference, in the background

Narrative synthesis, anecdotes, details

Several cycles

Constantly self- refining campaign reaching target communities, adapting to non-planned circumstances

Expectations of / attempts at producing

Several cycles

Evidence of effectiveness (?)

Figure 6.2 Cycles of evidence generation

The first element emerging from data was the peripheral position of both clinical/scientific evidence and evidence of effectiveness, and the much more prominent position of "community-generated" evidence. Evidence generation was a gradual, iterative process, in the development of the campaign. Campaigners were the main role related to this task: they acted as catalysts, summarizing disparate information coming from both commissioners and the community, so to be able to use it as a basis for decision. Although using semi-standardized methods for collecting information and data from communities, the process of evidence generation conducted by campaigners was not systematic, nor relying on rigorous methods. In general, actors continuously produced "facts" and acted upon them, but they very rarely verified or challenged such facts. No validation procedure for the synthesis of information obtained from communities was in place. Evidence seemed to crystalize through cycles of information exchange, and to be strictly related to practical outcomes. Anecdotes, especially if reported in different sessions, played an important role in generating evidence. Campaigners often used particular details of behaviours obtained by communities (e.g. the storytelling attitude) to justify decisions about practical outcomes of the campaign. A temporal dimension was also crucial: campaigners could not afford to wait until all evidence had been systematically collected and analysed either by themselves or by other actors. They needed to

deliver tangible outcomes (leaflets, posters, and sessions) in an acceptable time. Therefore, they frequently constructed evidence to make sense of a situation, in order to be able to generate a particular outcome in a specific context. Examples of this attitude include (but are not limited to): finding a suitable way to design a leaflet for a community; discovering the best strategy to involve participants in a session; obtaining feedback on produced leaflets from community members; checking the translation of stroke information with community members. In none of these circumstances, they performed complete analyses of "hard evidence". Campaigners collected as much information as possible from available informants, trying to maximise their range and diversity. The next step, then, involved practical action (producing a draft leaflet, designing a session, delivering a pilot event, etc.). Finally, the action allowed campaigners to return to collect more information and feedback to use as soon as possible, to advance and eventually finalize the project. Even already available scientific and clinical information needed adaptation, and campaigners and other actors integrated it in cycles of information exchange. For example, campaigners had to devise a "culturally appropriate" way to urge community members to present to emergency services with stroke in a short time, based on evidence coming from community sessions. They considered translation as both an opportunity and a danger to convey an adequate knowledge of stroke symptoms to communities, etc.

In describing this situation, I mostly focussed on the central role of campaigners. Other roles as well, however, shared a very similar attitude towards evidence, so that the results of the analysis can generalize to community gatekeepers, PCT commissioners and the Regional Network as well. Gatekeepers needed to collect evidence on what the campaigners wanted to do, and what this implied for their communities. Once they agreed to be involved, gatekeepers based their decisions (on involvement of community members, materials distribution and organization of events) on their knowledge of community, in turn related to their role in the community and their network of contacts. As for PCT commissioners and the Regional Network, they clearly showed an interest in obtaining a greater knowledge of how communities "work", in relation to health issues. Therefore, they showed a practical attitude towards evidence generation, appreciating how campaigners had developed and initiated the campaign working together with communities. However, they were conscious of the difficulties involved in producing evidence of effectiveness: they expected to obtain it, but they stressed the importance of a rich, qualitative understanding, as opposed to merely quantitative measures.

As noted, judging the processes of evidence generation from an academic point of view, it is questionable to what degree such evidence forms a viable and robust basis for a health promotion campaign. On the other hand, the campaign was largely built by different actors based on this kind of evidence, generated and interpreted in networks of contacts: facts seemed to produce other facts and outcomes, by means of particular actions, performed by network of actors with specific roles.

6.3 Information management and dissemination

As described in section 6.2, all campaign activities were integrated, sustained or based upon the acquisition, utilization, exchange and reconfiguration of information. I will therefore analyse how actors managed information during the campaign. Firstly, I will analyse the overall characteristics of information behaviour, showing its impact on the campaign. Subsequently, I will focus on examples of information exchanges and usage, to show how information behaviour worked in practice.

6.3.1 Information usage in the campaign: a synoptic view

Through network interactions, countless information exchanges shaped the campaign and allowed moving it forward. Such exchanges include evidence generation, but have a wider scope, since they incorporate also network interactions concerning the exchange of opinions, practical details, and any other content relevant for the campaign. Analysing information-related activities may be equated to analysing information behaviour of actors in particular roles. I chose to present and interpret the main features of information behaviour for actors with the most important roles, and for their most significant interactions.

Figure 6.3 shows the model of information behaviour emerged from data, and used to summarize the results of the present analysis.
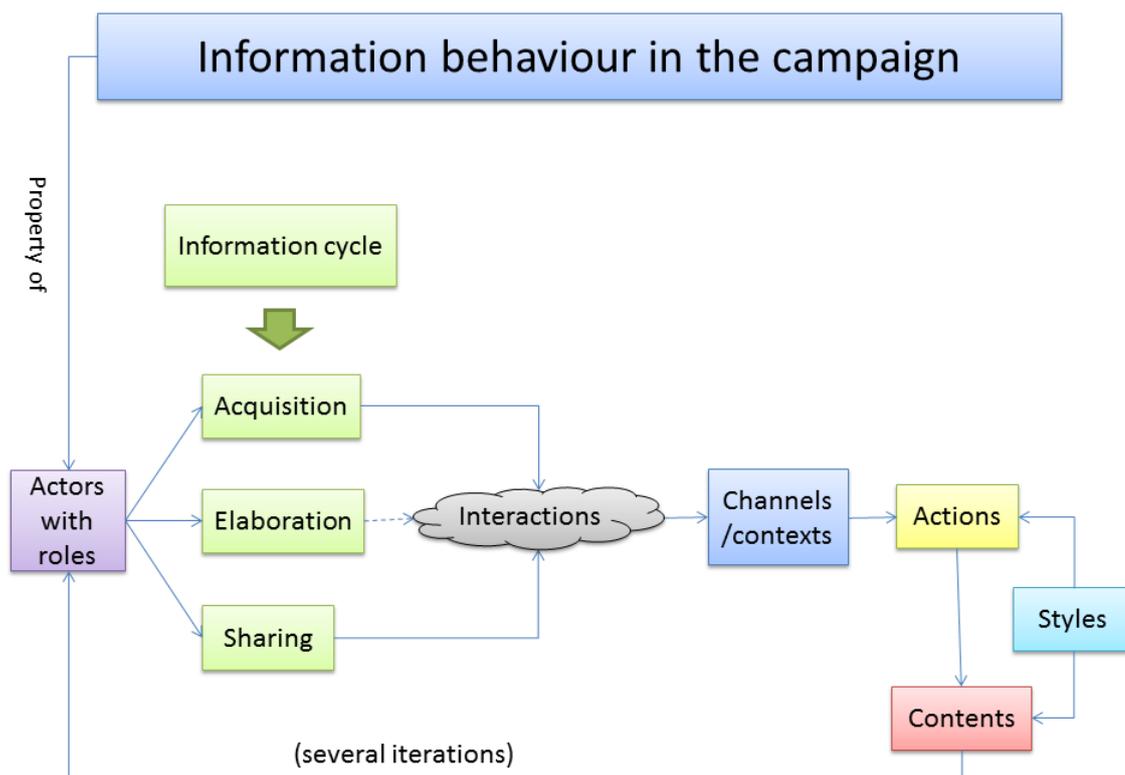
Figure 6.3 The model of information behaviour in the campaign

Information behaviour is a property of actors with specific roles. They can interact with information in one or more cycles, including acquisition, elaboration, sharing/dissemination. While acquisition and sharing obviously imply interactions with other actors, actors or groups may also perform elaboration on their own. Above and beyond, information behaviour generally concerns specific contents, such as theories, stories, opinions, facts, etc., channelled by interactions through specific channels and contexts (e.g.: media, translators, gatekeepers, physical venues, specific time frames, etc.). Finally, information behaviour materializes in actions (e.g. asking questions and receiving answers, prompting, debating, challenging, etc.) and according to particular styles (colloquial, informal, structured, etc.). The integrated analysis of the characteristics of information behaviour of different roles allows mapping information dynamics in the context of the campaign. To keep the analysis adherent to the most relevant dynamics, I will mainly focus on the information behaviour of campaigners, PCT commissioners/Regional Network, community members and gatekeepers.

6.3.2   Information behaviour of actors with specific roles

Campaigners aimed at acquiring information from two main sources: the project board and communities. Both were also the main targets to which campaigners needed to feed information back, after elaboration. From the project board, campaigners needed to obtain

information about funding, specific requirements for activities to be carried out, help in setting up contacts with communities and feedback expressing customer satisfaction for campaigners' achievement on the field (sometimes in the form of explicit sign-off). In turn, campaigners fed information back to the project board in different forms, including:

- structured verbal reports on field activities at meetings, sometimes integrated by GANTT charts, drafts of materials, community session briefs etc.;

- brief verbal or written communications by phone or email concerning practical problems (contacts with communities, materials development, etc.);

- a limited number of written reports of variable length after the completion of significant phases of the campaign (insight, pre-production, initiation);

- campaign materials and presentations prepared for final events, to obtain sign off and trigger organizational sharing and learning.

While PCT commissioners and the Regional Network generally appreciated feedback from campaigners (both for its timeliness, and for its perceived quality), the latter were not always satisfied with feedback or information provided by the former, especially after the change of board: they frequently pointed out delays in feedback or lack of answers. More specifically, two different contexts for this information exchange may be distinguished. In the formal context, structured reports and deliverables were shared by campaigners, and approved by commissioners; the only problem remarked by campaigners concerned delays in feedback. At the informal level, however, campaigners solicited a more interactive and frequent information exchange. Here, commissioners seldom interacted with the desired level of involvement, triggering alternative actions by campaigners to carry out necessary activities (production of presentations, involvement of health professionals, contacts with community members). The characteristics of such an information exchange are related to environmental variables such as involvement, roles expectations, and priorities, as outlined in previous chapters. Problems at this level had an impact on the campaign mainly in terms of delays.

Information behaviour of campaigners when confronted with communities was somewhat more complex, reflecting the shared perception that communities were a new target for health promotion, and both commissioners and campaigners knew little about health-related attitudes and perceptions of community members. In the context of communities, therefore, campaigners looked for different information contents already described in section 6.2 and including:

- stroke knowledge of community members;

- practical information about factors influencing effective delivery of a health promotion campaign in the community (important gatekeepers and hubs, times and places, communication techniques, culture-specific health attitudes, etc.);
- contacts for organizing sessions (venues, participants' recruitment, etc.).

As for the informational contents to feed back to communities, campaigners and the project board decided early in the process that they would include stroke awareness materials and presentations. The campaigners obtained the information they requested, but in a form that was difficult to elaborate, as described in section 6.2.2.2. Campaigners' questions during pre-production sessions were apparently simple, but in fact, they often proved ambiguous and difficult to answer in a uniform way. As a result, when answering campaigners' questions, community members mainly told personal stories or expressed lay theories about causes, consequences and response to stroke.

It was less clear what informational content community members expected to obtain from campaigners during delivery sessions. Since gatekeepers had recruited most of community members shortly before the sessions, and only generically explained them what the session would be like, participants probably expected that they would obtain from campaigners general information about stroke. Nonetheless, in pre-production sessions, community members expressed a marked interest and significant worries about stroke. They envisaged longer informational sessions including not only response to stroke symptoms, but also detailed medical explanations about pathogenesis, risk factors, prevention and management of stroke. Correspondingly, during several delivery sessions, participants asked questions aimed at obtaining more detailed knowledge. Campaigners only seldom answered these questions satisfactorily, either due to lack of clinical expertise, or to time constraints. Additionally, community members tended to expect to obtain detailed stroke information even during pre-production sessions, that instead had the aim of obtaining information from communities, and not to deliver information. Finally, it occasionally happened that community members explicitly challenged information delivered by campaigners, asking for statistical and clinical data to support it. In some circumstances, participants seemed also interested in receiving advice about personal health problems, and not just in obtaining general information about stroke.

Noticeably, the information exchange between campaigners and community members differed from the one between campaigners and the project board under several important aspects. Firstly, campaigners generally faced ever changing communication partners.

Therefore, expectations by community members were more difficult to establish, and in turn, campaigners often did not know the needs of their audience before a session started. Secondly, campaigners intentionally kept the style of the sessions informal. They flexibly followed topic guides for pre-production and final sessions, used a colloquial communication style, and frequently recurred to prompting, to stimulate feedback when participants seemed not to know exact answers or were not particularly willing to communicate. As a result, information acquisition, exchange and delivery happened in a much less structured way here. In fact, it is difficult to say whether campaigners and session participants shared similar assumptions about the goals, meaning and dynamics of the information exchange in which they were both involved. Finally, on several occasions, campaigners and community members could only communicate through bidirectional translations. Firstly, campaigners worked to produce multi-lingual leaflets and posters in line with perceived expectations of community members; in doing so, and together with the designers, they tried to simplify the message and style of stroke awareness materials and of sessions. I have showed, however, that this simplification seemed to result in the delivery of insufficiently detailed information during sessions, according to community members. Community translators also seemed to add details to what campaigners said during sessions, thus incurring the danger of introducing biases in information. Finally, the health professional expressed criticism towards the assumption that sessions might be "simplified" because they were targeted at ethnic communities. Consequently, it is difficult to say whether the information exchange between communities and campaigners (occasionally supported by health professionals) effectively delivered what community members expected.

Actors with different roles had different perspectives on how information exchanges happened. In general, however, misinterpretations of own role and the role of others, and changes in priorities after the change of board played a major role. Misunderstandings, delays and misinterpretations of other actors' intentions clearly emerged from data. As a result, information exchanges between different organizational roles in the campaign were suboptimal, and the communication style was seldom open and linear, with considerable impact on campaign development.

A final, related observation concerns the level of reported satisfaction about an information exchange. There were instances of exchanges defined as mutually satisfactory: for example, the one between campaigners and designers, campaigners and some gatekeepers, gatekeepers and community members. However, when analysing the outcomes of such exchanges from a wider perspective, several limitations are visible. Examples include the

limitations in the process of design of materials (sections 5.3.1.3 and 6.2.2.1), the only partial effectiveness of the recruitment of participants (section 6.3.2) and the possible biases that community gatekeepers may have introduced in the stroke awareness message when communicating it informally to the communities (sections 5.2.3 and 6.3.2). Therefore, defining an information exchange as mutually satisfactory, in the context of the campaign, is not in itself a guarantee of quality of the related outcomes, since informational contents and elaboration methods play an important role as well.

6.3.3   Information behaviour analysis: specific cases

Analysis of information behaviour of actors with specific roles tends to focus only on abstract dynamics. Consequently, in this section I will present some information behaviour maps, designed according to data emerging from interviews and observations, to show examples of information dynamics in specific, real-life contexts. Firstly, interview data will allow me to describe the information management perspectives of particular actors. I will also reconstruct the information behaviour maps of some community sessions. I will then close the section by analysing information behaviour in the distribution phase of campaign materials.

6.3.3.1   Interview data: information exchanges from the perspective of single actors

I have selected a number of interviews with participants, representing significant roles. For each one, I have produced maps of information exchanges, to outline the perspective of single actors on the workings of information and communication in the campaign. The first map concerns an interview with a campaigner and the topic is the pre-production phase. I represented in Figure 6.4 the most relevant informational interactions in this context.
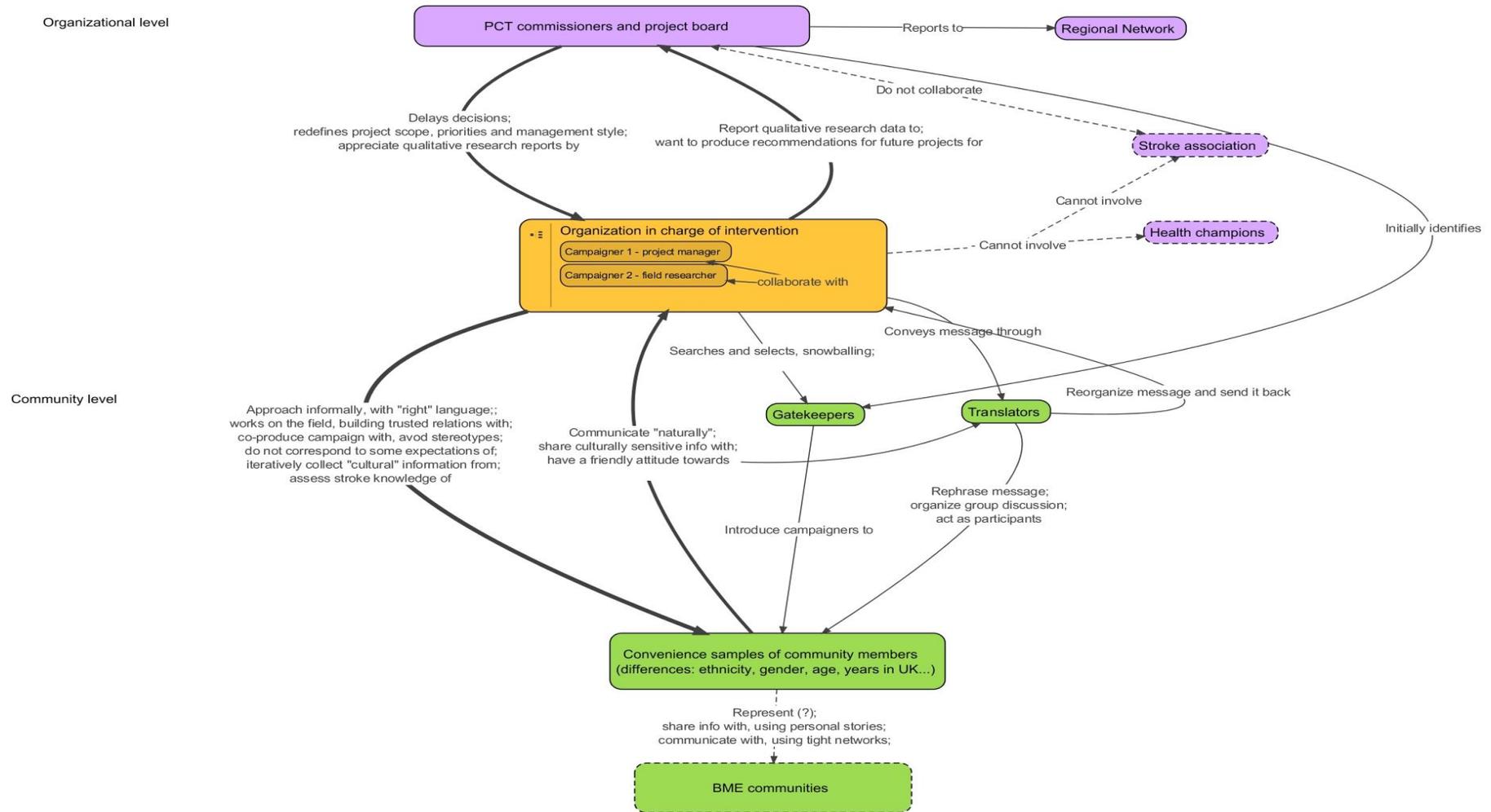
Figure 6.4 The pre-production phase, viewed by a campaigner

I represented with text linked to arrows the meanings ascribed by campaigners to information exchanges with communities, while the increased width of an arrow represents a particularly meaningful and rich interaction. From the Figure, the main axis of informational interactions emerges, extending from the project board to communities, but only with the intermediation and filter of campaigners. It is also clear that contacts between campaigners and community members only happened through the concurrent actions of several intermediaries (gatekeepers, translators, etc.), and therefore communication between the two parties happened through different filters. The position of the campaigner conducting field research emerged as related to several other organizational actors. Firstly, he collaborated with the project manager in his own organization, and – in a more mediated way – he shared the results of his work in terms of information content with the project board. The campaigner, however, pointed out that some important actors could not be involved (health champions and the Stroke Association); given their position in the map, they may well have been potentially missing links between communities and the NHS. Finally, the campaigner presents a very favourable view of his perceptions of the information content and style of communication during community sessions. Figure 6.8 reports my perception of one of the observed pre-production sessions, with a considerably greater number of nuances and criticalities.

Figure 6.5 represents the perceptions of designers about their involvement in the campaign, and their own information behaviour.

Figure 6.5 Self-described designers' information behaviour

Designers occupied a relatively marginal and temporary role in the campaign. However, they interacted, directly or indirectly, with the majority of other roles in. Their point of view as partial outsiders may therefore be useful when focusing on information dynamics not described so far, or on confirming patterns already detected. Firstly, the map shows the striking complexity of the networks of informational interactions in which designers were involved. It admittedly took designers time and effort to become acquainted with roles of other actors and their agendas and priorities. Their information exchanges show a significant evolution. Their initial contacts were only with campaigners. Thereafter, when copyright issues arose (section 5.2.2.3), they came to understand the complex network of actors involved. Thereafter, through a learning process, they negotiated a copyright agreement, allowing the NHS and communities to widely distribute and reproduce leaflets and posters in their current form, while acknowledging and protecting copyright owned by designers. Designers also remarked the importance of knowing actors personally, understanding their priorities and working style, in order to exchange information more efficiently.

Consequently, this map helps us by outlining two important features of information behaviour in the campaign. Firstly, an evolutionary dimension of information exchanges emerges from data, although my methods allow only for a limited analysis. The evolutionary dimension seems to appear in the form of iterative interactions, and to trigger a learning process lasting until actors reach the objectives that they had previously set. Moreover, I understood learning in this context also as a gradual, although often non-linear process in which actors acquire a better understanding of the configuration of some important parts of the whole network. Secondly, non-personal actors play an important role in information exchanges as well. Norms and laws (such working with the public sector or interpreting copyright laws), sources of information such as the Internet, contracts, or published evidence cannot obviously be considered actors in a network. Furthermore, they do not exist separately from the subjects that put them into practice and try to change them. However, during all phases of the information cycle (acquisition, elaboration and sharing) the contacts between actors in a network are mediated by a corpus of information or data, interpreted and operationalized in the exchange. This data can be more or less structured, exist in different forms (written, verbal, etc.), be more or less acknowledged, but it has nonetheless an impact on information behaviour and on the campaign itself – as exemplified by complex negotiations and agreements between the project board and designers concerning copyright issues.

With Figure 6.6, I move to an example of information behaviour of PCT commissioners.

Project board
- Other members
- CLAHRC

Regional Network

Expects "validation" of project from evaluation by

Is chair of;
facilitates work of, with "idea-based" style;
appreciates collaborative style of

Previously collaborated with

Stroke Association

Is better at coproduction than

Organization in charge of intervention

Negotiates production phase with;
struggles to understand roles of and funding arrangements with;
feels lacks control over the process with;
experience decision delays with

Department of Health

Wants to disseminate project learning to;
wants to negotiate sustainable follow up of campaign with

Local council

Appreciates product of;
thinks they know what to do;
likes coproduction, fieldwork, community involvemen, knowledge extraction;
appreciates because they show innovative way of working;
criticizes for long time to produce leaflets/posters;
appreciates outsourcing work and relationships development to

PCT Commissioner

Is worried about long-term sustainability of;
struggles to identify strategies to sustain in the future

Campaign

Wants to generalize learning from project to

Further health promotion

Criticizes for wrong, intermittent approach to BME communities;
criticizes for dropping projects once started;
criticizes for traditional, dull approach to health promotion;
acknowledges impact of reorganization on project;
describes as understaffed, overworked

Appreciates the building of contacts/networking with, for future health promotion;
selects as targets for the production phase, due to previous work done with;
expects to use practical learning from current, "exemplar" project for further projects with;
think they base knowledge on personal stories

Selected based on evidence from

NHS

Gets positive feedback from

Takes over as chair from

Discards as targets for the production phase

Yemeni, Somali, Pakistani communities

Perceives as an evaluator

Discarded based on evidence from

Likes 'cause different;
likes for visual appeal;
reassured as clinically signed-off

Different from traditional products by

Leaflets/posters

Initiator - PCT

Researcher

Gypsies

Health trainers

Whites

Figure 6.6 Self-described PCT commissioner's information behaviour

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The chief PCT commissioner mainly established contacts and information exchanges with other organizational actors, while during the campaign project board members had almost no direct contact with communities. Some of the information exchanges actually happened in the campaign, others were envisaged for the future (e.g. Department of Health, Local Council), while still others are referred to past projects (e.g. Stroke Association). Hence, an important diachronic dimension of information exchanges seems to emerge again, along with a distinction between actual and potential information sharing and contacts with other actors. In fact, both campaigners and especially project board members were constantly worried about generating organizational learning from the project – although I could not assess within the period of my research to what degree such learning actually occurred.

Moreover, the PCT commissioner generally attached value judgements to information exchanges: they were positive (e.g. towards the campaigners), or mixed (e.g. towards the Regional Network and the NHS); they concerned external organizations or her own. Finally, they ranged from very specific (e.g. appreciating a single aspect of the campaigners' work) to very general (about general attitudes and climate within the NHS), and were based on specific forms of "evidence" to different degrees. The fact that the actor frequently attached judgements to actual or potential information exchanges confirms findings reported in section 7.3 on the importance of judgements in the context of network dynamics. Furthermore, the PCT commissioner often expressed emotions related to information exchanges. Some examples are satisfaction and pride for the perceived originality and visual appeal of leaflets and posters, or worries about the sustainability of the campaign for the future; with the available data, however, I could not assess the impact of specific feelings expressed by interviewees on aspects or activities of the campaign.

Finally, Figure 6.7 contains a map of information exchanges for a Somali community gatekeeper.

Stroke awareness events

CLAHRC member

Experiences too short time to organize;
thinks should be refreshed regularly

Leaflets - posters

Directly organize, experiencing ownership, partnership, responsibility

Involves in project

Informally distributes in local shops (less competition);
appreciates visual appeal of

Female community leader

Imam

Somali community gatekeeper

Community centres

Organizes sessions with

Involves in campaign

Male community leader

Campaigners

Community activist

Which helps reaching

Involving them through stable contacts is valuable in itself;
recruits for events, through conversations and calls;
advertises events;
envisages health professionals involvement & train-the trainers approach;
voluntarily does health promotion with, through informal conversations;
distributes leaflets to;
suggests assessing stroke awareness with short conversations - network analysis;
suggests involving whole communities through gatekeepers

give positive feedback to, on "localized" leaflet (actor - language);
spread the message to friends-relatives;
discuss about health topic with and with each other;
refer personal stroke stories to;
(some) mistrust him, due to financial reasons;
would require funding to attend events with researchers;
express lay, imprecise theories about health - stroke;
need attention and listening to their problems;
tend to mistrust outsiders;
rely on oral/verbal communication;
won't corrupt message as it passes through;
(some) want to exchange favours with;
women > men in organizing events

Hard-to-reach groups

Within

Recruits for events, through conversations and calls

Somali community members

Figure 6.7 A Somali community gatekeeper's self-described information behaviour

As it might be expected, the gatekeeper enacted most information exchanges within the Somali community, although campaigners established the initial contact with the gatekeeper through a local CLAHRC member. Above all, however, the gatekeeper needed an impressive number of contacts, information exchanges and activities to organize campaign events and recruit participants. The map brings together and allows examination of several findings reported in other sections, about involvement, judgements, ethnicity and roles. To organize events and recruit participants, a gatekeeper firstly needed to involve other gatekeepers with different community roles (community leaders, community centre activists, religious leaders). Furthermore, the gatekeeper had to explain the importance of stroke awareness for the community and entrust community centre leaders with the organization of events. Gatekeepers also had to do enough "legwork" (together with other community activists) to recruit an adequate number of participants for sessions. After the events, and with other activists, the gatekeeper carried out further, informal health promotion activities in the community. A second relevant point is that information exchanges with community members implied several levels and important different nuances. Sharing the same community attitudes, the gatekeeper was conscious that – when recruiting a participant – he needed at the same time to explain in a rational way the importance of the topic both for the individual and for the community, appeal to the health needs of the community member, overcome possible criticisms and mistrust, and more. It seems therefore particularly important that campaigners and commissioners at least partially entrust recruitment of community participants to health promotion sessions to actors with a deep understanding of the different factors that may influence the decision of a community member to participate.

6.3.3.2 Observed information exchanges: community sessions and materials distributions

So far, I have referred to perceptions or self-perceptions of information behaviours by interviewees. I will subsequently integrate the analysis with data coming from observations of a number of situations. I have selected three different sessions as examples, one for each of the communities involved (Yemeni, Pakistani and Somali). The first map concerns a pre-production session with Yemeni women (Figure 6.8).
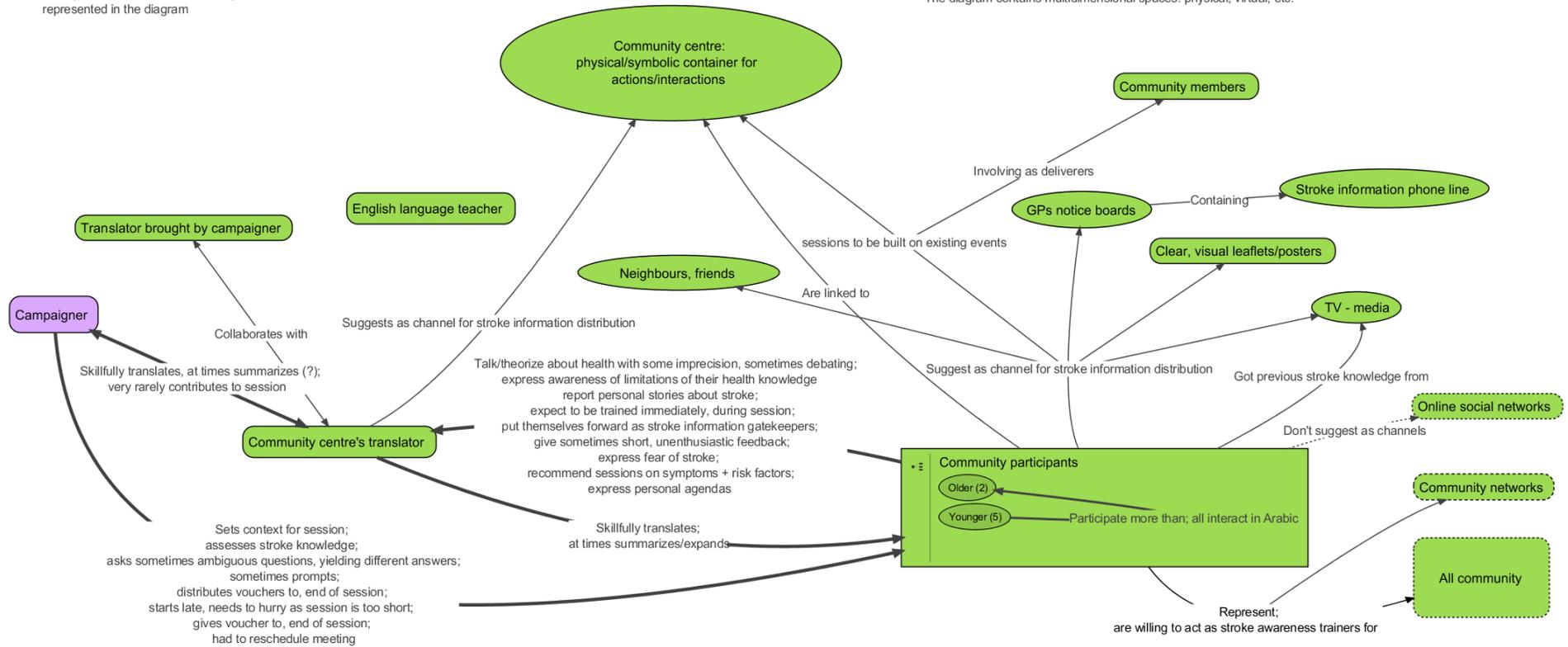
Figure 6.8 Information behaviour during a pre-production session. Yemeni women

There was a certain variance in participants' levels of involvement in sessions (see section 7.2). The example refers to a situation in which the involvement was "average", in relation to other sessions, so that no specific characteristic of the information behaviour in sessions is under- or over-emphasized. Firstly, the observed information exchange identifies nuances and criticalities already described in section 6.3.1: ambiguity of questions and answers on stroke awareness, possible misalignment between participants' expectations and the real aim of the session, etc. The role of translators was particularly important with this community sample taken from participants to an English language course in a community centre. The translator provided by the community centre was skilful, although she tended to expand and elaborate upon the campaigners' message (as did almost all other translators). The campaigner had recruited another translator, who also came to the session and collaborated with his colleague – an example of difficulties arising in organising sessions, even as far as very practical and relatively simple aspects are concerned. Moreover, in this case, the most immediate gatekeeper – the classroom teacher – did not occupy a specific role. The situation in other sessions varied greatly, probably according to the personal interest of gatekeepers for the session itself and their role in the venue.

Moreover, as it happened in most other pre-production sessions, participants noticeably pointed out several possible alternatives to leaflets, posters and events, only a few of whom could be chosen by the campaigners within to be used in the intervention.

As for sessions in the delivery phase, I have selected two different situations, represented in Figure 6.9 and Figure 6.10.
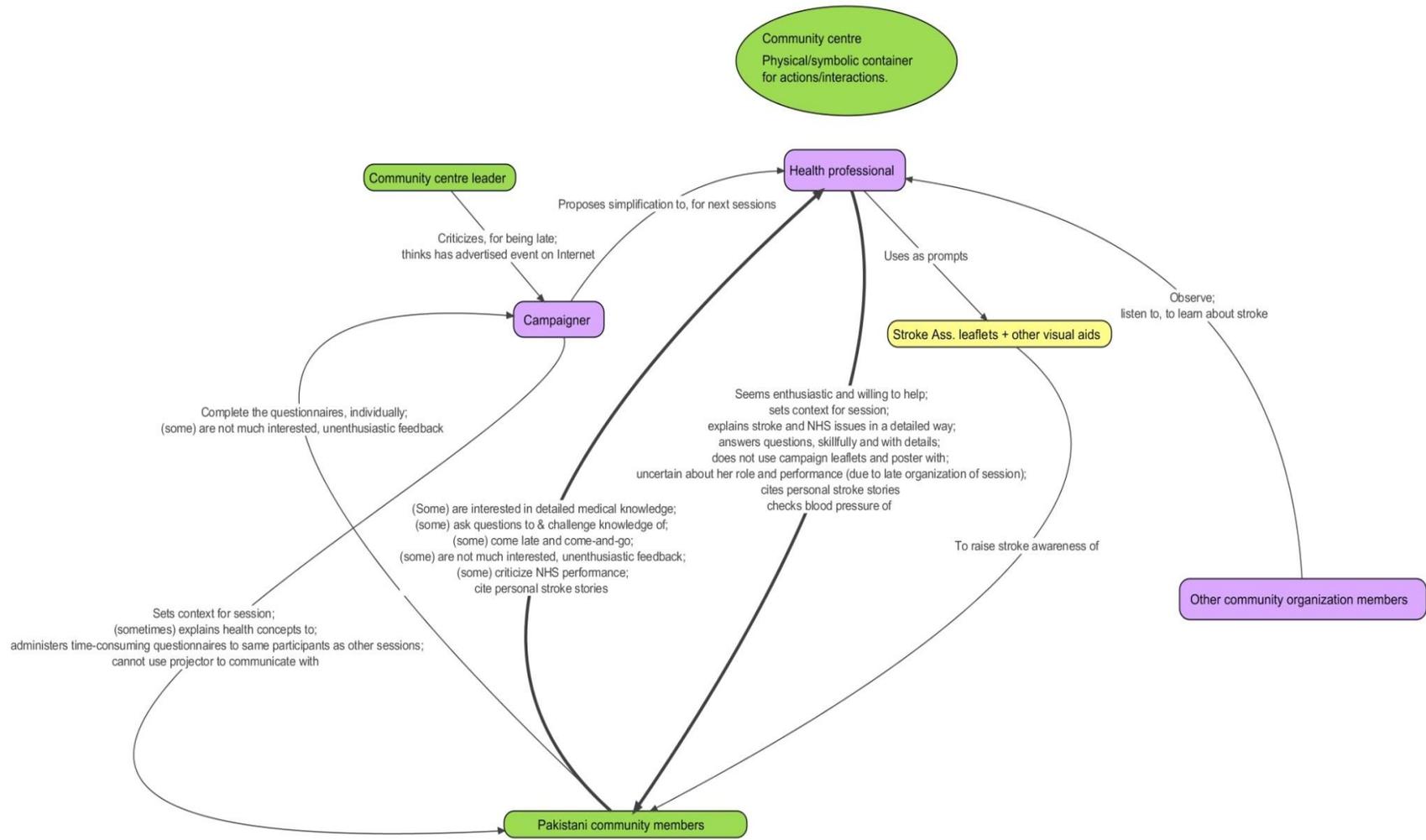
Figure 6.9 Stroke awareness session. Pakistani community

Community centre
Physical/symbolic container
for actions/interactions.

Community centre leader

Health professional

Proposes simplification to, for next sessions

Criticizes, for being late;
thinks has advertised event on Internet

Uses as prompts

Campaigner

Stroke Ass. leaflets + other visual aids

Observe;
listen to, to learn about stroke

Complete the questionnaires, individually;
(some) are not much interested, unenthusiastic feedback

Seems enthusiastic and willing to help;
sets context for session;
explains stroke and NHS issues in a detailed way;
answers questions, skillfully and with details;
does not use campaign leaflets and poster with;
uncertain about her role and performance (due to late organization of session);
cites personal stroke stories
checks blood pressure of

(Some) are interested in detailed medical knowledge;
(some) ask questions to & challenge knowledge of;
(some) come late and come-and-go;
(some) are not much interested, unenthusiastic feedback;
(some) criticize NHS performance;
cite personal stroke stories

To raise stroke awareness of

Other community organization members

Sets context for session;
(sometimes) explains health concepts to;
administers time-consuming questionnaires to same participants as other sessions;
cannot use projector to communicate with

Pakistani community members

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Figure 6.10 Stroke awareness session. Somali community

The main difference between the two sessions is that the health professional was present for the first one. As a visible consequence, in the first session the health professional attracts most of the information exchanges with participants. Comparing the information exchanges in the two sessions, the role of the campaigner appears marginal, when a clinically expert health professional delivers the health promotion session. Another difference is that the health professional uses several visual aids during the session (including plastic models), answering a clearly expressed need from participants to improve their knowledge of bodily modifications produced by stroke. Taking blood pressure at the end of the session also added a practical dimension, and opened up a more "private" space where participants could obtain personal health advice from the health professional. Moreover, there is a strong structural similarity between pre-production and delivery sessions – namely, a similar role for gatekeepers and translators, and considerable time taken by stroke awareness assessment by campaigners. In the final sessions, there is obviously more space for campaigner and/or health professional to deliver a stroke awareness message, but some information needs of participants are clearly not satisfied, and there is no particular emphasis on building participants' skills, beyond simple knowledge of symptoms and related behaviour.

6.3.3.3   Information behaviour in the distribution phase

A final context of analysis for information behaviour concerns the distribution phase, when campaigners delivered leaflets and posters to community venues, including pharmacies, libraries, GP practices and community centres in three areas of the city. Campaigners had prepared the distribution by calling each of the ca. 30 targeted venues to announce that a member of their organization would deliver stroke awareness materials on behalf of the NHS. In this circumstance, campaigners also asked for the name of a contact person in the venue. The information exchange, however, presented some problems. Firstly, campaigners had not included some potential venues in the initial list, hence local gatekeepers had not been informed beforehand. As for the targeted venues included in the list, only a few had agreed to receive the materials, while others had not answered the call. Finally, campaigners could not obtain a reference letter from the NHS to use at each venue. Therefore, the preparation of the distribution was only partially effective. This was confirmed by the attitude of gatekeepers towards campaigners. In most cases, they did not remember having been called, and were rarely enthusiastic or supportive, although on occasion campaigners obtained collaboration in displaying the leaflets in prominent places. In total, campaigners targeted about 30 venues for the distribution, although some of them were closed or not accessible. Most locations had adequate space to display and distribute leaflets and posters. However, only a minority of gatekeepers displayed the leaflets immediately. Especially in GP surgeries, but also elsewhere,

some gatekeepers needed to obtain approval by their supervisors before displaying the leaflets. In general, targeted venues were generally not designed to allow activation of network interactions and/or wider conversations than the ones necessary to carry out a brief information exchange, or a commercial transaction. Interactions between campaigners and gatekeepers were generally very quick, taking less than five minutes. Campaigners described the campaign and their expectations very briefly, in a generally unstructured way, without using a script. Some time was always devoted to negotiating the number of leaflets for each language to leave in the venue; the campaigner generally agreed with the gatekeepers' proposal, although on occasions they made some suggestions. With the leaflet, campaigners distributed the following brief to gatekeepers:

> "It's easy to help. 1. Place the poster so it can be seen by people entering or waiting 2. Put the leaflets somewhere near the poster or easy to pick up 3. Mention the leaflets to people during conversation. Thanks for helping the community".

However, in most cases, campaigners did not emphasize these instructions nor did they systematically go through them with the gatekeepers. As a result, gatekeepers only seldom followed these indications. Gatekeepers showed generally low empathy towards campaigners, with few exceptions; sometimes other customers were waiting and the gatekeepers could not dedicate enough time to the campaigners; other times such an attitude seemed more related to an absence of personal interest. As expected, a greater empathy, on occasions, was shown by people whose role routinely implies giving information to community members (e.g. members of community centres, some pharmacists); however, this was not always the case (e.g. with some of the librarians). The main goal pursued by campaigners seemed to be to complete work effectively, quickly, and – possibly – to establish some relationship. Gatekeepers seemed generally mostly interested in completing the interaction quickly, as they generally perceived the campaign as one of many similar initiatives involving the distribution of leaflets. In general, gatekeepers showed low ownership for the initiative – possibly, the phone call by the campaigners and the initial briefing were not sufficient to ensure their buy-in. Moreover, the campaign was not integrated with other similar initiatives or with the usual role of gatekeepers.

After about two weeks, I returned to the targeted venues to verify what had happened, and could collect data from 15 of them. In some venues, it was not possible to establish contact with those gatekeepers previously involved in the distribution. In many cases, I met different gatekeepers. In a minority of venues, no one had displayed the leaflets or posters. In others, they had been displayed, but only a minority of gatekeepers knew what had happened with

the materials, and just counted how many of them remained. In general, customers had taken some leaflets, but this varied greatly between the venues. In addition, materials faced strong competition from several dozen other leaflets displayed in the same places (see Figure 5.12 and Figure 5.13). Although "different", the stroke leaflets struggled to be visible, unless (as it occurred in four instances) the gatekeepers took particular care in displaying the leaflets in very prominent places. In two venues, the leaflets triggered interactions between pharmacists and customers, mainly as information requests about stroke. Again, just in a minority of venues gatekeepers distributed leaflets to selected customers. Some gatekeepers reported that members of ethnic minorities were interested in the leaflets and/or took some of them because they were in Somali, Arabic or Urdu. Finally, as noted, a considerable quantity of leaflets was distributed through "unofficial" or "informal" channels (e.g. community members, gatekeepers, health champions, etc.).

6.4 Summary

Data show multidirectional interactions and exchanges between evidence and practice in the context of the campaign, happening in the context of networks. Campaigners and designers correctly translated scientific evidence into leaflets, posters and events. However, they carried out such translation through narrative and unsystematic procedures, heavily relying on personal impressions, anecdotes and narratives. Campaigners and community members co-generated evidence about the best practical methods to carry out the campaign using similar methods. Campaigners subsequently used and further modified such evidence during activities aimed at creating materials and organizing events. Actors' information behaviour mainly materialized through local, short-range, face-to-face interactions. Most actors collected and disseminated information mainly reacting to external constraints. Through information exchanges, actors mainly tried to make sense of – and quickly adapting to – frequent unexpected situations and scenarios and unknown environments.

Chapter 7 Involvement, judgements and decision making as network dynamics

7.1 Introduction

I have analysed the importance of roles and identities in shaping the campaign as a specific social space, and the dynamics implied in evidence generation and translation in the context of the campaign. This chapter completes the findings, by covering the third research objective, concerned with network dynamics and mechanisms influencing the intervention. Three main mechanisms of influence of networks are analysed. Section 7.2 identifies dynamics and channels used by actors to involve other actors or to get involved in the campaign, and the meaning of such an involvement, alongside barriers and facilitators. Section 7.3 concerns mechanisms through which interacting actors formed judgements on specific actions or situations. Finally, section 7.4 covers dynamics of decision making.

7.2 Dynamics and patterns of involvement

The campaign was neither developed nor initiated in response to an expressed need of communities, neither was it carried out by actors inside the communities themselves. On the contrary, the NHS devised the initiative and an external company carried it out. For these reasons, the problem of involving community members in the campaign was in the foreground from the beginning. The first objectives of the campaign included being able to involve community members in receiving stroke awareness information and establishing contacts for further health promotion initiatives. Making sense of the dynamics related to involving actors in the campaign is therefore important in understanding the campaign as a whole. Hence, the present section aims at understanding who tried to involve whom, through what channels, for what activities and with what results. I will consequently analyse the role of networks, alongside the different meanings of involvement in the campaign, for actors with different roles (i.e., the reasons for involvement, the level of involvement and its sustainability over time). Finally, I will cover the main barriers and facilitators for involvement.

7.2.1 Dynamics, channels and reasons for involvement

Involvement in the campaign means to perform relevant actions– i.e. being an actor playing a specific role, as described in section 5.2. More specifically, I will analyse how someone accepts such a role, how actors sustain involvement over time, and how they involve other actors in the campaign, through which networks, etc. Some actors were initiators of the campaign (PCT commissioners and the Regional Network), while others were formally involved, having won a bid for an outsourced service (the campaigners). Other actors were automatically involved,

due to their institutional roles (Regional Network members), while for yet others involvement was partially or entirely voluntary (community gatekeepers and members). I have already observed that the campaigners seemed the most central role in the intervention (see sections 5.2, 5.4 and Figure 5.10). Hence, campaigners were, directly or indirectly, responsible for involving most other actors in the campaign. However, many more roles are concerned with the dynamics of involvement. Figure 7.1, Figure 7.2 and Figure 7.3 show network maps specifying who managed to involve whom for the co-production, pre-production and delivery. The maps also specify to which community gatekeepers and members belong. Here, involving an actor means recruiting him/her to take part in some significant activity of the campaign – either as a target or with an active role (organizer, translator, etc.).
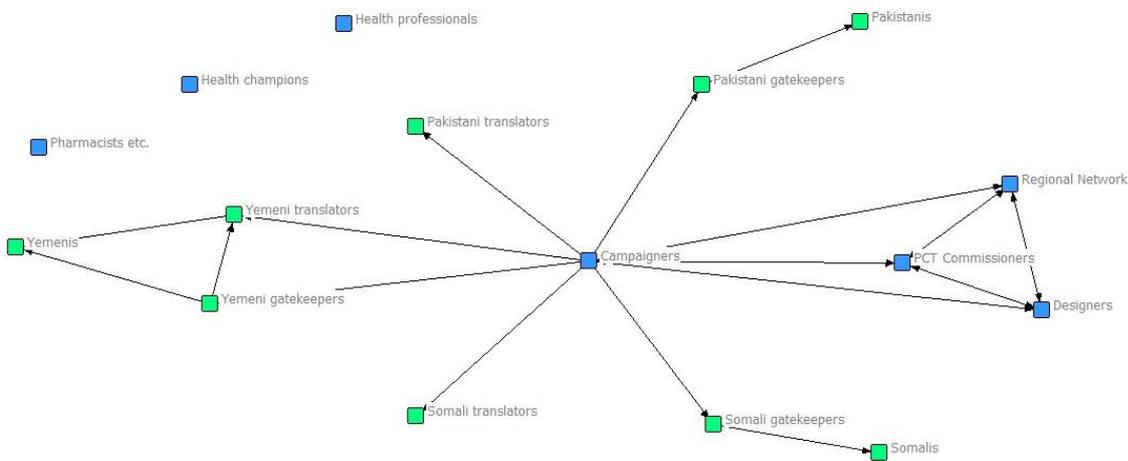
Figure 7.1 Network diagram: who involved whom (pre-production)?

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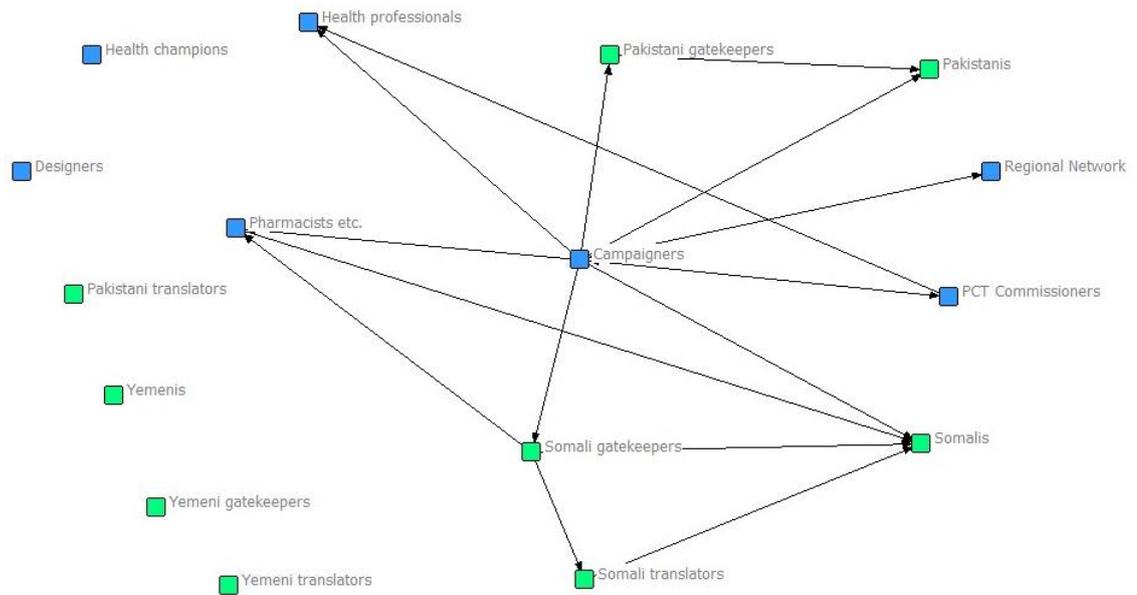
Figure 7.2 Network diagram: who involved whom (delivery)?
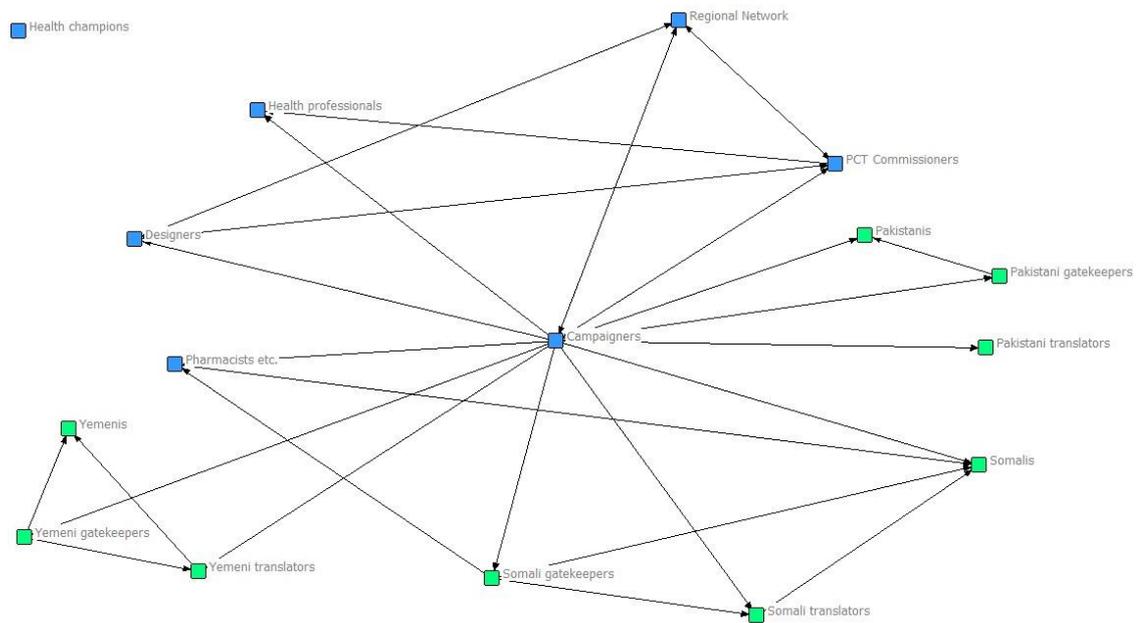
Figure 7.3 Network diagram: who involved whom (pre-production or delivery)?

Network maps of involvement have limitations. I did not assign a weight to the relationships (i.e. the edges of the network) according to their importance, although the level of involvement varies widely, as described later in the section. I also did not include my own role, since I "involved" most of the roles for data collection purposes only. Furthermore, I did not include unsuccessful attempts at involving actors, although such attempts had an impact on

the campaign as well. Noticeably, involving someone is not the same as having an operational relationship with him/her. The act of involving is directed (one actor requires the involvement of another) and not necessarily reciprocal. Additionally, the act of involving represents the initiation of a relationship between actors, without any direct link with its sustainability over time. During the pre-production phase, campaigners were by far the central role. They managed to involve gatekeepers in all communities, and through them, community members. However, the gatekeepers themselves decided who to involve in a specific community and in general, campaigners had no control on recruited participants for community sessions, during both pre-production and delivery. Hence, campaigners could perform no segmentation. As noted, campaigners could also not involve health champions, and managed to involve only a single health professional in the last steps of the delivery phase. Remarkably, campaigners and commissioners omitted other roles as well from the pre-production phase – such as pharmacists, librarians and other gatekeepers. Likewise, the Stroke Association could not be involved, several efforts by campaigners notwithstanding, and in spite of the fact that a Stroke Association representative sat in the Regional Network's Stroke Board. Campaigners tended to ascribe this difficulty to communication problems with the project board, and between the project board and other potentially useful contacts in the network.

During the delivery phase of the campaign, one whole community was not involved. Campaigners tried several times to set up at least a final event for the Yemeni community, but none of the established contacts proved useful in achieving the objective. Other roles omitted from the final phase were, understandably, designers (who had completed their job), and the Regional Network, who were waiting for the final evaluation. In addition, Pakistani interpreters were deemed unnecessary, given the perception by campaigners that Pakistani community members were proficient in English language. As observed, no significant interactions between members of different communities happened, and – with the only exceptions of pharmacists and one CLAHRC member – no one aside from the campaigners established contacts with any community member, gatekeeper, or translator.

What were the reasons for involving other actors during the campaign? The project board (and especially PCT commissioners) initiated the campaign by involving the company that had won the tender. Then, periodically, they involved campaigners again, mainly to monitor the process, evaluate the undertaken activities and make decisions accordingly, together with the Regional Network. Campaigners mainly recruited other actors to carry out specific work, according to how they perceived their potential role (see section 5.2): in particular, they involved community gatekeepers, designers and translators. Finally, the main role of

gatekeepers was to involve participants in pre-production and delivery sessions. Network maps give a clear representation of the division of labour within the campaign: a compartmentalized space emerged, since the involvement of actors proceeded in the form of a chain, with different levels of "outsourcing". For example, as mentioned, commissioners involved campaigners, who involved gatekeepers, who involved community members, etc. Consequently, there were few direct contacts between actors in different points of the chain, and this explains why – on several occasions – campaigners generally had not met most of participants before a session took place. For example, only a very small number of Somalis took part in more than one pre-production or delivery session. The campaign message thus reached more participants; however, contacts between campaigners and participants were occasional and brief, and both parties had difficulties in establishing a trusted and rich information exchange. In contrast, most participants in the two final events held in a Pakistani community centre had already been involved in pre-production, in the same place. Although they tended to be more open and even challenging at times, also because they knew the campaigners better, this raised an issue as well. In fact, the variety of points of view was minimal, and all participants belonged to the same group and attended the same community centre.

Such an issue seems in turn related to the channels used for involving participants in the campaign. The project board used a tender to recruit campaigners. Campaigners used lists of pharmacies, libraries and community centres to organize the distribution of materials, while the involvement of the Regional Network by PCT commissioners was part of specific institutional duties. Apart from these instances, however, almost all contacts were established (or attempted) through personal knowledge of campaigners, community gatekeepers, translators or community members and using a non-systematic approach. Especially for the involvement of community members, only informal channels and direct or indirect personal knowledge proved effective. The channel worked also for the involvement of designers by campaigners, and of the health professional by the project board. Channels such as advertising events through posters, or email contacts were usually ineffective. On the only occasion when campaigners directly advertised an event in the Somali community through email and advertisements, no one turned up to either of the sessions organized during a whole day. As a Somali gatekeeper says:

> "the community, mostly people rely on oral communication (…) don't read things, if you send them emails or (…) we hardly see people from the community carrying (…) diaries".

General reliance on personal contacts at all levels added to the perceived "informal" style of the campaign, which was on several occasions considered a positive attitude by campaigners to make contact with communities. However, an unsystematic approach to involvement also implied lost opportunities to establish contacts, and persisting uncertainty on how representative of the community the involved participants were.

7.2.2 The meaning of involvement: a qualitative analysis

This section analyses reasons for involvement, level and sustainability of involvement of actors over time. I interpret involvement here in a wider sense than in the previous section: it does not concern solely the initiation of the commitment of an actor to a campaign, but it also includes ongoing commitment to the whole project, or to some particular phases. Some actors were involved as a matter of commercial interest, or institutional duty. Even within those limits, the level of involvement and commitment varied widely, both between actors and for a single actor in different phases and moments. Project board involvement strictly concerned the organizational aspects analysed in section 4.2.2. In general, board members were only involved in the project on specific occasions, such as meetings. After the project redesign, PCT commissioners generally proved very slow to respond to the requests of campaigners and designers. Project board and designers perceived the campaigners' commitment as very high and commendable, and they praised the campaigners' enthusiasm and flexibility in adapting to continuously changing organizational priorities and management styles (see section 7.3). On average, campaigners showed a sustained commitment to the intervention over the whole period. However, even for the central role of the campaign, involvement was intermittent across the various phases. In most cases, delayed decisions by the project board caused this intermittency, while in another circumstance about two months were lost due to delays in payments and printing of materials. Sometimes, however, internal turnover and difficulties in making contacts with community gatekeepers made the campaigners' commitment intermittent, such as when – during the pre-production phase – five months were necessary to complete only six focus groups. Furthermore, campaigners had to work hard to sustain the involvement of the project board, much more than the other way round. It happened indeed quite frequently that campaigners sent updates, shared partial results with the project board, solicited comments and advice and requested contacts; on the other hand, there was very little pressure by the project board on campaigners to deliver expected outcomes.

For community gatekeepers and community members, the meanings of involvement are more complex. Firstly, they were in general involved on a voluntary basis. I have already accounted for the complex meaning of volunteering for the project in section 5.2.4. In the Somali

community, gatekeepers also used their role as acknowledged community leaders and their knowledge of the community to contribute to the campaign outside the centres and mosque, involving people in streets and squares, cafes, restaurants and shops. In the Pakistani community, gatekeepers operated almost exclusively within the boundaries of their community centre, and their contribution to the campaign was more limited. As for Yemeni gatekeepers, campaigners did not manage to involve them in the delivery phase of the campaign. Therefore, findings from this case study do not allow identification of a common attitude of gatekeepers towards involvement in a health promotion campaign. Campaigners perceived making contacts with gatekeepers as a difficult process: simply initially identifying gatekeepers through the NHS and making contacts was not enough, also because the project board lacked contacts with communities. As one campaigner put it:

"I had thought that we would be able to be put in touch with… many more people within these communities than we were able to by the NHS".

Campaigners had to build gatekeepers' involvement in several steps, and involvement had to be sustained over time and based on concrete requests and actions. Sometimes, campaigners had to overcome a threshold, before being able to involve gatekeepers. For example, a campaigner reports that people at a local BME community centre

"were […] quite difficult to get hold of but once we'd made the community contact, once […] seen as interested and involved, after that they were a great contact and were interested in us going backwards and forwards from the [community centre]".

Delays in project implementation led to lost opportunities to involve gatekeepers. According to a campaigner, they had to build contacts with communities too many times again from scratch during the project. Besides, she thought that intermittency of contacts added to the perception within the community that researchers and campaigners often came to obtain information, but then never returned to share what they had discovered or produced. She also observed how, ideally, contacts with the community should be "refreshed" every three weeks at least, to remain effective. This could be even more relevant given the high turnover I frequently observed within community members and gatekeepers. Campaigners were constantly worried about not being able to deliver what they had promised to communities. On the other hand, the structure of the campaign, with several different actors involved for relatively brief periods and no established agreements to sustain and replicate the health promotion initiative after the end of the campaigners' involvement, made the problem particularly difficult to address.

7.2.2.1 Community involvement

In the theoretical frameworks described in section 2.1, community involvement is considered vital for the success of CBHP interventions. In the specific instance, the project board and campaigners considered target communities as hard to reach, and community involvement would present challenges in itself. Did the campaign manage to obtain an acceptable level of community involvement? I have already analysed in previous sections the ambiguities of the concept of ethnic communities and the different expectations of the project board, campaigners and gatekeepers with regard to involving community members. Those factors influenced the perceived success of the campaign. For example, the project board, never involved in direct contact with communities, praised the attitude of campaigners and their ability to establishing contacts with communities. The designers as well defined a campaigner as

> "a fountain of knowledge [...] an expert in the field", due to "that one-to-one interaction with the end... community".

Campaigners themselves were quite pleased with their work, acknowledging in interviews their own ability in making contact with community gatekeepers and involving several community members during sessions. The analysis, however, showed different, complex dimensions of community involvement. Firstly, as discussed, "involving" someone refers both to establishing an initial contact, and to performing an activity producing tangible results according to a partially established method or process. For example, it is one thing to be able to organize a session with a number of community members, and a completely different thing to be able to obtain relevant information and translating it into evidence, usable as the basis for specific decisions. As for establishing contacts, I reported data about attendance to pre-production sessions in section 6.2.2.2. In delivery sessions, campaigners involved about 130 participants from the Somali community, and about 40 from the Pakistani community. No Yemeni community member was involved. In total, including the pre-production and delivery sessions, about 220 participants were involved. There were, however, some overlaps (i.e. participants taking part to more than one session), hence the number of participants involved was probably well under 200. The involvement of the Yemeni community was minimal (15 people, only in the observed pre- and co-production sessions). In the Pakistani community, there was the highest overlap in participants (section 6.2.2.2), therefore probably no more than 30 different participants took part in the sessions, all men, elderly, and routinely attending the same community centre. The Somali community was by far the most involved in the campaign, with some 150 participants in total, with minimal overlap. More than one third

were women, and the age groups were more mixed, although the elderly prevailed. I have no direct data about further diffusion of the message in the community, but five Somali gatekeepers reported in interviews that they personally promoted stroke awareness using leaflets in different locations, hence involving additional participants. From a quantitative point of view, therefore, the initiation of the campaign was quite intensive in the Somali community, while it seemed to produce very limited involvement for the Pakistanis and no involvement for the Yemeni. Even for the Somali community, however, it is noticeable that a campaign lasting for more than two years managed to reach directly only slightly more than 150 single participants with seven final events. However, given the innovative character of the campaign and the difficulties for this pilot project in establishing contacts, it would be unfair to focus only on the quantitative point of view when considering involvement.

It is also relevant to consider what happened once the contacts had been established – that is, the level of involvement, its intensity etc. For most community members, the involvement was very brief. Pre- and co-production sessions were short, and not all participants took actively part in the sessions. The same happened for the final events, when no session lasted more than one hour; excluding pre- and post-questionnaires, the interaction between participants and campaigners (occasionally supported by health professionals) was much shorter (lasting from 20 to 45 minutes). Campaigners tried to keep sessions interactive and language simple, stimulating participants to ask questions and checking their knowledge of stroke. Nonetheless, a consistently observed pattern was that a part of the audience did not interact, nor showed any particular interest. In several instances, some participants left earlier or arrived very late, so a part of the audience did not even listen to the main message; some other participants spent most of the time talking to each other. When feedback was required, often the majority of participants only gave very short, confirmatory responses, without enthusiasm or personal participation. This is unsurprising, if we refer to the barriers identified in section 5.4.2. In addition, although the campaign lasted for a long time, campaigners and gatekeepers organized the final sessions "at the last minute". Such a circumstance did not help to involve participants more in depth. Several gatekeepers raised the issue. One said:

> "the limitation of […] the campaign was actually time […] it was too fast and […] the emphasis was actually on holding these events and not, they were not much focused on the benefit of the awareness, so we wanted to hold the event as soon as possible".

Finally, campaigners delivered sessions in a standardized form, and pre-production sessions and final events tended to be quite similar (see section 6.3.3.2). As for final sessions, campaigners had originally devised to hold shorter sessions with smaller groups with a "train-

the-trainer" approach, with distribution of certificate of attendance. However, in fact, final sessions were all very similar, and campaigners did not place particular emphasis on training. Therefore, sessions followed a standard format, with explanations, some very brief questions and answers and no time for answering any question in depth. On occasions, both participants and campaigners regretted this, since stroke was an interesting topic for communities.

7.2.3   Barriers and facilitators for community involvement

The dynamics of involvement showed the patterns outlined in the previous paragraph due to the presence of specific barriers and facilitators to involvement, particularly for community members. Such factors were intrinsically relational –they do not seem to belong to a substantial nature of communities, but became relevant in the interactions happening during the campaign.

Gatekeepers' buy-in of the campaign's aims and methods emerged as a facilitator. Campaigners never attempted to approach community members directly; they always tried to obtain access through gatekeepers. When gatekeepers understood the importance of the initiatives for their communities, and acted accordingly, events were more easily organized, and both campaigners and gatekeepers considered community involvement as satisfactory. More noticeably, when gatekeepers took active part in sessions, participants showed more interest and sessions were more interactive, with a higher number of questions. For example, in a session, campaigners started the presentation before the community centre leader arrived, and raised limited interest. However, once the community leader acted as a translator in the session, participants almost stopped talking to each other and listened with much more interest. In another instance, the imam of the mosque hosting the session introduced the campaigner to the audience, underlined the importance of stroke awareness several times and linked it to religious themes. In turn, participants listened attentively and asked thoughtful questions, frequently interacting with the campaigner. In another mosque, participants attended a session with considerably less interest; in this case, the imam only briefly introduced the topic and the campaigner, and then left before the session started, while no other translator or cultural broker was available.

Involving communities in the organization of campaign events could also be a facilitator for active participation, as already mentioned. Involving community members directly in the practical organization of the events slightly differs from the concept of co-production, as applied in the campaign. Co-production implied that campaigners tried to acquire information from the communities, tested materials with community members, and involved community gatekeepers in the organization of events. Campaigners supervised the whole process from

design to evaluation. In the Somali community, an alternative and more "radical" attitude emerged. Gatekeepers started distributing materials themselves, autonomously raising stroke awareness between community members, i.e. taking control of the process. The two attitudes were not opposed in principle – the NHS may well want to initiate stroke awareness promotion in a "controlled" style, and then leave the initiative to the communities to make it progress further. They were however quite different, and the initiatives of gatekeepers were not taken into account and could not be evaluated as part of the campaign.

Trust was widely perceived as an important facilitator for involving community members in sessions. However, dynamics of trust were highly contextual. Firstly, campaigners had to obtain trust to access community gatekeepers. As outlined, this was a process, and not a single act; in addition, trust had to be reciprocal, to lead to positive outcomes. However, I could distinguish a narrower and a wider concept of trust. As for the latter, obtaining the trust of communities is a long, painstaking process, related to continuous involvement in community initiatives. One Somali gatekeeper states:

"being visible there and always supportive, being involved with local initiatives and championing people, […] build trust and bring […] good relationship in the communities, so it is easier for you then people trust you to do work with you, if you make sure that the community benefit and you try to build their long-term capacity".

During the campaign, however, actors tended to negotiate their involvement based on a narrower definition of trust, linked to establishing the minimum necessary conditions to overcome initial diffidence and start a productive relationship. Hence, both campaigners and gatekeepers focussed on a practical concept of trust, which they considered a prerequisite to carry out work with community members according to the sequence:

- being trusted;
- obtaining knowledge from informants;
- producing information corresponding to community needs;
- bringing culturally adapted and useful health knowledge back to the community for feedback;
- using trusted channels for delivering stroke awareness.

Due to intermittencies, however, this ideal cycle only seldom materialized and campaigners had to re-establish trusted contacts several times. Therefore, during delivery, campaigners mainly obtained community members' trust through gatekeepers' involvement; such trust was strictly contextual, and related to exchanging information and communication in the context of

a session. It is unlikely, however, that campaigners have establish deep, sustainable trust, and trusted channels would probably need to be re-established for further initiatives. In other words, there are different degrees of acceptance of an outsider inside a community context. Community members may accept outsiders along some dimensions, and perhaps kindly reject them according to others. Moreover, trust normally serves a purpose for both parties, and actors integrate it with their personal or group agendas. Further, both parties need to sustain trust over time with concrete actions. Consequently, trust seems a pre-condition for successful information exchange in health promotion, but it also seems that successfully delivering information suiting the needs of the community increases trust in view of subsequent occasions of health promotion. In contrast, lack of delivery of such information, probably decreases trust and makes more difficult the work for future health promotion activities: significantly, some community members commented that NHS members and researchers often come to their community, obtain knowledge and then never come back. Trust is therefore constantly fluctuating, subject to continuous behavioural evaluation on both sides, and in a complex relationship with information exchange and delivery. Finally, trust is personal, a matter related to how individuals perceive other individuals: "gaining community's trust" may not be a very meaningful expression. If an external company establishes contacts with specific community members on behalf of the NHS, it is difficult that the trust relationship remains sustained if in a brief time some of all of these actors change. It seems thus vital sustaining trust not only through a continuity of contacts, but also through continuous involvement in community activities.

Time was widely perceived as a barrier to an effective health promotion campaign in these communities, in the already described forms of intermittency of campaign activities, leading to lost contacts, the too short time to organize events and the insufficient duration of delivery sessions. Further barriers reported by interviewed gatekeepers related to economic/financial problems, linked to unemployment or difficult economic conditions of community members. Transportation, for example, was an issue perceived by most gatekeepers. A Somali gatekeeper said:

"one or two other people who I met after that event who didn't come to the event, they would say […] 'if […] they would tell us that you're going to pay us fare to come there, you know, or you pay us remuneration to attend, we would have attended".

Mistrust towards politics and the public sector also played a role in discouraging prospective participants. One interviewed Pakistani community leader observed: "if you came, they would

listen to you but not with the same concentration" since they would think that the outsider is there in the community just to "get their money".

Such an attitude resonates with the aforementioned incident (section 5.2.4), when a participant explicitly asked the campaigner how much he was going to be paid to hold the session. Also, mistrust or criticism towards the NHS (hospitals, GPs, etc.) was frequently expressed by community members themselves, both during interviews and in observed sessions; this may in turn have had an impact on the perception of stroke awareness sessions by participants and in their decision to be actively involved or not. On a related note, gatekeepers themselves, as they play an "interface" role between communities and the public sector, occasionally experienced diffidence or mistrust by community members. One of them reported that

> *"you sometimes feel reluctant to ask people to attend events, because people feel that they're doing you a favour in attending these events and you sometimes feel guilty asking them to attend, if they don't realise what the benefit for them to attend".*

Here, reciprocity works more like a "do ut des" ("I give that you might give"). Community members assume that the gatekeeper's interest is community members' participation in the session, while the prospective participant does not understand the potential benefits for his own health.

7.3   Multi-level judgements and feedback

In the section, I interpret evaluations, judgement or feedback on the campaign expressed by different actors. The result will be an analysis of the function, characteristics and dynamics of judgements and their impact on the campaign, rather than an evaluation of the intervention as such. I define judgement the expression of an opinion or evaluation of a fact or situation related to the campaign by actors involved. Feedback is a specific type of judgement, since it refers to specific products or events organized during the intervention. In particular, I will analyse the topics on which actors most frequently expressed value judgements: the content of judgements, who expressed them, and what purpose they served. Finally, I will take into account the consequences of judgements on relationships between actors in the network, and on the intervention itself. I discuss three main areas: appreciation of campaigners' work, judgement on the work of the project board and feedback from community gatekeepers or members.

7.3.1   Organizational feedback on the campaigners' work

According to a campaigner, commissioners expressed an "entirely positive" feedback on the insight report. More generally, organizational actors expressed positive judgements on the campaigners' work. As noted in section 7.2.2.1, designers praised the work of the campaigners as it allowed them to access knowledge extracted from communities in order to solve design issues. The project board appreciated campaigners' work for different reasons. Firstly, they considered campaigners as skilful and experienced in establishing relationships with hard-to-reach communities. The PCT commissioner in charge of the final phase of the project describes her role in the following terms:

> "My task was to organise, well, facilitate really, because the people […] involved with the campaign knew very well how to do the work […] because their experience of doing other campaigns in the past, so […] I was led by their expertise and […] their input, really, it's been excellent".

Similar comments came from Regional Network members, who highlighted that

> "This is their bread and butter. This is their work, […] on a daily basis. Work with hard to reach communities, […] you develop that expertise and that knowledge and that insight in terms of working in difficult environments".

The Regional Network member also said that campaigners adopted an "inclusive", "engaging" way of working, as opposed to the bureaucratic and intermittent approach to communities by the NHS:

> "There is something about how they work that is particularly engaging and makes you want to work with them. They have a non-judgemental way of working with you".

The project board also considered the campaigners' approach very innovative; one PCT commissioner thought that

> "there was nothing that I'd found anywhere that was similar, the co-production of materials in this way".

The judgement extended to the products of the campaign, although with some occasional criticisms. Another characteristic of the campaigners' encountering approval by the project board was their flexibility in adapting to changes and to the style of work in the public sector. According to a Regional Network member:

"we changed the scope of the project, because they were supposed to be taking forward five pieces of work and only ended up taking forward one, but their commitment to that project never changed".

The project board also particularly liked the campaigners' ability in carrying out qualitative research (in itself, very innovative for the NHS) and their skills in presenting and summarizing evidence from their field research both to the project board and to Regional Network's stroke board. All these judgements were clearly based on "evidence" (see section 6.2), and motivated with reference to specific facts and circumstances occurring in the campaign. However, positive judgements also confirm "a posteriori" that choosing an external company was a good choice – as it emerges from the explicit comparison between the NHS' "wrong" attitude towards community, and a perceived "right" attitude of campaigners. In praising the campaigners, the project board confirmed that outsourcing the campaign was a good choice. Further, positive judgements on campaigners' work contributed to establish and reinforce trust in their initiatives. However, they did not contribute to increase the direct involvement of the management in the project. Hence, the project board had an "external" point of view, as board members were not involved directly in the campaign. The content and facts they judged, therefore, were specifically related to outcomes and processes already reported, and thus filtered, by campaigners. The same is true for designers, who, in addition, were hired by campaigners – consequently their position may well influence the judgements they express. As an indirect confirmation, the point of view of one health professional on some activities of the campaigners (and project board) was slightly more critical, as reported in section 7.3.3. This may be referred to her different role, but especially to her position in the network, implying direct involvement in the delivery phase the campaign. Such an example seems to confirm that actors and roles in different positions in a network tend to express judgements, referring to the positions immediately linked to their own. In other words, they judge facts and events from a specific point of view on the network. Therefore, the more limited the number of contacts and the involvement of an actor in the campaign, the less complete the evidence base they can advocate as a basis for a judgement. However, nothing guarantees that being more central and involved in a network guarantees greater balance and objectivity in judgements. For example, in this case, campaigners were clearly the most central role in the campaign; nonetheless, they obviously needed to justify and "market" the outcomes of their work. Consequently, having a wider point of view is not necessarily a guarantee of an objective judgement, if vested interests represent a barrier.

Finally, and especially where a health promotion campaign targets a hard-to-reach population in a difficult-to-access environment, roles with a duty to evaluate outcomes may not be

located in the correct position to appreciate different aspects and points of view of actors in the network. This means that, for example, they may base their judgement on general impressions built on already filtered reports, since they are not in a position to form an independent opinion through direct community contacts. Furthermore, they can relate judgements to objectively low expectations – i.e., to the fact that the campaign is a first contact with communities, the project was only a pilot, very little is known about those communities' attitudes towards health, etc. In such cases, thus, an external observer (as a researcher), in spite of his/her subjectivity, prejudices, and personal points of view, may considerably enhance the variety of points of view on which a project board can express an informed judgement on a health promotion campaign.

7.3.2 Feedback on the work of project board

Actors express judgements at multiple levels, and concerning different objects. A rich and nuanced theme concerns judgements about the workings of the organizations in charge of commissioning, monitoring and evaluating the project. As displayed in Table 4.1, the campaign showed considerable turnover of people in charge, change in focus after some months, and a long time between design and delivery. Both project board members and campaigners judged causes and effects of these issues.

7.3.2.1 *The influence of turnover and the lack of organizational alignment*

Firstly, the project was strongly advocated by a NHS public health consultant (the initiator), who eventually left the organization. After the initiator left, there was a wide turnover and reorganization of the project, with new actors and a change in roles and responsibilities (see section 5.2). Most interviewees thought that the initiator's role was very important. According to campaigners she

> *"was an advocate of the project and having a clear direction of where she wanted it to go",*

while according to a Regional Network member the initiator

> *"was the driver for this project and I think once she wasn't there […] once she […] with that vision and that motivation and that responsibility and that drive wasn't there, that project lost something".*

Remarkably, in her interview the initiator was confident that – once she had left – the project would be completed quickly and successfully. However, the perception of other actors and the "real" situation were very different. In fact, after the initiator left, the project experienced serious delays. Thereafter, the network of organizational actors underwent reorganization.

According to a widespread perception, from that point onward, the project had lost strong leadership. On a positive note, a Regional Network member perceived leadership as "collective […] depending on what element of the project we're talking about".

This in turn allowed for a collaborative style in the management of the campaign. Such style spontaneously emerged although the project board had not made any explicit agreement on it. On the other hand, most actors acknowledged problems with the management of the campaign after the turnover, ascribing them to different factors. The new lead PCT commissioner expressed the following judgement on the involvement of her own organization:

> *"I don't actually think the NHS has contributed a whole lot in terms of this project. And that's partly because I feel that other colleagues in the NHS ha[ve] not taken this work forward in the way that it should probably have been taken forward. Because […] stroke care was meant to be an exemplar for the city or nationally and it didn't really get that far, because [the initiator] left and there were all sorts of changes within the NHS here, so really it lost its momentum from that point of view".*

In other words, organizational changes affected the ability of the project to deliver what was expected. Similarly, a campaigner thought that the causes of problems in the campaign management resided in a lack of organizational alignment, in spite of the interest showed by individual members of the NHS. For a project to succeed, in her opinion

> *"you need everybody, from […] people at the very top […] making the decisions to the people who are working with the communities to[…] want to do something, because unless you've got […] NHS and the steering group here driving things forward for you, […] there wouldn't be any point in [the company] doing any work with anybody".*

This only happened to a limited degree, and made especially difficult for campaigners to establish contacts with communities through the NHS. Moreover, at times PCT commissioners and the Regional Network expressed different requirements as for target communities and expected outcomes. According to Regional Network members, however, the main cause of management problems resided both in the confusion of roles described in section 5.2, and in the internal organization of the PCT. A Regional Network member observed that the whole NHS was involved in an important reorganization process, hence

> *"because of the reorganisation […] people's portfolios change, they take on additional responsibilities because other people leave or because of restructuring. And people then have to look at where their priorities are".*

In addition, the new project board established new priorities, and a new style of work. While in the initial phase the responsibilities lay mainly with the PCT and the initiator, with the new

board the role of the Regional Network increased, and more attention was devoted to details and sign-off. One campaigner said that

"a different agenda came in […] But […] there's positive and negative. […] we suddenly had someone […] who wanted to make sure things were done in a very rigorous way in terms of sign-off and direction, and making sure that it was discussed at multiple levels […], whereas before [the initiator's] role was more, 'well, let's get it done' ".

7.3.2.2 Causes and influence of delays

All interviewees agreed that – whatever the reason for the delays – these were detrimental to the project. According to a campaigner, between the first and the second phase

"there was a huge gap, because [the project] got lost between [the PCT] and the network and they didn't know who was funding it or who was in charge"

Consequently, campaigners thought that they could not meet community expectations, and relationships would be difficult to rebuild afterwards. PCT commissioners acknowledged the long time it took to obtain the final products for the project – and ascribed the responsibility for this delay jointly to PCT commissioners and the Regional Network for the slow decision making process on funding the second phase of the campaign. A Regional Network member, instead, thought that the lack of clear responsibilities and leadership on the project was the origin of all delayed decisions during the campaign:

"every time there was a major decision to be made it comes back to this stumbling block".

However, interviewees acknowledged that the need of becoming acquainted with each other and understanding the priorities in the "new" project board played a role as well. The Regional Network member also linked delayed decision making both to a lack of motivation by PCT commissioners, and to the fact that several steps were needed before making a decision inside the Regional Network itself.

7.3.2.3 Refocusing the project

Different actors expressed judgements about the decision of targeting the project only to the Yemeni, Somali and Pakistani communities in the city. According to campaigners, this decision detracted from the project, since they could not use many contacts they previously established with communities. They thought that the relationship between the NHS and the gypsy community would particularly suffer, since the latter would feel left behind. According to a campaigner, the decision to break down the delivery phase of the project into several smaller

locally-led initiatives related to the changes in the NHS. He observed that PCT commissioners wanted to emphasize the wider dimension of the project, to cope with nationwide changes and reform. The campaigner based this judgement on facts, but at the same time, the judgement could have been influenced by the fact that the project board commissioned less work to his company, than originally agreed. Moreover, according to campaigners, PCT commissioners focussed on selected BME groups because this choice "ticked more than one box", since both stroke and BME communities were a priority. They also thought that the choice might have been related to personal knowledge of some of those communities by the PCT commissioner, who eventually confirmed that she had previously done assessment and health promotion work with them. A Regional Network member thus explained the decision to split the project:

> "capability, capacity, resilience, people in the organisation to take forward the work in [the PCT] changed and their view was that they no longer had the capability to work with [the external company] and [...] take forward all five [...] pieces of work".

Finally, PCT commissioners observed that refocusing the project on three communities was functional, since they lacked understanding of the FAST message, and the NHS needed to establish and reinforce links with them.

7.3.2.4 Future sustainability

Finally, actors frequently expressed judgements on the sustainability of the results of the campaign once the company ends its direct involvement in the project. Campaigners were worried about this problem, since the NHS did not put in place any strategy to keep promoting stroke awareness in BME communities, although campaigners had recommended that both Stroke Association and the health champions, trainers and community workers be involved. According to a campaigner, the risk was not only of losing benefits of stroke awareness promotion over time, but also of losing relationships built with the communities, "because people don't know where this type of work should sit within the NHS".

The PCT commissioner partly confirmed these worries. She seemed aware that "who takes over what happens with this information" was an open issue, and she admitted not having a solution, at the moment of the interview. Additionally, she highlighted some barriers to take into account, such as the lack of staff, and the process of moving the public health sector from the NHS to the local councils by April 2013.

7.3.2.5 *Summary and interpretation*

To summarize, most judgements by actors in the network were negative towards the role, actions and level of involvement of the NHS. These judgements led the campaigners to try to establish contacts directly with communities, and to express worries about the sustainability of the stroke awareness project in the future. At the same time, negative judgements on PCT commissioners' role and involvement by Regional Network members may have contributed to delays and difficulties in decision making during the campaign deployment. Actors expressed almost all judgements only during one-to-one interviews. To my knowledge, therefore, there were hardly any occasions when they expressed judgements directly in the presence of other actors. This highlights the lack of open communication channels between actors in different roles. In such a case, being part of the same network of contacts and taking part in project board meetings did not allow to express judgements in the course of the project. Consequently, neither the project board nor the campaigners could take any remedial actions for problems that had arisen. Furthermore, the complexity of judgements taking place in the organizational area of the network is patent. When coupled with a lack of open communication, it is likely to generate a situation in which a multiplicity of network channels between different actors is formally open, but in practice acts as a barrier to jointly carrying out work. Finally, most of the judgements described in paragraphs 7.3.2.1 to 7.3.2.3 were double-sided, as already observed in section 7.3.1. On one hand, they referred to facts; on the other hand, "passing the buck" or highlighting issues in the organizational behaviour of other actors constitutes and implicit "a posteriori" justification of their own choices and activities. Hence, actors constructed a series of non-shared narratives about specific problems arising during the campaign. Issues are linked "a posteriori" to different elements, and links have different levels of plausibility. Once again, however, such narratives had only local "validity" related to specific nodes in the network, and did not contribute to a better understanding of global dynamics.

7.3.3 Feedback from "inside" the campaign: gatekeepers, community members and health professionals

7.3.3.1 *Community sessions*

Feedback on single campaign phases expressed by actors directly involved focussed on specific details of the campaign, such as materials, events, sessions, and other practical aspects. As for pre- and co-production sessions, I have already pointed out the short time available and the lack of reciprocal knowledge between campaigners and participants, along with some translation problems. Under such circumstances, it is hardly surprising that indirect feedback from sessions' participants was generally mixed. Session participants did not directly express

feedback on the sessions as such; however, I could indirectly infer how participants judged the session by how they participated. Level of involvement in sessions was variable. On several occasions, after a campaigners' question about stroke awareness, materials' production or events' organization, feedback was very scarce. Lack of feedback was particularly visible in the two sessions with Yemeni community members and in the two sessions in which campaigners submitted draft leaflets and posters for review to Somalis and Pakistanis. This was also partially the case with the Somali men, while on average Somali women and the Pakistanis were much more articulate and interactive during pre-production. In the majority of observed sessions, either there were frequent instances of absence of feedback to a question, or of very brief, confirmatory feedback; articulate answers, with lots of details, tended to be the exception rather than the rule. Two examples from my field notes illustrate the point.

> *"The campaigner asks: would the level of knowledge of stroke symptoms and related actions differ between younger and older generations? Participants agree that this is possible, but without giving further explanations".*

> *"The campaigner asks: what would it be better to avoid when running seminars? Participants do not indicate anything in particular to avoid. They joke and laugh about that".*

Participants did not actively refuse to contributing feedback, but participation was generally scarce in terms of contributing rich details about the community and its level of stroke awareness, although occasionally relevant details emerged. In almost all sessions a relatively small number of participants gave campaigners detailed information they deemed sufficient to back their decisions.

7.3.3.2   *Feedback on leaflets and posters*

The two testing sessions organized with community members to test draft leaflets and posters were admittedly practical, aimed at establishing whether the printed text and images were understandable by lay people in the community, correcting mistakes, etc. From this point of view, the sessions reached their aims, since even with a small number of participants it could be verified if the text was understandable and the images raised the right mental associations with stroke symptoms and related behaviours. However, interest and participation by community members was low. It is also unclear what decisions may have been made, should a negative answer have been received to questions related to the shape of the leaflet or the positive value of the "shocking" image on it, since the draft was already in its final version. Additionally, feedback on materials was collected during observations or interviews conducted during the initiation phase of the campaign. Here, judgements on leaflets and posters are

mixed, and vary according to the roles of actors. Designers stated how they explicitly devised the leaflets to be "different" from the standard NHS health promotion leaflets, so that they could stand out wherever they were distributed. They emphasized that, surprisingly, the NHS had approved their original design, since guidelines for producing NHS-branded health promotion materials apparently prescribe a very different layout and choice of colours for leaflets. Both PCT commissioners and Regional Network members praised materials for their originality. According to a PCT commissioner, the leaflet

> "is very different to anything else and […] tells the story in a different way and […] you can tell that it's been produced by the communities and I think that's important to hang onto because it's different, it's a different way, and they've been able to get their message across".

Such a "difference" was conceptualized alongside several dimensions by different actors, and went beyond shape, design and colours (see also section 5.3). The use of Urdu, Arabic and Somali language positively struck several community gatekeepers and members; this resonates with the fact that campaigners and community members had co-constructed language as one of the basic tenets of ethnicity (section 5.3). Furthermore, during pre-production sessions almost all groups were in favour of having a leaflet translation in Somali, Urdu or Arabic. For example, a Somali gatekeeper and translator comments:

> "when they put them posters in like a GP or something like that, and you would look at it in your language, automatically, you kind of have a look at it […] some they don't speak English. […] So […], as soon as they see the Somalian [sic] leaflet, they're going to pick it up, have a go for it".

Another Somali gatekeeper adds:

> "as soon as you translate it to a different language then you relate it to the community, so if he doesn't read it, he'll take it to somebody else in his community who will read it, yeah, oh this is a Somali so he'll start reading it to Somali people".

Hence, connection with the communities was another important, positive dimension of the leaflet, according to community gatekeepers, also because two Somali community members appeared on leaflets and poster as actors. Reportedly, this generated some confusion, since some community members worried about the fact the actor had really suffered a stroke; however, other gatekeepers thought that the presence of local actors attracted readers for leaflets as well. In addition, most actors perceived the leaflet as very "visual", as opposed to usual, text-based health promotion leaflet. Community members had underlined the

importance of the visual element of materials during pre-production sessions, and designers took it into account. Campaigners also preferred to rely on images since they thought that a part of the target audience would have difficulties in reading even community language. Feedback from most actors was positive. For example, the PCT lead commissioner commented that the leaflet

> *"was very visual, and there is something about being able to use visual prompts to put over a message, […] that's […] the most striking bit".*

This positive comment was echoed by the person who had initiated the project, with particular emphasis on the storyline featured in the internal part of the leaflet (see Appendix G). Moreover, most gatekeepers agreed on such a judgement. One of them commented:

> *"[the] leaflet […] is very clear and the message is very easy to understand and […], it was the pictures more than the written word, something visual, the community can relate to" (Somali gatekeeper).*

However, the health professional expressed some criticism on the balance between text and image:

> *"there was a lot of stuff on there and I wondered why it was so different from the ordinary FAST test leaflets".*

She therefore implied that "difference" of the leaflets and posters might prevent the target audience linking its content with the widespread FAST advertisement available through different channels.

However, actors also considered visual elements important because they related to the story told in the leaflet. As discussed in section 5.3.1.2, and as reported by designers

> *"the fact that these communities related to storytelling […] had been mentioned from the beginning".*

Hence, designers incorporated a story in the internal part of the leaflet, where they represented two courses of action: the right one, leading to recovery, and the wrong one, leading to a bad prognosis after stroke (see Appendix G.1). Two Somali gatekeepers showed appreciation for the narrative structure, since they considered it a successful attempt at integrating abstract concepts with concrete facts, situated in community places and linked to the life of communities.

There was further feedback about visual aspects and storyline, though. Firstly, some actors perceived the visual impact of materials as too strong. This was partly an intended consequence, since the campaigners had intended that materials

"be shocking […] to an extent, because that's a call to action, […] it triggers something in somebody's […] head to say […] this is serious".

Community feedback on the shocking nature of materials was polarized. According to two Somali gatekeepers, leaflets and posters were not scary; if someone in the community thought they were, "this is a personal opinion. It's not the opinion across the whole". Furthermore, during the testing session with three Somali community members, the campaigner had asked whether

"the image […] [was] too 'horrible' (because there is the brain coloured in red, etc.) or […] is acceptable for the community".

On this occasion, participants had said that it was acceptable, but without explaining why. According to other actors, however, the "frightening" aspect of leaflets and poster may turn away people from them. A Pakistani community leader suggested people should be slowly introduced to a subject, instead of frightening them. He advised that it would be good just to use the word 'stroke' or a logo, on the leaflet, not such a scary image (see Appendix G) – a suggestion echoed by Pakistani community members and from a GP assistant. One Somali gatekeeper explained how leaflets appeared scary at a first glance; however, if one read the details, he/she "will understand immediately" what the leaflet was about. On a related note, the initiator of the campaign commented, after seeing the final products:

"I also showed the materials to other people and they were very much liable to be misinterpreted because of the visual/script not being clear enough. Someone illiterate did not get it at all until I explained it".

Another Somali gatekeeper thought that

"the leaflet and the poster was great. […] it only just needed a little bit of explanation, […], somebody to explain little bit more".

This resonates with a suggestion expressed in the Yemeni pre-production session, where participants had observed that leaflets were good, but not in isolation, since some talk about them was necessary. This echoes another observation from the initiator:

"When we started I wasn't […] just thinking of posters and leaflets. […] I was thinking of creative ways of getting a message across, […], poems or rhymes or visuals or […] drama. […] yes […] [posters and leaflets] are targeted but to make a difference you need other innovative ways of passing on the message".

Hence, there were alternatives, possibly more effective in targeting the communities.

7.3.3.3 Summary

In summary, the campaigners actively wanted community members to express their judgments and feedback during pre- and co-production sessions and responded to these with tangible actions. Feedback on materials once they circulated was articulate, complex and often not unanimous. Obviously, it also did not lead to concrete actions, since campaigners could not consider it for the initiation phase of the campaign.

7.3.4 Concluding remarks

Feedback and judgements varied widely across the campaign. They were expressed on different topics; they varied in object (campaign materials, organizational behaviour, etc.), scope (specific to general), and effects (some feedback was a concrete basis for direct action, others failed to trigger relevant initiatives). In addition, actors situated in different points of the network, and who could often not reach each other, expressed feedback and judgements on topics relevant for the campaign; hence, such judgements tended to have only local effects. On some occasions, actors being "judged" knew the opinion of other actors on their behaviour and actions, while in most other circumstances this did not happen. Finally, actors did not base their judgements on evidence but on anecdotes and personal perceptions. By expressing judgements they often justified their own actions and behaviour "a posteriori" and in narrative form.

By expressing a direct or indirect, positive or negative judgement, actors made significant contributions to the campaign. However, except for the pre- and co-production phase, the campaign seemed to lack quick, ready and effective ways to capture judgements and feedback and make them effective in correcting and improving the organization and outcomes of the campaign itself.

7.4 Interactional and adaptive decision making

It is important to understanding what decisions were made, by whom and through which network processes in interpreting the workings of the campaign, and in particular, how it moved from brief to delivery stage. Therefore, this section explores different dimensions of the decision-making processes, including how rational, formalized and linear decision making was, whether it lead to expected or unexpected results, and finally the impact of network

interactions on decision making. In the campaign, decisions were acts of choice between different possible courses of action, made in a specific moment and by one or more actors, leading to significant outcomes. All elements described so far had an impact on decision making: roles, position in the network, available evidence, level of involvement and implicit or explicit judgements expressed on a context.

For example, campaigners decided how to recruit community gatekeepers through their personal contacts with communities rather than with the intermediation of the NHS, according to:

- self-perception and interpretation of their own role and of other roles, and what such perception entailed in terms of making contacts with communities;
- their level of personal and professional involvement in the campaign (priority assigned to the campaign, personal and professional values, etc.);
- evidence collected and judgements expressed about the role of the project board in helping to make contacts with communities;
- their own position in the networked space/time (number of contacts with communities, personal knowledge of community members, tightness of schedule, etc.).

However, those determinants of decision making tend to act in the background, and to influence only indirectly the decision making process. In fact, decision making followed specific patterns and dynamics that cannot be reduced to background factors. Firstly, decision making was hardly ever formalized by any of the actors in the campaign. It happened according to contextual constraints, anecdotal evidence, and reaction of actors to specific situations. Secondly, the process was seldom linear: both at the organizational (macro) level, and at the level of interface interactions between campaigners and communities, it was hardly ever the case that actors smoothly followed a devised course of actions from premises to consequences. Mostly, they adapted actions to unforeseen circumstances; hence, courses of action heavily depended on networked interactions between actors and led to outcomes that were considerably different from initial expectations. Hence, no strong influence of rational planning or rationalized decision making procedures appear to have influenced the course of the campaign. The differences between project and implementation, dependent on decision making, were visible at different levels.

7.4.1 Decisions related to campaign development

As described in section 4.1, the campaign moved through different phases. However, for the most part, the movement was not linear. This implies that the campaign progress was only partially the product of a series of conscious decisions between alternative, clearly outlined courses of action. On the contrary, I could distinguish a series of transitions between different phases, often mediated by delays and stand-by phases. In such a situation, "deciding to do (or not to do) something" was as important as "not deciding to do something", which equated with preventing something to happen (at all, or within a given time frame) since no explicit step was made by any actor to attain a certain goal. Analysing data related to the progress of the whole campaign, I could distinguish different decision-making processes, influencing the transition from one phase to the next. Figure 7.4 shows the differences between the sequence of actions in the campaign that had been initially devised, and what really happened.
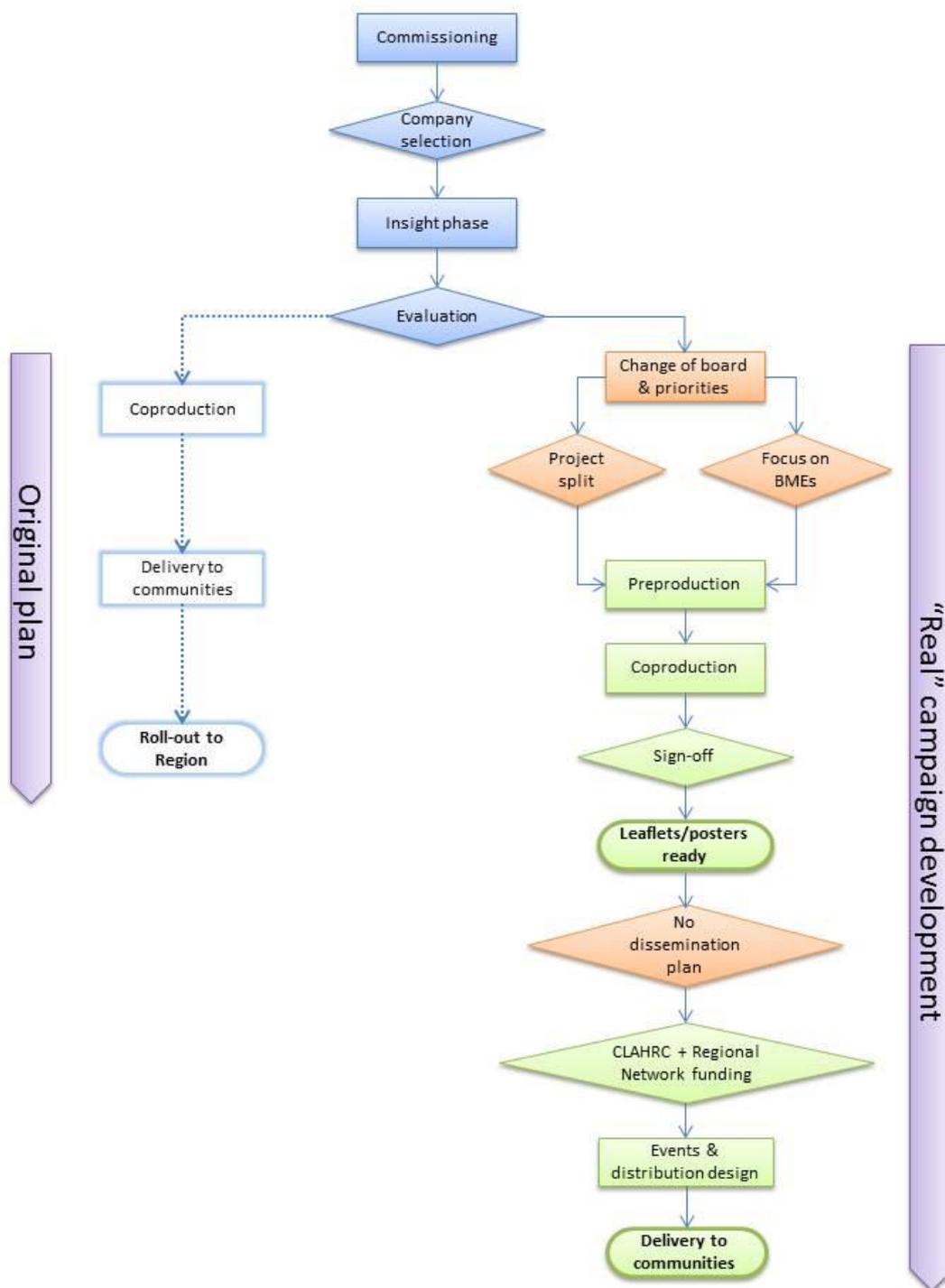
Figure 7.4 Differences between the original campaign plan and the real implementation

After the evaluation of the insight report, expected and real campaign development started to differ significantly: I described in section 4.1 and analysed in section 7.3.2.3 the sequence of events that led to focussing on three communities and to split the project. The latter, as a result, had to redesign the pilot phase of the campaign. The recruitment of community members was quite complex and depended on a wide range of micro-decisions and contextual

factors, including the following: previous knowledge of community gatekeepers, through contacts established during the insight phase; ease of access to gatekeepers and community members; lack of NHS contacts with communities (see section 7.2). Once contacts were established, campaigners only partially formalized the process of extracting information and knowledge from communities. In turn, such an approach led to a series of decisions about the best ways to carry out the stroke awareness campaign in targeted communities, which – while being linked to preferences expressed by community members – were not clearly formalized by campaigners and the project board. Consequently, there were no clear reasons why the campaigners and the project board chose leaflets, posters, and sessions, while excluding other potentially useful strategies (theatre and role plays, train-the-trainers approaches, etc.). Moreover, in designing leaflets, posters and sessions, there were several phases when individuals made decisions, hardly based on any kind of evidence. As noted, feedback by community members and the effective utilization of such feedback in designing and revising materials and sessions was also necessarily limited, given the approach and the contextual constraints. Once the materials had been designed, the project faced another period of inertia. While appreciating the campaigners' work, PCT commissioners and the Regional Network had not devised any plans for printing and disseminating materials and promoting stroke awareness in the communities. As for the campaigners, they felt that their involvement would need to end with the design of materials, since no funding was available for further paid work. Consequently, other organizational actors (Regional Network and local CLAHRC) had to ensure funding for printing the materials and initiate a dissemination phase in the communities (section 4.1). The input led to the need for additional decisions: PCT commissioners needed to approve the plans for dissemination presented by campaigners; the project board had to sign off the materials and establish adequate copyright agreements with the designers. While approval by commissioners was relatively straightforward, copyright agreements took slightly longer, and involved a negotiation between the project board and designers (section 6.3.3.1). Finally, once the materials were ready, campaigners and the project board decided which areas of the city to target for the distribution, and specific venues within the areas. Campaigners also decided, with community gatekeepers, where to hold final events, and for what communities. Campaigners also planned the choice of areas and venues for the distribution and substantially carried it out according to the plan, although the results were not in line with expectations (see section 6.3.3.3).

On several occasions, campaigners had to adapt to external circumstances, and decide the best course of action. They had to decide on a range of issues, from practicalities in the management of sessions, to situations in which they used the feedback from community

members to modify leaflets and posters, to a complex sequence of micro-decisions involved in the design of materials carried out in collaboration with designers. However, decisions related to the contents of sessions presentations were rarely linear (see section 6.2.2.1), and the choice of venues and format for final sessions was highly dependent on the level of involvement of community members and gatekeepers and time available. Not all the consequences of such an adaptive attitude were negative, however: following the suggestions of a Somali community gatekeeper, campaigners and the health professional carried out a previously unplanned informal health promotion session in a café, and this raised interest and participation in the community.

7.4.2 Interpretation

I found that decision making processes rely on different factors: level of planning and formalization; adaptation to contextual constraints and opportunities; involvement of actors with specific roles. I will show in Table 7.1 a synopsis of the main characteristics of decision making processes.

Decision making process	Main roles in charge	Other roles significantly involved	Process complexity	External constraints	Adaptation to constraints	Formalization of process
Project splitting / refocusing	PCT Commissioners, Regional Network	-	Low	Changes in board and priorities, health care reform, funding problems	High	Low
Pre-production: recruitment	Campaigners	Community gatekeepers	High	Access to and level of involvement of community gatekeepers and members	High	Medium
Performing pre-production sessions	Campaigners		Medium	Access to community members	Medium	Medium
Summarizing knowledge into campaign products, through co-production	Campaigners		High	Time, limitations of sessions	Medium	Low
Design of materials and choice of health promotion strategies	Campaigners	Designers	High	Adherence to community preferences	Low	Low
Further funding of project	Regional Network, local CLAHRC	PCT Commissioners, Campaigners	Low	-	Low	Low
Designing and performing materials distribution	Campaigners	Regional Network, local CLAHRC	Medium	Time, access to and level of involvement of pharmacists, librarians and community centre leaders	Medium	High
Sign-off of materials and copyright agreements	PCT Commissioners, Regional Network	Designers, Campaigners	Medium	Time	Low	Medium
Organization of events	Campaigners	Community gatekeepers	High	Time, access to and level of involvement of community gatekeepers and members	High	Low
Delivery of events	Campaigners	Community gatekeepers	Medium	Time, access to community members	Medium	Low

Table 7.1 Characteristics of decision making processes - synopsis

In the table, "main roles in charge" were chiefly responsible for making a decision, while other roles significantly involved in specific aspects of decision making were listed in the adjacent column. I did not measure process complexity according to specific parameters, but it emerged from data, in terms of intrinsic difficulty of making a choice, number of actors involved, difficulty in accessing an environment and building evidence to support the choice. External constraints were significant contextual factors having an impact on decisions, while the level of adaptation to constraints indicates the degree to which actors had to change initially devised decisions according to contextual variables. Finally, formalization of process indicates to what degree actors carried out a given decision making process according to formal procedures, both verifiable and transparently accessible to all actors involved.

The campaign involved several high- and medium-complexity decision making processes. The most complex related to activities directly involving contacts with communities. However, there was no direct relationship between the complexity of a decision making process and the level of adaptation to external constraints or the level of formalization. In general, where important constraints existed, there was considerable adaptation by actors, both for high-level decisions (e.g. funding, evaluation, etc.) and for more concrete decisions concerning the development of the campaign. Accordingly, the level of formalization of decision making was generally low, as actors usually followed very few explicit procedures to produce a decision. As a result, the development and evolution of the campaign seem driven by adaptation to opportunities and constraints emerging from fieldwork, more than by adherence to formalized prerequisites and procedures. The move from one phase to the next obeyed most frequently to complex and often unpredictable dynamics of transition, in which "absence of decisions" and implicitly discarded alternatives played a major role. Actors seldom followed a predefined plan from beginning to end; far more often, decisions were based on time constraints, capacity to involve communities and other external factors. Hence, actors in the campaign seemed to react constantly to external circumstances, more than following a clear path towards an end – although they could generally reach the initial aims, at least in part.

To reach a deeper understanding of decision making processes, however, it is also necessary to analyse the role that different roles played in some choices, either in isolation or jointly. Figure 7.5 summarizes the relationships between processes and roles, and the interaction of roles in making decisions.
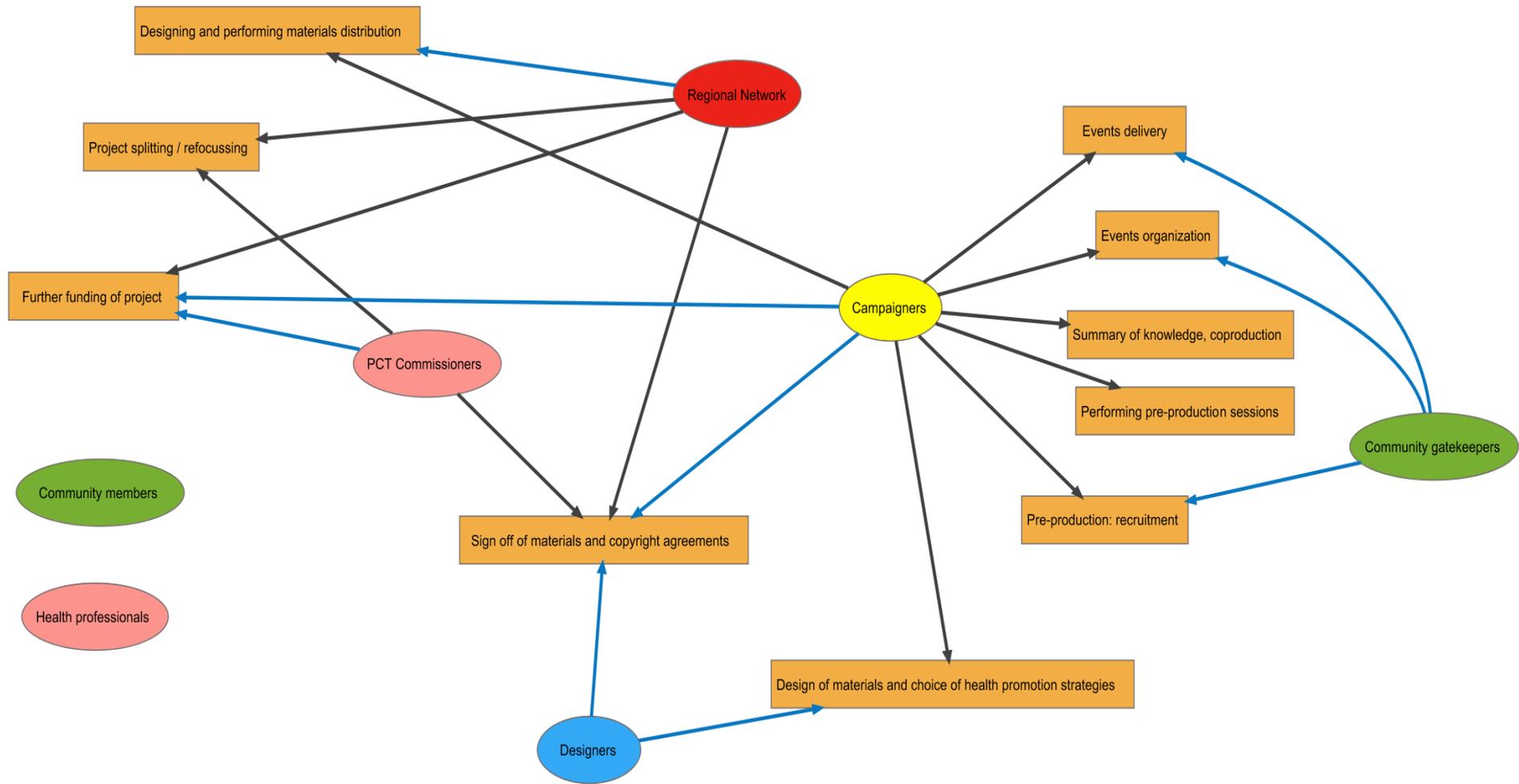
Figure 7.5 Roles in charge of or contributing to decision making processes

I represented decision making processes with square, orange boxes, and roles by circles. A black edge between a role and a process indicates that the role was mainly in charge for the process, while a blue line indicates that the role significantly contributed to the process. As in other network interactions, campaigners are central in decision making in the campaign, as far as field activities are concerned. However, they were not directly involved in one of the key decisions of the campaign, namely the splitting of the project and the focus on specific ethnic communities. On the other hand, the health professional and community members did not play any direct role in such processes, while community gatekeepers were in charge only of practical contribution to decisions related to event organization and participants' recruitment. Furthermore, organizational actors (including the project board) did not play an important part in making, stimulating or contributing to decisions related to fieldwork. There was a clear distinction between actors in organizational roles and actors in field-related roles; noticeably, targeted communities only marginally contributed to key decisions in the development of the campaign, although they contributed important information, forming the basis for many choices. Finally, one of the campaigners reported that, during the five months when the project board made decisions about the production stage of the campaign, "there was a lot of behind-the-scenes stuff going off there". Similarly, the health professional involved in the community health events observed:

> "I feel like I've not understood really where this has all come from, who's organising it, how it's being organised, it's all been a bit of a muddle to me!".

These quotes summarize the perception that actors not directly involved in decision making processes had of how and why some choices were made by other actors. According to the position of actors in the network, and to their effective involvement in decision making processes, some mechanisms of the campaign may have been non-transparent, a sort of "black boxes" whose internal workings were not known. In addition, as the only link between the organizational level and the target communities were the campaigners, community members involved in the campaign had no view on the other region of the network, and therefore they could not understand reasons behind delays, changes in programs of the campaign, etc. In other words, if the perception of communities by actors in organizational roles was mediated by campaigners' reports, community members and gatekeepers had no idea about what was happening at the organizational level that they confusedly perceived as "the NHS" "the Council", etc. It is thus possible that the overall characteristics of the campaign's decision-making processes have limited the effectiveness of the co-production approach envisaged by campaigners and explicitly chosen by the project board.

Chapter 8   Summary of findings, discussion and conclusions

8.1   Introduction

The present chapter aims at summarizing key findings, connecting them to my research question and objectives and discussing them in the context of the published literature. I will highlight strengths and limitations of the research, and discuss the implications for policy, practice and future research. A conclusion will summarize the main message of the thesis. I will show in section 8.3 that the literature on networks in CBHP highlights their importance for the promotion of knowledge dissemination to communities, and of learning to practitioners and organizations. Sometimes, however, they seem to represent barriers to diffusion of innovation. Network interactions may also help in coordinating actors and actions within a health promotion campaign; depending on their structure, however, they may constitute a barrier to coordination as well. Finally, networks are known to be referred to an increase in social capital in communities targeted by health promotion interventions. However, networks generally need optimization in health promotion interventions. Findings from this research fit within such a general framework; in addition, they may illuminate some specific mechanisms of network interactions possibly relevant for understanding and monitoring the process of a CBHP intervention, described in the network-oriented facilitation framework (section 8.4).

8.2   "Situational sense-making": summary of key findings

My research aimed at understanding how interactions happening in social networks may influence the development and initiation of a health promotion campaign aimed at increasing stroke awareness in BME communities. In particular, it was vital to analyse what characteristics of social networks were relevant for campaign-related activities; to understand how actors acquired, generated and translated evidence about stroke awareness and how they acquired, managed and disseminated information; finally, to grasp network dynamics and mechanisms influencing campaign development and initial dissemination of the stroke awareness message to the communities.

I found that actors in a health promotion campaign carried out activities through network interactions using "situational sense-making" (see Figure 8.1).
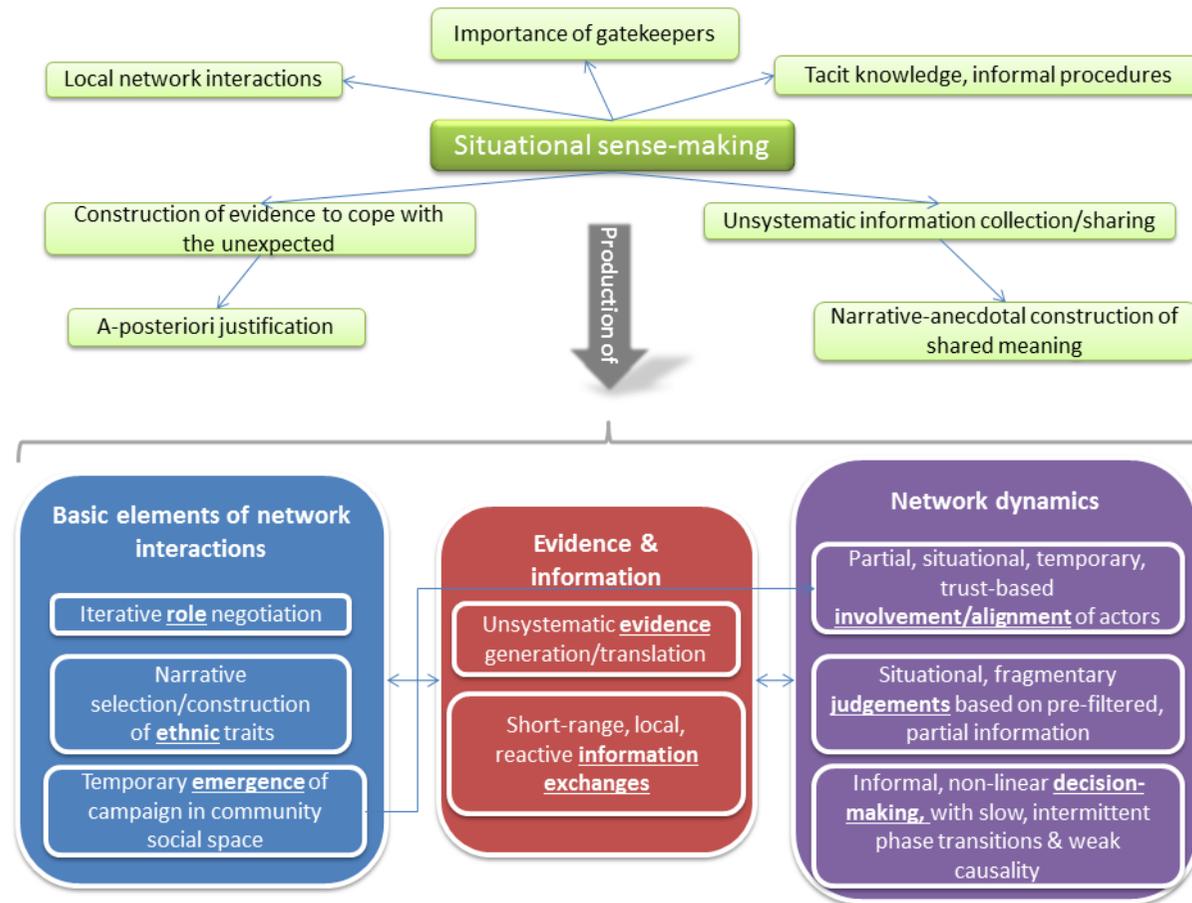
Figure 8.1 Thematic network of key findings

I have used the term "situational sense-making" to describe the major overarching theme that helps characterising the very pragmatic and situations-led way in which many actors operated in and made sense of the campaign, as opposed to a systematic or pre-determined approach.

By "situation", I mean the dynamic set of processes that are triggered when actors interact in a network in a given context; by "sense-making" the activities carried out by actors when they:

- understand what happens in an often unexpected scenario;
- produce a (shared or conflicting) meaning out of their interactions;
- as a consequence, produce actions or outcomes based on that "sense", or they co-produce an order and specific effects based on a meaning.

Hence, sense-making is not only an intellectual or mental activity, but a whole process of production of meanings and effects in a situation through network interactions (for a discussion of the concepts, see sections 8.3.1 and 0).

Situational sense-making unifies several subthemes. Firstly, I observed a short-range, local dimension of exchanges between actors through the network, together with a great importance of intermediaries (gatekeepers). Secondly, actors adopted situational, unsystematic methods for collecting and sharing information and resources, mainly based on tacit knowledge and informal procedures. Furthermore, actors used narrative, anecdotal re-elaboration of information aimed at achieving a shared construction of meanings. Finally, I observed frequent *a posteriori* justification of actions, linked to iterative sense-making procedures: actors constructed evidence to cope with unexpected or unknown situations, and subsequently used such evidence to justify practice. In turn, these characteristics were linked with two main issues. The first was the lack of strong central control on the campaign. The second was the fact that actors lacked a global view of the network and consequently they often could not share the same understanding of the meaning of the campaign.

Networks of actors involved in the campaign enacted "situational sense-making", which covers several dimensions. Firstly, actors made sense of their roles in the campaign, as describe in section 5.2: they managed role overlaps and evolution by iterative, unsystematic negotiations. In parallel, actors co-constructed through narrative procedures the ethnic identity of communities targeted by the campaign. This implied that no strict scientific approach was adopted either by campaigners or by community members to define ethnicity: therefore, they selected the ethnic traits of the community unsystematically, through conversations and discussion, and attaching a strong importance to anecdotes (section 5.3). Secondly, situations-led, short-range network interactions allowed for the emergence of the campaign as a

contested temporary space within the wider social space of the community, characterized by pre-existing logic and rules, including compartmentalization and competition. Moreover, campaigners and designers translated scientific evidence into campaign materials through unsystematic, narrative processes. Through the same processes, campaigners and the community co-generated "evidence" about the best ways to carry out the campaign and campaigners used it as a basis for practice. Actors mainly managed information exchanges through short-range, frequent, iterative face-to-face interactions; their approach to collection and dissemination of information was generally reactive to external constraints and to the need to cope with unexpected situations.

Furthermore, involvement of actors in the campaign was related to multiple, direct, iterative contacts aimed at creating and sustaining relationships over time. Involvement was based on trust that actors, in turn, established or granted for specific purposes; consequently, the campaign only managed to generate partial, situational and temporary alignment of actors. Finally, actors judged situations and behaviours to make sense of the context and make appropriate decisions; however, actors often built judgements on partial, often pre-filtered information and such judgements frequently aimed at *a posteriori* justification of actions. As a result, actors made decisions through informal, non-linear procedures, leading nonetheless to specific actions and outcomes. The campaign progressed through slow transitions between phases, the causal relation between antecedents and consequences seemed weak, and relevant actors were often not involved in important decisions.

8.3   Discussion of findings in the context of the literature

8.3.1   "Situation" and "situated action" as conceptual tools to clarify how actors in the campaign coped with the unexpected

I have shown in the results that situational factors were of utmost importance in understanding the workings and outcomes of the campaign. It seems therefore important to understand how the concept of situation is described in the literature, and how and why it contributes to understanding both the interactions of actors in the campaign and the products of such interactions.

Different philosophical and sociological traditions contributed elements to the concept of situation – in particular, phenomenology and symbolic interactionism (Ciborra 2005; Gonos 1977). However, according to Yang (2009), "situation" remains a somewhat blurred and vague concept. Two main elements are frequently associated with a "situation": firstly, its nominal, idiosyncratic, unique and precarious dimension: a situation is a locale where actors interact in

and with a context to pursue their goals, and the context is far too complex for them to predetermine or analyse in details in advance (Yang et al. 2009; Gonos 1977). On the other hand, a situation is not generally described exclusively as an objective fact, but as "culturally construed". As such, a situation heavily depends both on meanings ascribed to it by the individuals involved, and on wider, "culturally shared, explicit, and common understandings of the surroundings that produce and constrain human behaviour" (Yang et al. 2009). An example of such common understandings may be represented by Goffman's "frames" or "frameworks": "When the individual in our Western society recognizes a particular event, he tends (…) to imply in this response (…) one or more frameworks or schemata of interpretation of a kind that can be called primary". Such frameworks contribute to render "what would otherwise be a meaningless aspect of the scene into something that is meaningful". (Goffman 1974, p.21):

In other words, a situation is a process, where actors pursue specific goals interacting with each other and with a wider context: in interacting, they define and negotiate meanings ascribed to the situation (Perinbanayagam 1974; Thomas 1923). Therefore, as Clarke suggests drawing on Blumer, a situation also shows a particular "gestalt - how a situation is always greater than the sum of its parts because it includes their relationality in a particular temporal and spatial moment" (Clarke 2005, p.23). As Tiryakian (1968) puts it: "the notion of situation has a phenomenological status that differentiates it from the physicalist notion of the environment (…) The site is a physical locale of potentiality, but the situation is an actualization of the locale as a result of the meaning the person finds in it".

In recent years, the related concept of situatedness has gained wide recognition, especially in the context of "situated knowledge", "situated learning" and situated action (Ciborra 2005). Of particular interest is the position held by Suchman (2007), who highlights a contrast between plans and situated actions. As opposed to plans, situated actions are "actions taken in the context of particular, concrete circumstances…the circumstances of our actions are never fully anticipated and are continuously changing around us… situated actions are essentially ad hoc" (cited in: Ciborra 2005). Hence, actions are made possible by local interactions in a specific situation, and are only indirectly "informed by reference to abstract representation" (Suchman 2007).

Finally, given the specific elements described so far, "situated" actors have to be open to surprises, as the emerging properties of situated interactions often differ from initial expectations (McDaniel Jr et al. 2003). Hence, the reaction of actors, as often described in my field data, may well be inspired by a coping attitude representing a mix of improvisation, rapid

learning, tinkering and bricolage (see for example: Brown & Duguid 1991; Gobbi 2005; see also: De Certeau 2011 for the related concept of a "tactical" attitude).

Although not specifically worked out in the context of health promotion, the concepts of "situations" and "situated action" drawn from the literature help in interpreting the findings. Firstly, the data suggest that the intervention was designed from a "planned" perspective (see section 2.1.8), but was enacted using an attitude implying constant coping with unexpected situations through tinkering, bricolage and improvisation. Commissioners and campaigners, standing in a specific social space (the NHS), isolated specific communities as the "places" where the intervention should be co-designed and delivered. However, this proved true only *in theory*: in practice, community boundaries were almost impossible to define; moreover, campaigners were caught in a network of people, places and institutions where they had to work their way through situated actions, in order to design materials, recruit participants and deliver the intervention. Hence, on one hand, it seems that commissioners and campaigners need a strategic attitude to design an intervention; however, it should be recognized this strategy only worked in the background when doing work in the field, as an abstract frame of reference. In fact, campaigners experienced the field, as an almost entirely "foreign" situation, with different rules and unknown relationships between actors. In such a space, it was vital to seize opportunities as soon as they presented. Sometimes, opportunist contact proved far more important to recruit participants than utilisation of existing institutions and networks. Further, time proved of utmost importance: campaigners and gatekeepers underlined the importance of specific situations in which a "critical mass" of participants was achieved, and the stroke awareness message started to circulate in the community. On the other hand, results show that long delays between insight, design and delivery phases proved detrimental to the intervention, since campaigners had to reconstruct from scratch the situational awareness of the field.

Finally, as showed in section 5.4.2, all actors perceived the campaign as a temporary space or situation, struggling to emerge between competing forces or more consolidated situations. As such, a CBHP intervention seems structurally in a "weak" position, as opposed to the stronger position of more stable social spaces: hence, situated actions need to grab opportunities to promote health and disseminate the message in an environment governed by different rules. Importantly, improvisation and tinkering are also often employed when it is not possible to objectify the whole (or at least the essential) of a social situation: this was exactly how commissioners, campaigners and gatekeepers behaved, when they had to recruit participants, co-design and deliver the campaign only acting through local contacts, lacking a global view of

the community. As a conclusion, it is reasonable to assume that most CBHP interventions will be carried out in contexts requiring specific coping strategies with respect to situational factors. For example, community members may often perceive health promotion efforts as explicit and conscious attempts by an "outsider" at modifying specific, deeply ingrained health behaviours in the community. Therefore, campaigners will probably face very frequently the need to use a "situational" attitude in the field, and thus a facilitation framework may be useful to optimize situational sense-making. However, the model can be useful only if it takes into account several details emerging from the findings that will help to understand the dimensions in which the situation-oriented attitudes may yield optimal results. I will discuss such details in the next sections, especially when referring to sense-making.

8.3.2   Role management: social interactions and networks

Having acknowledged the need to manage the situational dimension of the campaign, the first element on which to focus is the complex landscape of local interactions through the network of actors involved in this CBHP intervention. Objectives would include optimizing understanding and evolution of roles inside the network, and allowing actors to co-construct an acceptable and shared identity of the target community, as a base to design and deliver the intervention. Monitoring role boundaries, especially between campaigners and community members, is important for ethical reasons, as well. Gilchrist makes the following point about the wider topic of community development:

> *"notions of 'good practice' include attention to role boundaries, operating as transparently as possible, maintaining accountability and ensuring that relationships are balanced and non-dependent" (Gilchrist 2004, p.99).*

The author also suggests that "managers should help community workers to clarify their roles and to review on a regular basis the effectiveness of their networking" (Gilchrist 2004, p.100; See also: Gilchrist 2003). This resonates with some of the results, concerning the difficulty of clearly understanding the role of voluntary work in the campaign, from the perspectives of both the campaigners and the gatekeepers.

More generally, in fact, networks of interacting, competing and cooperating actors and groups populate the social space of the communities. As shown in section 2.1.4, literature abounds with theories, models and frameworks used for different purposes. Examples include the optimization of social networks, the prediction of the outcomes of interactions, and the analysis of the complexity and multi-dimensionality of such interactions, either in the context of public health or health promotion (Luke & Harris 2007; Valente 2010), or with a wider applicability (Borgatti & Lopez-Kidwell 2011; Hollstein 2011; Valente 2012) – see also section

2.1.4. However, such frameworks usually apply in health promotion contexts where networks are relatively stable, roles are clearly identifiable and actors can negotiate identities within an acceptable range of possible variation, in a relatively well-known environment and with medium-to-long temporal perspectives. Examples may include workplaces, schools, nursing homes, etc.: in such settings, researchers can carry out careful analyses of networks, roles and identities and design specific interventions aimed at optimizing the workings of a network of actors. In such settings, it is reasonable to assume that "it is difficult to overstate the length of time that is needed to gain familiarity with a focus community and identify factors influencing recruitment" of participants (McLean & Campbell 2003).

In situations similar to the studied campaign, instead, most of those assumptions do not hold: high actor turnover hinders network stability, the environment and the identity of the community are almost unknown to most actors, and the intervention needs to yield concrete results in a relatively short time. Nonetheless, network interactions are at the core of processes allowing the campaign to obtain specific results. As such, these interactions need management through a systematic approach, although permitting maximum flexibility, so that the intervention can easily adapt to a complex environment. In such an environment, as Gilchrist (2004, p. 104–5) points out, it is important

> "to acknowledge the serendipity effect in community work, namely that many perfectly useful and decent outcomes are not planned, nor even sometimes imagined. They appear instead from a fortuitous synchronicity to be found in everyday interactions".

The same author also highlights the importance of integrating spontaneous involvement of actors and a systematic approach to managing CBHP interventions. Moreover, it seems particularly important to know as much as possible about networks in a community, before engaging in recruitment, co-production and delivery. An in-depth analysis of networks does not seem appropriate: hence, it may be advisable to start, as soon as possible, rapid, iterative network mapping of community social networks. Such an objective would take some elements from what Gilchrist (2004, pp.73–75) calls meta-networking, namely "knowing how networks operate and having a mental map of the relations and attitudes of the individual members". The same author further suggests:

> "network mapping exercises enable people to be more aware of existing links among organisations, and more explicit about how they use (…) connections (…). By identifying actual and potential forms of cooperation, it is suggested that people can become more proactive, and consequently more effective, in their networking" (Gilchrist 2004, p.115).

This task would benefit from adopting appropriate visualization techniques, to outline "spheres of influence, potential scopes of action, and contexts of entities that are mutually significant" (Krempel 2011). Visualization would be detached from its traditional integrative role towards mathematical analysis of network properties, and would instead serve two main purposes. Firstly, it would allow campaigners to identify nodes that would be particularly fit for particular purposes, given their position in the map. For example, actors with a particularly central position may potentially act as gatekeepers, actors representing "bridges" may be appropriately involved to access particular subsets of communities, etc. (Borgatti & Lopez-Kidwell 2011). Secondly, sharing network maps between participants with different roles would improve the understanding of each actor's position inside the network, roles of other actors, and opportunities for further synergies; perceiving of being part of a network, understanding its boundaries and relationships between nodes may represent an incentive to engage more actively and with a clearer role. In fact, research suggests that the perception of the structure of a social network by actors representing internal nodes is influenced both by personality traits and by position in the network (Casciaro 1998; Borgatti & Foster 2003, p.998). Hence, although the link between cognitive improvement and decisions about involvement is far from clear, shared maps may improve network perception and therefore enhance the likelihood and quality of involvement.

Noticeably, although the application of network mapping to health promotion initiatives is quite recent, some interesting results are described by Hoeijmakers et al. (2007), and by Lewis (2005) in the related field of inter-organizational partnership in health promotion. As noted, the context differs considerably; however, an adaptation of network mapping and visualization techniques to the situational dimension of a CBHP campaign seems possible, provided that an individual or group is entrusted the role of "situational manager", and that three key issues are addressed. Firstly, mapping should be quick, otherwise it would drain too many resources. Relatedly, mapping should also be recursive, i.e. maps should be quickly sketched at the beginning and then progressively refined. Finally, network maps should be ideally constructed collaboratively, but at least they need to be constantly shared between actors in an intervention. In summary, available network mapping techniques and visualization tools may be applied quickly and fruitfully to optimize the situational dimension in a CBHP, especially as far as roles are concerned.

8.3.3 Ethnic identity of the campaign target: co-construction and negotiation

8.3.3.1 Co-construction

Further to the relevance of networks in role management, the findings highlight the importance of the construction of the identity of the target community through iterative, local network interactions. The literature confirms that identity construction in the context of health promotion is a complex process, highly dependent on situational factors (i.e., non-linear, difficult to predict, and weakly linked to strong objective facts). When restricting the focus to ethnic identity, for example, the literature confirms, on a wider theoretical scale, my findings concerning the selective enactment of ethnicity by community members (section 5.3.1.5) and the difficulty of establishing clear characteristics of ethnicity based on uncontroversial "facts". This aspect matches the difficulty of establishing clear boundaries for social networks of community actors targeted by the campaign.

In fact, Barth (1969; see also: Fenton 2010, p. 89–92) acknowledges the existence of real differences between ethnic groups, identifiable as specific cultural traits at a given moment of time. However, the essential feature of ethnic groups is linked to

> *"the maintenance of a boundary. The cultural features that signal the boundary may change, and the cultural characteristics of the members may likewise be transformed, (…) yet (…) dichotomization between members and outsiders"*

remains vital to understand the salient characteristics of ethnic groups. While the distinction between insiders and outsiders is very clear, the elements on which social actors build it may vary widely, and are therefore difficult to identify when, for example, a health promotion initiative needs to deliver contents appropriately tuned with specific cultural traits. Brubaker (2002) further notices that "groupism", as "the tendency to take discrete, sharply differentiated, internally homogeneous and externally bounded groups as basic constituents of social life" may lead to wrong representations of the reality of ethnic groups. In fact, identity of such groups is much more "constructed, contingent, and fluctuating". Ethnicity, in his opinion, is related to events when specific categories are chosen in a process of group-making as specific characteristics around which a group may converge, and hence interpret reality, establish boundaries, classify insiders and outsiders – and also, "'doing being ethnic' in an ethnomethodological sense" (Brubaker 2002).

Ethnic identity is fluctuating and difficult to define for empirical, historical reasons as well: the intensification of migrations and the relatively easy and quick transportation links with the homeland produce a high and constant turnover between members of ethnic minorities (Hugo

2005). Finally, individuals can easily belong to different communities and assume multiple identities at the same time. The balance of power between individual and community has changed in favour of the former, whose possibilities of choice (in terms of connections / disconnection from communities) have been amplified: "belonging, referred to a network (…), tends to become an extension of an ever-changing identity, following (…) re-negotiations and redefinitions of identity itself" (Bauman 2007). Health-related empirical research seems to confirm this interpretation, since a recent survey of academic health sciences researchers showed that "respondent understandings of race and ethnicity were confused and inconsistent" (Baer et al. 2012)

In the context of health promotion, however, it is frequent to find definitions of communities based on a strong meaning of identity, such as the following:

"A community is (…) characterized by (…): (1) membership - a sense of identity and belonging; (2) common symbol systems (…) (3) shared values and norms; (4) mutual influence (…); (5) shared needs and commitment to meeting them; and (6) shared emotional connection" (Israel et al. 1994).

My findings suggest that such a strong meaning of community identity may be hypothesized when planning and designing CBHP campaigns to establish boundaries for an intervention (see section **Error! Reference source not found.**), but are not likely to be useful at the situational, everyday level of the intervention. At this level, instead, my findings indicate that ethnic identity of the target was largely co-constructed – hence the need for different interpretation frameworks. As for roles, the important matter here is how to conceptualize systematically the situational process of identity co-construction, to guide the process while allowing for flexibility.

8.3.3.2 *Identity negotiation*

The contribution from distinct social research traditions will help in framing the problem of ethnicity construction with reference to findings. I will then develop the discussion in the last sections. Firstly, interactionist sociology sets the stage for understanding situational identity management. As Bissell et al. (2002) notice, interactionism considers interactions between individuals as the basis of social life. Interactions, in turn, are mainly concerned with actors continuously creating and recreating meaning to assign to objects, situations, etc. Given that in this process reflection and self-reflection by actors play a big role, the always-in-process creation and negotiation of meanings involves a complex, continuing work on identities of actors as well. As Annandale specifies, in the context of health and medicine:

"negotiation connotes meaning which develops in the course of interaction; it is through meaning-making that individuals know the world and are able to act effectively in it. Consequently, action in the health-care context involves a process of definition of others, and, thereby, negotiating a consensus" (Annandale 1998, p.25 ; cited in Bissell et al., 2002).

This interpretive framework is coherent with the findings, that repeatedly highlight the importance of negotiation between actors in defining the identity of the communities targeted by the campaign – and more widely, in defining meaning of different contexts where actions take place (e.g.: involvement of actors, delivery of health promotion initiatives, etc.). Moreover, literature on health identities suggests that they should not be considered as properties of single actors or bodies, but as "assemblages of relations" between a body and its physical and social environment (Fox 2012; Deleuze & Guattari 2004). Consequently, and even considering groups and not individuals, it is important to focus the analysis not on single identities but on the ongoing, social process of construction of identities through continuous relations, conflicts and resistances. This perspective also highlights the importance of the complex ecology of relations showed in the results, as it comes to defining the identity of actors in the context of a CBHP campaign.

In summary, interpretive frameworks identified in the literature confirm the salience of the complex identity co-construction process in social settings in general, and in the context of health services in particular. However, such a complexity is not without rules. Indeed, one of the main tenets of interactionist sociology is that actors skilfully manage the processes of identity construction during everyday interactions. Therefore, the problem in a CBHP perspective is to help managing shared identities through interactions between health promoters and target communities. The problem is thus, how actors in asymmetric positions of power, role, motivation, etc. may respectfully negotiate their identities in such a way that they become operational in the context of an effective CBHP campaign. To such a question, different answers may obviously come from several perspectives (psychological, anthropological, political, etc.). From the perspective of my study, two elements of a possible strategy emerge. Firstly, commissioners and campaigners should adopt a systematic attitude towards identity co-construction, and make it explicit since their earliest interactions with target communities. The adoption of such an attitude may include, for example, explicitly (although tactfully) stating that some cultural difference should be taken into account to design the intervention. By this I mean that community members should reflect about whether and how they are culturally "different" from the ethnic majority, and negotiate with campaigners what traits are relevant to define such difference in order to produce an effective

health promotion intervention. Secondly, since actors will construct identity through iterated conversations, it may be helpful that they keep track of how identity emerged. For example, campaigners and commissioners may make explicit the process of construction of identity, using a short document containing the main specific characteristics of the target community deemed relevant for the intervention. Thereafter, they may share such a document with the community, so that campaigners and members of the community can jointly perform a reality check. Such an activity would share similarities with "member checking" (Harper & Cole 2012; Lincoln & Guba 1985, chap.13), a procedure through which qualitative researchers involve participants in verifying the research findings, to improve the validity of results. The document may also include a concept map or a storyboard, highlighting the contributions of different actors to the identity definitions – as this will highlight the dynamic nature of the process and avoid attaching labels, which community members may be perceive as constraining and discriminatory. This document would bring two main enhancements to a CBHP intervention. Firstly, it may be a practical reference point for actors involved in developing appropriate materials and interventions in relation to a target community. Secondly, it may be used during the evaluation, as a proof that campaigners have set up a transparent and participatory process of community involvement.

In conclusion, as already suggested for role management, making explicit the content and results of cultural practices usually based on tacit knowledge may be effective in reaching at least a minimal degree of shared understanding between the actors in a network. This, in turn, will be a basis for developing the intervention with the support of a shared understanding of the context, although actors in the field will still need to be alert to "situational" opportunities and favourable occasions to deliver (and make the most of) a CBHP initiative.

8.3.4 Contributions from the sociology of ethnicity: ethnic categorization, power balances and multiculturalism

The relational point of view and the focus on the network dynamics influencing the co-construction of ethnic identity is far from implying a reductionist attitude, according to which ethnicity is *only* constructed through network interactions, in a CBHP campaign. As already underlined in the analysis of the context of the campaign (section 4.2.2), there are important "non-network" factors acting on the perceptions of ethnic identity and the very way in which this is constructed. Moreover, the sociology of ethnicity suggests some possible ways to comment and discuss the findings.

Firstly, on one hand it seems correct (and true to the findings) taking into account the critiques of ethnic "groupism" already referred to in section 8.3.3.1 (see also Fenton 2010, pp.110–11,

114). However, on the other hand, ethnic groups, and especially ethnic minorities, cannot be simply represented as a reservoir of values and identities from which single members "peacefully" pick and choose elements to create a customized identity. As Jenkins (1994) points out, categorizations are often imposed on social groups, as a result of power imbalances. Being categorized as an ethnic minority, in particular, is not a choice, but is imposed on a particular group of citizens by another entity – for example by the state, as in census categories. Hence, categorization is "a political project" in addition to being an "everyday social practice" (Brubaker et al. 2004). To reinforce the point, categorizing a group as an ethnic minority almost always implies its disadvantaged position in a society (Giddens & Sutton 2009, p.635), and this was certainly the case for the minority groups I studied. In fact, social disadvantage emerged from conversations with informants, often citing unemployment, difficult relationships with institutions as the NHS and the police, etc. as difficulties experienced by community members. Also, the definition of ethnic groups used to be a relevant practice in the colonial period: colonial powers often performed "the identification, labeling, and differential treatment of ethnic groups" (Brubaker et al. 2004), and this practice also influenced the perception and self-perception of ethnic groups during the post-colonial period. Furthermore, ethnic categorization is often linked to stereotypes and prejudices – both directed towards the ethnic minorities, and towards the ethnic majority.

The elements discussed add a further interpretive dimension to the discussion of the co-construction and negotiation of the ethnic dimension of the campaign target. As the data show, both campaigners and ethnic community members show clear pre-conceptions about each other. Hence, network relationships during the campaign are often underpinned by stereotypes and pre-oriented expectations about the behaviour of actors belonging to a particular ethnic group. There are different situations in which these pre-conceptions emerge. Examples include the differences in the management of time by communities and campaigners and the mistrust of the NHS showed by some Pakistanis and Somalis. Also relevant are the (contested) belief by campaigners about the "narrative" attitude of community members, and the effort by some Pakistanis to behave not-like-an-ethnic minorities (e.g. by stressing their good knowledge of English and the fact that stroke awareness campaigns should *not* be aimed at ethnic minorities only), to name just a few instances.

These and similar examples were often cited in the findings as barriers or important variables in network processes emerging from the campaign. This discussion, however, allows to frame them also as important non-network factors that influence network processes. In fact, ethnic minorities are "real", in that belonging to one such minority is often related to disadvantaged

socio-economic conditions, experience of prejudices and several other difficulties often not experienced by most members of the ethnic majority.

It should therefore be clear by now that the present study does not adopt a "network reductionist" point of view. Adopting an analytical point of view based on network interactions does not imply that the findings did not take into account the existence of non-network factors. On the contrary, I described and interpreted the dynamics of networks as means through which concrete instances of power relationships, experiences of prejudices and difficult and conflicting occasions of interaction between ethnic majority and minorities could emerge. In other words, the relational approach to analysis acted as a lens through which – at a particular level – dynamics of a CBHP campaign could emerge, with their wider socio-political implications, not as a filter to exclude anything that did not seem "relational" in nature. This framework and approach strongly resonates with the theory about the main determinants of health, which stretch from general dimensions such as "socio-economic, cultural and environmental conditions" to individual factors related to age, gender and constitution of the individual (see section 2.1.2). Hence, when focussing the analysis on a level, it is nonetheless possible to take into account higher or lower levels as well.

From a more specifically sociological point of view, I take into account Richard Jenkins' discussion of the concept of ethnicity (1994), when he points out that there should be no conflict between emphasizing the importance of everyday interactions in defining ethnicity, and long-term, historical processes and patterns influencing the names, boundaries and nature of ethnic groups. In fact, his theoretical framework aims at connecting two different dimensions: the "micro-interaction" level, in which individuals relate to each other through a myriad of routine, daily network contacts, and "the larger social register of groups and categories", in which the definition and evolution of social and ethnic identity takes place, channelled in specific historical, political and social macro-patterns.

Jenkins outlines a theory of the emergence of ethnic identity which I will briefly discuss here with reference to my results, as it allows to illustrate the interconnection of the micro- (networks) and macro- (patterns) dimensions in my study. Firstly, according to Jenkins, categorizing an ethnic group as such is always the result of a two-sided process. On one hand, the group starts perceiving itself as a group, through a process of internal definition, entailing the selection of particular cultural features, as outlined by Barth (1969). However, self-definition is always a social process, and to a degree is always intertwined with a categorization imposed on the group by external social groups – in this instance, for example, the ethnic majority. From this perspective, what it is like to be a member of the Somali

minority group in a British city is defined through micro-interactions within the group, and between the group and the ethnic majority and other minority groups. Power asymmetries obviously play a major role in these dynamics: for example, the ethnic majority exerts power and authority to categorize the minority group by selecting some stereotypical features. In turn, the social world of the minority group is modified by such categorization, even if, to a degree, they resist the categorization and try to modify its implications for their everyday lives.

Even more interestingly, however, exerting a classificatory power towards a minority group also contributes to establish and modify the social identity of the ethnic majority itself. Ethnic categories assigned to the "categor* *ed*" most of all "tell us about the categoriz*ers* – how they see themselves and their objectives", and it is the ethnic majority's ethnicity "that is under construction as much as anything else" (Jenkins 1994).

Finally, Jenkins highlights how the "powerful" majority can make the categorization count for the everyday lives of the categorized minority groups. Hence, categorization is not just that – assigning names to entities, and thus objectify them. "Making categorizations count" implies that a virtual dimension is added to the nominal dimension of ethnic categorization: virtuality here means the "potential to define what it means to bear" a categorization for a minority group, its everyday experience, and the like.

This interpretive framework fits the data and allows highlighting further dimensions of the results. Firstly, social co-construction of the target group identity through network interactions happens on the background of categorization practices that are both complex and structured according to general patterns. In my case study, the NHS had identified some minority groups as needing specific attention – hence contributing to their initial categorization, and to the possible reinforcement of their "diversity". Campaigners and other actors contributed to this categorization process that – interestingly – allowed them defining their own role and identity in the campaign as well. For example, by emphasizing the "narrative" attitude of communities towards stroke awareness they implicitly tended to reinforce their own rigorous and scientific attitude towards health promotion. Furthermore, on the other hand, the interactional processes of self-definition conducted by minority groups took place within a categorization which was – although unintentionally – imposed upon them, and to which they reacted in different ways. At times, they emphasized their cultural diversity in order to reach specific goals, while at other times some actors challenged the superimposed categorization, with attitudes that questioned the purported importance of their diversity for the campaign. For example, they stressed that using Urdu was unimportant, or challenged campaigners and

health professionals to provide scientific, rigorous evidence of the impact of stroke on ethnic minorities.

A final contribution from the sociology of ethnicity allows shedding light on the co-construction of the ethnic identity of the campaign target. A problem often raised in sociological debates on ethnicity in Western societies concerns the advantages and disadvantages of three different models for the integration of ethnic minorities. The assimilation paradigm holds that, over time, ethnic minorities should be "dissolved" in the majority, sharing most of the cultural values, norms and attitude of the latter. At the other extreme, theorists of the "melting pot" envisage a blending of the minorities and majority' cultures to "to form new, evolving cultural patterns" (Giddens & Sutton 2009, pp.643–4). Sociologists hold that UK policies lean more towards a middle-ground attitude named multiculturalism (Koser 2007, p.24), that encourages different ethnic groups to preserve their diverse cultural attitudes, at the same time finding a way to collaborate and live alongside each other (Giddens & Sutton 2009, p.644; Fenton 2010, pp.181–4). In the context of public policy, multiculturalism is declined as the need to recognize ethnic identity and cultural difference and to promote the progress of different ethnic groups while preserving their identities (Fenton 2010, p.183).

Our data show that both the NHS and the campaigners held a multiculturalist attitude towards the target ethnic communities. Both NHS managers and the campaigners built the CBHP intervention on the assumption of ethnic diversity as a cultural value to take into account using co-production, dialogue and cultural adaptation or tailoring. Moreover, the observed interactions between campaigners and community members show respect for cultural differences, efforts directed at interpreting cultural diversity and "translating" health promotion materials in a form that could be understood by members of a different culture. However, a criticism commonly directed towards the policies of multiculturalism allows adding depth to the interpretation of my results. As Joppke (1996) states, multiculturalist policies seem to imply an "ontological primacy of the group over the individual", and the assumption that minority disadvantaged groups are somewhat "inert, homogeneous and mutually exclusive". Such a view may explain why both the NHS and the campaigners spent so much time trying to extract and interpret specific and "typical" ethnic features of the target communities, without being conscious of the social construction of the ethnic target that was going on during the campaign (see section 5.3). A less "groupist" attitude (section 8.3.3.1) may likely have contributed to a more efficient and situational approach to the campaign. This would have allowed, in turn, to take into account the diversity of contexts between different

ethnic communities, and to focus on holding successful events rather than on extracting "essential" features of communities to be taken into account in future health promotion initiatives (sections 5.4, 8.4.2). In summary, it may be the case that both the NHS and the campaigners implicitly adopted a multicultural attitude. This, on one hand, allowed them to adapt to some (ironically, constructed) ethnic features of the target, but on the other hand prevented substantial "learning" that – from both sides – assumes an open communication attitude and the possibility for each side to question and possibly change cultural attitudes in a process characterized by both negotiation and conflict.

8.3.5 Sense-making

My findings often highlight the importance of sense-making procedures, whether in role management, identity co-construction, or more generally in producing context-aware, effective, temporary CBHP events. In section 8.3.3.2, I briefly commented on the centrality of meaning-making to social interactionism, a particularly relevant way of framing the issues emerging from the results of this thesis. However, shared construction of meaning is a particular instance of sense-making procedures, emerging as one of the main activities carried out by actors in the CBHP intervention I studied.

The concept of sense-making was introduced in the social sciences in the 1960s (e.g. Garfinkel 1967), and it played a particularly important role in ethnomethodology, symbolic interactionism and social constructionism. Sense-making indicates the processes through which actors make sense of the context where they established and maintained relationships with other actors: "through processes of sensemaking people enact (create) the social world, constituting it through verbal descriptions which are communicated to and negotiated with others" (Brown et al. 2008). In this framework, sense-making is a characteristic feature of everyday social life, since all actors need to negotiate and establish meanings for their actions (Berger & Luckmann 1991). In recent years, Karl Weick (1995; Weick et al. 2005) popularized the concept of sense-making in organizational studies. He described sense-making, by stating that "identities are constituted out of the process of interaction" (Weick 1995, p.20), and therefore sense-making is first and foremost "grounded in identity construction" (Weick 1995, p.18). Consequently, the same process operates when actors pursue their objectives and when they establish and re-negotiate their and others' identities: such processes are mostly concerned with how actors make sense of the social setting in which they operate, the objects they manipulate, etc. Secondly, "sensemaking involves the ongoing retrospective development of plausible images that rationalize what people are doing" (Weick et al. 2005). Actors only make sense of actions and contexts *after* and not *while* something is happening: they

selectively direct their attention to experience, being influenced by the projects they pursue at the moment, the risks and opportunities they spot in situations, and the related attitude – e.g. strategic versus tactical (Weick 1995, p.27). Hence, sense-making is also about selecting significant details in an otherwise overwhelming flow of experience and information, and enacting such meanings through actions and relations with other actors. Such relations, in turn become concrete "through talk, discourse and conversation", when actors align with each other, although not necessarily sharing their views (Weick 1995, pp.41–3). Finally, sense-making happens through "bracketing" and "punctuating". Focussing on specific cues, sensemakers isolate traits of a situation from the flow of events, and use them to build narratives, in turn helping to make sense of situations. Such narratives obey the principle of plausibility, rather than accuracy: "People who make sense are just as likely to satisfice as are people who make decisions" (Weick 1995, p.42) – i.e., sensemakers privilege the establishment of plausible meanings, instead of perfectly accurate, "true" interpretations.

The features of sense-making seem to match most of the dynamics of judgement and decision making described in the findings, and they fit with the characteristics of the processes of translation of evidence into practice and practice into evidence. Firstly, sense-making was the main mechanism through which actors defined, negotiated and discussed roles and identities. Sense-making applied both to situations in which actors reached a shared understanding of roles, and to contexts where this did not happen. In both cases, actors used retrospective sense-making to produce "documentary evidence" after the events, through iterative processes. Secondly, the focus on plausibility rather than accuracy is a very good definition of dynamics of judgement and decision making. Under no circumstance did any of the actors collect evidence *and then* made judgements or decisions; on the contrary, gatekeepers, community members, campaigners and commissioners, moved the campaign forward through micro-decisions and micro-judgements, justifying their choices with "hindsight". Finally, throughout the campaign I frequently observed the selection of cues for sense-making from an ongoing flow of activities. The findings confirm that the boundaries of target communities, their "ethnically relevant" traits and the evolving characteristics of roles were selected by actors between a range of possibilities, and then enacted while making sense of them along the way. External rules, protocols or strategies existed, but had a very limited impact on the development of campaign, as noted in section **Error! Reference source not found.**. Therefore, it seems sensible that the label "situational sense-making" represents a sufficiently accurate description of the general attitudes of actors in the field, and can contribute a significant understanding of the inherent logic of action of all parties involved in this CBHP intervention.

The sense-making paradigm has not been widely adopted in health promotion studies. A study in the context of health services research, perhaps useful as a starting point for an application of sense-making to health promotion is Currie and Brown's (2003) work on actors' narratives in a UK hospital during a major reorganization. In a public health context, Kothari et al. (2012) have analysed how public health practitioners use tacit knowledge to make sense of the complex contexts where interventions need to be designed and to make the most of opportunities as they appear. A wider application of the sense-making paradigm in health services research and health promotion may help assess its usefulness in understanding important details of the behaviour of health promoters and target communities in the context of CBHP interventions. My study markedly differs from most other studies making use of the sense-making approach in that they refer to organizational contexts, while this thesis, although taking into account organizational dynamics, analyses network interactions between organizational and campaign targets in a community setting. Hence, the applicability of the perspective as such will probably need confirmation from further research, as community dynamics may considerably differ from organizational dynamics. On one hand, it seems that sense-making can not only allow for a general interpretation of dynamics in a CBHP intervention, but also for the individuation of specific details worth identifying and optimizing (see the proposal of a network-oriented facilitation framework, section 8.4). However, a more specific point needs consideration. Simply stating that the key attitude of actors in a CBHP is "situational sense-making" is not likely to be useful in improving the processes of CBHP. In fact, my findings show the importance of specific network interactions, with regard to how actors produce meaning and make sense of situations. Specific characteristics of network interactions should then be analysed in view of a possible situational management – as proposed in previous sections for network visibility optimization, event orientation and explicit documentation of the ongoing identity development process.

Consequently, I will discuss the narrative or conversational aspect of "situational sense-making" as a target for possible optimization. Firstly, I will discuss the concepts of narrative and conversation and their application to health promotion research, with a particular focus on the concept of narrative, and how such concepts relate to a network- or relational analytical perspective. Secondly, I will link such a perspective to the paradigm of practice-based evidence with some final remarks on the role of reflexivity in the process of design and delivery of CBHP interventions.

8.3.6 Networked narratives

Defining narrative is not an easy task. Several time-honoured historical and critical traditions have contributed multiple perspectives on the topic. From the twentieth century, a growing interest in narrative has emerged in the human and social sciences as well, as Larkey & Hecht (2010) point out. One of the most widely acknowledged definitions of narrative was provided by Jerome Bruner, who described narrative as "an instrument of mind" (Bruner 1991) to construct social reality, hence shaping the understanding that social actors have of experience. In detail, narrative is a temporal sequence of particular events. Stories refer to wider types, acquiring an "emblematic" nature: genres represent social realities and guide readers to use their minds in specific contexts. Stories concern characters performing actions with a degree of freedom. Hence, stories help in interpreting "reasons" rather than explaining causes of phenomena. Narratives always presuppose an intention to say, by the storyteller, and background knowledge by the reader: intention and knowledge come together in interpretation, being involved in "negotiating how a story shall be taken – or (…) should be told" (Bruner 1991). Moreover, a story implies unusual events, breeches in canonical situations, triggering fresh interpretations. Additionally, stories only aim at verisimilitude.

Social actors mutually interpret each other's stories, whose meaning is therefore the outcome of a negotiation between different perspectives on reality. There is then an "interplay of perspectives in arriving at 'narrative truth' " (Bruner 1991) in social exchanges; this also resonates with Geertz's interpretive perspective on local knowledge (Geertz 1973). Finally, individual stories produced by self, families, institutions, etc. *accrue* to produce a whole (culture, history or tradition). Different from scientific verification, narrative accrual proceeds through strategies, such as fake historical-causal links, or "the belief that things happening at the same time must be connected". Nonetheless, such collective shared representations can reach the status of external facts with a durkheimian "power of constraint". Culture and traditions "provide precisely (…) canonicity that permit us to recognize when a breach has occurred and how it might be interpreted" (Bruner 1991). In parallel with the increased relevance of research paradigms such as social interactionism, ethnomethodology and – more in general – with the increasing importance of qualitative research in health the reconstruction and analysis of narratives in different health-related contexts has become increasingly popular in the last decades[10].

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[10] A search for `qualitative research` in Pubmed conducted on 24.12.2012 yielded 7,294 results published in 2012; there were only 2,338 results published in 2002, and 803 in 1992. A search for `narrat* NOT review*` on the same date yielded 1297 results published in 2012, 309 in 2002 and

From a general point of view, the concept of "documentary method of interpretation" developed by Garfinkel (1967, chap.3) is a useful integration, since it represents how narratives are enacted by social actors to assign meaning to events. Both social scientists and lay people face the problem of assigning the correct meaning to observed facts. Social actors can assign meaning to facts by referring to a context, and choosing between different possible interpretations of an observation. Following Mannheim, Garfinkel explains the processes involved in the sense-making activity by referring to the documentary method of interpretation:

> *"The method consists of treating an actual appearance as "the document of," as "pointing to," as "standing on behalf of" a presupposed underlying pattern. Not only is the underlying pattern derived from its individual documentary evidences, but the individual documentary evidences, in their turn, are interpreted on the basis of "what is known" about the underlying pattern. Each is used to elaborate the other"* (Garfinkel 1967, p.78).

Similarly to Bruner, Garfinkel points out that in most social situations there is no simple, dual-stage process leading from a fact, to its interpretation, and so on. Facts are always recognized, selected, and observed as facts through the lens of one or more underlying patterns, before putting in place more complex interpretations. Therefore, in every social process, evidence, knowledge, or information may be represented as the content of a narrative – e.g., in the studied CBHP campaign, its message about stroke awareness. On the other hand, however, before actors are able to interact with such a message, a complex interpretive activity has to take place. The activity consists in recognizing the message as such, that is, as a fact worth taking into account, interpreting, locating within the coordinates of a given culture or community. Thereafter the fact may be challenged, or eventually absorbed to trigger behavioural change. Noticeably, construction of a social fact always takes place through interactions between actors and with reference to social institutions. According to Garfinkel, assigning a fact a "reasonable sense" involves assigning it six characteristics:

> *"(1) its status as an instance of a class of events; (2) its likelihood of occurrence; (3) its comparability with past and future events; (4) the conditions of its occurrence; (5) its place in a set of means-ends relationships; and (6) its necessity according to a natural (i.e., moral) order"* (Garfinkel 1967, p.94).

Such characteristics are comparable to Bruner's characterization of the essence of narrative, both from the point of view of content and of the importance of the co-construction of its

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100 in 1992. Even if adjusted for the increased number of articles indexed in the database in recent years, such results clearly show that interest of researchers in those topics has increased.

meaning. Garfinkel and Bruner's points of view shed a strong light on the narrative dimension of social processes that may be relevant for a CBHP intervention. In fact, several findings can be usefully integrated in such a framework: the attitude of actors to organize narratively their involvement in the campaign; their tendency to negotiate their actions according to meanings often co-constructed during the interaction; a-posteriori justification of actions based on evidence, in turn previously co-constructed.

Moving to scientific literature more directly concerned with the health sector allows me to locate the findings of my study within specific contexts for "situational sense-making". Studies on narrative-based medicine (Greenhalgh & Hurwitz 1999; Greenhalgh & Hurwitz 1998; Greenhalgh 1999), focus on the importance for clinicians to understand patients' stories, on the role of interpretation of meaning in clinical judgement and formulation of diagnosis and in a more holistic understanding of the patients and their illness. Much less attention, however, has been devoted to how narratives and stories are exchanged between networks of users and/or practitioners and the impact of such sharing on the delivery and use of services. In addition, the relationship between narrative and evidence still needs in-depth study, to improve the understanding of the mechanisms through which actors performing narrative interactions translate evidence into practice. Insights on the relationships between evidence and narrative were produced by Gabbay & Le May (2004; 2010), in an ethnographic study of two English general medical practices. The authors emphasize the importance for doctors of tacit knowledge and informal procedures, both to make decisions and to share information, and the relevance of social construction of knowledge through network interactions. Their results, however, refer to a context that significantly differs from CBHP interventions.

From the perspective of my present work, narratives are relevant for several reasons. Firstly, they are specific mechanisms through which users and professionals make sense of a situation and build a shared frame of reference for their interactions (although sometimes conflicting and contrasted[11], and ever changing). Furthermore, by using narratives, actors accumulate and challenge "evidence", produce and share contents and the consequent interpretations through which meanings emerge. In a recent attempt to discuss the role of narratives in the health promotion sector, with comparable aims, Larkey & Hecht (2010) propose a model of how culture-centric narratives may influence behaviour change in the context of health promotion interventions. According to the authors, anthropology, psychology and communication studies suggest that narratives are more than just contents; in fact, they are crucial tools for actors to

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[11] Clear examples of conflicting narratives in the results include the very different and at times opposed narratives of campaigners and commissioners, campaigners and community members, etc. Such narratives often include totally different judgements and evaluation on the same events and topics.

constantly enact and redefine their identities. Therefore, health promotion needs to move forward from "simple reproductions of reified cultural values" (Larkey & Hecht 2010) in health promotion contents, and also from translation of scientific evidence about health behaviours in culturally appropriate terms (appropriateness being usually assessed through formative field research – a technique adopted by campaigners in the intervention I studied). Instead, health promoters should use stories both as a way of communicating the need for behaviour change, and as contents of the health promotion intervention – generated by direct community involvement. The proposed model identifies mediators such as transportation ("engagement or absorption"), eventually leading to "identification with characters, story and cultural elements" and to "social proliferation" (i.e. "discussion/diffusion, rehearsal/reinforcement, reciprocal support") of behavioural change stories in the target community. Such narratives should focus on engaging stories and characters and on cultural embeddedness, to produce behaviour change.

This model is both theory-driven, and grounded on several empirical examples of health promotion interventions. However, it does not aim to study practical mechanisms related to network interactions, such as those discussed in my thesis. Therefore, the network-oriented facilitation framework (section 8.4) may usefully integrate with Larkey & Hecht's model, since the former highlights, and is based on, an analysis of contextual factors in a specific category of CBHP interventions. In the thesis, I have repeatedly highlighted attempts to construct coherent stories during the intervention, the role of narratives in "situational sense-making" by campaigners, commissioners, gatekeepers and community members. Hence, suggestions contained in the network-oriented facilitation framework could facilitate the task envisaged by Larkey & Hecht, especially where cultural difference is one of the issues in a CBHP intervention.

8.4   The network-oriented facilitation framework

8.4.1   Justification of the framework
I showed in the literature review and the discussion that CBHP is often difficult to plan, monitor and evaluate (sections 2.1.3, 2.1.7, 2.1.8). Firstly, demonstrating effectiveness is challenging, since in public health interventions causal chains influencing behaviour change may be long, behaviour changes follow non-linear dynamics, and sustainability of change is often uncertain. In addition, the factors influencing process and outcomes are numerous and complex. Involving actors and understanding community dynamics is also difficult: for campaigners and health professionals, communities are often "unknown environments", unstable and dynamic, with unclear boundaries. Furthermore, each program has unique

features, hence results are difficult to compare or generalize, and interventions are difficult to standardize since their appropriateness and success are highly dependent on contextual factors. Therefore, guidelines for best practice are generally not available, and published evidence may generally be insufficient to plan implementation – apart from some general, common-sense rules about entering the field, or getting to know the basics about the target. Finally, in a single community, there are often several competing CBHP initiatives at a given moment.

Moreover, CBHP programs are often under-funded, funded for short periods, and affected by continuing organizational changes affecting national and local health services; consequently, they tend to experience low strategic guidance, and high level of turnover. Hence, they struggle to obtain sustainable results and to show their efficacy and tend to adopt planning, monitoring and evaluation procedures that fit with scarce time and resources. A recent review produced by the National Institute for Health and Clinical Excellence has summarized these factors of complexity of health promotion programs, along with the need for adequate methods to produce knowledge concerning the effectiveness of such interventions (Swann et al. 2010, pp.69–70). The last point is echoed by Kothari et al. (2012).

The problem arises of monitoring and understanding process evaluation of CBHP projects in such conditions. Conceptual frameworks and planning/evaluation models described in section 2.1 have brought important contributions to CBHP practice, highlighting key factors for planning, monitoring and evaluating interventions. For example, they described mechanisms for behavioural change at community level, highlighted the importance of holistic approaches to health promotion, focussed on the analysis of users' needs and their involvement in program design and evaluation, contributed to an understanding of communities as complex, dynamic settings where actors and institutions interact. In summary, such models and frameworks are very useful in outlining the strategic dimension of a campaign. However, my findings show the importance of the situational dimension, with its practical, daily activities allowing the campaign to produce concrete outcomes. However articulate and complex, the situations may be analysed and decomposed in a number of different, interrelated processes with different meanings. Therefore, I suggest that a framework for monitoring situational processes of CBHP interventions to guide everyday activities, may usefully integrate strategic frameworks, important to keep the intervention aligned with organizational strategies and prospective impact on communities. Moreover, although every health promotion program has both a planned and a situational dimension, the importance of the framework may be emphasized by considering the importance of the situational dimension in CBHP programs, for

the outlined reasons. In other words, my findings highlight the importance of situational management when the targeted behavioural change is complex, the setting is difficult to interpret and analyse, the intervention is occasional, a high turnover of actors is involved and central control on the initiative is weak.

The aim of managing and monitoring the situational dimension in CBHP interventions resonates with recent developments in organizational theory, concerning a more specific focus on understanding and managing practical complexities of organizational processes in an era of constant and rapid changes (Hernes & Maitlis 2010). In addition, it is both well documented in the literature and clearly perceivable in the field the wide gap between academic research and practical implementation of programs (Gabbay & le May 2010, p.5). Academics usually complain about a lack of rigour in implementation and evaluation, while practitioners tend to highlight that academic frameworks and models are too difficult to implement in practice, due to a lack of resources and the distance between theoretical models and the characteristics of the settings. In such a context, practitioners may consider useful a light-touch framework for guiding situated, everyday actions, largely based on practitioners' behaviour and the study of community settings, and at the same time generated through a rigorous analytical process

Conceptual frameworks are often used in qualitative research as interrelated sets of concepts taken from theory, similar fields of inquiry and the researcher's previous experience. They help outlining the interpretive structure of a study from the outset, and also contribute to structuring the findings and the discussion, after several iterations (Miles & Huberman 1994, pp.18–22; Smyth 2004). Here, I use the concept of framework in a slightly different way: based on the data and their interpretation presented in the findings, I try to distil what appeared to be the most important practical lessons learned for the health promotion practitioner. As I will argue in the next section and in section 8.6.3, the framework is very rudimentary, and needs testing and improvement. However, it seemed appropriate to develop it, since it is based on patterns and interpretations strongly grounded in the data. To create the framework, I systematically went through the themes and subthemes identified during data analysis, summarized in the thematic network of main findings displayed in Figure 8.1. Subsequently, I identified the aspects of those themes that I deemed more relevant from a practical point of view for health promotion practitioners, based on the analysis of both network characteristics and network dynamics. The main limitation resides in my role as a researcher, and not a health promoter. However, from the field experience and the data collected I was able to gain a robust insight of the main worries, goals and objectives of practitioners in the field. The result, therefore, was a framework that, however tentative, is strictly related to the interpretation of

findings and allows linking the most relevant dimensions of my data and interpretations to the practical objectives of health promoters, in the form of a guidance which is itself the product of a prolonged immersion in the field. In the next section, I try to work out some of its basic elements.

8.4.2 Description of the framework

Taking into account the aforementioned structural and contextual challenges, I adopted a network-oriented perspective: since multiple actors were involved in a complex intervention in a difficult-to-define environment, focussing on networks (what actors "do" versus what actors "are") brought several advantages. Firstly, this approach enabled me to compare multiple, and often competing, perspectives/narratives of different categories of actors, together with the interactions of their roles. Secondly, it was possible to analyse the exchange of resources (information, skills, trust, local knowledge, …) and the execution of actions (evidence translation, decision making, co-production of identities, delivery of materials, …) between nodes of a network, thus attaining a more systemic and holistic understanding of the setting and the intervention. Finally, I analysed issues of coordination between actors, alongside the role of the whole network in facilitating or hindering coordination and alignment: a view of the intervention emerged as a temporary, contested space in a complex and competitive network of other community initiatives.

Section 8.2 showed the prevalence of situational sense-making by actors in their network interactions, to the point that I could define the whole project development as situations-led. Since it seems reasonable that a similar attitude may prevail in comparable CBHP interventions, a framework derived from such data is likely to be useful in similar situations. **Error! Reference source not found.** is a graphical representation of the network-oriented facilitation framework.
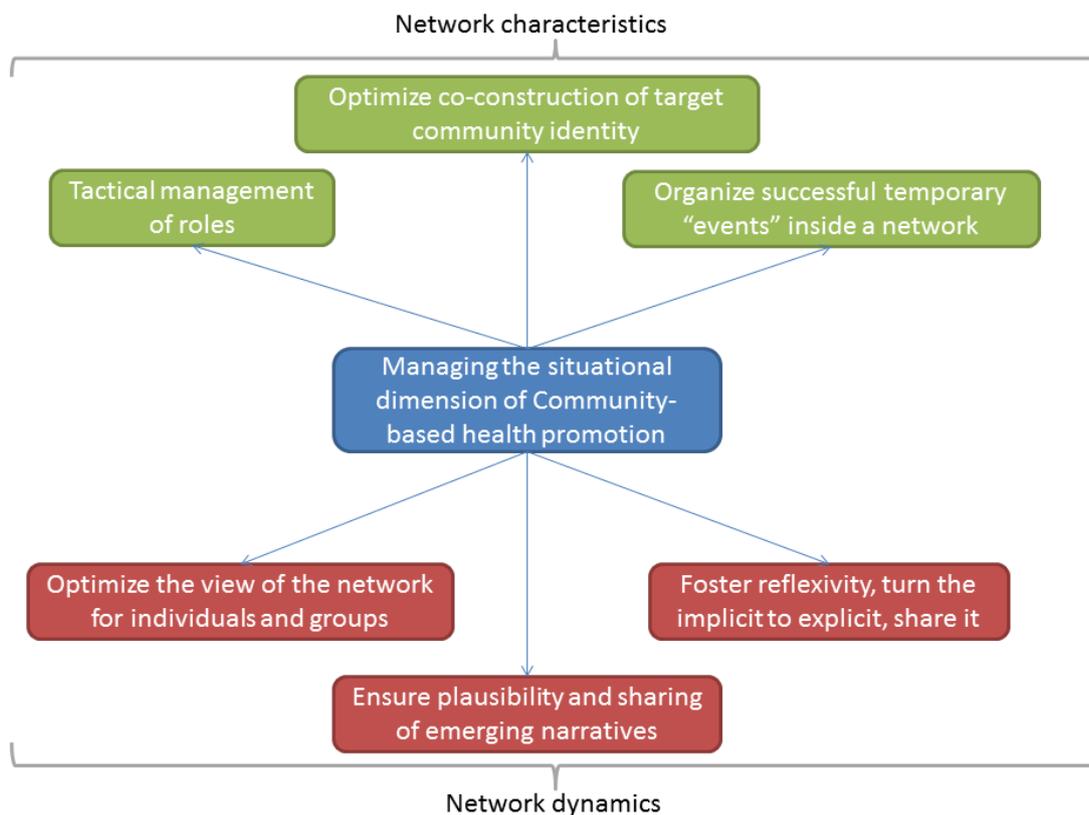
Figure 8.2 The network-oriented facilitation framework

Some assumptions linked to study findings underpin the framework. Firstly, it may prove unhelpful trying to plan in too much detail what may happen once CBHP practitioners enter the field and make contact with a complex and "unknown" environment. Therefore, the primary aims would be allowing flexibility and best management of the situational sense-making process, ensuring that narratives and co-constructed meaning maintain an acceptable coherence and the overall goals of the intervention are attained. In addition, it should help avoiding or reducing major criticalities in implementation (delays, role conflicts, conflicts with communities, etc.), and making good use of scarce resources in a short time and in a temporary, precarious situation.

Finally, all elements of the framework address a network of actors, and can be effective only in the context of such a network; therefore, the primary aim is optimizing workings and interactions within the network itself. In summary, the focus is less on enhancing implementation fidelity or prescribing the rigid attainment of pre-established outcomes, and more on practical, flexible guidance for program implementation. I will introduce, discuss in the context of the literature and illustrate with examples the main elements of the framework. The framework may be useful both for academics in studying an intervention, and for health promoters in monitoring the implementation of an intervention.

A further element of reflection concerns who should have the responsibility for implementing the framework in practice. In a sense, its elements refer to all actors in the network. On the other hand, exactly as a project manager is usually in charge of presiding over the strategic dimension of an intervention, a similar figure should probably take responsibility of implementing the framework for optimizing situational sense-making. As shown in the findings, in this particular intervention I partially played such a role, although limited to collecting information and without the possibility of acting. The challenge would probably consist in the individuation of a "situational manager" or facilitator, involved in the project only to a degree, so that he/she can be free to address the problems in communication, role conflicts, network representation by actors, and the like, and try to correct them. In the framework, I will therefore refer to a provisional "situational manager" as needed.

One: take advantage of a situational, flexible management of roles. The first key element consists in managing role overlaps and evolution, while keeping roles flexible and adaptable. The situational manager should clearly identify roles as soon as possible in the course of the project. However, roles are enacted only through network interactions, and evolve through the same interactions. The situational manager, and all actors should acknowledge such a fact, and facilitate interactions between roles, as this may improve actors' ability to seize opportunities as they present. Optimizing network interactions and monitoring the evolution of roles may help in identifying how the campaign has progressed and in considering unexpected opportunities. On the other hand, roles evolving against or outside the scope of the campaign may indicate critical issues to solve. (Self-)perceptions, overlaps and evolution of roles are the basis for network interactions in the context of the campaign, and monitoring their co-variation may allow for a deeper understanding of its dynamics and for rapidly correcting conflicts, negative overlaps as soon as they present.

In section 5.2 I have showed different processes that this approach may help to optimize. Some examples follow. Firstly, monitoring in real time role overlaps may have contributed to reducing delays by clearly agreeing roles of regional network members and commissioners. In addition, monitoring role evolution of Somali community gatekeepers in organizing the final events may have helped in trying to adopt quickly the same model for the Yemeni and Pakistani community.

Two: Optimize co-construction of the identity of target communities. Actors should acknowledge that the identity of the target community (in so far as it is relevant for the health issue faced by the health promotion initiative) is not an essence to grasp through interpretation, but the object of a co-construction and negotiation between actors with

different roles. The negotiation, in fact, happens in a network of "insiders" (e.g. commissioners and campaigners) and "outsiders" (e.g. community members and gatekeepers), *strictly finalized to pursuing the objectives of the campaign*. Therefore, the focus should be on immediate results, rather than making contacts "just in case" they may be useful again in the future[12]. The co-constructed identity would thus represent only a temporary compromise, reached through an open negotiation. It may be useful for campaigners to include the available evidence as an element to discuss with the community, as well as to include in the process of definition individuals and groups representing different perspectives inside the community. Such a process would be systematic, but only to a degree (given the time and resources): it would resemble more an open conversation – and in this effort the rigour should mainly concern the way in which such conversation is organized and its results are iteratively obtained and shared – sometimes also through unavoidable misunderstandings and conflicts.

In the studied intervention, such an approach may have contributed to sparing time of both campaigners and community gatekeepers and members, especially when campaigners and designers had to take into account the cultural adaptation of the intervention. Focussing on a narrower, more operational concept of identity and cultural diversity emerging from conversations may have contributed to two different outcomes. Firstly, campaigners may have held shorter and more focussed community sessions in the design phases. Secondly, acknowledging narrative identity co-construction between different actors may have ensured that the contribution of each node in the network was explicit, and that selection of ethnic traits was more transparent and effective.

Three: campaigners should organize successful temporary "events" inside a network, without necessarily aiming at global transformations. The latter may well be strategic objectives of a health promotion program, but CBHP interventions are more likely to materialize as encounters between health promoters (or health promotion materials, or both) and target communities in one or more specific places and times. As such, they will probably be temporary "events", challenging community norms, in a dynamical, changing and competitive environment. Situational managers should therefore place an emphasis on carefully planning and delivering high-quality events, reaching the best possible alignment of actors, being ready to seize further opportunities for health promotion arising during or after the event, with new appropriate moves. Also, the aim should consist in creating a framework where partially irreducible diversities may openly meet and debate on a particular occasion,

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[12] This is true unless the focus of the intervention is explicitly on long-term community capacity building, which is not the case for the typology of interventions I am considering here.

which may then be reminded and used in the future as a trigger (but not a prerequisite) for further, intrinsically different – but linked – dialogues and events.

In the stroke awareness campaign, competitive pressure from different health promotion initiatives clearly emerged (see section 5.4), thus justifying the need for this approach. A dialogic approach, clearly acknowledging differences and helping all different groups to express themselves and communicate, although in a limited time frame, may improve the frequently observed situations in sessions in which no two-way communication exchange was established.

Four: Ensure plausibility and sharing of emerging narratives and constructed meanings (i.e. allow for interaction of evidence and practice). The intervention is unlikely to represent top-down translation of scientific evidence into practical behavioural change. More probably, scientific evidence about necessary behaviour change will undergo multiple translations as it flows through network exchanges. At least as important will be the capture of knowledge and evidence arising from practice and constructed together with communities (for the importance of this type of knowledge see Pawson et al. 2003). These multiple translations arise during situational network exchanges, constitute complex processes and take the form of stories, expressing the perspectives of actors and groups. Implementation of a successful intervention will require three steps. Firstly, monitoring of how these stories emerge; subsequently, checking the plausibility of stories against hard facts and ensuring that stories are shared between different groups of actors; finally, being able to show the link between actions performed in the intervention and the evidence on which they were based.

There was limited awareness of such narrative mechanism of translation of knowledge into practice within the studied intervention. Lack of awareness lead to multiple, different and often not-communicating accounts of the same events. A situational manager in charge of monitoring the emergence and plausibility of stories in the campaign might have improved the communication between network actors, thereby possibly making the whole process more efficient and successful.

Five: optimize the view of the network for individuals and groups. Information and resource exchanges through the networks in a CBHP intervention obey a logic related to situational sense-making – i.e. they happen in a local dimension, and tend to be short-range. Consequently, actors often lack a view of the whole network, which may improve their ability to form less biased judgements and make better decisions. A situational manager may significantly contribute to the success of a CBHP initiative by ensuring that each actor has a

clear idea of how the network is organized, who the other partners are and what their objectives are, and finally how they can be reached.

One of the specific traits of the stroke awareness campaign was the fact that no actor had a clear view of the whole network: this often led to uncertainties in decision making, difficulties in interpreting the context, etc. It is likely that obtaining a clear perspective about who-does-what-in-what-position would have improved the choices available for each actor to make informed decisions in the campaign, and hence probably improved its overall effectiveness.

Six: foster reflexivity – turn the implicit to explicit and share it (as much as possible). Most of the information exchanges, judgements and decisions happening through a network in a CBHP initiative are based on implicit assumptions, and – although they contribute to the ideas that actors form about their (and other actors') role and identity – are rarely made explicit and understandable to actors not directly involved in an exchange. Similarly, reflection upon the meaning of events and actions for actors and groups happens all the time, but actors seldom make it explicit and available to the network. A situational manager may help optimize judgement and decision-making process influencing the outcomes of a CBHP intervention by fostering reflexivity and making explicit and shared, as far as possible, the perspectives of actors and their understanding of events.

I often noted in the studied campaign that the only virtual space where assumptions briefly became explicit and reflected upon were interviews I carried out during data collection. The existence of a shared forum where all actors could contact each other and verify their assumptions would have likely improved communication, avoided misunderstandings and contributed in reaching a shared (although not necessarily consensual) evaluation of the events of the campaign.

8.5 Strengths and limitations of the research

To the best of my knowledge, this work represents the first in-depth study of the dynamics of design and initial delivery of a CBHP intervention for ethnic minorities in the UK, adopting a relational and interactional perspective centred on networks. As for the content, observing and reconstructing the concrete, day-to-day interaction of health promotion practitioners, community members and a number of gatekeepers allowed constructing a dataset, which is both original and relevant for the health promotion community. The adopted methods allowed approaching the fieldwork and the data analysis with an open mind, without consciously superimposing interpretive schemes to the emerging findings. In particular, I made every effort to take into account diverse perspectives of actors occupying different roles and positions. The

relational and interactional perspective adopted in data analysis permitted me to focus on processes and the value of interactions, while preserving the value of individual statements and positions. One of the strongest points of the present work is therefore the richness of data and the vivid depiction of rarely studied interactions involving difficult-to-access populations, without retreating from analysing and describing instances of conflict and disagreeing interpretations by different actors.

This thesis aims to operate at an interpretive, rather than merely descriptive level. Balancing the two levels proved very difficult, especially because I had to interpret an original dataset while respecting the dynamics emerging from the data, at the same time trying to integrate them in the context of theories, paradigms and models usually adopted in different disciplinary areas and for different aims. Nonetheless, I am confident that the results are relevant to the field of study, because I have constantly discussed theories and models in strict relationship with data. As a result, the research has produced insights on mechanisms influencing the process of design and initial delivery of a CBHP intervention. Finally, both data collection and analysis resulted from my prolonged, intensive involvement and engagement with actors, events and circumstances of the CBHP intervention. On one hand, this represents a point of strength of the thesis, since I collected data directly, without further intermediation. Furthermore, having adopted a relational point of view towards the analysis of data, it seemed only appropriate to collect such data through direct networking with actors involved in the campaign.

On the other hand, however, my subjectivity as a researcher also operated as a barrier, as well as a facilitator. Firstly, as an observer involved in the campaign, it proved impossible to be absolutely detached from the events and people I studied. Given my personal interest in the topic, I could not avoid feeling disappointed when delays hindered the progress of the campaign, delighted when events were finally organized and thrilled at the perspective of interviewing actors after weeks of preparation. However normal, those feelings were linked with expectations of positive outcomes, and may have therefore influenced the data collection phase, perhaps more than the analysis of data: in fact, the emotional situation at the moment of collecting data may have influenced how I selected details from observations, or the focus or emotional relationship established with an interviewee. Secondly, during data analysis, although I made every effort to avoid forcing external interpretive schemes on the data, it seems impossible that a researcher faces such a difficult task entirely without prejudices and pre-existing interpretive schemes. As an example, my background as an information professional may have influenced the way in which I looked at data concerning evidence

translation and information sharing. Moreover, as a non-native English speaker and non-British citizen I had at times obvious problems in interpreting shades of meaning in expressions of both English speakers and people from BME communities. Over and above language, I was in the both difficult and interesting position of a non-participant observer trying to interpret the interaction between a majority culture and three minority cultures without belonging to any one of them. This acted as a barrier since the lack of familiarity with a culture may have prevented me from being sensitive to important details. However, my position may also have been a facilitator, since I was able to have a fresh look to the interaction between different cultures, exactly because I was a kind of double "professional stranger" (Agar 1996) – both as a non-participant observer and a non-member of any of the cultures involved. Furthermore, the different changes in the focus of the project meant that I had to refocus my own research interest several times. While this may have been a useful opportunity to learn about coping with difficulties, which often arise during qualitative research projects, it may also be true that keeping the same focus and research question/objectives from beginning to end may perhaps have resulted in a more cohesive and sharper analysis and discussion.

Looking at objective factors, other limitations of the study include the short time frame available for data collection, concentrated in very short, intensive periods, since at least the possibility of doing the observations was dependent on the progress of the campaign. As a result, I could not collect data to analyse the diachronic evolution in the attitudes of some actors about the campaign, for example. This may have produced a more complete point of view on the campaign. In other words, views of actors may not always refer to the whole process, but just to specific segments. Additionally, due to reasons specified in section 3.4, community members were under-represented in interviews.

As for the possibility to generalize the results from my study, the next section identifies further research needed to confirm and integrate the findings. On one hand, I tried to conform to the most rigorous standards for data collection and analysis; on the other hand, as a PhD researcher I could not work with other co-investigators. This proved a strong limitation in the analysis of a qualitative dataset, since for example it is very useful to analyse and code the same dataset with another researcher, to increase the reliability of the analysis and the richness of interpretive perspectives. A final limitation was that I only studied a single CBHP intervention, without the possibility of comparing it with similar "matched" interventions. Such a limitation would explain why the main themes emerging might not be exhaustive, and more research on the topic with the same approach would be needed to confirm or challenge them.

8.6   Implications of the findings

The present section will describe the implications of findings for the practice of CBHP, for CBHP-related policy and for further research.

8.6.1   Implications for practice

Fieldwork in implementing a CBHP intervention was largely led by "situational sense-making" and storytelling. Hence, health promoters needed to make the most of network interactions with communities, to set up effective events and be open to unexpected opportunities. Managing the situational level of CBHP interventions seems therefore relevant, to make sure that interactions produce the best results. This does not imply abandoning traditional strategic planning, but on the contrary integrating it with real-time process management specifically targeted at optimizing network interactions whenever possible.

Likewise, it seems vital to focus on a specific present initiative, more than on its future sustainability, which may lie far beyond the reach of campaigners. Delivering high quality events and hence creating an efficient, although temporary, environment where health promotion is performed can trigger further opportunities for campaigners to seize.

Finally, in CBHP, although each actor adopts a specific role and identity, roles and identities are largely co-constructed through network interactions. On one hand, it seems necessary to accept flexibility and even a degree of challenges and conflicts, since it can open up opportunities for health promotion. On the other hand, health promoters should ensure that evolution happens in line with the overall project aims, co-constructed stories are plausible and each actor has a comprehensive view of the whole network, so to be able to make the most of the health promotion experience.

8.6.2   Implications for policy

Process evaluation in CBHP interventions presents major challenges. However, process evaluation adds value to implementation as it helps practitioners to "understand how and why interventions work" (Thorogood & Coombes 2010, p.87). Therefore, having acknowledged the situational nature of sense-making and storytelling happening through networks of actors in a CBHP intervention, it is helpful to resort to a light-touch tool for process monitoring, such as the network-oriented facilitation framework. The main goal should be to prevent the occurrence of major deviations from established objectives, and not to rigidly enforce the attainment of pre-established, specific goals. Furthermore, monitoring the process should aim at helping actors make the most of their interactions to design and deliver effective health promotion initiatives. Finally, facilitating open and explicit interactions, while being open to

unexpected contexts and results is a further vital point both for planners and for roles in charge of monitoring CBHP interventions.

Although strategic planning and monitoring should not be dismissed, it seems very important that planning and process evaluation are mostly focussed on facilitating situated interactions between actors and on exploring difficult-to-identify possibilities, rather than continuously check whether or not the project is on track with respect to original, detailed schedules and objectives. In summary, stimulating negotiation and creating productive transactions between actors should be the main goal of process evaluation in CBHP interventions.

8.6.3   Implications for future research

This thesis has demonstrated that it is possible to understand the main dynamics of network interactions in a CBHP intervention, with important consequences for the appreciation of the most important characteristics of such an intervention. The present work, however, has also highlighted significant gaps in current understanding of CBHP interventions, which may be explored by research. In detail, if further CBHP interventions are to be studied within a network perspective, the current thematic network linked to "situational sense-making" and storytelling may be improved, by criticizing and reshaping some of the subthemes, by highlighting the importance of new themes, and most of all, by establishing new relationships between subthemes. Studies with similar methods and participants may therefore play an important role in validating the current findings, and in analysing more in depth their implications for how to successfully plan and monitor situational sense-making in a CBHP intervention.

It may be important to replicate the present study with different target communities, to understand whether negotiations and identity/role construction follow similar or different path. Replicating the study with even slightly different health promotion content may help understand limitations in the generalizability of the present findings to situations in which the message is more complex, or where the effect of behaviour change is easier or more difficult to achieve, etc. Finally, campaigners and/or commissioners with different backgrounds, and located in alternative organizational contexts, should also be studied – for example, in health service organizations situated in different countries, and with different contractual agreements (e.g., with or without outsourcing). This may improve knowledge of the importance of some of these variables on how the interactions are deployed, on the dynamics of involvement and information sharing in the field.

A further direction for research would imply criticizing, extending and testing the network-oriented facilitation framework. At the present stage, this represents only a first, incomplete attempt at applying some conclusions from the findings to the management of situational sense-making in a CBHP campaign. However, as knowledge about the dynamics of CBHP interventions increases, the framework may evolve into a fully-fledged model, with richer details, clearer connection between parts and more directly applicable to CBHP interventions. Such applicability may also be tested, perhaps again from a qualitative research perspective, to understand the implications for practitioners of my framework.

An integrative direction for future research may include eliciting the opinions and views of CBHP practitioners and community members on the framework. This would allow incorporating directly their experience of how situational sense-making is carried out in an intervention (i.e. how participants are involved, what seems to work best as far as shared decision making is concerned, etc). In addition, it would be useful to review, criticize and integrate the theoretical frameworks employed to make sense of the experience in the field. The present work mainly used theories and conceptual frameworks from different disciplinary fields to help discuss and integrate in a wider perspective the findings emerging from data collected in the field. Eventually, however, as evidence accumulates, it is vital to verify whether the "situational sense-making" and the narratives-in-network frameworks are the most adequate conceptual tools to interpret CBHP interventions. It would also be important to integrate such tools and to explore alternative conceptual frameworks, which may better illuminate and contextualize themes and subthemes.

On a different note, researchers may employ formal social network analysis to understand characteristics of networks influencing CBHP interventions, especially for medium- to large-size campaigns, and when specific variables of interest are taken into account. Moreover, a limitation of the present study was that I was only able to capture evolution of the campaign via a series of snapshots taken at different times. Adopting longitudinal, cross-sectional approaches may ensure that the views of actors are more comprehensively captured and emerging themes relate more directly to what happens in the field. Finally, as process dynamics become clearer, it will be worth exploring the links between the characteristics of process of CBHP interventions and their outcomes. Consequently, further research should aim at increasing the understanding of how situational network interactions contribute not only to the implementation process but also to outcomes of interventions.

8.7 Conclusions

The present qualitative study adopted a network perspective in the attempt to understand the main dynamics operating in a CBHP intervention aimed at improving stroke awareness, targeting BME communities in a large urban area in England. The results point to "situational sense-making" as one of the most important dynamics in the field, in turn related to narratives and storytelling enacted in social network interactions to iteratively define roles and identities, share information, make judgements and decisions. All such mechanisms were linked to situational sense-making, operating mainly locally inside the network, but with widespread effects on the outcomes of the campaign. The campaign as such, could be characterised as a series of localized events each with their own rules and specific set of interactions, enacted in the wider space of the communities, in the context of a strong competition and different, established rules.

The task facing the campaigners was highly complex, since they had to make sense of a mostly unknown environment, involve participants in the design and delivery of the campaign and adopt an attitude oriented towards co-production and acknowledgement of cultural difference. Moreover, the level of support by commissioners proved quite low, commissioners significantly changed the focus of the project and long phases of delays and interruptions undermined the efficacy of the campaign. Unfortunately, however, such conditions are not unusual, in today's CBHP landscape. It was therefore important to analyse the facts, attitudes, interactions of actors in this campaign to discover the social forces and mechanisms operating to produce specific outcomes in the given (however suboptimal) situation.

Ultimately, while analysing the findings emerging from my dataset, I discovered that "situational sense-making" and storytelling through social network interactions were the most relevant attitudes and dynamics. These attitudes allowed actors to make sense of what happened and produce concrete results, although on occasions such results differed significantly from those envisaged prior to the development of the intervention. It then became apparent that – if situational sense-making in CBHP interventions was so important, although so infrequently acknowledged in the literature – then two alternative courses of action were available.

The situational dimension could simply be considered as a "black box", something varying so much according to the situation of the community, the personality of actors and the external constraints, that any interpretive effort aimed at sharing the lessons learned from this case study is substantially useless. Alternatively, and more constructively, it was possible to outline

ways to manage and monitor situational sense-making, strictly based on the findings and in the context of wider theoretical frameworks. In doing so, I elaborated the network-oriented facilitation framework for CBHP interventions, as a light-touch process monitoring tool. Its main tenets include:

- the value of situational, flexible management of roles;
- optimization of the co-construction of the identity of target communities;
- focus on organizing successful temporary "events" inside a network;
- ensuring plausibility and sharing of emerging narratives and constructed meanings (i.e. allowing for interaction of evidence and practice);
- optimizing the view of the network for individuals and groups;
- fostering reflexivity; turning the implicit to explicit and sharing it.

I then discussed both my findings and the emerging, provisional framework for process monitoring in the context of philosophical, sociological and health promotion theories and frameworks. The most fruitful of these frameworks seemed to be the concepts of situation and situated action, the tradition of studies about sense-making inaugurated by Karl Weick, and the theories involving the application of narrative theory to the social sciences as suggested by Jerome Bruner. The result is not so much a fully developed theory-of-situational-sense-making in CBHP, nor a cookbook for practitioners wishing to distil learning from my field experience. It is in fact more similar to an attempt at understanding in-depth what happens in a CBHP interventions when networks and interactions of individuals are taken into account, instead of established roles or prospective outcomes. When focussing on processes and interactions, highly complex, and partly idiosyncratic and non-generalizable dynamics emerge. Hence, I cannot claim to have found explanations for specific behaviours, nor specific barriers or facilitators for successful implementation of CBHP interventions, as this would be difficult to expect in such an early phase of study.

In my opinion, the contribution of the study is threefold. Firstly, I have shown that a complex social phenomenon can be studied productively through a qualitative social network approach that has yielded insights with potentially important implications for health promotion. Secondly, I have demonstrated that a so-called secondary aspect of a CBHP intervention – situational sense-making effected through interactions in a social setting – is not secondary at all, and has a disproportionate impact on concrete implementation processes of such interventions. Thirdly, I suggest that such situational network processes, although too highly

variable to be predicted, can nonetheless be managed and optimized and I also tried to suggest paths for future optimization.

This is a first attempt to interpret an established social reality (CBHP interventions) through partially new lenses – although the component parts of my approach are well described in the literature. The results seem promising, at least as far as they allow for a lively and varied description and interpretation of a specific setting. The interpretations and the framework following from the results may (and should) be criticized, challenged and integrated as new data are collected and analysed over time. I hope, nonetheless, that the present work offers a viable analytical and interpretive perspective, to help practitioners and academics alike to take several steps forward in the path towards overcoming present limitations to planning and monitoring CBHP interventions.

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Appendix A   Observation checklists

A.1   Checklist for observations of sessions and events

This checklist is drawn from Spradley (1980) and Fox (2008) and adapted to the goal of observing how knowledge translation takes place.

A.1.1   Spatial/network dimensions

1. **Place**: in which physical/metaphorical place and in which broader environment do the observed information interactions take place? How does the place influence the information exchange? Is the place structured into networks?

2. **Objects**: the physical things that are present. (How) do objects and actors interact?

A.1.2   Time and events (narrative)

3. **Time**: the sequencing that takes place over time, i.e. how things happen as time flows? Continuities and discontinuities (e.g.: moments of silence, breaks in the communication flow, misunderstandings, synchronicity of acts, …).

4. **Acts**: single actions that people do, meaningful and relevant for the knowledge transaction practices taking place, and worth making a note. →

5. **Activity**: a set of related acts people do, including verbal and non-verbal communication, and all language-related issues (jargon, specialism, translation, etc.). →

6. **Events**: a set of related activities that people carry out. Do real "events" happen, or just micro-interactions?

(NB: how important is the role of networks in the transition between 4-5-6, which might or might not happen?)

A.1.3   Actors, goals, feelings

7. **Actors**: which people are involved? Which roles do they adopt in the information and knowledge exchange? Do these roles mutually adapt and change, or remain stable, or conflict against each other? Are these roles relating to each other in a network/networks?

8. **Goals**: what people are trying to accomplish in/by the information exchange: explicit/implicit agendas, etc.

9. **Feelings**: the emotions expressed, related to the accomplishment of goals, (mutual) understanding, conflicts, etc.

A.1.4   Researcher's reflection

10. **Reflection**: the researcher's personal response to any of the above, in terms of feelings,

insights, emergence of critical issues.

A.2 Observation schedule for the distribution phase of leaflets and posters

A.2.1 Background
The distribution phase will take place during 1 or 2 days.

It will target three different areas of [the city], in which most members of the Somali, Yemeni and Pakistani community live.

One member of [the organization in charge of the campaign] will distribute the leaflets and posters in venues such as community centres, mosques, GPs practices and pharmacies.

Most stakeholders for each venue should have been contacted first by [the organization in charge of the campaign], explaining the aims and timing of the distribution of leaflets and posters.

A.2.2 Observation schedule
The researcher will go along with the [the organization in charge of the campaign's] employee distributing leaflets and posters.

The overall goal for the researcher would be to observe how the information exchanges take place, taking networks into account, according to the general research question of the PhD project. Observing the context of the interactions will be as important as observing the interactions themselves.

Field notes will be made about the following general areas of interest:

A. Description of each venue in terms of:
   a. physical environment (location, objects, etc.)
   b. networking taking place in the venue (actual and potential: what is the institutional goal of the venue? How do people seem to interact in it? How do people and physical place seem to interact? How does the structure of the venue seem to influence information exchange?) + "ecology" of the venue
B. Interactions taking place between [the organization in charge of the campaign's] employee (E) and stakeholder (S), in terms of acts, activities, events:
   a. Was the stakeholder aware of the distribution?
   b. What does the information exchange between E and S imply in terms of content, communication style (e.g. use of jargon, level of knowledge of English by S, body language, etc.), empathy between the parties?
   c. How does S seem to react to the distribution and what actions, if any, does S engage to do with leaflets/posters?
   d. Does any discussion take place about practical implications of usage of materials, E's and/or S' expectations etc. take place?

e. How does the closure of the interaction between E-S happen? Where are the leaflets/posters placed?

f. Are there any significant reactions to the presence of the researcher?

g. Which are the goals (explicit or implicit) pursued by both parties during the interaction? What feelings are perceivable? How can the roles of both E and S be described?

h. Does a wider network of roles, relations, etc. appear (or is cited) during the information exchange between E and S and from the observation of the venues?

After the analysis, in transcribing field notes, the researcher will also report his feelings and perceptions about facts observed and about his own involvement.

It is anticipated that such analytical field notes will allow for comparisons to be made in the analysis phase according to the venues and other dimensions for each of the points above. E.g.: what venues/stakeholders seemed more interested? Were there any common features of interactions/reactions? Etc. Besides, results of such comparisons will be checked against further data obtained two weeks after from short interviews and observations.

From a practical point of view, the researcher will:

- introduce himself at each venue, and explain his role;
- ask, at the end of the interaction, whether S will be happy to have a conversation with him/her after a couple of weeks about their experience with the leaflets/posters (stressing the fact that this won't be an evaluation).
- get hold of any copies of freely available documents in each venue, if this does not interfere with the information exchange or create problems of any sort.
- make notes about possible unobtrusive measures about the usage of leaflets and posters in the venue, to be assessed two weeks after.

A.2.3   Questions for selected stakeholders to be asked after 2 weeks

After two weeks from the distribution, the researcher will get back to some venues selected according to their "information potential" as revealed from the data collected in the observational phase. As a strategy, both health-care-related and non-health-care-related venues will be selected.

More specific questions, specifically related to the features/climate of a venue, will be produced after the observation of the distribution phase. However, some possible questions include the following:

- What happened to the leaflets/posters in your venue? (without particular prompts – the goal would be to start a brief conversation between the researcher and S about S' experience)
- What did people say about the leaflet/posters? Were any comments reported to you?

- What was your role in the distribution of these materials?
- What is your overall impression and what are your feelings (both positive and negative) about this experience?

Particular care will be taken not to "lead" the interviewee to express particular opinions/views. Besides, it will be important that the researcher clearly explains that the interview does not imply any form of evaluation.

If possible, photos of the venues will be taken (at the end of the conversation), with permission from interviewees.

Appendix B   Participant information sheets

B.1   Observations. Information sheet for campaigners.

Information for prospective research participants – Non participant observation of co-production phase of the social marketing campaign

Research title: Does a social marketing campaign enhance community capacity for collective decision making when a stroke is witnessed? A qualitative analysis of knowledge translation and utilization through social networks.

What are the aims of this project?

Stroke is a major problem nowadays, especially in some communities. An information campaign is therefore being developed, that aims at improving the knowledge of what a stroke is and what needs to be done when a patient with stroke symptoms is identified (namely, calling the emergency medical service).

However, it is not always easy to translate information into practical knowledge. Since most individuals in a community have a "network" of relatives, friends and acquaintances, it is possible that such network might help people to pass through the message about stroke symptoms and actions. However, it might also be the case that this message is not properly "translated" as it flows from person to person in these networks.

Therefore, this project studies how the message about stroke gets translated from the experts to the community, and how it circulates through individuals in the community once it has been proposed. It does not imply "testing" the knowledge of individuals, but involves identifying how the community as a whole is aware of stroke symptoms and related actions.

What will the project do?

In a first phase, the researcher will observe what is going on when the organizers of the campaign and selected individuals in the community get together to contribute to the development of the message on stroke awareness and to discover how it can be circulated in the community (the so-called "co-production" phase). After that, people who took part in the co-production and distribution of materials (e.g.: leaflets, etc.) will be interviewed by the researcher, individually and as a group; group interviews are called "focus groups". In a second phase, individual community members (both lay people and persons particularly relevant for the community) and health professionals such as doctors, nurses, etc. will be interviewed after being exposed to the campaign message. The objective is to see if, how and through which personal contacts they have learned the basics about knowledge of stroke symptoms and related actions.

Why have I been asked to take part in the research?

You have been asked to consider taking part because you are a member of the organization in charge of the stroke awareness campaign in the community.

Is the participation in the research free and voluntary?

Yes. You will be involved in the research only if you want to.

What will I have to do if I take part in the research?

Since you are involved in the co-production phase of the campaign, the researcher will simply observe the what goes on when members of the community and organizers of the campaign meet to produce together the content of the campaign. You do not need to behave in any particular way, just carry out your activities as usual, and the interviewer will make notes about what happens, to collect data for the research project. No activity, utterance, comment or act of any of the participants will be shared by the researcher with third parties, unless they are made anonymous. Therefore no one will be able to find out or guess who has said a particular thing or carried out a particular activity.

What if I change my mind?

You may change your mind at any point without giving a reason, even when the observation by the researcher has already began. Just let me know, and the data collected from you will not be included in the analysis and results, and will be destroyed.

When and where will the research take place?

The collection of data will begin in January 2011 and will be concluded by September 2012 at the very latest. Observations will take place in the places where the community members and campaign organizers meet, or in public places, when the materials produced will be distributed in the community.

Is the research confidential?

All data will be held in confidence at the University of Sheffield under the control of the researcher. All audio recordings will be deleted as soon as the final data analysis has been completed. All data will be used only for the purposes of this research and will not be passed onto anyone else.

Who will have access to the data and where will it be held?

All data will be held in confidence at the University of Sheffield under my control. All audio recordings will be deleted as soon as the final data analysis has been completed. All data will be used only for the purposes of this research and will not be passed onto anyone else.

What will happen to the results of this research?

Results will published and presented both in scientific journals and in scientific meetings, so as to reach the widest possible audience. Participants in the study will not be identifiable in any of the reported material.

Who is funding the research?

The research is funded by the National Health Service – National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for South Yorkshire (CLAHRC SY), and supervised by the University of Sheffield.

Has the research been reviewed by an ethics committee?

The research has been granted a favourable opinion by Ethics Committee of the School of Health and Related Research of the University of Sheffield.

Are there any possible risks to taking part in the research?

The presence of the researcher as an observer will not imply any particular risk for the participants.

Are there any possible benefits to taking part in the research?

Although the individual participant will not receive any direct benefit from taking part in the research, it is possible that the results of the research will be of direct or indirect benefit to the participant's community or to other communities in the future.

What should I do now?

Once you have informally expressed consent to the researcher, you do not need any further actions to take part in this phase of the research.

Who should I contact for further information?

If you have any questions about the study or require any information, please do not hesitate to contact me:

☎ Mobile phone: xxxxxxxxx

🖥 E mail: paolo.gardois@shef.ac.uk – PhD student

🗎 Post: Paolo Gardois. ScHARR, The University of Sheffield

               Regent Court, 30 Regent Street. Sheffield, S1 4DA

THANK YOU FOR TAKING THE TIME TO CONSIDER THIS RESEARCH

B.2 Non-participant observations. Information sheet for community members. Pre- and co-production phase

Information for prospective research participants – Non participant observation of co-production phase of the social marketing campaign

Research title: Does a social marketing campaign enhance community capacity for collective decision making when a stroke is witnessed? A qualitative analysis of knowledge translation and utilization through social networks.

What are the aims of this project?

Stroke is a major problem nowadays, especially in some communities. An information campaign is therefore being developed, that aims at improving the knowledge of what a stroke is and what needs to be done when a patient with stroke symptoms is identified (namely, calling the emergency medical service).

However, it is not always easy to translate information into practical knowledge. Since most individuals in a community have a "network" of relatives, friends and acquaintances, it is possible that such network might help people to pass through the message about stroke symptoms and actions. However, it might also be the case that this message is not properly "translated" as it flows from person to person in these networks.

Therefore, this project studies how the message about stroke gets translated from the experts to the community, and how it circulates through individuals in the community once it has been

proposed. It does not imply "testing" the knowledge of individuals, but involves identifying how the community as a whole is aware of stroke symptoms and related actions.

What will the project do?

In a first phase, the researcher will observe what is going on when the organizers of the campaign and selected individuals in the community get together to contribute to the development of the message on stroke awareness and to discover how it can be circulated in the community (the so-called "co-production" phase). After that, people who took part in the co-production and distribution of materials (e.g.: leaflets, etc.) will be interviewed by the researcher, individually and as a group; group interviews are called "focus groups". In a second phase, individual community members (both lay people and persons particularly relevant for the community) and health professionals such as doctors, nurses, etc. will be interviewed after being exposed to the campaign message. The objective is to see if, how and through which personal contacts they have learned the basics about knowledge of stroke symptoms and related actions.

Why have I been asked to take part in the research?

You have been asked to consider taking part because you are a community member involved in the co-production of the stroke awareness campaign.

Is the participation in the research free and voluntary?

Yes. You will be involved in the research only if you want to.

What will I have to do if I take part in the research?

Since you are involved in the co-production phase of the campaign, the researcher will simply observe the what goes on when members of the community and organizers of the campaign meet to produce together the content of the campaign. You do not need to behave in any particular way, just carry out your activities as usual, and the interviewer will make notes about what happens, to collect data for the research project. No activity, utterance, comment or act of any of the participants will be shared by the researcher with third parties, unless they are made anonymous. Therefore no one will be able to find out or guess who has said a particular thing or carried out a particular activity.

What if I change my mind?

You may change your mind at any point without giving a reason, even when the observation by the researcher has already began. Just let me know, and the data collected from you will not be included in the analysis and results, and will be destroyed.

When and where will the research take place?

The collection of data will begin in January 2011 and will be concluded by September 2012 at the very latest. Observations will take place in the places where the community members and campaign organizers meet, or in public places, when the materials produced will be distributed in the community.

Is the research confidential?

All the research is strictly confidential and the identity of participants will not be revealed to anyone. All views expressed and actions observed will remain anonymous in all the analysis and reporting of the research.

Who will have access to the data and where will it be held?

All data will be held in confidence at the University of Sheffield under the control of the researcher. All audio recordings will be deleted as soon as the final data analysis has been completed. All data will be used only for the purposes of this research and will not be passed onto anyone else.

What will happen to the results of this research?

The research results will published and presented both in scientific journals and in scientific meetings, so as to reach the widest possible audience. Participants in the study will not be identifiable in any of the reported material. Participants will have the opportunity to ask to receive a copy of the final research report.

Who is funding the research?

The research is funded by the National Health Service – National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for South Yorkshire (CLAHRC SY), and supervised by the University of Sheffield.

Has the research been reviewed by an ethics committee?

The research has been granted a favourable opinion by Ethics Committee of the School of Health and Related Research of the University of Sheffield.

Are there any possible risks to taking part in the research?

The presence of the researcher as an observer will not imply any particular risk for the participants.

Are there any possible benefits to taking part in the research?

Although the individual participant will not receive any direct benefit from taking part in the research, it is possible that the results of the research will be of direct or indirect benefit to the participant's community or to other communities in the future.

What should I do now?

Once you have said to [the organization in charge of the campaign] that you agree to be observed, you do not need any further actions to take part in the research.

If you need further information, please contact me at the details below

My details are as follows:

☏ Mobile phone: xxxxxxxxx

🖥 E mail: paolo.gardois@shef.ac.uk – PhD student

📧 Post: Paolo Gardois. ScHARR, The University of Sheffield

                    Regent Court, 30 Regent Street. Sheffield, S1 4DA

THANK YOU FOR TAKING THE TIME TO CONSIDER THIS RESEARCH

B.3   Non-participant observations. Information sheet for community members. Delivery phase

Information for prospective research participants – Non participant observation of co-production phase of the social marketing campaign

Research title: Does a social marketing campaign enhance community capacity for collective decision making when a stroke is witnessed? A qualitative analysis of knowledge translation and utilization through social networks.

What are the aims of this project?

Stroke is a major problem nowadays, especially in some communities. An information campaign is therefore being developed, that aims at improving the knowledge of what a stroke is and what needs to be done when a patient with stroke symptoms is identified (namely, calling the emergency medical service).

However, it is not always easy to translate information into practical knowledge. Since most individuals in a community have a "network" of relatives, friends and acquaintances, it is possible that such network might help people to pass through the message about stroke symptoms and actions. However, it might also be the case that this message is not properly "translated" as it flows from person to person in these networks.

Therefore, this project studies how the message about stroke gets translated from the experts to the community, and how it circulates through individuals in the community once it has been

proposed. It does not imply "testing" the knowledge of individuals, but involves identifying how the community as a whole is aware of stroke symptoms and related actions.

What will the project do?

In a first phase, the researcher will observe what is going on when the organizers of the campaign and selected individuals in the community get together to contribute to the development of the message on stroke awareness and to discover how it can be circulated in the community (the so-called "co-production" phase). After that, people who took part in the co-production and distribution of materials (e.g.: leaflets, etc.) will be interviewed by the researcher, individually and as a group; group interviews are called "focus groups". In a second phase, individual community members (both lay people and persons particularly relevant for the community) and health professionals such as doctors, nurses, etc. will be interviewed after being exposed to the campaign message. The objective is to see if, how and through which personal contacts they have learned the basics about knowledge of stroke symptoms and related actions.

Why have I been asked to take part in the research?

You have been asked to consider taking part because you are a community member involved in the delivery of the stroke awareness campaign.

Is the participation in the research free and voluntary?

Yes. You will be involved in the research only if you want to.

What will I have to do if I take part in the research?

Since you are involved in the delivery phase of the campaign, the researcher will simply observe what goes on when members of the community and organizers of the campaign meet. You do not need to behave in any particular way, just carry out your activities as usual, and the interviewer will make notes about what happens, to collect data for the research project. No activity, utterance, comment or act of any of the participants will be shared by the researcher with third parties, unless they are made anonymous. Therefore no one will be able to find out or guess who has said a particular thing or carried out a particular activity.

What if I change my mind?

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When and where will the research take place?

The collection of data will begin in January 2011 and will be concluded by September 2012 at the very latest. Observations will take place in the places where the community members and campaign organizers meet, or in public places, when the materials produced will be distributed in the community.

Is the research confidential?

All the research is strictly confidential and the identity of participants will not be revealed to anyone. All views expressed and actions observed will remain anonymous in all the analysis and reporting of the research.

Who will have access to the data and where will it be held?

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What should I do now?

Once you have said to [the organization in charge of the campaign] that you agree to be observed, you do not need any further actions to take part in the research.

If you need further information, please contact me at the details below

My details are as follows:

☎ Mobile phone: XXXXXXXXX

🖥 E mail: paolo.gardois@shef.ac.uk

🖹Post: Paolo Gardois – PhD student. ScHARR, The University of Sheffield

              Regent Court, 30 Regent Street. Sheffield, S1 4DA

THANK YOU FOR TAKING THE TIME TO CONSIDER THIS RESEARCH

Appendix C   Interview topic guides

C.1   Interview topic guide. Campaigners

C.1.1   Focused history
Brief description of the interviewee's role in the campaign.

→ list of people he was in contact with (name the ten most important), and their roles.

C.1.2   Details of experience
Pre-production, co-production phase:

- how did the information flow?
- Which kind of information?
- How did the evidence-base get built? Through which networks?
- Difference between networks of/with communities and of/with NHS and other stakeholders

C.1.3   Reflection on the meaning
Which were the main barriers to information flow (i.e. evidence building and evidence communication)?

Which were the main facilitators?

As for communities, which were the most important ethnicity-related issues, barriers and facilitators?

C.2 Interview topic guide. Community gatekeepers

This topic guide is to be used with any gatekeepers who had a significant role in organizing community events related to the campaign.

The interview is divided into three main areas:

A. **Role and activities in the campaign**: this will elucidate the place of the interviewee in the networks who have been used to organize the campaign.

B. **Impressions and feelings about the training and the leaflet/poster**: this will help to understand if any factors have influenced the take-up of the message by community members, or any other insights from participants in both the materials and the training.

First of all, could you tell me a little bit more about you? (you can answer only the question you want to, no question is mandatory).

- [Make note of gender and name of interviewee]
- How long have you been living in [the city] for, now?
- What is your current role in your organization?
- What kind of social activities do you practice in your community, if any?

A. Role and activities in the campaign

- Do you remember how you got involved in the campaign and why?
- What activities did you undertake to organize the training (or public) event?
- What people did you get in touch with, to organize the event and why?
- Did you encounter any difficulties in organizing this event?
- How did the organization of this event compare to other events you have organized or been involved with?
- What do you think about the specific contribution your organization and your role offered to this even?
- What do you think the main barriers/opportunities were for this campaign, taking into account the fact that it was targeted at ethnic community members?

B. Impressions and feelings about the training and the leaflet/poster

- How did you feel about the training event and the poster/leaflet?
- What is your general impression of the event and of its impact on your community's members?

Finally: thank you for your time.

C.3   Interview topic guide. Community members

The interview is divided into three main areas:

- Impressions and feelings about the training and the leaflet/poster: this will help to understand if any factors have influenced the take-up of the message, or any other insights from participants in both the materials and the training.
- Recall of the message: the objective is mainly to allow the individual to focus back on the message, in order to proceed with the following section.
- Practical activities undertaken with the acquired information: this will allow to reconstruct if and how the acquired information/knowledge has been operationalized, in which contexts and with which results.

First of all, could you tell me a little bit more about you?

A. Impressions and feelings about the training and the leaflet/poster

- What do you think the organization in charge of the learning event was?
- How did you feel about the training event and the poster/leaflet?
  - What do you think about the training event?
  - What do you think of the leaflet and the poster you have seen at the event?

B. Message recall

- Two weeks have now passed since when you attended the community training event. Do you think you can remember the main symptoms of stroke? Could you summarize them for me?
- What should you be doing if you witnessed a stroke?

C. Practical activities undertaken with the acquired information

- In the time between the training event and today, what did you do (if anything) with the leaflet that has been distributed during the event?
  - If so, what? Why? Did you distribute any copies to other people?
    - If so, to whom? Why?
  - If you didn't, why?
- Did you happen to talk about what you learned about stroke to someone else?
  - If you did:

- what did you say?
- To whom? (and why to these specific people?)
- Can you recall how the conversation proceeded?
- Do you think the people you spoke to have talked in turn to other people?
  - If you didn't:
    - Are you planning to speak to someone? To whom? Why?
- Are you planning to do something about stroke now?
  - If so, what are you planning to do?

Finally: thank you for your time.

C.4   Interview topic guide. Designers

Two participants (designers at xxxxxx).

- Can you briefly describe the production process? (*Objective: find out what the input was, what was the output, and what work has been carried out in between, as an "information translation"*)? Possible sub-questions (if such things do not emerge spontaneously):
  - o When and how did you get involved? (*Objective: bring back the participants to the concrete and specific experience*)
  - o Could you list people you were in contact with to carry out this work (name the ten most important), and their roles? How did you feel about these relationships? (*Objective: identifying the designers' egocentric networks and see what impact they had on information flow between campaigners/NHS and designers*).
- Could you describe specific issues that you have found particularly meaningful (*Objective: find out whether specific aspects of the experience were positive or negative, and why*)? → Be open to what they say, even if unexpected, but try to probe the following:
  - o How did you feel about working with materials designed for improving the health of ethnic communities? (*Objective: find out whether this aspect – e.g. translations, etc. – had an impact on the designers work*)
  - o Were there any moments when the information flow was difficult? How did you feel about that? (*Objective: find out specific barriers/facilitators for this segment of work in the campaign*)?
  - o What were your feelings about copyright/intellectual property issues as they emerged during the work and negotiations? (*Objective: to probe the role IP issues had in this specific project from the designers' point of view, as they significantly impact the circulation of the products and the message*)
  - o What do you feel is the main contribution design has brought to the campaign? (*Objective: to elicit the role the designer felt they had in the campaign, and probe/double check if the issues previously mentioned are specifically related to their role, or are more general/abstract statements about design in general*)

Further topics to be assessed if they emerge from the interview.

C.5   Interview topic guide. Translator / community gatekeeper

One participant (independent translator).

1. Can you briefly describe your background, current work and you specific **involvement** in the campaign? (*Objectives: find out when, how and by whom the translator was involved in the campaign*; *bring back the participant to the concrete and specific experience*)

2. What where the **activities** you carried out, and the roles you covered? (*Objectives: same as above*)

3. What were your **expectations** before beginning, and how do you feel now about the work you have carried out for the campaign? (*Objective: after a more general and neutral introduction, to find out what the significant experience were for him, and what kind of information sharing/translating and "networking work" they implied*)

4. Could you **list** people you were in contact with to carry out this work (name the ten most important), and their roles? How did you feel about these relationships? (*Objective: identifying the designers' egocentric networks and see what impact they had on information flow; ascertain if and how much this person can be considered a "gatekeeper", for which community or segment of community*).

5. If the following aspects did not emerge from answers to the above questions, try to probe:
   a. What did the specific experience of **translating** campaign materials imply?
   b. How did you get about **enrolling** community participants in the campaign?
   c. What do you think are the most interesting **features** of the leaflet and poster, for the ethnic communities you know best?
   d. (*Objective: since the translator is by the definition a "bridge" between two different worlds, it would be important to elicit what his perspectives on the process were both from "our" and from "their" point of view, though being aware of the filters and possible blockages due to the situation – i.e. "feeling evaluated" by the interviewer, etc.*).

6. According to the role(s) you covered in the campaign, what were the most **exciting**/interesting experiences, and what were the most difficult/**challenging** ones?

Further topics to be assessed if they emerge from the interview.

C.6 Interview topic guide. NHS Employees / 1

Three participants, in three separate interviews

Can you briefly describe your role and involvement in the stroke BME social marketing campaign? (*Objective: find out what role the participant had as an "information translator" and which network she was in contact with. Specifically, what did the managerial role involve, in terms of reporting, evaluation, etc.*)?

Possible sub-questions (if such things do not emerge spontaneously):

- When and how did you get involved? (*Objective: bring back the participant to the concrete and specific experience, allow for it to emerge spontaneously*)

- Could you list people you were in contact with to carry out this work (name the most important), and their roles? How did you feel about these relationships? (*Objective: identifying the designers' egocentric networks and see what impact they had on information flow, evaluation and management issues).*

Could you describe specific issues that you have found particularly meaningful (*Objective: find out whether specific aspects of the experience were positive or negative, and why*)? →

Be open to what she says, even if unexpected, but try to probe the following:

- How did you feel about managing and evaluating the whole process of the campaign? (*Objective: find out the most meaningful aspects of the participant's role in terms of information exchange and organizational learning, but without asking explicitly if possible*)

- Were there any moments when the information flow or decision making was difficult? How did you feel about that? (*Objective: find out specific barriers/facilitators for information flow and decision making as experienced by the participant during the campaign*)?

- What were your feelings about the specific role of your organization in the campaign? What are your feelings, now, about the process and the outcome of the campaign? (*Objective: understand the participants' point of view over the experience as a whole*)

- What do you feel is the main contribution your organization and your specific role has brought to the campaign? (*Objective: to elicit the role the participant feels she had in the campaign, and probe/double check if the issues previously mentioned are specifically related to their role, or are more general/abstract statements about management, decision-making etc.)*

Further topics to be assessed if they emerge from the interview.

C.7   Interview topic guide. NHS Employees / 2

One participant – Skype interview. The interviewee was the NHS project manager for the first phase of the campaign, then moved to another organization.

Can you briefly describe your **role and involvement** in the stroke BME social marketing campaign? (*Objective: find out what role the participant had as an "information translator" and which network she was in contact with. Specifically, what did the managerial role involve, in terms of reporting, evaluation, etc.*)? Possible sub-questions (if such things do not emerge spontaneously):

- o What was the **initial idea** for the project? Where did it come from? What were your **expectations**?

- o What was exactly your **involvement**, in details? (*Objective: bring back the participant to the concrete and specific experience, allow for it to emerge spontaneously*)

- o Could you list people you were in contact with to carry out this work (name the most important), and their roles? How did you feel about these **relationships**? (*Objective: identifying the designers' egocentric networks and see what impact they had on information flow, evaluation and management issues*).

- Could you describe specific **issues** that you have found particularly meaningful (*Objective: find out whether specific aspects of the experience were positive or negative, and why*)? → Be open to what she says, even if unexpected, but try to probe the following:

  - o How did you **feel** about what happened in the phase of the campaign that you personally managed? (*Objective: find out the most meaningful aspects of the participant's role in terms of information exchange and organizational learning, but without asking explicitly if possible*)

  - o What about the **information flow and decision making**? How did you feel about that? (*Objective: find out specific barriers/facilitators for information flow and decision making as experienced by the participant during the campaign*)?

  - o What were your feelings about the specific **role** of your organization in the campaign? What are your feelings, now, about the process of the campaign? (*Objective: understand the participants' point of view over the experience as a whole*)

o   What do you feel is the main **contribution** your organization and your specific role has brought to the campaign, for the phase in which you were involved? (*Objective: to elicit the role the participant feels she had in the campaign, and probe/double check if the issues previously mentioned are specifically related to their role, or are more general/abstract statements about management, decision-making etc.*)

-   What were your thought and feelings when you **handed over** your managing role in this project? (*Objective: to see the handover from the point of view of the person who has left, and not just from the point of view of the ones who have been assigned the new role*)

Further topics to be assessed if they emerge from the interview.

C.8 Interview topic guide. NHS health professional

Can you briefly describe your role and involvement in the stroke BME social marketing campaign? (*Objective: find out what role the participant had as an "information translator" and which network she was in contact with*?) Possible sub-questions (if such things do not emerge spontaneously):

- When and how did you get involved? (*Objective: bring back the participant to the concrete and specific experience, allow for it to emerge spontaneously*)

- Could you list people you were in contact with to carry out this work (name the most important), and their roles? How did you feel about these relationships? (*Objective: identifying the designers' egocentric networks and see what impact they had on information flow, evaluation and management issues).*

Could you describe specific issues that you have found particularly meaningful (*Objective: find out whether specific aspects of the experience were positive or negative, and why*)? → Be open to what she says, even if unexpected, but try to probe the following:

- How did you feel about delivering the presentation and the information of the campaign to community members? (*Objective: find out the most meaningful aspects of the participant's role, but without asking explicitly if possible*)

  o Any specific problems/opportunities related to the fact that those participants were from ethnic communities?

- Were there any moments when the information flow or decision making was difficult? How did you feel about that? (*Objective: find out specific barriers/facilitators for information flow and decision making as experienced by the participant during the campaign*)?

- What were your feelings about the specific role of your organization in the campaign? What are your feelings, now, about the process and the outcome of the campaign? (*Objective: understand the participants' point of view over the experience as a whole*)

- What do you feel is the main contribution your organization and your specific role has brought to the campaign? (*Objective: to elicit the role the participant feels she had in the campaign, and probe/double check if the issues previously mentioned are specifically related to their role, or are more general/abstract statements*)

Any specific learning points? Any comparisons with other health promotion experiences?

Further topics to be assessed if they emerge from the interview.

Appendix D   Semi-structured interviews. Information sheets

D.1   Semi-structured interviews. Information sheet. Campaigners

Information for prospective research participants - Interviews

Research title: Does a social marketing campaign enhance community capacity for collective decision making when a stroke is witnessed? A qualitative analysis of knowledge translation and utilization through social networks.

What are the aims of this project?

Stroke is a major problem nowadays, especially in some communities. An information campaign is therefore being developed, that aims at improving the knowledge of what a stroke is and what needs to be done when a patient with stroke symptoms is identified (namely, calling the emergency medical service).

However, it is not always easy to translate information into practical knowledge. Since most individuals in a community have a "network" of relatives, friends and acquaintances, it is possible that such network might help people to pass through the message about stroke symptoms and actions. However, it might also be the case that this message is not properly "translated" as it flows from person to person in these networks.

Therefore, this project studies how the message about stroke gets translated from the experts to the community, and how it circulates through individuals in the community once it has been proposed. It does not imply "testing" the knowledge of individuals, but involves identifying how the community as a whole is aware of stroke symptoms and related actions.

What will the project do?

In a first phase, the researcher will observe what is going on when the organizers of the campaign and selected individuals in the community get together to contribute to the development of the message on stroke awareness and to discover how it can be circulated in the community (the so-called "co-production" phase). After that, people who took part in the co-production and distribution of materials (e.g.: leaflets, etc.) will be interviewed by the researcher, individually and as a group; group interviews are called "focus groups". In a second phase, individual community members (both lay people and persons particularly relevant for the community) and health professionals such as doctors, nurses, etc. will be interviewed after being exposed to the campaign message. The objective is to see if, how and through which personal contacts they have learned the basics about knowledge of stroke symptoms and related actions.

Why have I been asked to take part in the research?

You have been asked to consider taking part because you are a member of the organization in charge of the stroke awareness campaign in the community.

Is the participation in the research free and voluntary?

Yes. You will be involved in the research only if you want to.

What should I do? What is my role in the research?

You will be asked some questions by the researcher, about your experience of the stroke awareness campaign, its meaning for you, and how you think that networks in the community will impact on the ability of people to get to know the symptoms of stroke and the requested actions. Each interview will last for about an hour. It is not compulsory to answer all the questions. The interview will be audio-recorded, so that the researcher can transcribe the conversations and use them for data analysis.

In both cases, no activity, utterance or act of any of the participant will be shared by the researcher with third parties, unless they are anonymized, so that no one will be able to know or guess who has said or done a particular activity.

What if I change my mind?

You may change your mind at any point without giving a reason, even when the interview has already began. Just let me know, and the data collected from you will not be included in the analysis and results, and will be destroyed.

When and where will the research take place?

The collection of data will begin in January 2011 and will be concluded by September 2012 at the very latest. Interviews will be held in suitable quiet places, which will guarantee confidentiality.

Is the research confidential?

All the research is strictly confidential and the identity of participants will not be revealed to anyone. All views expressed and actions observed will remain anonymous in all analysis and reporting of the research.

Who will have access to the data and where will it be held?

All data will be held in confidence at the University of Sheffield under the control of the researcher. All audio recordings will be deleted as soon as the final data analysis has been completed. All data will be used only for the purposes of this research and will not be passed onto anyone else.

What will happen to the results of this research?

The research results will published and presented both in scientific journals and in scientific meetings, so as to reach the widest possible audience. Participants in the study will not be identifiable in any of the reported material. Participants will have the opportunity to ask to receive a copy of the final research report.

Who is funding the research?

The research is funded by the National Health Service – National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for South Yorkshire (CLAHRC SY), and supervised by the University of Sheffield.

Has the research been reviewed by an ethics committee?

The research has been granted a favourable opinion by Ethics Committee of the School of Health and Related Research of the University of Sheffield.

Are there any possible risks to taking part in the research?

The participation in an interview will not imply any particular risk for the participants.

Are there any possible benefits to taking part in the research?

Although the individual participant will not receive any direct benefit from taking part in the research, it is possible that the results of the research will be of direct or indirect benefit to the participant's community or to other communities in the future.

What should I do now?

Before taking part in the interview, you need to complete and sign the informed consent sheet which you have received together with this information sheet.

Who should I contact for further information?

If you have any questions about the study or require any information, please do not hesitate to contact me:

☎ Mobile phone: XXXXXXXXX

🖥 E mail: paolo.gardois@shef.ac.uk

🖹Post: Paolo Gardois – PhD student. ScHARR, The University of Sheffield

               Regent Court, 30 Regent Street. Sheffield, S1 4DA

THANK YOU FOR TAKING THE TIME TO CONSIDER THIS RESEARCH

D.2   Semi-structured interviews. Information sheet. NHS Employees

Date of information sheet: 9.5.2011. Version: 1.

Information for prospective research participants - Interviews

Research title: Does a social marketing campaign enhance community capacity for collective decision making when a stroke is witnessed? A qualitative analysis of knowledge translation and utilization through social networks.

What are the aims of this project?

Stroke is a major problem nowadays, especially in some communities. An information campaign is therefore being developed, that aims at improving the knowledge of what a stroke is and what needs to be done when a patient with stroke symptoms is identified (namely, calling the emergency medical service).

However, it is not always easy to translate information into practical knowledge. Since most individuals in a community have a "network" of relatives, friends and acquaintances, it is possible that such network might help people to pass through the message about stroke symptoms and actions. However, it might also be the case that this message is not properly "translated" as it flows from person to person in these networks.

Therefore, this project studies how the message about stroke gets translated from the experts to the community, and how it circulates through individuals in the community once it has been proposed. It does not imply "testing" the knowledge of individuals, but involves identifying how the community as a whole is aware of stroke symptoms and related actions.

What will the project do?

In a first phase, the researcher will observe what is going on when the organizers of the campaign and selected individuals in the community get together to contribute to the development of the message on stroke awareness and to discover how it can be circulated in the community (the so-called "co-production" phase). After that, people who took part in the co-production and distribution of materials (e.g.: leaflets, etc.) will be interviewed by the researcher, individually and as a group; group interviews are called "focus groups". In a second phase, individual community members (both lay people and persons particularly relevant for the community) and health professionals such as doctors, nurses, etc. will be interviewed after that the community has been exposed to the campaign message. The objective is to see if, how and through which personal contacts community members have learned the basics about knowledge of stroke symptoms and related actions.

Why have I been asked to take part in the research?

You have been asked to consider taking part because you are a member of the NHS Sheffield, who has taken part in either delivering or organizing the stroke awareness campaign in the community.

Is the participation in the research free and voluntary?

Yes. You will be involved in the research only if you want to.

What should I do? What is my role in the research?

You will be asked some questions by the researcher, about your experience of the stroke awareness campaign, its meaning for you, and how you think that networks in the community will impact on the ability of people to get to know the symptoms of stroke and the requested actions. The interview will last for about an hour. It is not compulsory to answer all the questions. The interview will be audio-recorded, so that the researcher can transcribe the conversations and use them for data analysis.

In both cases, no activity, utterance or act of any of the participant will be shared by the researcher with third parties, unless they are anonymized, so that no one will be able to know or guess who has said or done a particular activity.

What if I change my mind?

You may change your mind at any point without giving a reason, even when the interview has already began. Just let me know, and the data collected from you will not be included in the analysis and results, and will be destroyed.

When and where will the research take place?

The collection of data has begun in January 2011 and will be concluded by September 2012 at the very latest. Interviews will be held in suitable quiet places, which will guarantee confidentiality.

Is the research confidential?

All the research is strictly confidential and the identity of participants will not be revealed to anyone. All views expressed and actions observed will remain anonymous in all analysis and reporting of the research.

Who will have access to the data and where will it be held?

All data will be held in confidence at the University of Sheffield under the control of the researcher. All audio recordings will be deleted as soon as the final data analysis has been completed. All data will be used only for the purposes of this research and will not be passed onto anyone else.

What will happen to the results of this research?

The research results will published and presented both in scientific journals and in scientific meetings, so as to reach the widest possible audience. Participants in the study will not be identifiable in any of the reported material. Participants will have the opportunity to ask to receive a copy of the final research report.

Who is funding the research?

The research is funded by the National Health Service – National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for South Yorkshire (CLAHRC SY), and supervised by the University of Sheffield.

Has the research been reviewed by an ethics committee?

The research has been granted a favourable opinion by Ethics Committee of the School of Health and Related Research of the University of Sheffield and by the NHS Research Ethics Committee.

Are there any possible risks to taking part in the research?

The participation in an interview will not imply any particular risk for the participants.

Are there any possible benefits to taking part in the research?

Although the individual participant will not receive any direct benefit from taking part in the research, it is possible that the results of the research will be of direct or indirect benefit to the participant's community or to other communities in the future.

What should I do now?

Before taking part in the interview, you need to complete and sign the informed consent sheet which you have received together with this information sheet.

Who should I contact for further information?

If you have any questions about the study or require any information, please do not hesitate to contact me:

☎ Mobile phone: XXXXXXXXX

🖳 E mail: paolo.gardois@shef.ac.uk

🖃 Post: Paolo Gardois – PhD student. ScHARR, The University of Sheffield

Regent Court, 30 Regent Street. Sheffield, S1 4DA

THANK YOU FOR TAKING THE TIME TO CONSIDER THIS RESEARCH

D.3 Semi-structured interviews. Information sheet. Community gatekeepers and community members (English)

NB: Arabic, Somali and Urdu translations of this item were used in data collection and can be made available in electronic form.

Information for prospective research participants - Interviews

Research title: Does a social marketing campaign enhance community capacity for collective decision making when a stroke is witnessed? A qualitative analysis of knowledge translation and utilization through social networks.

What are the aims of this project?

Stroke is a major problem nowadays, especially in some communities. An information campaign is therefore being developed, that aims at improving the knowledge of what a stroke is and what needs to be done when a patient with stroke symptoms is identified (namely, calling the emergency medical service).

However, it is not always easy to translate information into practical knowledge. Since most individuals in a community have a "network" of relatives, friends and acquaintances, it is possible that such network might help people to pass through the message about stroke symptoms and actions. However, it might also be the case that this message is not properly "translated" as it flows from person to person in these networks.

Therefore, this project studies how the message about stroke gets translated from the experts to the community, and how it circulates through individuals in the community once it has been proposed. It does not imply "testing" the knowledge of individuals, but involves identifying how the community as a whole is aware of stroke symptoms and related actions.

What will the project do?

In a first phase, the researcher will observe what is going on when the organizers of the campaign and selected individuals in the community get together to contribute to the development of the message on stroke awareness and to discover how it can be circulated in the community (the so-called "co-production" phase). After that, people who took part in the co-production and distribution of materials (e.g.: leaflets, etc.) will be interviewed by the researcher, individually and as a group; group interviews are called "focus groups". In a second phase, individual community members (both lay people and persons particularly relevant for the community) and health professionals such as doctors, nurses, etc. will be interviewed after being exposed to the campaign message. The objective is to see if, how and through which personal contacts they have learned the basics about knowledge of stroke symptoms and related actions.

Why have I been asked to take part in the research?

You have been asked to consider taking part because you are a community member involved in the co-production phase of the stroke awareness campaign.

Is the participation in the research free and voluntary?

Yes. You will be involved in the research only if you want to.

What should I do? What is my role in the research?

You will be asked some questions by the researcher, about your experience of the stroke awareness campaign, its meaning for you, and how you think that networks in the community will impact on the ability of people to get to know the symptoms of stroke and the requested actions. Each interview will last for about an hour. It is not compulsory to answer all the questions. The interview will be audio-recorded, so that the researcher can transcribe the conversations and use them for data analysis.

In both cases, no activity, utterance or act of any of the participant will be shared by the researcher with third parties, unless they are anonymized, so that no one will be able to know or guess who has said or done a particular activity.

What if I change my mind?

You may change your mind at any point without giving a reason, even when the interview has already began. Just let me know, and the data collected from you will not be included in the analysis and results, and will be destroyed.

When and where will the research take place?

The collection of data will begin in January 2011 and will be concluded by September 2012 at the very latest. Interviews will be held in suitable quiet places, which will guarantee confidentiality.

Is the research confidential?

All the research is strictly confidential and the identity of participants will not be revealed to anyone. All views expressed and actions observed will remain anonymous in all analysis and reporting of the research.

Who will have access to the data and where will it be held?

All data will be held in confidence at the University of Sheffield under the control of the researcher. All audio recordings will be deleted as soon as the final data analysis has been completed. All data will be used only for the purposes of this research and will not be passed onto anyone else.

What will happen to the results of this research?

The research results will published and presented both in scientific journals and in scientific meetings, so as to reach the widest possible audience. Participants in the study will not be identifiable in any of the reported material. Participants will have the opportunity to ask to receive a copy of the final research report.

Who is funding the research?

The research is funded by the National Health Service – National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for South Yorkshire (CLAHRC SY), and supervised by the University of Sheffield.

Has the research been reviewed by an ethics committee?

The research has been granted a favourable opinion by Ethics Committee of the School of Health and Related Research of the University of Sheffield.

Are there any possible risks to taking part in the research?

The participation in an interview will not imply any particular risk for the participants.

Are there any possible benefits to taking part in the research?

Although the individual participant will not receive any direct benefit from taking part in the research, it is possible that the results of the research will be of direct or indirect benefit to the participant's community or to other communities in the future.

What should I do now?

Before taking part in the interview, you need to complete and sign the informed consent sheet which you have received together with this information sheet.

Who should I contact for further information?

If you have any questions about the study or require any information, please do not hesitate to contact me:

☎ Mobile phone: XXXXXXXXXXX

🖥 E mail: paolo.gardois@shef.ac.uk

🖅Post: Paolo Gardois – PhD student. ScHARR, The University of Sheffield

              Regent Court, 30 Regent Street. Sheffield, S1 4DA

THANK YOU FOR TAKING THE TIME TO CONSIDER THIS RESEARCH

Appendix E   Consent forms for interviews

E.1   Consent form for interviews. NHS employees

Consent Form for research participants

Version 1, 9.5.2011

Title of Research Project: Does a social marketing campaign enhance community capacity for collective decision making when a stroke is witnessed? A qualitative analysis of knowledge translation and utilization through social networks

Name of Researcher: Paolo Gardois

Please check the boxes below

1. I confirm that I have read and understand the information sheet explaining the above research project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. My legal rights won't be affected by this decision. In addition, should I not wish to answer any particular question or questions, I am free to decline to do so at any time.

3. I understand that my responses will be kept strictly confidential. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.

4. I give permission for the researcher's university supervisors to have access to my anonymised responses.

---

5. I agree for the anonymised data that is collected from me to be used in future research.

6. I agree to take part in the above research project.

_____   _____   _____

Name of Participant   Date   Signature

_____   _____   _____

 Researcher   Date   Signature

To be signed and dated in presence of the participant

Original + 2 Copies: one for the researcher and one for the participant.

Any questions?

Please feel free to contact me by:

☎ Phone: xxxxxxxxxx ; Mobile phone: xxxxxxxxxx

🖥E mail: paolo.gardois@shef.ac.uk

🖃 Post: Paolo Gardois – PhD Student. ScHARR - The University of Sheffield. Regent Court, 30 Regent Street Sheffield, S1 4DA

E.2   Consent form for interviews. Other participants (English)

NB: Arabic, Somali and Urdu translations of this item were used in data collection and can be made available in electronic form.

University of Sheffield - Consent Form for research participants

Title of Research Project: Does a social marketing campaign enhance community capacity for collective decision making when a stroke is witnessed? A qualitative analysis of knowledge translation and utilization through social networks

Name of Researcher: Paolo Gardois

Please check the boxes below

1. I confirm that I have read the information leaflet explaining the above research project and I have had the opportunity to ask questions about the project.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline to do so at any time.

3. I understand that my responses will be kept strictly confidential. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.

4. I give permission for the researcher's university supervisors to have access to my anonymised responses.

5. I agree for the anonymised data that is collected from me to be used in future research.

6. I agree to take part in the above research project.

_____ _____ _____

Name of Participant   Date   Signature

_____ _____ _____

 Researcher   Date   Signature

To be signed and dated in presence of the participant

Original + 2 Copies: one for the researcher and one for the participant.

Any questions?

Please feel free to contact me by:

☏ Mobile phone: XXXXXXXXXX

🖥E mail: paolo.gardois@shef.ac.uk

🖃 Post: Paolo Gardois – PhD Student

                ScHARR. The University of Sheffield

                Regent Court, 30 Regent Street

                Sheffield, S1 4DA

Appendix F   Synopses of data collection

F.1 Synopsis of non-participant observations

ID	Item	Campaign phase	Duration (')	Date
O1	Observation Somali women - pre-production	Pre-production	90	19-01-11
O2	Observation Somali men - pre-production	Pre-production	60	26-01-11
O3	Observation Yemeni men - pre-production	Pre-production	60	08-03-11
O4	Observation Yemeni women - pre-production	Pre-production	60	16-03-11
O5	Observation Pakistani men - pre-production	Pre-production	60	23-03-11
O6	Observation in the Somali community [with community gatekeeper]	Pre-production	180	23-03-11
O7	Observation co-production session – Somali	Co-production	60	20-10-11
O8	Observation co-production session – Pakistani	Co-production	60	26-10-11
O9	Observation of distribution - day 1	Delivery	240	31-01-12
O10	Observation of distribution - day 2	Delivery	120	01-02-12
O11	Observation of distribution/event - day 3	Delivery	300	02-02-12
O12	Observation of distribution - day 4	Delivery	180	07-02-12
O13	Observation of training event – community centre – Pakistani Community	Delivery	120	08-02-12
O14	Observation of training event – community centre – Pakistani Community	Delivery	60	10-02-12
O15	Observation of distribution - day 5	Delivery	60	13-02-12
O16	Observation of final event – community centre – Pakistani Community	Delivery	260	15-02-12
O17	Post-distribution observation-conversation with gatekeepers – 1	Delivery	90	17-02-12
O18	Post-distribution observation-conversation with gatekeepers – 2	Delivery	90	20-02-12
O19	Observation of training session - Somali mosque	Delivery	40	21-02-12
O20	Observation of training session – Mosque – mixed communities	Delivery	45	22-02-12
O21A	Final event Somali community – community Centre – men	Delivery	75	29-02-12
O21B	Final event Somali community – community Centre – women	Delivery	75	29-02-12
O22	Post-distribution observation-conversation with gatekeepers – 3	Delivery	45	29-02-12
O23	Observation of instant-training sessions with Somali community members	Delivery	140	02-03-12
O24	Post-distribution observation-conversation with shopkeepers – Somali community	Delivery	40	16-03-12

F.2 Synopsis of semi-structured interviews

ID	Item	Participants	Duration (')	Date
I1	Interview with Campaigner 1 / 1st part	1	40	29-07-11
I2	Interview with Pakistani community gatekeeper 1	1	60	02-08-11
I3	Interview with Campaigner 1 / 2nd part	1	60	03-08-11
I4	Interview with Campaigner 2	1	60	16-08-11
I5	Interview with Designers	2	80	11-11-11
I6	Interview with PCT employee 1	1	45	09-12-11
I7	Interview with Regional Network member 1	1	80	12-12-11
I8	Interview with translator	1	40	13-12-11
I9	Interview with PCT employee 2	1	40	14-02-12
I11	Interview with Pakistani community gatekeeper 2	1	30	22-02-12
I10	Interview with Pakistani community members	11	90	22-02-12
I12	Interview with health professional	1	45	06-03-12
I13	Interview with Somali community gatekeeper 1	1	45	07-03-12
I14	Interview with Regional Network member 2	1	55	08-03-12
I15	Interview with Somali community gatekeeper 2	1	30	09-03-12
I16	Interview with Somali community gatekeeper 3	1	40	12-03-12
I17	Interview with Somali community gatekeeper 4	1	31	16-03-12

Appendix G   Campaign leaflet and poster

G.1   Leaflet (English)

NB: Arabic, Somali and Urdu translations of this item were used in data collection and can be made available in electronic form.

STROKE
TIME LOST IS BRAIN LOST

Inside you can read a story with two different endings. Remember the symptoms of stroke are:

• Facial Drooping
• Arm or Leg Weakness
• Speech Difficulties
  and that
• Time Lost is Brain Lost

So if you suspect someone has any of the above symptoms
CALL 999 IMMEDIATELY.

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Stroke
Time Lost
is Brain Lost

G.2 Multi-lingual poster