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# Can community-based peer support promote health literacy and reduce inequalities? A realist review

Janet Harris, Jane Springett, Liz Croot, Andrew Booth, Fiona Campbell, Jill Thompson, Elizabeth Goyder, Patrice Van Cleemput, Emma Wilkins and Yajing Yang



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### Abstract

# Can community-based peer support promote health literacy and reduce inequalities? A realist review

Janet Harris,<sup>1\*</sup> Jane Springett,<sup>2</sup> Liz Croot,<sup>1</sup> Andrew Booth,<sup>1</sup> Fiona Campbell,<sup>1</sup> Jill Thompson,<sup>1</sup> Elizabeth Goyder,<sup>1</sup> Patrice Van Cleemput,<sup>1</sup> Emma Wilkins<sup>2</sup> and Yajing Yang<sup>2</sup>

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**Background:** Community-based peer support (CBPS) has been proposed as a potentially promising approach to improve health literacy (HL) and reduce health inequalities. Peer support, however, is described as a public health intervention in search of a theory, and as yet there are no systematic reviews exploring why or how peer support works to improve HL.

**Objective:** To undertake a participatory realist synthesis to develop a better understanding of the potential for CBPS to promote better HL and reduce health inequalities.

**Data sources:** Qualitative evidence syntheses, conceptual reviews and primary studies evaluating peer-support programmes; related studies that informed theoretical or contextual elements of the studies of interest were included. We conducted searches covering 1975 to October 2011 across Scopus, Global Health (including MEDLINE), ProQuest Dissertations & Theses database (PQDT) [including the Education Resources Information Center (ERIC) and Social Work Abstracts], The King's Fund Database and Web of Knowledge, and the Institute of Development Studies supplementary strategies were used for the identification of grey literature. We developed a new approach to searching called 'cluster searching', which uses a variety of search techniques to identify papers or other research outputs that relate to a single study.

**Study eligibility criteria:** Studies written in English describing CBPS research/evaluation, and related papers describing theory, were included.

**Study appraisal and synthesis methods:** Studies were selected on the basis of relevance in the first instance. We first analysed within-programme articulation of theory and appraised for coherence. Cross-programme analysis was used to configure relationships among context, mechanisms and outcomes. Patterns were then identified and compared with theories relevant to HL and health inequalities to produce a middle-range theory.

**Results:** The synthesis indicated that organisations, researchers and health professionals that adopt an authoritarian design for peer-support programmes risk limiting the ability of peer supporters (PSs) to exercise autonomy and use their experiential knowledge to deliver culturally tailored support. Conversely, when organisations take a negotiated approach to codesigning programmes, PSs are enabled to establish meaningful relationships with people in socially vulnerable groups. CBPS is facilitated when organisations prioritise the importance of assessing community needs; investigate root causes of poor health and well-being; allow adequate time for development of relationships and connections; value experiential

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cultural knowledge; and share power and control during all stages of design and implementation. The theory now needs to be empirically tested via further primary research.

**Limitations:** Analysis and synthesis were challenged by a lack of explicit links between peer support for marginalised groups and health inequalities; explicitly stated programme theory; inconsistent reporting of context and mechanism; poor reporting of intermediate process outcomes; and the use of theories aimed at individual-level behaviour change for community-based interventions.

**Conclusions:** Peer-support programmes have the potential to improve HL and reduce health inequalities but potential is dependent upon the surrounding equity context. More explicit empirical research is needed, which establishes clearer links between peer-supported HL and health inequalities.

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## **List of abbreviations**

AIDS	acquired immunodeficiency	НВ	health behaviour
	syndrome	HIV	human immunodeficiency virus
CBPS	community-based peer support	HL	health literacy
CD	community development	HP	health professional
CE	community engagement	MeSH	medical subject heading
CERI	Community Engagement to Reduce Inequalities	OR	odds ratio
CHW	community health worker	PCT	primary care trust
CI	confidence interval	PS	peer supporter
СМО	context-mechanism-outcome	RCT	randomised controlled trial
ERIC	Education Resources	RR	rate ratio
Enic	Information Centre	TAFE	Institute of Technical and
GMTF	Gay Men's Task Force		Further Education
GP	general practitioner	VPE	volunteer peer educator
GUM	genitourinary medicine		

## **Terminology and illustrations**

The unit of analysis in this synthesis was programme theory. When describing programme theory, we refer to clusters.

*Cluster* A set of papers relating to a single study. The relationship may either be direct (i.e. 'sibling' papers produced from the same study) or indirect ('kinship' studies that inform theoretical or contextual elements of the study of interest). (See *Chapter 2, Cluster searching*.)

For this report, the Advisory Network discussions, conclusions and recommendations were recorded in illustrations by an artist (Sarah Smizz). The drawings are placed at appropriate points in the report to support the points made in the text.

## **Plain English summary**

Many of us have problems using health information to improve our health. Research says it might be easier for people to be 'health literate' if they have support from their peers. Peers are people who have had to deal with the same challenges, who give each other emotional support, reassurance and advice about health issues. They help us to make sense of complicated information, and reflect on whether it can be used to make our situation better.

In our project, peer-support workers formed an Advisory Network to assist with the review process. The network explained what they do to help people. We compared their descriptions with research to find out:

- What approaches are most effective in promoting peer support?
- How does community-based peer support help people to use health information and health services?
  Does it improve health and reduce health inequalities?

We found that before setting up a peer-support programme, organisations need to involve local people in recruiting workers, and in designing training for workers. After the initial training, peer-support workers also benefit from ongoing support to feel confident in using their skills.

We concluded that community-based programmes are likely to promote health literacy when peer-support workers:

- have something in common with the participants
- get participants involved in social networks, through which people discuss their problems and get tips from each other on how to manage
- allow participants to discuss a range of issues that are not just about health.

## **Scientific summary**

#### Background

We are surrounded by health information but many of us have problems using it to improve our health. The process of accessing health information and using it to stay healthy is called 'health literacy' (HL). HL is much more than reading and writing – it means being a critical consumer and deciding whether or not information is relevant to our particular situation and can be used to improve health. It is also about being able to communicate health needs and understand what health professionals (HPs) are saying.

Research says it might be easier for people to be 'health literate' if they have support from family, friends or support groups. Peer support happens when people who have things in common give each other emotional support, reassurance and advice about health issues. Peers can help us to make sense of complicated information, and to decide if it is useful for our particular needs. Peers can also help us to prepare for visits to the doctor and help in making sense of information after the visit.

Community engagement (CE) is now being used in many places to show us how to use information to improve our health. Research indicates that CE can be successful for many reasons, but we think that the peer support that occurs during community projects may be one of the main factors that help us to be health literate.

#### **Objectives**

The aim of our systematic review is to develop a better understanding of the potential for community-based peer support (CBPS) to promote better HL. We aim to find out:

*Research question 1* What approaches to CE are most effective in promoting peer support, to which people and in what circumstances?

*Research question 2* How does CBPS impact on understanding of existing health information and use of health information and health services to improve health and reduce health inequalities?

#### Methods

The systematic review used a realist synthesis methodology to evaluate the evidence for community-engaged peer support. Realist synthesis is a theory-driven approach that is increasingly being used to study health-care interventions. It allows the theoretical basis for the intervention (why and how it works) to be the focus of analysis rather than empirical performance (whether or not it works). Our approach to realist synthesis was participatory, engaging peer-support practitioners to work alongside an academic research team to unpick the complex relationship between context, content, application and outcomes, and develop a situational understanding of how peer support can contribute to HL and reduce health inequalities. Participatory realist synthesis allows for prolonged engagement with people who have expertise in the topic/field, enabling a comparison of empirically supported and culturally supported interventions by an Advisory Network working in collaboration with systematic reviewers with expertise in realist synthesis.

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We conducted an initial scoping of the literature to identify the specific focus for the subsequent search process. Searches that were not limited by study type were conducted across Scopus, Global Health (including MEDLINE), ProQuest [including Education Resources Information Center (ERIC) and Social Work Abstracts], The King's Fund Database and Web of Knowledge. We also examined the database at the Institute of Development Studies; this resource had significant overlap with the Global Health database. The period covered was 1975 to October 2011, with language of publication restricted to English only. We developed a new method of systematic searching, referred to as 'cluster searching', which uses a variety of search techniques to identify papers or other research outputs that relate to a single study. For designation as a 'cluster', a study was required to include at least one included paper from the team sift and to be linked – through supplementary searches performed by the information specialist (AB) – to at least two or more additional papers, thereby potentially adding conceptual richness and contextual thickness.

Articles were appraised in the first instance for relevance and included if they focused on CBPS, for example peer-support programmes that were situated in communities. Many papers met the 'CE' requirement but were subsequently excluded because they focused on 'CE' in the education of professionals in community-based participatory research, non-health contexts or the relationship between an individual's engagement and their health-related outcomes. Included papers had to describe research/evaluation/models. Of the 570 included papers, 39 were directly attributable to a UK context. From these papers, seven 'clusters' were identified. There were 122 papers identified from the clusters that related to models and theories.

Data were extracted and synthesised in three phases.

#### Phase 1 within-programme analysis

- 1. *Theory scoping* Identifying the theories that were explicitly used and/or cited within studies in the clusters.
- 2. *Articulating theories of change* Theories of change were identified for each programme cluster, and the clusters were appraised for methodological coherence.
- 3. *Identifying theories of action* Case studies were developed with propositions for what works, for whom, in what circumstances and at what point in time within each cluster.

#### Phase 2 cross-programme analysis

1. Organising data by programme stage Comparing context–mechanism–outcome (CMO) configurations across programmes by each respective stage of peer support in order to identify patterns of CMO.

#### Phase 3 theory testing and development

- 1. *Theory testing* Reviewing the goodness of fit for the emerging theory in relation to theories for peer-support HL and health inequalities.
- 2. *Producing a mid-range theory* Show how different configurations of context and mechanism influence the trajectory of the intervention and subsequent outcomes.

Throughout data extraction and analysis, an Advisory Network of 120 lay health workers (paid and volunteer), clients, patients, providers and researchers were involved in defining components of peer-support interventions, commenting on research findings, and coconstructing explanations of peer support.

#### Results

# Research question 1: what approaches to community engagement are most effective in promoting peer support, to which people and in what circumstances?

The approaches to engagement varied by stage of programme design and implementation. At one end of the engagement spectrum, there were organisations that took an informing approach characterised by using researcher and policy-maker views of what would work to develop the theory of change. The theory of action for these programmes used an 'authoritarian' design through which implementation was prescribed by the host organisation with limited community consultation. During implementation, peer supporters (PSs) subsequently felt limited in terms of using their tacit and experiential knowledge, although it was actually supposed to be the active ingredient of the intervention. Programmes that appeared to have the more prescriptive approach, however, still 'worked' in some cases. Closer examination reveals that there were positive mechanisms – such as demonstrating respect for the knowledge of PSs – manifested in willingness to allow them to use their community-based experience to tap into existing networks and create new networks. Thus higher degrees of initial control over the programme were moderated when organisational sponsors and professionals supported a more collaborative model of implementation. At the other end of the spectrum were programmes that embodied a philosophy of active CE from the outset. These programmes were based on a 'negotiated' design, for which implementation was codesigned by the sponsoring organisation and community members/community organisations. In both designs, programme success was influenced by the degree of control and autonomy that the sponsor organisation allowed the PSs and participants to assume.

Therefore, on a health systems level, the sponsor organisations and HPs need to be skilled at establishing and sustaining an 'equity context' in order to promote CBPS programmes. We define an equity context as a context in which organisations prioritise the importance of health inequalities in policy and funding; community challenges and needs are recognised; people are ready to investigate root causes of poor health and well-being; the sponsor allows adequate time for development of relationships and connections; experiential cultural knowledge is recognised and valued; there is awareness of the importance of sharing power and control; collective beliefs and customs; world views and social identity are acknowledged and actively used in programme planning and implementation (cultural literacy); PSs are given control of how, when and where to deliver the intervention; and emergent outcomes are used to inform and modify the intervention.

#### Research question 2: how does community-based peer support impact on understanding of existing health information and use of health information and health services to improve health and reduce health inequalities?

At the implementation level, maintaining an equity context is also instrumental in enabling participants to understand information and use health services. Recruiting participants was based on the principle of homophily – the assumption that perceived similarities with PSs would foster relationships of trust. Perceived similarities may provide a window of opportunity when first establishing a connection, but homophily alone is not enough to establish trust. PSs need to be skilled in establishing equitable relationships with participants, which promote a dialogue of active and critical reflection on the root causes of poor health and well-being. The ability to establish positive relationships is challenged, however, by negative attitudes towards the health behaviour (HB) in question. PSs therefore need time to develop relationships with communities, because in cases when there is fear of being judged in the community, and a lack of readiness to consider change, repeated contact may be needed to motivate and sustain engagement.

Successful peer-support programmes have the potential to reduce health inequalities by changing perceptions of social status. They do this by creating a common bond with disadvantaged and vulnerable individuals or groups, promoting social interaction, and sharing of problems and experiential knowledge. This dialogue among equals promotes participatory parity and encourages the formation or strengthening of social groups. The individual's perception of their own social status improves from being included in a group and the loss of social identity that they may have experienced as a result of their low social status is restored. As this bond develops, people come to trust the group and reflect critically on their circumstances, their aspirations and their capabilities. Anxieties about being evaluated negatively for their health condition or inability to manage HB are mediated by affirmational and instrumental support from the group. People become more confident – both individually and collectively – to consider behaviour changes. Practical and informational support enable them to select goals that they are capable of achieving, and success with small changes increases confidence and motivation to negotiate and self-manage health.

Groups that are enabled to take control of their own situations have the potential to collectively change social norms and practices for themselves and within their social networks. The ability to assess the scale of the change across the wider community, in terms of the relationship between HL and social action for health, was limited by the fact that most of the evaluations occurred in the early stages of programme implementation.

#### Conclusions

From the synthesis, we conclude that CBPS is likely to be effective when the surrounding context, for example the people and the organisations that are designing and developing the programme allow adequate time for engagement in the processes of:

- identifying community and cultural needs
- using learning from the needs assessment to design appropriate strategies for recruitment and training
- involving local people in the recruitment process
- building on experiential knowledge to codesign training materials
- using empowerment education approaches to deliver the training
- promoting partnerships between PSs, community organisations and HPs to facilitate embedding of the programme within existing health services and community activities
- providing ongoing support that focuses on problem-solving to PSs, enabling them to develop capabilities in delivering the intervention
- allowing PSs to exercise autonomy and control over the tailoring and delivery of the intervention.

We further conclude that CBPS is likely to promote the development of HL when PSs are given time to:

- engage with community members and develop enough rapport to get them involved in social networks
- facilitate social networks to enable community members to create new and further enhance existing relationships that incorporate dialogue, critical reflection and development of critical consciousness related to the social determinants of health
- allow participants to be in control of identifying what they would like to do to address health and other issues, as well as taking action to develop capabilities.

Peer-support programmes have the potential to improve HL and reduce health inequalities but potential is dependent upon the surrounding equity context. More explicit empirical research is needed that establishes clearer links between peer-supported HL and health inequalities.

#### **Study registration**

This study is registered as PROSPERO CRD42012002297.

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### Chapter 1 Background

#### About this chapter

In the first section of this review, we want to introduce the concepts of peer support, health literacy (HL) and health inequalities in order to frame the task of developing theory for how peer support might work to promote HL and subsequently reduce inequalities in health. Peer support has been used in health education and health promotion for decades, and recently there has been increasing interest in the development of the concept of HL that both duplicates and builds upon health education concepts. Interest in using peers to work with disadvantaged communities and reduce inequalities in health has grown in tandem. As a result, studies are now appearing in the separate fields of peer support, HL and health inequality that conceptually overlap. The aim of this review is to pull together the separate strands of literature to examine how health education – framed as HL – can be used by those who provide peer support to increase health equity. We start by providing an overview of the health-care context that has acted as a driver for peer-support initiatives. The definition of peer support in a health-care context is examined, followed by discussion of the evolving concepts of HL. The various stances that are adopted in terms of engaging communities in peer-support programmes are then outlined. Possible relationships between peer-support interventions and the outcomes of HL and health are suggested and linked to the focus for the review and the review questions.

#### Peer support in a health system context

Over the past 30 years, it has been internationally acknowledged that our needs for health care are changing, as a result of eradicating many of the world's communicable diseases. People are living longer, particularly in higher income countries, placing a different set of demands on health services in terms of having to respond to increasingly prevalent conditions associated with older age, such as cancer, coronary heart disease, diabetes, arthritis and Alzheimer's disease. Some of these diseases are now occurring at a younger age, when changes in lifestyle, activity levels and diet lead to weight gain. As a result, the health system has needed to move away from providing acute care in response to communicable disease. Health systems have also responded to the changing face of health care by exploring how people can reduce their own risk by maintaining health and well-being and 'self-managing' long-term and chronic conditions. A wide and diverse range of patient education programmes have been developed for specific conditions, such as diabetes and back pain, which are hosted within the health service environment. At the same time, health systems are increasingly focusing on developing community-based services that can augment and complement patient education in primary and acute health. One of the approaches enabling people to use health information that has been widely tried and tested is peer support.

#### What is peer support?

'Peer support' within a health system context has been described as 'the provision of emotional, appraisal and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population'.<sup>1</sup> Research indicates that the peer needs to be part of an existing social network, or introduced into a network in which they are accepted because they share common characteristics (e.g. age, sex, disease status) with the individual or group of interest. These common characteristics enable the peer to relate to, and empathise with, the person they are supporting on a level that a non-peer would be unable to manage.<sup>2</sup>

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Common characteristics of peers vary and may include age, gender, disease status, socioeconomic status, religion, culture or education.<sup>3</sup>

It is generally agreed that peer support embodies several overlapping dimensions, which are most commonly described as emotional, affirmational, informational and practical support. Emotional support includes expressions of caring, empathy and encouragement, and is seen to enhance self-esteem. Affirmational support acknowledges feelings of uncertainty, encourages persistence and reassures people that they have the ability to deal with frustration and resolve problems. Informational support provides advice, suggestions, alternative actions, feedback and relevant information for the health issue. Practical support, also referred to as tangible or instrumental support, involves showing people how to do things, doing them together, and/or removing barriers by assisting with transport or child care and connecting people to appropriate services.

Peer support can be based on experiential knowledge alone, or supplemented with formal training. Dennis<sup>1</sup> has developed a typology of peer support, situating peers on a continuum from informal to formal, in which 'informal' represents family, friends and social networks (*Figure 1*). Her continuum notes the difference between natural lay helpers and paraprofessionals. Natural helpers offer support by way of their personal relationship with people who are within the same familial or social networks. When peer support is created as an intervention, the support may be offered by helpers from outside the social network. These created networks may be organised by lay helpers with no formal training, who operate independently from the health system, or lay helpers may collaborate with health professionals (HPs). In both cases, the helpers develop peer relationships with participants. At the far end of the spectrum, support is offered by trained paraprofessionals but this rarely results in the creation of a peer relationship.

Peer support includes a diverse and bewildering array of approaches, including practical and social telephone support in remote rural areas provided by peer advisors; help with navigating clinic, family and community environments from promoter as buddy systems to connect women via mobile phone texts;



FIGURE 1 Typology of peer support. Reproduced with permission of Elsevier Limited from Dennis CL. Peer support within a health care context: a concept analysis. *Int J Nurs Stud* 2003;40:321–32.<sup>1</sup>

health trainers who provide support for diabetes management; and self-help groups for rehabilitation and chronic conditions. Peer supporters (PSs) fall into two groups: those who tap into existing social friendship groups and those who construct groups for the purpose of peer education. They may be placed to work within networks that are created by the health service or they may act as a 'bridge' between created and embedded social networks.

Much of peer support falls under the banner of peer education. Peer education has been most popular when working with children and young people in educational settings. The majority of peer education interventions focus on health education for young people and adolescents, focusing on behavioural change around smoking, alcohol, substance abuse and human immunodeficiency virus (HIV)/ acquired immunodeficiency syndrome (AIDS).<sup>4,5</sup> Despite peer education being a popular intervention, it has often been described as a method in search of a theory.<sup>4</sup> The growth in popularity of peer education is premised on the notion that peer educators will automatically have more credibility because of homophily, a factor identified as important for someone acting as a change agent. Homophily refers to the tendency for people to have (non-negative) ties with people who are similar to themselves in socially significant ways.<sup>6</sup> For example, the effectiveness of lay health workers, health champions and promoters is based on the premise that a person will be perceived to share similar characteristics and experiences by virtue of living in the same community. The precise nature of the social tie varies, from perceived similarity related to living in the community or sharing experiences similar to those of community members, such as common age, gender, ethnicity or health condition. In the case of popular opinion leaders, the leaders may share similar characteristics or have characteristics to which others aspire.<sup>7</sup> Although the theory of homophily has some merit, there is an inherent contradiction in placing peers in a position where they are responsible for influencing behaviours when the principal determinants of the behaviours are located in social and environmental conditions beyond their control.8 Submitting to peer influence in the context of health education but resisting it in other areas of life may be an unrealistic assumption. However, despite potentially unrealistic expectations for peer support it has been described as 'a veritable industry'<sup>9</sup> and interest in using peers as a bridge between communities and health services is on the rise.

#### What is health literacy?

The term 'health literacy' has become used only recently in the literature to define and incorporate approaches previously found subsumed under the label 'health education'. Interest in the relationship between literacy and health began in the 1990s, with research indicating that poor adherence to medication, and incomplete knowledge of how to cope with disease were related to literacy.<sup>10</sup> By 2004, the relationship had been extensively documented, with the USA and Canada describing the problem as a 'HL epidemic'.<sup>11,12</sup> The Commission of the European Communities prioritised HL in their 2008–13 strategy as a core competency for promoting citizen empowerment and reducing health inequalities.<sup>13</sup>

Health literacy has been variously defined as the ability to read and understand health information but the term has now developed a much wider scope.<sup>14</sup> HL has been defined as the cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand and use information in ways that promote and maintain good health.<sup>15</sup> HL means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, HL is critical to empowerment. Thus, HL is often seen as the outcome of health education and health promotion. Using methods that go beyond information diffusion and entail interaction, participation and critical analysis increases the agency of people to make their own decisions, developing the skills, knowledge and efficacy to act on their knowledge to improve their health. The concept has multiple dimensions, including functional, interactive and critical HL.<sup>15</sup> Functional literacy is the ability to understand written information and numeracy; interactive literacy is the ability to assess the quality and relevance of information and advice to one's own situation. At the time of this review, the concept of HL was still relatively new<sup>16</sup> and the number of articles testing HL interventions were few in number.

Moreover, most of the research focuses on promoting functional literacy.<sup>17</sup> The process of promoting functional literacy is framed as giving information to people at a level that matches their reading and numeracy skills. This 'medical' or clinical view of HL is reinforced by a health education model that emphasises information giving. The provider selects the information that they believe will be most relevant to the condition, with the expectation that it will produce adherence with recommended care regimens and/or changes in behaviour. This not only ignores whether or not the receiver of information has the agency to act upon the information that may be beyond the person's control.<sup>18</sup> There are now multiple and contested definitions of HL, reflecting the multidimensional skills needed to cope with information complexity and proposing the importance of concepts related to personal, cognitive and social skills, with emphasis on individual, group or community levels.<sup>19</sup>

Sorensen *et al.*'s<sup>19</sup> recent conceptual analysis of HL (*Figure 2*) aims to synthesise these various definitions, moving away from the medical and functional paradigm to produce a more public health-orientated perspective. The definition, however, still reflects the dominant information-giving model, which focuses on getting individuals to use health messages to maintain or improve their health:

Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.<sup>19</sup>

The model frames HL promotion as a process of four steps: enabling people to develop *Awareness; Access* information; *Appraise* it critically to decide if it is trustworthy and relevant; and *Apply* it to improve health. The process of helping people at each of these stages is not described, reflecting the peer education literature in which the majority of evaluations assess quantitative outcomes rather than the processes underpinning peer education.<sup>5</sup>

Research in education and community development (CD) has shown that helping people learn requires active involvement, that is, participation is central to learning. Supported by adult and social learning theory, drawing on a long history based on the work of authors such as Freire, <sup>20</sup> Kolb, <sup>21</sup> Mezirow<sup>22</sup> and Brookfield, <sup>23</sup> and, more recently, Wenger,<sup>24</sup> as well as communication theorists such as Shorter,<sup>25</sup> there has been a shift to realising that process is as important as content.<sup>26</sup> Educators in CD no longer see learners as empty vessels to be filled with knowledge but rather aim to build on their prior learning and experience.<sup>27,28</sup> The ways in which learning needs differ according to the individual, and the stage of change,<sup>29</sup> as well as the style of learning interaction are taken into account. Interaction is influenced by the change agents' characteristics, particularly the principle of homophily<sup>30</sup> – the tendency to associate and interact with people who are perceived to be similar to oneself – which is so core to peer education. Central to adult learning is the key notion of the intrinsic value of people. The practice of participatory approaches to education involves a dialogue between equals, whereby one starts with people's own knowledge and experience. Through structured dialogue, colearners identify their problems and critically analyse the social context that creates or allows these problems to occur. The ultimate goal is praxis – the process of engaging people in a cycle of reflection and action, which allows them to move towards taking control of their lives, including their health.31,32

With most of the attention focused on the functional model of HL, very little has been published on approaches to promoting critical or interactive HL. Most of the work linking functional with critical and interactive concepts has been done by Doris Gillis,<sup>33</sup> and explores the barriers encountered by HPs in terms of integrating more interactive HL promotion into their daily practice. Gillis<sup>33</sup> explores the dissonance encountered between the clinical orientation of 'doing information to' someone, and the adult learning model of 'creating information with' someone, through which learning is problem based, and emphasises equality and collaboration between teacher and learner.



Adult learning is based on the premise that information is offered when the individual needs to know; it is tailored to the self-concept and prior experience of the learner; and it is sensitive to the individual's motivation and readiness to learn.<sup>34</sup> This conflicts with the traditional clinical orientation, when the HP generally decides what scientific and technical information to offer at each patient encounter.<sup>18</sup> There is rarely participatory parity in discussions between HPs and patients,<sup>35</sup> despite the fact that providers are in positions to facilitate or impede the access, understanding, and use of health information by individuals in their various roles as patients, consumers, caregivers and citizens. Although the concept of participatory parity when exchanging health information is congruent with the concept of peer support, it conflicts with the positionality of HPs who offer peer-support programmes. As a result, the health research field has, for the most part, evaluated didactic approaches to education, with fewer examples of programmes that build on adult learning principles which are more participatory.<sup>5</sup>

Theories from adult education, which are most commonly found in the field of CD, have not been drawn upon in functional HL models, despite the fact that critical and interactive HL draw on the orientation of adult learning, social psychology and empowerment models of change. There is no published research on community-based HL. We can therefore say that the HL models are pretheoretical, and that interactive and critical HL in community-based peer support (CBPS) are concepts that need conceptual analysis.

#### What is community engagement?

The term 'community engagement' (CE) is another term that has gained in popularity in recent years. Many existing discussions of CE downplay its complexity, abstracting and dissolving the heterogeneity of most communities. Indeed, the term 'community' often has attached to it a positive association of fellowship and inclusion, and, together with the terms 'community based' and 'CE', is often used uncritically or even interchangeably – as are the terms 'participation' and 'involvement'. The CD literature is highly critical of the misappropriation of the term by organisations who merely consult while calling it engagement. Engagement is a relational developmental process that involves mutual respect, dialogue and participation in decision-making to be successful. CE, therefore, involves a systematic approach to actively involving the community in addressing an issue, <sup>36</sup> paying attention to how people are involved and ensuring that there are opportunities for mutual learning and action. A key element is that such engagement operates at the collective rather than individual level, so as to provide a supportive environment for change. Building on existing relationships is well documented in the literature as one of the strategies to engage the greater community,<sup>37–39</sup> while there is also evidence that the type of engagement needs to be very population and context specific. Popay<sup>40</sup> reinforces the idea of context specificity, noting that the appropriate level of engagement will range from provision of information, consultation, coproduction, or delegated power, to full community control (Figure 3). She further asserts that level of engagement is dependent on the desired outcome of the engagement.<sup>40</sup>

Although community control would be interpreted by some to be the ideal, the type of issue that is being addressed and the risks compared with the benefits of adopting more deliberative and participatory stances to health need to be carefully weighed.<sup>41</sup> Peer-supported health education for HL offers an opportunity to capitalise on the shared characteristics of the teacher/supporter and the learner/supported to enhance learning and, therefore, change. However, such a process needs to be fully consistent with the social context in which it operates. CE then can be seen as the vehicle through which this is achieved, and also potentially the means by which to achieve changes in the social environment that are necessary for sustainability or, at the very least, a supportive learning environment.

Knowledge on how to encourage involvement or participation is well developed within the field of CD. One of the most fundamental elements of CD approaches is the so-called 'bottom-up' approach, whereby the community is engaged in a process of storytelling, dialogue and reflection to identify community needs and resources, and to decide on the issues that need addressing.<sup>42</sup> Although information of various kinds including research evidence is explored, value is given to local understandings and local and relational


**FIGURE 3** Framework illustrating pathways from community participation, empowerment and control to health improvement. Reproduced with permission from Springer, NY. From Popay J. Health empowerment and health improvement: the English experience. In Morgan A, Davies M, Ziglio E, editors. *Health Assets in a Global Context.* New York, NY: Springer; 2010. pp. 183–95.

knowledge. Through a continual process of dialogue, reflection and action, appropriate joint action is taken, evaluated collectively and changed. The literature emphasises that unless the community's concerns are addressed then action on those things of importance to outsiders is unlikely to gain traction.<sup>26</sup> The focus therefore is encouraging arenas for dialogue, or what Cornwall<sup>43</sup> calls Spaces for Change, while at the same time operating from a position of mutual respect – what Fraser<sup>44</sup> calls participatory parity. In this way partnership is built and trust is developed.

These tensions and orientations between top-down and bottom-up approaches to health education and engagement are manifested in notions of CBPS. The term 'community-based peer support' is often used merely to distinguish an everyday setting from a clinical one. The clinical reference point, however, is maintained and manifests itself in the orientation to peer support, which is to encourage compliance or to support a goal defined and developed by a health service or system. In this orientation, CBPS is most often defined as the introduction of peers into a community setting, with the express purpose of enabling participants to achieve goals that are set by a health service or a health system. The 'community' setting may be schools, health services and/or geographical areas that have been targeted for a health intervention; occasionally, it might be a community health service. Introducing interventions into a community differs from the definition of CE, which is

the process of working collaboratively with and through groups of people affiliated by geographic proximity, identities, special interest or similar situations to address issues affecting the well-being of those people. Proponents of CE believe that it can improve community health when partners develop relationships with the aim of mobilising resources and instigating changes in polices and practice.<sup>45</sup>

# Outcomes for community engagement, peer support and health literacy

Outcomes for peer support in a CE context can be characterised as individual, leading to collective outcomes for community health. They can also be conceptualised as a process that contains intermediate

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as well as long-term (also referred to as 'high-level') outcomes.<sup>46</sup> Outcomes as described by the National Institute for Health and Care Excellence<sup>47</sup> include:

- improved information flows between the community and service provider (and vice versa)
- more accurate identification of community needs
- improved CE
- development or improvement of networks of support and mutual reciprocity (social capital), for example by helping to enhance trust and reciprocal relationships
- increasing the sense of empowerment among target communities to enable them to change the social, material, cultural, environmental and political factors that affect their lives
- improved partnership working between communities, institutions and governments
- improvements in individual- and population-level morbidity and mortality
- reduction in health-related risk factors, such as fewer people smoking and more people physically active
- enhancement of community well-being
- reduction of health inequalities within and between communities.

Although these outcomes could emerge as a consequence of a CBPS programme, CE can also be an antecedent or it can occur in tandem with establishing a CBPS that addresses HL.

Health literacy has emerged out of two very different sources: CD approaches that are based on the model of empowering adult education, and a more medical concern focusing the inability of patients to read and understand health information.<sup>48</sup> As a result, outcomes are conceptualised differently in accordance with aim and setting. In medical settings, literacy outcomes are usually defined as functional, for example the ability to understand – and therefore adhere to – instructions about treatment regimens or prevention programmes. Functional outcomes are presumed to be related in a direct and linear fashion to high-level outcomes, such as reduction in morbidity and mortality. In contrast, the public health model conceptualises HL as a set of intermediate and staged outcomes, with ability to access information being followed by ability to understand, appraise and apply information. At the time of this review, the concept of HL was still relatively new<sup>16</sup> and the number of articles testing public HL outcomes were few in number.

Outcomes relating to interactive HL have been conceptually defined by Nutbeam<sup>15,16</sup> and Zarcadoolas *et al.*<sup>49</sup> as:

- better access to health information
- better awareness of one's own situation in terms of health risk, prevention and maintenance
- better understanding of how to maintain health and well-being
- increased skills in maintaining a healthy lifestyle and managing conditions
- increased ability to explain symptoms and situations to health providers, and to navigate the health system to get needs met
- better clinical outcomes.

The directionality or temporal sequence of these processes and outcomes has yet to be established.

## The relationship between community engagement, community-based peer support and health literacy

Within the field of health education the distinction is made between health education as 'persuasion' and health education as 'empowerment'. The persuasion orientation is associated with coercing people to adopt 'approved' behaviours to prevent disease and improve health and health education. On the other hand, the empowerment orientation is concerned with strengthening capacity to control individual health and work collectively to achieve supportive environments for health.<sup>50</sup> In either case, some type of learning

is required for change to take place. The aim of health education thus is to create the conditions for learning. Learning can be conceived as a relative permanent change in capability or disposition. Learning needs to be cognitive, affective and conative, for example directed towards action and change. It is also focused on the development of psychomotor, social interaction and problem-solving skills. Our preliminary review of the concepts of CE, CBPS and HL indicates some overlapping concepts as well as some tensions. These can be conceptualised as:

- health education as persuasion compared with health education as empowerment
- taking a top-down approach to deciding what someone needs to know (pedagogical approach to health education) compared with a bottom-up approach of deciding what needs addressing (adult education in a CE context)
- assuming that individuals will translate information into behaviour change compared with acknowledging that a social and collective process is needed to enable reflection, and translation of information into meaningful information and action
- assuming that individuals have the skills for critical analysis compared with enabling individuals to develop skills through social interaction and learning
- assuming a stance of provider as 'expert' compared with a stance of parity when participating in learning about health.

The location of the PS in the community is therefore of paramount importance and it needed to be investigated in the literature, as well as through practitioners' experience of the tensions outlined above.

# The relationship between health literacy, health inequalities and health equity

Interactive and critical HL embody a deliberative dialogue with the aim of taking action, and programmes that support disadvantaged groups to develop this form of HL consequently embody the concept of empowering individuals to address social determinants of health. Health inequalities are systematic, avoidable and important differences in health, which are associated with exposure to unhealthy, stressful living and working conditions; inadequate access to essential health and other public services; reduced social mobility, as a result of illness or disability; and lack of lifestyle choice, leading to health-damaging behaviours.<sup>51</sup> Although the terms 'equality' and 'equity' are often used interchangeably, underlying both terms is the idea that avoidable differences in health are unfair because they are differences that arise when people have little control over their life circumstances – their ability to access health care, to utilise it equally and to receive equal treatment is compromised by circumstances beyond their control.

Health inequalities are defined in terms of both absolute inequality and relative inequality. Absolute inequality refers to the concept that unequal health is associated with differences in living standards and material circumstances.<sup>52</sup> Relative inequality, on the other hand, refers to social status – the psychosocial effects of being in a socioeconomic position that places you in a lower status than other people. Status may be determined by personal characteristics, such as age, disability, ethnicity, faith/religion, gender and/or sexual orientation. Social attitudes towards any of these characteristics can place people at a disadvantage and cause them to be treated unfairly, with a range of consequences. Psychosocial stress can, for example, lead people to risky health behaviours (HBs), such as smoking, drinking and overeating. Social isolation can deter people from seeking the help that they may need. Level of education and socioeconomic class are two other common markers that are used to imply social position in society. Relative inequality arises when one or more of the characteristics described here place people at a disadvantage – or expose them to outright discrimination – in terms of their aspirations or capabilities to maintain or improve health. Such factors can operate at different ecological levels that are nested and interact with one another, as demonstrated in *Figure 4*.

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**FIGURE 4** The main determinants of health. Reproduced with permission of World Health Organization from Dahlgren G, Whitehead M. European strategies for tackling social inequities in health: levelling up Part 2. 2007. Copenhagen: World Health Organization Regional office for Europe.<sup>53</sup>

Health inequalities are associated with levels of HL in several ways. First, low literacy is directly associated with poor HL. A systematic evidence review extensively documented that poor health is consistently related to low HL in a number of ways, including:

... more hospitalizations; greater use of emergency care; lower receipt of mammography screening and influenza vaccine; poorer ability to demonstrate taking medications appropriately; poorer ability to interpret labels and health messages; and, among elderly persons, poorer overall health status and higher mortality rates.<sup>17</sup>

Perceptions of lower social status can be reinforced by HPs or by people themselves. When the recently validated HLS-EU HL questionnaire was administered in a large cross-sectional survey across seven different European countries, there was a strong correlation between people's perceptions of where they placed themselves in terms of social status (high to low) and their self-rated HL.<sup>54</sup> People reporting low social status also reported that they had problems understanding health information, and felt challenged in terms of describing health needs to HPs. The survey indicates that issues with understanding the information that is provided may be related to perceptions of social status and issues with communication, making it difficult for people to get their health needs met.

Health professionals' perceptions of their patients' health conditions and needs in relation to their social status can compound the problem. HPs commonly assume that patients have a higher level of understanding in terms of being able to read and comprehend written information about health<sup>11</sup> despite research documenting the functional gap between level of education and health information that has

been documented since the 1980s.<sup>55</sup> When there is a mismatch between the level of education needed to understand and the patient's functional literacy level, patients have difficulty following instructions and accessing care. Doak *et al.*<sup>55</sup> described a typical scenario in hospitals and clinics as:

Doctor: Do you understand what to do when you get home?

Patient: Oh, yes.

Doctor: Well, here's a pamphlet with all the facts. Read this if you have any questions.

Over 20 years later, Gillis et al.<sup>33</sup> presented a very similar description:

We just assume that everybody can read that pamphlet that we hand them – which knowing the literacy levels of the community, we know not to be true.

Our HPs are not only agents of their respective health-care systems, but also they are representatives of the society in which the system is nested, reflecting the common misconceptions and assumptions of the general population. What arises from this scenario is a mismatch between the level at which the health system and the larger society would like people to function, and the level at which they are capable of functioning. Indeed it has been argued by some that HL needs to be a feature of the health system as a whole, not just the clients/patients.<sup>56</sup>

We know that people with low literacy need to have information described to them in a variety of ways to promote understanding.<sup>55</sup> Recent HL research also notes the fact that people need opportunities to explore the meaning of health information across a variety of settings, with a range of different people, in order to make sense of it.<sup>35</sup> People who are socially isolated as a result of age, disability, ethnicity, faith or sexual orientation may have less opportunities to appraise information with others, thereby limiting their ability to make informed choices about health risk or health promotion.

There is also a collective community dimension that is associated with HL and inequality relating to the interlocking concepts of social identity, empowerment, critical consciousness and social capital. Health-related behaviours are recognised as being shaped and constrained by collectively negotiated identities rather than individual decisions. It can also be argued that health-related behaviour is influenced by community norms about what is possible. These norms are negotiated in group settings through dialogue. Disempowered people on the margins of society with little actual and perceived control over their lives are less likely to see how they can take over control of their own health. Context is also important. People are more likely to act as agents in their own health if they live in communities with a high level of trust, reciprocal health and support, i.e. social capital.<sup>57,58</sup> This further demonstrates that being respected and having one's needs valued by society is also a component of agency in health. Inequality within a society can diminish these attributes. Empowerment therefore is potentially an integral component of peer support. This is not only individual empowerment, but also emotional and motivational empowerment, as well as a sense of the ability to act. Freire,<sup>20</sup> a key writer in adult education, added a cognitive element, which is directly related to critical HL, namely the development of people's ability to analyse their own circumstances, arguing that it plays an important role in behaviour change in marginalised social groups. This can be achieved only through an active participatory dialogical programme of education and support.

In summary, the preliminary scoping for this topic indicated that:

- Concepts for peer support, CE and HL vary, and are, in some cases, contested.
- There is an apparent tension between concepts for HL and CE or CBPS.
- HL, as health education, is interpreted alternatively as a didactic form of pedagogy and an interactive form of andragogy.
- There are 'packages of concepts' that indicate that there are at the least two different models of CBPS for HL: an egalitarian adult education model aiming for parity between the teacher/supporter and the learner/supported compared with a more traditional pedagogical approach through which the provider, as expert, takes on the role of persuader.
- The adult education model appears to value CD approaches through which HL aims to develop critical consciousness and empowerment enabling choice, when the more medical model of peer support and HL appears to value transmission of information and adherence to instructions.

It is currently unclear how peer support in a community context enables individuals within their social context to achieve and maintain good health. A collation of the literature is needed in order to clarify the conceptual development of the concepts, as well as to better delineate their possible relationships to each other. Our initial programme theory has been constructed from research on peer support and health inequalities that had been conducted through 2010. This was supplemented by our experiences working in CBPS programmes, and evaluating peer support. We posited that:

Peer support provided via CE which is situated within communities has the potential to not only inform, but also engage people in a process of interaction and critical reflection about their health situation, producing improvements in interactive and critical HL. The process of critical and interactive HL will, in turn, enable people to transform health information into meaningful knowledge, and to develop a critical consciousness of the factors influencing their health in the broader environment, and the potential to change them. Community-based interaction may also lead to collective action to address community conditions affecting health and well-being. The subsequent empowerment – both individual and collective – could potentially bring about a reduction in health inequalities.

As a starting point for our review, we used Nutbeam's model of HL<sup>15</sup> (*Figure 5*) as a public health goal.

Nutbeam's model<sup>15</sup> presents an iterative pathway and interaction between:

- (a) health promotion actions, which include patient education, CD and group facilitation, leading to
- (b) health promotion outcomes, including HL, community participation, community empowerment and social norms, *which are associated with*
- (c) intermediate health outcomes (modifiable determinants of health), including appropriateness of health services, access to health services, provision of preventative services, healthy lifestyles, *leading to*
- (d) health and social outcomes such as morbidity, mortality, quality of life, disability, dysfunction, functional independence and quality of life.



FIGURE 5 Conceptual model of HL as an asset. Reproduced with permission of Elsevier Ltd from Nutbeam D. The evolving concept of health literacy. Soc Sci Med 2008;67:2072–8.<sup>15</sup>

## **Objectives and focus for the review**

The aim of our systematic review is to develop a better understanding of the potential for CBPS to promote better HL. We aim to find out:

- Research question 1 What approaches to CE are most effective in promoting peer support, to which people and in what circumstances?
- *Research question 2* How does CBPS impact on understanding of existing health information and the use of health information and health services to improve health and reduce health inequalities?

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# Chapter 2 Methods

### **About this chapter**

This chapter begins with our rationale for using realist synthesis. It also outlines changes in the original protocol, in accordance with the reporting standards developed by the RAMESES (Realist And Meta-narrative Evidence Syntheses: Evolving Standards) project.<sup>59</sup> Approaches to scoping the literature are then outlined, with a detailed description of the methods that we developed for searching, selection and data extraction.

## **Rationale for realist review**

The systematic review used a realist synthesis methodology to evaluate the evidence for community-engaged peer support. Realist synthesis is a theory-driven approach that is increasingly being used to study health-care interventions.<sup>59,60</sup> It allows the theoretical basis for the intervention (why and how it works) to become more important than its empirical performance (whether or not it works) in any particular study.<sup>61</sup> Thus the theoretical basis is the focus of analysis, recognising that the same intervention may perform very differently when the context, content and application vary. The purpose of realist synthesis is to establish when, how and why the intervention works, to unpick the complex relationship between context, content, application and outcomes, and to develop a necessarily contingent and situational understanding of effectiveness.<sup>62</sup>

Realist synthesis has particular value when seeking to explore the evidence for complex interventions because it looks for explanations for effectiveness rather than examining effectiveness alone – therefore recognising that one intervention in one setting may not transfer to another without, for example, the need to be adapted. Complex interventions contain several interacting components. Although there is no clear delineation between simple and complex interventions, the number of components and range of effect may vary widely.<sup>63</sup> A complex intervention may also be characterised by the number and relative difficulty of behaviours required by those delivering or receiving the intervention, the number of groups or organisational levels targeted by the intervention, the number and variability of outcomes and the degree of flexibility or tailoring of the intervention permitted.<sup>63</sup> CBPS is a complex educational intervention.<sup>64</sup> The intervention is complex because different types of people choose to use CE and peer support in different ways to promote HL; these choices can produce a range of different outcomes. The pathway to HL and the influence of context on development of interactive and critical literacy are essential parts of the mapping process that can be used to inform and evaluate future interventions. A feature of CBPS is its responsiveness to need, and it demands flexibility therefore allowing interventions to be adapted to suit the context in which it is being delivered. Outcomes may not be prespecified at the outset because a positive outcome might be that participants make the decision to work towards goals that they decide are important for them rather than for those who may be evaluating the intervention. The intervention may use educational materials but the main 'tool' is the relationship between the PSs and peers, and the nature of the relationship is crucial to CBPS. Such relationships cannot be standardised across intervention groups. Thus the complex nature of the intervention under review makes the use of realist reviewing methods particularly appropriate for this study.

Another advantage of realist review stems from its being a qualitative approach to synthesising qualitative, quantitative and mixed-methods evidence from programme interventions.<sup>62,65</sup> A method that allows the inclusion of a range of different study designs has considerable merit as each design approach may reveal different elements of the intervention are important in fully understanding the mechanisms, and how they are shaped by context and to what types of outcomes these might lead. This is especially relevant for our

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topic, for which much of the literature is available as 'grey' literature, and perhaps not evaluated using rigorous research designs.

A realist review and synthesis comprises review questions that focus on why and how something works, for whom and at what point in time. Sources of information are identified depending on their relevance to the review questions, and may include empirical data as well as information of programme theory. The quality of the information is appraised according to its ability to contribute to the development and testing of theory. The analysis aims to develop insight into local interactions between context and mechanisms, while aiming to develop an overall set of patterns or demi-regularities that can explain variations in how things work.

## **Changes in the review process**

The team revised the original protocol in response to what was found in the literature on CE, peer support and HL.

The team originally planned to include all study types that evaluated CE interventions with the aim of increasing HL and reducing health inequality. The comprehensive search and abstract sift revealed that articles with peer-support interventions did not focus on evaluating the effects of CE on HL or health inequalities. We therefore chose to include articles that focused on CBPS, for example, peer-support programmes that were situated in communities. The vast majority of papers were excluded at the first abstract sift as a result, with few subsequent exclusions at full-paper screening.

A review of the full texts revealed that completeness of reporting was an issue, particularly in terms of describing the context, relating context to mechanisms, and providing a complete description of the intervention. We therefore modified our search strategy, giving primacy to 'supplementary' strategies of author contact, 'pearl-growing' through forward and backward chaining. We added an additional methodological refinement by searching for related articles that provided more detailed explanations of emerging programme theory (cluster searching; see *Scoping the literature* and *Searching process*).

We originally planned to assess rigour across study types, using critical appraisal tools appropriate to the study design. After a comprehensive abstract sift, we decided to privilege relevance as the principal marker of quality (see *Selection and appraisal of documents*) and appraise the methodological coherence of the clusters at the stage of data analysis (see *Assessment of study quality*).

We found that the concepts for interactive and critical HL were disputed, with a wide range of competing definitions in the literature. Much research on HL operationalised functional literacy and researchers had not operationalised variables for critical and interactive HL – indeed, researchers in the field were calling for creation of measurement tools for critical and interactive literacy at the time of our review. We therefore extracted data on health education and health promotion and mapped these to concepts of HL.

We originally envisaged that our community experts would be involved in the realist review in tandem with the review team, describing the key components of culturally supported interventions, while the academic team identified empirically supported interventions from the literature. From a mixed-methods perspective it was assumed the both sources of information would contribute equally to development of a peer-support model. In actual fact, the participatory element of the review was instrumental in helping the team to address incompleteness of reporting in the published studies. Advisory Network members achieved a consensus on the key elements to providing peer support – as well as valued outcomes – that facilitated data analysis. Our work with the Advisory Network became instrumental in defining key concepts.

## **Scoping the literature**

Initial exploratory work revealed little explicit overlap between the three concepts of CE, peer support and HL. This was subsequently confirmed when we created separate Reference Manager, version 12.0.2 (Thomson ResearchSoft, San Francisco, CA, USA) bibliographic databases of records for CE and HL. Our initial scoping proved problematic for numerous reasons:

- 1. The diffuseness of the concepts and subsequent terminology.
- 2. The relative newness of CE and HL as accepted labels and the lack of explicit mentions of these concepts in journal abstracts.
- 3. CE was often implied within a wider literature relating to aspects of the community, for example participation, involvement, etc. Perversely, CE is the topic of most interest as a defining characteristic and yet it is least likely of the three to be mentioned explicitly in an abstract.
- 4. The concept of peer support was present in a wide and disparate range of roles. In addition, although many papers included the concept of lay involvement it was often difficult to discriminate where these roles were specifically drawing upon the notion of 'peerness'. This occasioned an extensive discussion within the team as with our Advisory Network (see Assessment of study quality) to define what being a peer actually means.

The significant nature of these challenges is indicated by the fact that a search specifically on 'community engagement', 'peer support' and 'health literacy' on the multidisciplinary Scopus database resulted in zero hits. More worryingly, articles identified through other routes appeared to satisfy the review requirement but would not be retrieved by any three-way permutation of search terms.

We therefore decided to use a recognised strategy for circumstances where retrieval is less effective than anticipated. This method is designated 'drop a concept',<sup>66</sup> resulting in three separate two-way combinations of the three review concepts (i.e. community engagement *and* peer support; peer support *and* health literacy; and health literacy *and* community engagement). This strategy did lead to the retrieval of more relevant references; however, it produced large numbers of obviously irrelevant references and, again, missed significant examples of relevant records (i.e. it had both poor sensitivity and poor specificity). Again the non-specification of the HL concept in retrieved articles was particularly problematic, meaning that two of these permutations proved non-viable. We therefore faced using a strategy based on combining an exhaustive list of CE-related terms with a broad and sensitive 'peer-support' strategy. The team did recognise that CE and peer support were partially overlapping concepts but considered that such reinforcement through overlap of these key terms would be a possible marker of relevance. Judgements about HL would, therefore, be made from subsequent expert judgements based on the title and abstract, not from explicit terms used for retrieval.

In addition, the specific focus of realist synthesis on the identification of theories and models led to a supplementary strategy requiring the coexistence of CE and terms relating to models/theories/ frameworks, etc.

### **Searching process**

#### Community engagement and peers or models/theories

Following the scoping, which helped to identify the specific focus for the subsequent search process, we conducted searches across Scopus, Global Health (including MEDLINE), ProQuest [including the Education Resources Information Center (ERIC) and Social Work Abstracts], The King's Fund Database and Web of Knowledge. We also examined the database at the Institute of Development Studies; this resource had significant overlap with the Global Health database. The period covered was 1975 to October 2011 with language of publication restricted to English only. However, only eight references preceded 1990,

indicating the self-defined limits for the concept of CE within health. Supplementary strategies were used for the identification of grey literature. The two strategies were:

- 1. CE (with all synonyms and permutations) combined with 'peer'
- 2. CE combined with models/frameworks and theories.

After the removal of duplicates, a total of 1347 records were available for sifting by the review team. These were divided into six approximately equal allocations and imported into an Excel database, version 2013 (Microsoft Excel, Microsoft Corporation, Redmond, WA, USA) with tailored drop-down menus representing the inclusion criteria. A total of 144 articles were identified from this first sift. The project team agreed that the education of professionals in community-based participatory research was outside the review scope (except where it is used as a method to explore CE).

After double reviewer sift, 570 articles were included representing 122 models and theories and 448 empirical papers (*Figure 6*).



FIGURE 6 Flow chart showing iterative stages of the search process for realist synthesis. CINAHL, Cumulative Index to Nursing and Allied Health Literature; MeSH, medical subject heading.

#### Peer support and health education/health promotion/health literacy

Review of the initial sift process revealed that reviewers were being required to interpret the concept of 'HL' from explicit mentions of 'health promotion'. It was therefore decided to operationalise this within the next iteration of the search process. The medical subject heading (MeSH) terms for 'health promotion' and 'peer group' were identified from a key highly relevant citation pearl<sup>67</sup> (*Table 1*).

These MeSH terms were combined on PubMed MEDLINE to retrieve a highly relevant subset of 516 records. The review methodology was therefore modified to require examination of these abstracts/ articles in order to identify particular approaches to/components of 'CE', typically implicit in abstracts but more fully described in articles.

The obvious relevance of a large proportion of this result set led to a major shift in emphasis of the literature search strategy. It was decided to use the older and more established terms of 'health education' and 'health promotion' as surrogate terms for 'HL', with more detailed itemisation of HL components at the full text data extraction stage. A revised search strategy sought to combine the concepts of peer support *and* health promotion *or* health literacy *or* health education.

Simultaneously, the decision was made to broaden the concept of peers. Our peer-support strategy was based on previous reviews from the University of Lancaster<sup>69</sup> and the University of Durham,<sup>36</sup> and included an exhaustive list of about 70 such peer-support roles, for example mentor, health trainer, coach, community health worker (CHW), navigator, etc. Upon initial inspection, the resultant set revealed a high proportion of relevant records. Between 20% and 24% of records were removed, using automatic deduplication, to reduce the number to approximately 14,488 records (across MEDLINE, EMBASE, Web of Knowledge and Cumulative Index to Nursing and Allied Health Literature (CINAHL). Further manual deduplication of the remaining duplicates brought the total number of records to below 12,000. A single reviewer sift was then performed as triage to remove non-research publication types. Only those non-research articles that documented models, theories or frameworks were preserved in the finalised list. The result was a significantly pruned result set for examination by the full team. Lay perspectives, as opposed to involvement, and peer review were also removed at this triage stage. This triage resulted in a second set – for sifting by the full team – of 6864 references.

Although the research team expressed increased satisfaction with the improved specificity of the new retrieval set, concern was still articulated at the ongoing limitations regarding sensitivity (i.e. relevant items not necessarily retrieved by the strategy). In particular, there was concern that inadequacies in terminology and indexing might result in one or more references issuing from a particular study being retrieved, although other reports from the same study would be missed, either at searching or sifting stages. Clearly, a realist synthesis approach requires that all available study data relating to a particular included

#### TABLE 1 Terminology associated with cluster searching

Concept	Description			
Cluster searching	A systematic attempt, using a variety of search techniques, to identify papers or other research outputs that relate to a single study; this relation may be direct (i.e. 'sibling' papers produced from the same study) or indirect ('kinship' studies that inform theoretical or contextual elements of the study of interest)			
Key pearl citation	A key work in a topic area, specifically, in this context, a report of a research study that acts as a retrieval point for related outputs that may help to explicate theory or to understand context			
Kinship study	A study subsequently identified as being related to an original study of interest; kinship studies may share a common theoretical origin, links to a common antecedent study or a contemporaneous or spatial context			
Sibling paper	A paper subsequently identified as being an output from the same study as an original paper of interest			
Study cluster	A group of inter-related papers or other research outputs that relate to the same single research study			
Reproduced fro	Reproduced from Booth et al.68			

study should be included through 'recommendation' by the original included study. In addition, it was necessary to perform a far more extensive – and more iterative – scoping than originally envisaged to develop strategies for dealing with these issues.

Search methods using forward and backward citation tracking are considered to be 'particularly valuable in finding the documents necessary to develop and then test provisional theories'.<sup>59</sup> The information specialist (AB) therefore decided to resort to more iterative search strategies, including citation mapping for forward and backwards tracking of relevant research. Although this is more time-consuming, the team were convinced that this would produce a better conceptual analysis and contribute to defining the concepts for future research studies. This genuinely innovative information retrieval approach for finding both sibling and kinship studies has been embodied as the cluster method. This innovative method was developed for this specific project but is of wider relevance, particularly for realist syntheses and other theory- and context-sensitive reviews. The cluster method has been the focus of a published peer-reviewed paper<sup>68</sup> and is briefly described below.

#### **Cluster searching**

'Cluster searching' is the label that our review team has given to any 'systematic attempt, using a variety of search techniques, to identify papers or other research outputs that relate to a single study'<sup>68</sup> (see *Table 1*). For further clarity we have identified that such a relation may either be direct (i.e. 'sibling' papers produced from the same study) or indirect ('kinship' studies that inform theoretical or contextual elements of the study of interest). There is little published guidance on how to identify and retrieve a 'study cluster'. In particular there is little empirical work associated with the characteristics of sibling studies. The emphasis of the 'CBPS: Developing a model for promoting HL (COPES)' project on developing a theoretical model indicated against a need to identify a comprehensive sample of study reports. Instead, the review team chose to prioritise relevance to the commissioners (i.e. research relevant to the UK NHS), conceptual richness and contextual thickness.

Seven UK clusters and one US cluster were identified for this project. For each cluster an index citation (key pearl citation) was identified as a starting point for exploration. Based on this citation the team formed a consensus that the project did represent genuine CE. First, the reference list of this key pearl was checked for any associated publications. The large reference management database set of over 4500 references on peer support was then checked for any additional citations by the authors of the pearl citation. Then a Google search (Google Inc., Menlo Park, CA, USA) was conducted on the name of the lead author(s) of the key citation and associated reports to identify a contact e-mail, a curriculum vitae or publications list and/or an institutional repository.

In addition to 'back chaining' through the reference list of the key citation, searches were conducted on Web of Science and Google Scholar for any more recent references citing the key citation (i.e. 'forward chaining'). By this point, any project name or identifier linking the published accounts was clearly identifiable [e.g. the ASSIST (an informal school-based peer-led intervention for smoking prevention in adolescence) study, Smoking Fag Ends, Diabetes Sharing Stories] and this identifier became a search string for subsequent searching. Contact was made with the lead author where available and appropriate.

Additional steps were taken to enhance the identification of theory, a key stage in realist synthesis. First, the full text of the key citation was closely examined for any occurrence of theory. When a specific theory was mentioned (e.g. Diffusion of Innovations Theory), this phrase was searched across other references in the peer-support Reference Management database of over 4500 references. When appropriate, we would then revisit the original set of bibliographic databases with a search combining the named theory with the health condition of interest (e.g. 'Diffusion of Innovations' *and* 'AIDS OR HIV'). This frequently yielded valuable theoretical insights. A further type of relationship within the cluster was that of kinship (i.e. where a project was based on an antecedent project or where several associated projects shared a common heritage). Frequently earlier projects revealed more details of the theoretical underpinnings of an intervention as originally conceived and associated projects facilitated comparison between different contexts. When the earlier or related projects themselves had a distinct identifier, or when a citation was readily identifiable, these could be used as further access points for retrieving more details. Project name searches could thus be conducted for the antecedents across Google Scholar and Web of Science. Finally, equipped with the project identifiers for all associated projects you can seek overviews or cross-case syntheses that distil the experience from the different related projects, with an emphasis on comparison and contrast.

This cluster-based approach provides both a description of each CE intervention and its context ('contextual thickness') together with 'a degree of theoretical and conceptual development that explains how an intervention is expected to work'.<sup>68</sup> The cluster-based method recognises that, frequently, the theoretical content is detached from the trial, being located in an associated publication. Hence these characteristics provide justification for systematic techniques of cluster searching.

The review team sought to understand context by examining studies that have been conducted alongside an effectiveness study,<sup>70</sup> either within an integrated mixed-methods study or as a 'sibling study'.<sup>71</sup> Sibling studies may include qualitative research studies, economic evaluations or process evaluations associated with specific randomised controlled trials (RCTs). Such studies are particularly valuable because they explore the context surrounding an effectiveness study, with the explicit aim of documenting the process and explaining contextual factors that influence implementation and/or outcomes.

Limitations on reporting placed by individual journals and their respective guidelines further constrain data on the context for an intervention. Typically, trials provide only a brief description of 'setting'. In contrast, studies that contribute most to understanding of an intervention or service will possess greater 'thickness' of detail.<sup>72,73</sup> Contextual thickness can be seen to require sufficient detail to enable the reader to:

- 1. establish what exactly is going on both associated with the intervention and associated with the wider context
- 2. infer whether the findings can be transferred to other people, places, situations or environments.<sup>74</sup>

Such thickness is unlikely to be present within a single published peer-reviewed report in the journal literature.<sup>75</sup> Instead, a review team will need to examine a 'study cluster' – that is, all reports, published or unpublished, that may directly inform the specific context or, indirectly, illuminate the theoretical ancestry of the study in question. Such a study cluster may include quantitative and qualitative research, grey literature reports to supplement formal published literature and may include informal types of data (such as information from project web pages), as well as theory papers associated with the intervention. It may further include data on cost-effectiveness, from published studies or from accompanying technical reports. Such a cluster will expand longitudinally throughout the life of the study. Relevant study reports may include preparatory information from the study protocol or from a pilot or feasibility study. They may also extend beyond the life of the project to reports of long-term follow-up or critiques and commentaries of the project and its associated papers. When direct evidence from sibling studies does not exist there may still be value in retrieving studies from a common temporal and/or geographical context. Such an affinity equates more to 'kinship' (see *Table 1*), particularly when contrasted with the direct comparisons offered by sibling studies.

This approach was initially piloted on one of the review topics (HIV Safer Sex), suggesting that cluster searching may be both practicable and desirable as a technique for harvesting rich and thick data. Such data can prove valuable when integrating quantitative and qualitative evidence and, specifically, in supporting realist synthesis. A suggested procedure for cluster searching, generalised from the individual case study, is presented in *Table 2*, and the essence of the cluster search method is embodied in the 'cluster mnemonic' (*Table 3*).

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#### TABLE 2 Suggested generic procedure for cluster searching

Step	Procedure	Source(s)			
Steps to enhance exploration of context					
1	Identify at least one key 'pearl' citation, agreed through consensus by the review team	Preliminary search of bibliographic databases			
2	Check reference list for any additional relevant citations by the authors	Full text of pearl citations			
3	Recheck for additional records by the authors	Reference management database			
4	Search for lead author identifying contact e-mail, publications list, institutional repository	Google			
5	Conduct citation searches on key pearl citation (and other publications Web of Science/Google as appropriate)				
6	Conduct searches on project name/identifier	Google Scholar			
7	Make contact with lead author	Personal web pages			
Steps	to enhance identification of theory				
8	Follow up key pearl for citation of theory	Full text of pearl citations			
9	Recheck for theory in titles, abstracts, etc.	Reference management database			
10	Perform iterative searches for theory in combination with condition of interest	Original set of bibliographic databases			
Steps	to broaden the search to other relevant information				
11	Follow up key pearl citation and other cluster documents for project antecedents/related projects	Full text of pearl citations			
12	Conduct named project and citation searches for relevant projects identified from cluster documents	Google Scholar/Web of Science			
13	Seek cross-case comparisons by combining project name/identifier for cluster with project name/identifiers for other relevant projects	Original set of bibliographic databases			
Adapt	ed from Booth <i>et al.</i> 2013. <sup>68</sup>				

## TABLE 3 Cluster mnemonic for components of cluster search methodology

Element	Procedural steps (see Table 2)		
Citations	Step 1		
Lead authors	Steps 2–4		
Unpublished materials	Step 7		
Scholar searches	Steps 5–6		
Theories	Steps 8–10		
Early examples	Step 11		
Related projects	Steps 12–13		
Reproduced from Booth et al. 2013.68			

Our proposed cluster methodology utilises most of the six procedures suggested by Bates.<sup>76</sup> 'Cluster procedures systematize and formalize existing processes, and assign a clear responsibility for supplementary searching. . . . Cluster procedures are supplementary, complementing deficiencies or omissions from topic-based searches. Cluster searching offers a greater potential contribution to realist reviews, qualitative syntheses of complex interventions or reviews in which implementation-related issues figure prominently.<sup>68</sup> A recent realist review independently utilises a cluster-based approach to enhance the richness of data. The authors identified '23 partnerships, collectively composed of 276 documents, including peer-reviewed and non-peer-reviewed publications and websites'.<sup>77</sup> Noticeably, however, this other review did not use a systematic approach to identify its clusters. Contact with authors was the single method used in this instance. Contact with authors may help to identify most, if not all, papers directly associated with a named cluster. However, it would not reveal either additional papers invoking theory or related projects with a common provenance.

## Selection and appraisal of documents

#### Initial sift: community engagement and peer support or models and theories

The study identification screening tool required the title and abstract actually embody the team's derived definition of 'CE'.<sup>60</sup> Studies appearing to fulfil this minimum criterion were further required to either describe peer support or make a specific contribution relating to models, theories and frameworks. Both retrieval sets were combined at this point, as it was felt that they need not necessarily be exclusive. Included records for peer support in health were further coded for geographical area and for population. The three particular foci for the sift process were identification of Research studies *or* Models/Theories *or* Review articles (whether systematic or not).

Many papers met the 'CE' requirement but were subsequently excluded because they focused on 'CE' in the context of educational institutions, non-health contexts or the relationship between an individual's engagement and his or her health-related outcomes.

A total of 144 articles were identified from this first process of sifting, which was completed in November 2011. Two challenges were identified from the initial sift process; the potential for subjective interpretations of essential term definitions, and uncertainty about strategies for including 'unsures' (i.e. when concepts such as HL might be present in the full-text paper but when the necessary indications were missing from the titles and abstracts). In response to these challenges, the team produced consensual definitions of the key terms (CE, peer support and HL) and decided that a positive indication would be required for inclusion but that the nature of this indication (e.g. mention of information or of health promotion for 'HL') would be interpreted liberally. The team completed a consensual resift of the 144 articles to embody the more secure use of definitions in December 2011.

Initial descriptive variables against which the studies were mapped included author (date); research question; study type (and summary quality assessment); study population; setting and country; CE method/approach; description of intervention/peer support; HL outcomes; and main results at short term (6–12 weeks), medium-term (12 weeks to 1 year) and long-term (1 year and beyond) intervals. An initial challenge related to the fact that studies, rather than papers, were identified as the unit of analysis, throwing into doubt the value of conventional approaches to quality assessment (e.g. where one paper constitutes a RCT report yet other studies in the same cluster utilised less robust designs). Studies were selected in the first instance for relevance – whether or not they could make a relevant contribution to theory identification, theory building and/or theory testing.<sup>59</sup> This enabled us to first look for global patterns across local interactions and actions.

The aim of cluster searching was to identify families of papers on the same project or related projects, enabling us to build up a conceptual picture of the programme or intervention over a period of time from inception through implementation to assessment of outcomes. We originally proposed to do a quality

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assessment at the first stage of full-text review. This approach was based on the assumption that we would obtain study types where strength of evidence could be graded. When looking at the papers retrieved, however, we realised that much of the useful information on context and mechanisms was contained in discussion of how and why an intervention could work – which is often found in the introduction and discussion sections of the paper. Subjecting papers to quality assessment risked excluding methodologically weak or 'thin' papers that could contain key bits of explanation for the relative effectiveness of the theory of change.

The scientific strength of the papers was defined as coherence between the initial theory of change for the programme and the various components in the intervention. We also looked at whether or not the theory of change was reflected in the process of design and implementation. Scientifically strong clusters selected an appropriate theory of change for the intervention, aligned the design of the intervention with the theory, and used logical measures at the appropriate points in time to evaluate if the theory of change worked. Clusters that were scientifically weak claimed to be using a specific theory but the theory was not obviously used in the programme design or implementation. Further, the nature of the community-based intervention needed investigation, particularly for community interventions that used theories of individual behaviour change and used individuals as the unit of analysis. One strategy for dealing with empirically weak papers that provide little conceptual contribution is to assign them a secondary place in the data analysis. This is entirely appropriate when the focus of the review is to establish effectiveness based on strength of empirical evidence. In our realist review, however, we wanted to iteratively build an explanation for how and why peer support worked, which requires analysis of all explanatory material.

The quality assessment therefore was redefined as coherence – the degree of alignment between theory, design, implementation and evaluation. We assessed coherence during the in-depth analysis (see *Chapter 3*).

# Second sift: peer terms and health promotion, health education and health literacy

The second sift, combining an exhaustive list of peer terms with health promotion, health education and HL, resulted in 6864 references. These references were distributed among the review team in batches of 750, with two team members completing double batches. A rapidly operationalisable first sift question was used: 'Does this paper describe research/evaluation/models?' When the answer was 'yes', further coding required identification of terms relating to 'peer support' (included in the search strategy). Finally, terms specifically relating to either HL and/or CE were sought. Team members were asked to 'refer' in any cases of uncertainty. At this stage 570 'includes' were identified from the selection process. Following advice from the Project Steering Group, it was decided to focus on studies with sufficient explanatory depth and contextual relevance to deliver against the aims of the review. This decision determined the subsequent UK cluster-based approach.

#### Cluster-based approach

Of the 570 included papers, 39 were directly attributable to a UK context. From these papers seven UK-based 'clusters' were identified. Overall, 122 papers related to models and theories. We focused predominantly on UK programmes, as we were uncertain as to the degree of variation across contexts for CE in diverse cultures, and experience among those in the review team indicated that CE is conceptualised and implemented differently in different countries. In addition, one US-based cluster was included from the remaining 409 papers to maximise opportunities for comparison and contrast (see PRISMA diagram, *Figure 6*). For designation as a 'cluster', a study was required to include at least one included paper from the team sift and to be linked – through supplementary searches performed by the information specialist (AB) – to at least two or more additional papers, thereby potentially adding conceptual richness and contextual thickness.

In addition, an unpublished set of cluster data was attributed to the Advisory Network, with access to Advisory Network members satisfying the criteria for conceptual and contextual contribution. This cluster was given the same status as the published studies, providing opportunities for obtaining descriptive information on intervention components, contexts and mechanisms that could be used for verification, respondent validation and member checking of culturally supported interventions with the research literature. During the course of working with the Advisory Network, however, unpublished materials were identified, as well as several published studies that evaluated Advisory Network projects. Our review sample therefore comprised nine clusters in total (*Table 4*).

Taken individually, each data source from a cluster will possess differential scientific rigour and external validity.<sup>59</sup> Conventional systematic review methodology requires each study to be individually appraised. However, given the sibling relationship of studies in contributing to a holistic picture of a cluster it appears likely that quality assessment would most appropriately be performed using the cluster as the unit of analysis, rather than at the level of an individual paper or study report. Taken as a body of evidence, privileging contextual relevance, the collective accounts offer a value added contribution to the phenomenon under study. For this project, therefore, appraisal of included studies related to informational (not study design) quality components. This approach was considered appropriate in view of the need – identified within the realist synthesis methodology – to optimise both rigour and relevance. For inclusion, a paper had to describe the process and context in sufficient detail.

Brief initial analysis of characteristics of included studies revealed a substantial evidence base concentrated around a few topic areas, for example smoking, breastfeeding, nutrition and HIV/AIDS (or sexually transmitted infections more generally). These were felt to provide a good representation of many of the preoccupations of public health involvement in promoting peer-support-/CE-type interventions. Topic areas also mapped to 'Marmot' priorities with regard to health inequalities.<sup>86</sup>

#### TABLE 4 Characteristics of the selected clusters

Name of cluster	Health topic	Study design for index paper	Index paper	Lead
Advisory Network (UK)	All	Not applicable	Not applicable	JH
Breastfeeding (UK)	Breastfeeding	Mixed-methods evaluation	Condon <i>et al.</i> <sup>78</sup>	JH
Diabetes Sharing Stories (UK)	Diabetes	RCT	Greenhalgh <i>et al.</i> <sup>79</sup>	JT
Healthy Living Older People (UK)	Healthy lifestyles	Qualitative evaluation	Holland <i>et al.</i> <sup>80</sup>	AY/EW
HIV Safer Sex (UK)	HIV prevention	Quantitative evaluation	Flowers et al. <sup>81</sup>	AB
Healthy Eating (AUS), qualitative evaluation, Abbott <i>et al.</i> ; <sup>122</sup> Healthy Eating (UK), randomised effectiveness trial, Hillier <i>et al.</i> <sup>132</sup>	Nutrition	Randomised effectiveness trial	Resnicow <i>et al.</i> <sup>82</sup>	FC
Smoking in Schools (UK)	Smoking cessation	Pre-post cohort	Campbell <i>et al.</i> <sup>83</sup>	LC
Smoking in Ethnic Minorities (UK)	Smoking cessation	Randomised cluster trial	Begh <i>et al.</i> <sup>84</sup>	AY/EW
Smoking Cessation Fag Ends (UK)	Smoking cessation	Longitudinal quantitative evaluation	Springett <i>et al.</i> <sup>85</sup>	AB

Note

See Appendix 2 for details of references within each cluster.

## **Data extraction**

Categories for data extraction were derived from information reported in the clusters. One team member developed a draft data extraction sheet in Microsoft Word, version 2013, using categories related to the design of the programme, the intervention, and elements related to peer support, CE and HL. We independently piloted the data extraction sheet, which led to the identification of additional categories. These categories were compared, and agreement and refinement were reached via discussion. Final categories covered programme design and theory; peer selection and training; the peer-support intervention; relationships between CE, HL and peer support; the identification of articles on the same programme, related programmes, useful background articles, or articles related to programme theory; and a final category for reviewers notes and comments (see *Appendix 3*).

The piloting process revealed potential issues that might arise from not being able to differentiate between participant quotes, author's reflections, study findings and reviewer's interpretations when extracting data. In realist synthesis, all sections of an article or report represent potentially fruitful sources of explanation for what works for whom, in what circumstances, and at what point in time. We distinguished between author and reviewer interpretations and study findings by including a data source category.

One team member took the agreed data extraction sheet categories and developed a Microsoft Excel spreadsheet for each team member to use as a data repository when reviewing included articles. Each team member was assigned a cluster (or two) of articles for data extraction (see *Table 4*). The process for capturing data was iterative: extraction sheets were reviewed by the team and, after discussion, studies were revisited to ensure consistency in the format and level of detail for extraction. A cluster template was completed for each original index article, allowing us to summarise the data for the original index article, and documenting the antecedent and descendant articles that contributed to the programme theory for each cluster (see *Appendix 2*).

After extracting data on study characteristics (see *Appendix 3*) we agreed that the level of granularity we hoped to capture was poorly reported in most of the peer-reviewed literature. For example, an explanation of why certain peer-support practices worked or did not work was often not articulated. If an explanation was included, it was not due to explicit testing in the intervention but rather author's views or anecdotal reports from participants or PSs. Furthermore, explicit descriptions of the relationship between peer support and HL were rare, mainly because studies used health education as a proxy for 'HL' concepts. Similarly, there was a lack of information on CE; the focus of the studies was mainly implementation of the peer-support intervention and its immediate effects on health outcomes, and not whether or not communities were engaged in the development of the intervention. It became clear that the likelihood of a study reporting on the relationship between peer support, CE and HL was rare. We attempted to supplement the data by contacting authors of the papers and locating sibling papers but found that in cases the incompleteness of reporting was an extension of incomplete documenting of the breadth and scope of impacts. Other researchers have encountered similar challenges when carrying out realist reviews.<sup>77</sup>

### Assessment of study quality

Although some studies clearly articulated the theories upon which they were based, others did not explicitly describe the underpinning theory of change or were not theory based. This raises the issue of coherence – the degree of alignment between theory, design, implementation and evaluation (see *Selection and appraisal of documents*). We appraised coherence by extracting programme theory within each cluster. The outcomes were then extracted, and working backwards we attempted to establish the 'chain' between outcomes, mechanisms and context (see *Appendix 4*). Outcomes chaining revealed some issues with methodological quality. The first issue was lack of a stated theory. Two clusters

(Healthy Eating Aboriginal Australians; Smoking in Ethnic Minorities) had no theory but several assumptions could be derived from the description of the interventions. Both clusters used health workers of the same ethnicity but, in both cases, they were used to provide information. In the Aboriginal cluster, indigenous workers also provided transport but there was no reporting of other forms of support in either cluster.

Three clusters appeared to use programme theories when the individual was the focus of change. Health Eating Middlesbrough used the theory of planned behaviour and social cognitive theory to encourage people to make healthy pledges. Although this was billed as a community challenge, the intervention focuses on individuals. Healthy Living Older People used a helping model, for which the focus of interest is on the dyadic relationship between supporter and supported, but the intervention emphasised involvement in groups to reduce social isolation. Similarly, Smoking Cessation Fag Ends was modelled on stages of change and motivational interviewing but the intervention itself emphasised drop-in at centres where there was a great deal of social contact.

All of the clusters used health outcome measures for individual behaviour change. In two cases (Breastfeeding and Diabetes Sharing Stories) we questioned whether or not the period of time between implementation and evaluation was long enough to be able to demonstrate some of the health outcomes.

These issues with theoretical coherence were not deemed great enough by the review team to exclude any of the clusters at this stage of analysis. The appraisal was useful in that it enabled us to identify possible mediating factors for the relative effectiveness of various programmes. For example, the extent of community involvement in recruitment appeared to dilute success (Healthy Eating Middlesbrough; HIV Safer Sex), whereas the extent of social involvement appeared to enhance interventions. Consulting with stakeholders became a critical part of the process because studies tended to focus on tangible processes and formally measurable outcomes. Informal or tacit information relating to interpersonal relationships and the subtle contextual conditions that may cause interventions to succeed or fail were often missing from the papers. For this reason, our review was a participatory realist review in which we planned to gather experiential knowledge and information from lay experts working as PSs, who would become part of a large Advisory Network.

## **Obtaining information from the Advisory Network**

We established an Advisory Network in order to obtain pragmatic views of peer-support interventions, which could be compared and contrasted with the empirical literature. In much empirical literature human involvement is seen as a contaminant, so safeguards such as randomisation, placebos and blinding are put in place to eliminate the impact of human involvement. Peer support, however, is a complex intervention that achieves effects via the active input of people (such as clinicians, patients, managers, community members). Because these programmes work through stakeholder reasoning and personal choice, developing an understanding of that reasoning is integral to analysing the successes and failures of these interventions. It was hoped that the Advisory Network would provide a rich source of information on culturally supported interventions, as well as insight into some of the tensions noted in *Chapter 1* regarding the various models of introducing peer support into a community compared with working within communities to develop HL.

We identified potential Advisory Network members using a snowballing technique<sup>87</sup> in which members of the project team used existing contacts in the community to identify and approach individuals and organisations known to provide grass roots peer support. This process was augmented by a collaboration with Sheffield Well-Being Consortium, a third-sector collaboration made up of organisations providing health and well-being services to meet the needs of local people. The Consortium (subsequently reorganised and renamed as 'Sheffield Cubed') assisted in identifying and recruiting appropriate groups and individuals to the Advisory Network. Recruitment took place for the duration of the project with some

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participants contributing on multiple occasions, and others making a single contribution at a particular stage in the project. We also drew upon previous contacts from a national evaluation of the reducing inequality in the NHS (Harris J *et al.*, University of Sheffield 2010, unpublished.) where projects aiming to reduce health inequality had been initiated in various parts of the UK. The network comprises a diverse group of people with expertise in using peer support to promote health and well-being across a range of conditions and areas. Salaried workers, health trainers, volunteer health champions and programme co-ordinators participated, as well as people who had originally been recipients of support before going on to become a volunteer health champion or a qualified health trainer. The collaboration with Sheffield Cubed allowed us to tailor recruitment to those groups and individuals working in topic areas that linked to those covered in our literature clusters (*Figure 7*).

Some of the different organisations represented included condition-specific groups, for example stroke, learning disability, chronic pain and diabetes groups; population-specific groups, for example Gypsy, Roma and Travelling populations, minority ethnic carers of older people, and more broad CD groups. Within these organisations there were many aims, purposes and motivations for the different peer-support interventions, giving us a wide range of expertise in providing CBPS to promote health and well-being and reduce health inequalities. Participants were able to contribute by attending face-to-face events, responding to e-mail discussions or through opportunistic contacts with members of the team. We collected data via five cross-organisation events for the wider Advisory Network. We also facilitated seven within-organisation events for groups and individuals who might be disadvantaged or under-represented if asked to attend a mixed group in an unfamiliar setting. These groups included people with learning disabilities and people from Gypsy, Roma and Travelling communities. In total we made approximately 240 contacts with around 120 participants.

We initially planned to explore the literature and present our findings to the Advisory Network with the intention that they would fill in any gaps in our knowledge (*Figure 8*). However, our preliminary work with the literature revealed very little information about the process of peer support, and descriptions of the interventions used were lacking in detail. As a result, we collaborated with Sheffield Cubed to plan activities through which peer-support volunteers and workers could share experiential knowledge and information about culturally supported models of peer support. We asked our Advisory Network to tell us what happens and what works in a peer-support intervention, and also what constrains peer support.





Торіс	Advisory Network				
Breastfeeding	Sheffield Well-Being Consortium; Sheffield Breastfeeding study Darnall Wellbeing				
Diabetes	AGE UK; Stroke Association				
Healthy Living Older People	Irish Gypsy and Travellers Movement in Britain; Leicester Health Ambassadors				
HIV/AIDS	Centre for HIV and Sexual Health; Parent to Parent, Shout; Sheena Amos Trust; Expert Patients Programme				
Health trainers	Sheffield Community Chronic Pain; Manor and Castle Development Trust MECOPP Minority Ethnic Carers of People Project;				
Nutrition	Autism Plus				
Smoking	Sharrow ShipShape; Sheffield Primary Care Trust MIND; Mencap Sheffield City Council				
	SOAR (Southey Owlerton Area Regeneration) ZEST Community Development Trust				

FIGURE 8 Working in tandem across the literature and the Advisory Network to compare empirical research and culturally supported interventions.

Questions we set out to answer included:

- What is a peer?
- What makes you a peer?
- What is important in being a peer?
- What components make up peer support?
- What do you do and how do you do it?
- When do you do it and why?

During network events we used participatory methods and tools to promote discussion allowing us to explore these questions. We adopted the stance of researchers as partners in a process of reflection and learning, making it explicit that we needed to gain a better understanding of what actually happens during a support intervention by listening to people who provide it.<sup>20</sup>

Community workers were used as facilitators, which allowed members of the review team to take on the role of listeners and learners. Although the discussions had some structure, participants were allowed to spend a greater or lesser amount of time on the various questions, and to take the discussion in different directions when issues needed to be explored in greater depth. We recorded information in a variety of different formats. We made notes, used flipcharts, audio-recorded some discussions and asked participants to make posters with Post-it<sup>®</sup> stickers. The events were enjoyable, and feedback from participants was positive, suggesting that they felt valued and affirmed in their role. This was evidenced by ongoing participation from the same individuals and organisations at subsequent events.

We reviewed the information in collaboration with members of the network to develop a list of themes relating to our questions. For example, with the Irish Travellers Movement we developed a written account that was exchanged several times with participants to ensure that it captured all of the peer-support components and processes that were felt to be relevant to the success of the initiative. Information from other events was reviewed by network members to arrive at preliminary themes. Using an iterative approach we presented these themes, and the ideas within them, for further discussion at subsequent Advisory Network events (*Figure 9*). The discussion moved from description of the complex intervention of peer support, to active questioning of what makes it work. At each stage, we also played 'devil's advocate'



FIGURE 9 Synthesis of information from the Advisory Networks. SWBC, Sheffield Well-Being Consortium.

by asking people to tell stories of the challenges of providing support, ranging from concerns about individual capability to issues in dealing with systems.

As new information was generated, it was incorporated into an overarching synthesis of ideas across events. These preliminary themes included the environment for peer support, the attributes and skills of the PSs, attitude of PSs when initiating contact, attitudes to maintaining the relationship, what the client needs to feel supported, practical tips, and approaches and messages.

Peer supporters described the attributes and skills that they brought to their work, and discussed the importance of attitudinal approaches which were facilitative, non-threatening, person centred, flexible and empowering. The theme 'what the client needs to feel supported' incorporated the steps PSs took to establish what the client wanted to change and then explore what support they needed to achieve this. This was followed by any practical steps that PSs would take to provide this support to the client and any key approaches or messages that PSs used.

Approaches that were discussed included cycle of change, mentoring and role modelling. PSs used a variety of these approaches, along with more intuitive messages of affirmation and encouragement. Finally, there was discussion about the need to provide peer support in a familiar and safe environment.

We asked participants if it would be possible to construct a model of peer support from their accounts, and people responded by saying that the model was best conceptualised as a journey through which the support accompanies the client, aiming to get the client increasingly connected with social networks and enabling him/her to interact with organisations, institutions and systems to get what he/she needs. The preliminary model used the network's analogy of a bicycle to illustrate the way that relationship-building and the development of trust were seen by the Advisory Network to be essential to help people move forwards, in terms of taking positive action to improve their well-being. What became known as the 'bicycle model' was sent round various community organisations for feedback, and further comments and

embellishment. The final model was drawn by a local artist, who interacted with the group to capture all of the important elements of peer support (*Figure 10*).

In considering information from the Advisory Network and data from the published evidence it is clear that there are differences in emphasis. The literature emphasised the information that was conveyed during the peer-support intervention, whereas the network described in rich detail the process of peer support and how the provision of peer support actually takes place. In the literature, priority was given to informational support and reference to instrumental support was missing.<sup>1</sup>

The Advisory Network stressed the importance of practical, instrumental support and described this as an important form of support to enable individuals to act. In many cases, people started with issues that were not directly related to health before they were ready to consider health information. They focused on doing things *with* people and showing them *how* to do things, providing practical help to enable clients to achieve their goals.

In summary, we adopted several variations on the usual approaches to realist review, which included:

- greater emphasis on what are normally considered 'supplemental' searching methods to identify clusters of related articles
- use of a network of practitioners to develop definitions for concepts and identify theory for culturally supported interventions working alongside reviewers who collated research evidence (see *Figure 8*).

The information from the network was used to illuminate possible configurations of context, mechanism and outcome; to develop programme theory; and to create a model of what works in peer support. We collected this information in tandem throughout the review, and the various ways in which it illuminated the published literature are presented in *Chapters 4* and 5.



FIGURE 10 The peer-support journey (artwork: Sarah Smizz).

# **Chapter 3** Analysis within programmes

### About this chapter

This chapter is the first of three chapters describing the process of analysis and synthesis for realist review. Analysis and synthesis is an iterative process in realist review. The variation in articulated theories in some of our clusters led us to perform three stages of analysis (*Box 1*). This chapter describes the various strategies that were used to articulate programme theory for each of our clusters.

## **Theory scoping**

The first step in identifying programme theory involved scoping the articles in each cluster to identify the theories that the authors referred to using in designing and evaluating the intervention. For the purposes of the scoping, we looked for groups of relational statements about peer support that were used to describe, explain, predict or control the intervention.<sup>88</sup> We used the definition of programme theory as 'an explicit theory or model of how an intervention, such as a project, a program, a strategy, an initiative, or a policy, contributes to a chain of intermediate results and finally to the intended or observed outcomes'.<sup>46</sup> Programme theory encompasses two different components, which are called the theory of change and the theory of action. Theories of change provide explanations for why a particular intervention ought to work, whereas theories of action outline the specific activities and processes that will actually produce the change.

#### BOX 1 Phases of analysis, synthesis and theory development

#### Phase 1: within-programme analysis

- 1. Theory scoping Identifying the theories that were explicitly used and/or cited within studies in the clusters.
- Articulating theories of change Theories of change were identified for each programme cluster and appraised for coherence.
- 3. *Identifying theories of action* Case studies were developed with propositions for what works, for whom, in what circumstances, and at what point in time within each cluster.

#### Phase 2: cross-programme analysis

1. Organising data by programme stage Comparing CMO configurations across programmes by each respective stage of peer support in order to identify patterns of CMO.

#### Phase 3: theory testing and development

- 1. *Theory testing* Reviewing the goodness of fit for the emerging theory in relation to theories for peer-support HL and health inequalities.
- 2. *Producing a mid-range theory* Show how different configurations of context and mechanism influence the trajectory of the intervention and subsequent outcomes.

CMO, context-mechanism-outcome.

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Our data extraction showed that programmes in our clusters referenced a very wide range of theories but some referred to theories of change to inform the design of the study, whereas others mainly used theories of action. The extent to which the study design could be linked to theory varied and in the case of one 18-year programme it was difficult to link to programme theory because 'the model as it evolved did not consciously draw on theories', although it reflected aspects of the transtheoretical stages of change model.<sup>85</sup> The theories used were diverse, indicating an epistemological stance that targeted individual behaviour change in community-based programmes at one end of the spectrum and approaches to activating entire communities at the other end (Table 5). In realist synthesis, candidate theories are often identified at early stages of the review, by finding a behavioural or social science theory that is either commonly used in the included studies or imported from elsewhere because it is a good explanatory fit.<sup>101</sup> We chose to take a more grounded approach, however, because although our studies used theory in relation to peer support, only two clusters contained studies that were explicitly testing/generating theory in relation to HL (Diabetes Sharing Stories and Breastfeeding). We therefore focused on developing programme theory within clusters before selecting possible mid-range theories. We identified theories of action in the first instance because several studies contained little explicit description of the theory of change. In other words, studies were much better at reporting what they did, for the most part, than at explaining the underlying theory for how and why the activities related to their intervention would bring about change.

## Articulating theories of change within clusters

Programme theory can either be used explicitly to design the intervention or it may be implicit. In prospective planning, ideas for the key activities that are needed to bring about the desired change are generated and outcomes are defined. When an explicit approach is used, researchers and other participants may base their programme theory on practitioner knowledge, on participant experiences and/or refer to more general social science theories for ideas. The knowledge from these sources is combined

Theories cited	Topic cluster
Health belief model <sup>89</sup>	Healthy Eating Aboriginal Australians
Theory of planned behaviour <sup>90</sup>	Healthy Eating Middlesbrough
Socioecological framework91	Healthy Eating 'Body and Soul'
Multidimensional model of HL <sup>49,92</sup>	Breastfeeding
Social support model of peer support <sup>1</sup>	Diabetes Sharing Stories
Carkhuff's helping model <sup>93</sup>	Healthy Living Older People
Transtheoretical stages of change94	Healthy Eating 'Body and Soul'
Diffusion of innovations theory <sup>95</sup>	Smoking in Schools; HIV Safer Sex
Stages of change or transtheoretical model <sup>94</sup>	Smoking Fag Ends; Advisory Network
Social action model/community activation approach <sup>96</sup>	Smoking in Ethnic Minorities
Social learning theory <sup>91,97</sup>	Healthy Living Older People; Smoking in Ethnic Minorities
Ludman's theory of education <sup>98</sup>	Healthy Living Older People
Social cognitive theory <sup>91</sup>	Smoking in Ethnic Minorities, Healthy Eating Middlesbrough
Carkhuff's helping model93	Healthy Living Older People
Control theory <sup>99,100</sup>	Advisory Network

#### TABLE 5 Theories cited for peer-support programmes

to produce a model that justifies why a particular approach will work. A prospective approach to developing programme theory is encouraged in fields such as international development and resource management, but the use of theory to inform the development of health interventions is a relatively new phenomenon.<sup>4</sup>

It is usually the case in health research that reviewers are challenged to work with studies that have no stated theory. Implicit programme theory can be extracted retrospectively by identifying assumptions about how and why an intervention would work. As most of our studies contained implicit assumptions about theories of change, we applied the following steps to articulate theory within clusters (*Box 2*, adapted from Leeuw 2003<sup>102</sup>).

A theory for each programme was drafted, topic leads reviewed the emerging theory for their respective clusters, and a summary of each step was then produced:

- 1. Problem-framing: why was this seen to be a problem?
- In all cases, the decision to offer an intervention was, in the first instance, triggered by public health data, for example data on consequences of weight gain, smoking, drinking, unsafe sex, lack of breastfeeding, lack of physical activity, low rates of cancer screening, and poor nutrition and falls in the elderly. Previous attempts to provide education to reduce smoking, reduce risks of cardiovascular disease or diabetes through healthy lifestyle programmes, promote safe sex, promote breastfeeding, and improve healthy lifestyle in older people had not been successful for several reasons, described primarily as issues of sender-message-receiver. Problems with senders - the type of person delivering the message – were generally framed as an issue with credibility and lack of trust. They were unable to communicate in the participants' preferred language (Smoking in Ethnic Minorities); were perceived to be different from the target group (Smoking in Schools; HIV Safer Sex), delivered judgemental and unrealistic messages about behaviour and the need for behaviour change (health services smoking campaigns); and delivered scientific and technical information (Breastfeeding). In some cases the messages conflicted with embedded social norms. National smoking campaigns, for example, use scare tactics to increase awareness of the risks, and present smoking as a socially unacceptable behaviour, whereas advertising glamorises smoking. Breastfeeding campaigns that urge women to breastfeed for the health of their baby compete with formula companies that promote the convenience of bottle feeding and social norms that deem public breastfeeding to be unacceptable. Safer sex campaigns aim to encourage people to discuss safer behaviour with partners, although people commonly experience discomfort about discussing sex with friends or acquaintances. The content of messages was felt to be difficult to understand, not only due to language problems, but also because of the complexity of some messages. This was noted in the Smoking in Schools programmes, which tried to convey messages about safe levels of drinking to young people.<sup>103</sup> Interventions that were delivered using scientific technical language made it difficult to translate into everyday meaningful statements (breastfeeding,

#### BOX 2 Articulating programme theory. Adapted from Leeuw 2003<sup>102</sup>

- Problem-framing What is the problem? What is the extent of the problem? For whom does this problem exist? Why does this problem occur? What are its causes? What, if anything, is known about what has, and has not, been effective in addressing this problem? What are the consequences of the problem for those directly affected by it?
- 2. What were the goals of the programme or intervention? e.g. How did the programme plan to address the problem?
- 3. What specific mechanisms were expected to solve the problem? How did the interventions interact with provider or participant attitudes, behaviours, environment to bring about the desired improvement?

smoking). In the case of breastfeeding, women felt guilty and embarrassed when they were unable to follow instructions given by HPs; in the case of smoking cessation, messages constructed and delivered by the health service were seen to be negative and judgemental.

Receivers were described as people with poor English language skills (Diabetes Sharing Stories), people with low HL in their own language (Diabetes Sharing Stories), people who had trouble understanding scientific and technical information (breastfeeding and smoking), people who had restricted ability to access information due to social isolation (Diabetes Sharing Stories, Smoking in Ethnic Minorities, older people) and people who experience marked socioeconomic disadvantage and health inequalities (healthy nutrition).

#### 2. Goals of the programme, for example 'How did the programme plan to address the problem?'

- Credibility of the sender was addressed by selecting people who were felt to have similar characteristics to the target population and/or were respected by the target population. Popular opinion leaders were used in two clusters (Smoking Cessation in Schools; HIV Safer Sex). Similar characteristics included people who had the same language (Diabetes Sharing Stories; Smoking in Ethnic Minorities); people who had experienced the same health problem (Smoking in Ethnic Minorities; Breastfeeding; Healthy Living Older People; HIV Safer Sex); and/or people who shared the same ethnic background (Healthy Eating). The type of peers believed to be effective ranged from peers coming from outside the community who shared similar characteristics with participants, or peers who lived and/or worked within the target communities. Programme goals addressed problems with message content by including PSs in the design of health information (Diabetes Sharing Stories; Smoking in Ethnic Minorities). including community-based organisations as stakeholders in design of the intervention (nutrition; Smoking in Ethnic Minorities); and/or by conducting a community needs assessment to determine the most appropriate ways to provide information (Breastfeeding; Smoking in Ethnic Minorities; Diabetes Sharing Stories). PSs were identified who spoke the local language (Smoking in Ethnic Minorities; Diabetes Sharing Stories) or who knew the local jargon and used vocabulary that was familiar to participants (Smoking in Ethnic Minorities; Smoking Fag Ends). The issue of messages that conflicted with social norms was addressed by having peers who encouraged discussion of healthy behaviour – the barriers to achieving it and the strategies that might work based on the experiences of others (Diabetes Sharing Stories; Smoking in Ethnic Minorities; Breastfeeding). Another strategy for making sense of messages and understanding how to use them was to provide opportunities to 'observe' how others managed the condition, by listening to their stories (Diabetes Sharing Stories; Healthy Living Older People) and/or watching them perform the behaviour (Breastfeeding).
- Attention was given to finding settings that people normally frequented or that would be considered as acceptable settings for the activities. Some programmes introduced support activities into pre-existing groups, although the concept of 'group' is used to cover both tight social networks (such as diabetes lunch clubs); venues where the same people tend to gather (gay bars; postnatal clinics); and settings where there may be several well-defined social groups (schools). Messages were in some cases 'standard', for example taken from existing training packages or well-known health promotion materials. During the training stage, the standard material was in some cases discussed with the PSs (codesign) to ensure that the messages selected for the intervention were relevant and understandable to the target audience. Some programmes noted that they expected PSs to tailor the messages during their interactions with participants. The process of creating the intervention was led by HPs in four of the eight clusters, with only one cluster using what we would call a coproduction approach to design and delivery.

- 3. What specific mechanisms were expected to solve the problem? What were the assumptions about how the interventions would interact with provider or participant attitudes, behaviours, environment to bring about the desired improvement?
- Assumptions about participant attitudes and behaviours:
  - Popular opinion leaders were assumed to be credible senders of health messages because they were already shown to be able to influence and persuade in prior research.<sup>95</sup> It was posited that people would look up to them, want to identify with them and emulate their behaviour (Smoking in Schools; HIV Safer Sex) (*Figure 11*). It was assumed that people would tend to trust peers more if they had experienced the same condition or health challenges (Diabetes Sharing Stories; Healthy Living Older People; Advisory Network). It was thought that if people saw them as believable role models then they may feel that making the proposed change was feasible (Advisory Network; Healthy Living Older People). Peers with experience of the situation could demonstrate what to do, how to change things and provide practical tips, thereby increasing confidence in attempting new and possibly challenging HBs (Breastfeeding). Many of these mechanisms are triggered by social learning.
  - Two of the clusters included peers in the design of the intervention and one was entirely community based. The approach to creating the intervention points up two different sets of assumptions about health information. When HPs select the content, there is an assumption that the message is inherently good and that imparting the information will lead to change. Cocreating the intervention, in contrast, based message content on peer experience and community knowledge. This was assumed to produce more relevant messages that would address people's concerns, in a format that was culturally appropriate and acceptable.
  - Peers who spoke the same language, or were able to use the same local parlance, were assumed to engender feelings of being on the same level and having something in common with participants. Their ability to avoid medical jargon and scientific language could narrow the gap between understanding of facts and ability to understand how health messages could be applied to personal situations. PSs who were visible in the local community, who made efforts to become or who were already part of the social network, and who could reach out to people could have more frequent contact. If PSs were able to be there for people, they were able to build relationships, establish rapport and a feeling of trust (Breastfeeding; Advisory Network).



FIGURE 11 Peers can inspire others to change.

- Assumptions about provider attitudes and behaviours:
  - Several of the programmes involved community providers from the start, as well as HPs. The
    assumption for early involvement was that engagement at the stages of designing the programme
    would create a feeling of ownership, as well as shared understanding about the issues to be
    addressed and the aims of the programme (e.g. Diabetes Sharing Stories; Smoking Fag Ends).
    In contrast, some programmes assumed that design by HPs was entirely appropriate (Smoking in
    Schools; Smoking in Ethnic Minorities). In the case of breastfeeding, one of the studies in the cluster
    included breastfeeding women in programme design.<sup>78</sup>
- Assumptions about the environment:
  - Some studies contained no information on the surrounding environment. In the programmes that acknowledged importance of the environmental context (Breastfeeding; Smoking Fag Ends), a cultural or community needs assessment was planned, which aimed to look at where people would normally congregate. The planned approaches to working with the environment ranged from introducing interventions into existing social networks, to working alongside social networks to cocreate and deliver the intervention. Several programmes located support services in well-used local venues in order to help people feel at home and more inclined to participate.

### Plotting health literacy outcomes

Each of the clusters presented intended outcomes, which were listed as impact or high-level outcomes.<sup>46</sup> For some clusters, the stated programme design presumed a linear sort of 'pipeline' model which did not include intermediate 'process' outcomes, assuming instead that high-level outcomes would follow logically from the programme plan of action. Outcomes for peer support that related to Nutbeam's model<sup>15</sup> included:

- knowledge and personal skills development to promote active engagement with health decision-making
- developed knowledge and capability
- improved HL
- engagement in social action/advocacy for health
- active participation in health decision-making, changing service expectations and practices
- changed HBs and practices
- improved health outcomes, health services and clinical practice.

Preliminary outcomes of knowledge and capability are assumed to lead to intermediate outcomes of improved HL and change in behaviours, which, in turn, are necessary to achieve the higher-level (and longer-term) outcomes of improved health. Using this model, we plotted an outcomes chain to illustrate the presumed cause-and-effect relationships between shorter- and longer-term outcomes for each programme (see *Appendix 4*). A summary of this outcomes chaining is presented in *Table 6*.

From this exercise, both positive and negative cases emerged. The negative outcomes related to a lack of engagement with community organisations during design, recruitment and delivery of the intervention [HIV Safer Sex; Smoking in Ethnic Minorities; Healthy Eating Middlesbrough], and issues in training PSs to deliver sensitive and complex messages (HIV Safer Sex and Alcohol Reduction in Schools).

Alcohol Reduction in Schools							
Alcohol Reducti in Schoo	×	×>	×	×	NR	×	ge and
Smoking in Ethnic Minorities	/x	×	×	NR	NR	NR	loped knowled
Healthy Eating Middlesbrough	×	×	×	×	NR	×	on-making; C, deve t: NR. not reported.
Smoking in Schools	`	`	NR	`	NR	NR	n health decisi Is developmen
Smoking Fag Ends	>	`	`	`	NR	`	engagement i d personal skil
Healthy eating 'Body and Soul'	`	`	`	`	NR	NR	health; AE, active 'S, knowledge and
Healthy eating Aboriginal Australians	>	×	>	>	NR	`	<ul> <li>positive outcome; x, negative outcome; ADV, engagement in social action/advocacy for health; AE, active engagement in health decision-making; C, developed knowledge and carability: HB, changed health behaviours and practices; HO, improved health outcomes; KPS, knowledge and personal skills development; NR, not reported</li> </ul>
Healthy Living Older People	>	`	`	`	NR	NR	gement in soci
HIV Safer Sex	>	>	NR	>	×	×	DV, enga d practice
Diabetes Sharing Stories	`	>	>	NR	NR	×	ve outcome; A behaviours an
Breastfeeding	`	`	`	`	`	×	outcome; <b>X</b> , negativ B, changed health
Outcome	KPS	AE	U	HB	ADV	ОН	<ul> <li>, positive c</li> <li>capability: H</li> </ul>

TABLE 6 Summary of HL intermediate and higher-order outcomes

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Programmes with positive outcomes appeared to incorporate active engagement including:

- *Community engagement* Engaging with local and respected organisations to develop the programme; engaging with community members to provide the service.
- Social engagement Engaging with the PSs; talking to others, developing trust and building relationships; drawing upon the experiences of others to further one's own learning and coping strategies.
- Engaging with information Looking for more information on health; developing an understanding of information through discussion and narrative.
- Engaging with systems Accessing health services for screening, prevention and treatment.
- Engagement with other health-promoting initiatives.

The clusters that included negative processes indicated:

- Lack of CE This was exhibited in the Smoking in Ethnic Minorities cluster, for which outreach workers were able to establish rapport but, subsequently, referred people to disengaged community organisations.
- Lack of social engagement For example, recruiting PSs who were not known to the community.
- Limited social engagement Characterised in the HIV Safer Sex cluster, in which supporters were comfortable in discussing testing for health risks but not safer sex behaviour. Those who had repeated contact with a supporter reported that they were more likely to take up advice, which may indicate that PSs who were previously unknown to the community may be able to influence if additional time is given to developing relationships. Similarly, in the Smoking in Ethnic Minorities cluster people who were originally disengaged came back at a later date for advice, indicating that time allotted to engage with participants (and time period for the evaluation) may be key in interpreting effectiveness.

Social engagement increased knowledge and skills but not active engagement with the intervention itself. This was found in the Aboriginal cooking cluster, for which the advice and recipes were culturally inappropriate for the community. Despite the negative mechanisms that were triggered by providing unrealistic advice, the group still reported engagement in healthier behaviours overall.

## **Relating organisational activities to peer-supporter outcomes**

Some of this engagement was concerned with the way in which the sponsoring organisations related to the communities in which the intervention was going to be based, whereas other engagement occurred between PSs and participants. There appeared to be stages of engagement that extended from programme development through to implementation (*Box 3*).

#### BOX 3 Stages of engagement across organisations, PSs and participants

- 1. Initiate contact with stakeholders to develop the programme.
- 2. Initiate contact with potential PSs.
- 3. Train PSs and providing support.
- 4. PSs reach out to community members and enrol participants.
- 5. PSs interact with participants over the short term.
- 6. Interaction is sustained.
- 7. Participants engage with the intervention.
- 8. Participants engage with health services.
- 9. Participants engage with other health promotion activities.

We therefore split the programme theory into two, representing the relationship between organisational activities and the outcome of producing qualified PSs as the first half of the theory (steps 1–3, above). The programme theory for these steps is presented in *Figure 12*.

Each activity appeared to be related to a process that had the potential to trigger mechanisms that would either enable people to become effective PSs or constrain them from being effective. For example, if the sponsoring organisation's activities followed the process depicted in the bottom row of boxes (see *Figure 12*) then it was likely that people would be enabled to deliver effective support. These stages contained hidden mechanisms that could provide clues to how and why people became more capable in some situations but not in others.

# Relating peer-supporter activities to capabilities and health literacy

When peer support is provided, active engagement in health decision-making is encouraged, with an intermediate outcome of developed knowledge and capability. We were interested in exploring the concept of developing capability because there has been interest over the past 5 years in conceptually integrating the social determinants of health as conceptualised in health research, with the concept of capability in the context of social justice.<sup>104</sup>

The capabilities approach frames health and well-being as having opportunities to do what a person chooses to do and to be what they value.<sup>105</sup> A central tenet of the model is the concept that people should have the freedom to achieve well-being. This is directly related to social justice in health and the right to be capable of being healthy.<sup>106</sup> Peer support may motivate people to reflect on their circumstances. Out of this interaction and action arises what is called a 'capability set'. The capability set includes:

- What people are entitled to In this case, health and well-being.
- What people can do What they are endowed with, in terms of HL.
- What people can get How people can use their interactive and critical HL to improve their health and well-being.

Surrounding this set are the broader social and material conditions that individuals must deal with when trying to achieve health and well-being. In theory, peer support aims to improve HL with the aim of increasing agency – the ability to interact with the surrounding material and social conditions to get what one is entitled to in terms of health.

At present, the capabilities approach is not a fully developed theory – it has been described as a model or a partial theory.<sup>104</sup> We felt that it was important to use this model as a device for examining whether or not peer support could promote capability, particularly in relation to dealing with conditions that create health inequalities.



FIGURE 12 Relationship between organisational activities and PS outcomes. KPS, knowledge and personal skills.

A capabilities template (*Figure 13*) was used to explore potential relationships. In the template, context is defined as the broader political, policy and social environment, and social conditions surrounding the programme.

Political and policy aspects include national drivers for focusing on health improvement, and political attitudes towards those drivers, which can be manifested as the amount of system support.

The presence of existing social networks within a community, and the amount of social isolation versus cohesiveness and trust may also interact with the programme. Finally, the design of the programme in the sense that it either enables or restricts a responsive and opportunistic approach to needs – may either work with aspiration and peer support or dilute effectiveness.

The endowments of participants at baseline, in terms of what they 'bring to the table' interact with the context and the peer support. This gives rise to mechanisms – psychological, social, cognitive and other processes – that either incline people to consider their health situation or render them unready to deal with it. This template was applied to the programmes and discussed with members of our Advisory Network. Several interesting insights arose from this process.

Aspirations In the programmes, aspirations were often reflected as the opinions or views of the researchers and sponsor organisations rather than reflecting a process through which people were helped to identify what they would like to do. The Advisory Network, in contrast, unanimously focused on establishing a facilitating relationship through which people were engaged in reflecting on what they would like to be able to manage.

Attributes Physiological and psychological abilities in some of the programmes had already been defined before the intervention was developed. In contrast, the Advisory Network thought that finding out what people were currently capable of doing was part of the peer-support process.



- Health literacy: functional; critical; interactive; ability to access, understand, interpret information; judge its relevance; make informed decisions about how to improve
- Agency: individual or collective ability to act on and achieve what I/we would like to be capable of

FIGURE 13 Exploring relationships between context, mechanisms and capabilities.
*Social networks* The relevance of social networks was largely ignored in the programme literature, whereas the Advisory Network practitioners explained how they routinely spent time finding out if people were connected.

*Type of peer support* When the programme literature focused on providing informational support as a key component, which was often provided early in the peer/participant encounter, Advisory Network practitioners described many scenarios in which information was offered at a later stage, after aspirations had been identified and when people were ready for it. The conceptual analysis that we used to initially define peer support stated that 'the literature clearly demonstrated that peer support primarily occurs without the provision of instrumental support'.<sup>1</sup> Our Advisory Network, however, agreed that instrumental support was essential when working with marginalised and vulnerable groups.

The findings from the Advisory Network discussions of capability were summarised as user-friendly documents and diagrams, and fed back to members for further discussion. This produced a list of components that are present in peer support (*Box 4*). The components illustrate the importance of establishing connections first, describing a situation in which personal information relevant to the encounter is shared. This places the relationship on an 'equal footing' from the start, laying the foundation for participatory parity.

The principle of homophily is emphasised in the programme literature, but the Advisory Network stated clearly that skills in making connections and establishing relationships were equally as important as similar characteristics, and, in some cases, relationships could be developed based on an interest in differences between supporter and supported.

# Theory of change for peer support and health literacy

The theory of change which emerged from the programme analysis and discussion with the Advisory Network proposes that if PSs are recognised as similar to participants then participants will be willing to initiate some engagement with them, consider health messages and their feasibility, and develop capability for behaviour change – demonstrating improved HL, change in HB and longer-term improvements in health outcome. These mechanisms are dependent upon the PSs' ability to deliver flexible and tailored support that is appropriate to needs, establish rapport and develop a trusting relationship with participants (*Figure 14*).

#### BOX 4 Advisory Network components of peer support

- Establishing a connection; sharing a bit about yourself.
- Finding common ground.
- Active listening to get a picture of the entire situation: problems, challenges, social networks.
- Finding out what the client or patient needs.
- Providing encouragement for clients to reflect on what they would like to be able to do (aspirations).
- Looking at what the client is currently capable of.
- Setting small and realistic goals.
- Reviewing progress; affirming frustrations; celebrating achievements; dealing with setbacks (affirmational, emotional support).
- Showing people how to do things and going places with them (practical support).
- Offering information opportunistically, on an as-needed basis.



FIGURE 14 Relationship between implementation activities, capability and outcomes. HO, health outcome.

The exercise flagged up potential interactions between context and mechanisms that could affect implementation, which included:

- acceptability and appropriateness of the intervention
- degree of engagement with communities in exploring need
- nature and degree of partnership
- control when shaping the programme theory
- allowing flexibility in delivering the intervention
- cohesiveness of social networks.

Acceptability and appropriateness were potential issues if the programme aspired to a particular behaviour change that conflicted with the personal attributes or aspirations of participants. Aspirations therefore seemed to be related to *control*, in terms of who shaped the theory of change for the programme. *Engaging with communities in exploring need* for the programme appeared to be a significant factor influencing acceptability and appropriateness.

The nature and degree of *partnership* was identified as another factor that could influence success of the intervention. Degree of partnership varied, with some programmes representing an 'internal' partnership, for which PSs worked in the health services, receiving referrals from providers as in the Diabetes Sharing Stories programme. Alternatively, PSs conducted outreach and referred people to providers, as in the case of some smoking programmes for ethnic minorities. Cross-programme partnerships were encouraged in the UK Infant Feeding initiative, for which there were linkages and mergers between breastfeeding programmes located within health services and peer-support programmes located in the community. In contrast, the Smoking Fag Ends programme worked independently instead of partnering with the health system because the community organisations felt that health organisation presented negative messages.

Partnership and control also appeared to be related to the degree of *flexibility* that the organisation allowed in delivering the intervention. Some organisations allowed peers to use their tacit knowledge to tailor interventions. Other organisations, such as the Aboriginal and Ethnic Minorities programmes, included inflexible materials and delivery, which seemed to be associated with poorer HL outcomes.

The cohesiveness of social networks in communities varied and this appeared to pose a challenge for PSs. In the case of HIV, for example, people in the social network had loose ties but it was common for people to float from one venue to another. The Smoking in Ethnic Minorities communities appeared to contain some sort of inter-relatedness, as young people who were smoking were afraid of coming into contact with members who knew them. Diabetes Sharing Stories, Smoking in Schools, and Smoking Fag Ends worked within cohesive networks, for which PSs were able to work in existing community groups of which they were already a part. The Aboriginal Healthy Eating programme had a different configuration, for which people were part of a community of ethnicity and place but were 'going outside' their community to attend a cooking class. The PSs were theoretically located within the communities where they worked

(*Table 7*) but closer examination indicated that they were not recognised as known members of some networks. For example in the Smoking in Ethnic Minorities programme peer educators needed to introduce themselves to many people although they were from the same 'community'. Engagement and relatedness to social networks therefore appeared to be relevant to success of the implementation.

# Looking for outcomes related to social action and advocacy for health

Nutbeam's model<sup>15</sup> of HL includes two additional outcomes that can occur alongside improved HL:

- engagement in social action/advocacy for health
- active participation in health decision-making, changing service expectations and practices.

Most of the programmes in the review did not explicitly aim to encourage social action or change service practices. There were indications, however, that in some cases the experiences of people participating in groups were associated with collective agency. We define collective agency in a CE context to be groups working together to develop a shared understanding of issues that affect their health, supporting each other to change HB, and acting collectively to change health services and/or surrounding values, norms and conditions that affect health.

# Acting together to develop shared understanding

When PSs facilitated groups in supporting each other, people were enabled to look things up together, and support each other in taking action. Community-engaged peer support enabled people to collectively access information on the condition, develop an understanding of it, and appraise it through discussion (*Table 8*). Interactive HL occurred as people participated in discussing their conditions, and critical HL was developed by critiquing and making sense of the information with other people.

#### Acting together to change values and norms

There was evidence that PSs in breastfeeding initiatives acted as role models, demonstrating how participants could conquer embarrassment at breastfeeding in public. Willingness to challenge norms was developed in PSs, as a consequence of their training together, as well as in the women who they supported. One breastfeeding participant, for example, said 'I can breastfeed anywhere now, in the park or on a bench in the town'.<sup>107</sup> Some women also related having different interactions with HPs, indicating that they had developed interactive HL: 'I used to take everything the health professional said as gospel. If the doctor said it, then it must be right. Then I figured out (it was incorrect information about teething symptoms) so I actually told him he was talking out his arse'.<sup>108</sup>

Evidence of changing norms also arose from the Smoking in Schools programme, where teachers working with a 'tightly knit' grade 8 community used a Diffusion of Innovations approach,<sup>109</sup> through which students identified those who were perceived to be popular opinion leaders rather than using a top-down form of selection. This sort of engagement was key in finding young people with whom other students would want to engage and demonstrated that teachers were willing to respect students' tacit knowledge, giving them some autonomy in engaging with others: 'The intervention . . . included the peer supporters themselves making pragmatic decisions whether to intervene with the young people whom they identified as potentially susceptible to the non-smoking messages and whom they could have influence over'.<sup>83</sup> This represented an example of allowing a group of PSs to exercise agency, which, in turn, led to a reduction in smoking.

Conversely, the HIV Safer Sex programme – which also used Diffusion of Innovations<sup>109</sup> – did not produce any collective agency. The original mechanism was envisaged to be community selection of popular opinion leaders, from involving gay men frequenting bars in Glasgow. This form of recruitment proved unsuccessful, and the project leads had to resort to recruiting people themselves. Individual agency was demonstrated in terms of an increase in gay men attending sexual health clinics for hepatitis B and HIV antibody testing, but the original aim to diffuse messages about safer sex, enabling collective agency, was not realised.

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Cluster	Problem	Receiver: target population characteristics	Existing or created social network	Setting	Sender – peer characteristics matched on:	Embedded within vs. outside community	Message content: standard/ tailored/ codesigned	Delivery: individual or group	Created by:	Length (years) <sup>ª</sup>
Breastfeeding	Low breastfeeding uptake; high breastfeeding discontinuation	Prepartum and postpartum women	Created	Community and hospital	Age; breastfeeding experience	Within	Standard; tailored	Group	۵.	7
Diabetes Sharing Stories	Poor English language skills; poor HL in own language	Adult ethnic community members with diabetes, established and newly diagnosed	Existing; created	Community	Bilingual; fluent in participants' language	Within	Codesigned	Group	Sd .	7
Healthy Living Older People	Transitional and chronic stressors of becoming older	Older people; male and female who need assistance with health promotion	Existing; created	Community	Age	Within	Tailored; codesigned	Individual; group	P: PS	7
Healthy Eating 'Body and Soul'	Health inequalities higher cancer incidence and mortality	African American people. Churches were the focus because of their importance within African American communities	Existing	Community	Fellow church members	Within	Codesigned	Individual; group	Sd .	<del>~</del>
Health Eating Middlesbrough	Growing levels of obesity, inequalities in health	Adults living in low socio-economic areas of Middlesbrough	Created; existing	Health service drop-in centre, participants' homes, local community centres, university building	No match due to poor recruitment – undergraduate university students were recruited	Within – although the 'community' was defined by locality and the shared characteristics were therefore perhaps limited	Standard	Individual	۹	<del>~</del>

TABLE 7 Intervention characteristics by programme

Cluster	Problem	Receiver: target population characteristics	Existing or created social network	Setting	Sender – peer characteristics matched on:	Embedded within vs. outside community	Message content: standard/ tailored/ codesigned	Delivery: individual or group	Created by:	Length (years)ª
Health Eating Aboriginal Australians	Diets high in fat and carbohydrate and low in fruit and vegetables; inequalities in health	Aboriginal Australians with diabetes, and their families	Created; existing	Local health centre	Cultural background, ethnic origins	Within	Tailored	Group	P; PS	ŵ
HIV Safer Sex	Low uptake of sexual health services; high rates of risky behaviour	Gay men all ages	Existing	Gay bars	Popular opinion leaders; sexuality	Within	Tailored	Individual; group	S S S	-
Smoking in Ethnic Minorities	High rates of smoking	<ol> <li>Urban African American adults, churchgoing population;</li> <li>Latino low- income female and male adults;</li> <li>Pakistani and Bangladeshi male adults</li> </ol>	Created; existing		Community- based stop smoking advisors; same language for PS; ethnicity, religion	Within	Codesigned; tailored	Group; individual	۹	7
Smoking Fag Ends	High rates of smoking	Adult smokers	Existing	Community	Ex-smoker volunteers	Within	Codesigned	Individual; group	U	18
Smoking in Schools	Smoking health promotion	Year 8 students	Existing	Secondary schools	Fellow students in Year 8	Within	Standard	Individual; group	٩	m
C, Community; a Point in time b Retrospective <b>Note</b> See Appendix 2	C, Community; P, Professional. a Point in time when evaluation was conducted. b Retrospective qualitative evaluation. <b>Note</b> See <i>Appendix 2</i> for detailed information and refe	C, Community; P, Professional. a Point in time when evaluation was conducted. b Retrospective qualitative evaluation. <b>Note</b> See <i>Appendix 2</i> for detailed information and reference material for each cluster.	erial for each	cluster.						

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	Ability to:					
Disease prevention	Access information on risk factors	Understand information on risk factors and derive meaning	Interpret and evaluate information on risk factors	Judge the relevance of the information on risk factors	Change in HB	Change in health outcome
Diabetes Sharing Stories	Attendance at group Suggestions for ways to negotiate health systems	Development of meaningful knowledge through sharing of stories	Looking up information together Exchanging tacit knowledge relating to diet, physical activity,	Supporting each other in terms of taking action	Groups all decided to include some health activities, such as organising walks or chair-based	Highly significant difference in Patient Enablement Score between intervention and control groups: 8.3 PE intervention, 5.9 PE control; <i>p</i> -value 0.002 No significant change in UKPDS score, HbA <sub>10</sub> cholesterol, systolic blood
			selt-monitoring and managing medication		exercise	pressure or total well-being
HIV Safer Sex	Peer opinion leaders made themselves available to	Peer educators reported it was easier to talk about sexual health		Intervention was successful in increasing uptake of hepatitis B vaccination and HIV testing among	Failure of the intervention to effect sexual	Sexual health awareness higher among contact men in general
	disseminate information	than safer sex behaviour		those men in Glasgow who reported direct contact with GMTF	behaviour change	Failed to identify any demonstrable community-level intervention effects on five key sexual HBs, including HIV risk-related behaviours

	е	r in ol schools at after fferences ker in th control	% Cl 0.59 (95% Cl ant)	dds of an ared with	ained ained	es Study.
	Change in health outcome	Smoking prevalence lower in intervention than in control schools at all three follow-up points after adjustment for baseline differences Odds ratio of being a smoker in intervention compared with control	group: at 1 year-0.77 (95% Cl 0.59 to 0.99); at 2 years-0.85 (95% Cl 0.72 to 1.01) (not significant)	A 22% reduction in the odds of being a regular smoker in an intervention school compared with a control school	Average of 32% of clients (between 2001 and 2004) who achieved 4-week quit remained smoke free at 52 weeks	Kingdom Prospective Diabete
	Change in HB				Annual average of 57% of clients successfully abstained four consecutive weeks; at least 70% validated using CO monitor	element; UKPDS, United F
	Form a reflected opinion on health issues					Cl, confidence interval; CO, carbon monoxide; GMTF, Gay Men's Task Force; HbA <sub>1c</sub> , glycated haemoglobin; PE, patient enablement; UKPDS, United Kingdom Prospective Diabetes Study.
	Interpret and evaluate information on health-related issues				Service customised for each individual, based on initial needs assessment session	ask Force; HbA <sub>1c</sub> , glyca
	Understand health-related information and derive meaning				Received information from positive, relevant role models from within their own community – 'people like us'	noxide; GMTF, Gay Men's Ta
Ability to:	Update oneself on health issues	Informal channels of information exchange and peer influence outside the classroom to discuss smoking			Variety/quantity of drop-in locations at which individuals can access help	e interval; CO, carbon mor
	Health Promotion	Smoking in Schools			Smoking Fag Ends	Cl, confidenc

Supporters described how they try to put people in control at the outset, through active listening and mutual reflection on the current situation and what the client would like to change. Again, this is very different from a public HL model in which the aspirations are set by the policy or the programme rather than the community. Another major difference in emphasis was the provision of practical support. The concept analysis that we originally used for our review by Dennis<sup>1</sup> states that in terms of practical help 'the literature clearly demonstrated that peer support primarily occurs without the provision of instrumental support'.<sup>1</sup>

The Advisory Network members had numerous stories and examples of how peer support helped people to become capable; learn how to access information and resources for themselves; and become part of networks in which they could make sense of information and decide its relevance. These descriptions concurred with reports that had been commissioned by members of the Advisory Network to inform their programme theory. Further, some of the reports published on the projects demonstrated marked benefits for HL, as well as documenting health outcomes.<sup>110–117</sup>

Interestingly these reports contain a wealth of information on the process and intermediate outcomes that explain success, whereas the small number of empirical studies documenting higher order outcomes does not.<sup>111,112</sup>

# Summary of within-programme analysis

The within-programme analysis was conducted using several different tools and approaches, which included:

- scoping of the stated programme theories via extraction of references from the included studies
- mapping intervention characteristics to obtain an overview of settings, populations, PS characteristics, degree of tailoring of messages, and degree of cocreation
- articulating theory through in-depth review of each programme
- plotting health promotion and health education outcomes as HL outcomes
- relating organisational activities to the enablement of effective peer support
- drafting a programme theory for peer support and HL.

The incompleteness of reporting (as demonstrated in *Tables 6* and *8*) prevented aggregative analysis of the relationships between HL, HB change and outcomes, indicating that a more configurative approach was required.

A different way of combining data was needed in order to confirm or refute some of the potential relationships between peer support, HL and HB. The next stage of analysis therefore focused on combining the data across programmes and analysing it by stage of programme development and implementation.

# **Chapter 4** Cross-case analysis and synthesis by stage of programme development

# **About this chapter**

The emerging programme theory was further developed by conducting cross-case analysis in order to identify patterns for peer-support programmes. As noted in the previous chapter mechanisms and outcomes were operating on two different levels: the level of organisational engagement with communities in designing the programme and the level of implementing peer support with participants in communities. This chapter describes how data were synthesised at the organisational level; *Chapter 5* describes how data were synthesised for the peer-support interventions. Organisational engagement was analysed by stages of programme design, recruitment and training, an approach that has been used in other realist reviews.<sup>118</sup> Rather than seeking a single explanation for how CBPS works to promote HL, we sought demi-regularities, for example a range of regularly occurring mechanism–outcome configurations that were either constrained or enabled according to variations in context.<sup>58</sup> Cross-case analysis was conducted by using a data extraction template for each respective stage of the programme. Based on the data reported, four stages were identified: programme design, recruitment of PSs, training of PSs, and implementation of peer support (see *Appendix 5, Data extraction template for programme stages*).

A definition for each programme stage was constructed based on the data reported in the clusters. The definitions were then piloted on a subset of context–mechanism–outcomes (CMOs) to produce a final definition and list of components for each stage. Each team member took responsibility for populating a stage with the programme data and developing propositional statements explaining relative success or failure. The 'stage documents' were then read through by the team and subjected to multiple iterative comparisons with programme CMOs to arrive at the main propositional statements for CBPS and HL. The propositional statements for each stage are presented in the next section. The chapter concludes with a discussion of the emerging patterns in terms of how organisational context influenced design of the programmes.

# **Stage analysis**

Each stage includes:

- a stage definition presenting a general overview of the activities in the stage
- definitions for what we refer to as 'components' of the stage, for example the common activities or challenges to completing activities
- propositional statements explaining how and why activities either achieved the desired result or failed
- supporting data illustrating the evidence base for the propositional statements.

# Stage 1: designing the programme (stage lead JT)

#### Stage definition

This stage concerns the elements that make up the design process for the peer-support programme. This might include stakeholder involvement (who was involved in the design process, how they were involved, where involvement took place and at what stage?); cultural needs assessment to understand the contextual factors impacting how the programme might be designed and delivered; and understanding broader policy and/or organisational contexts (e.g. managing staff attitudes towards peer support, aligning programmes with national policy initiatives, organisational planning and support).

For the purposes of this review, the design stage is considered to end once the programme begins, people are recruited to the programme and the training of PSs has occurred.

#### Stakeholder involvement in designing the programme

#### Component definition

Stakeholder involvement is defined as the active involvement of key people in the peer-support *design process*. The term 'stakeholder' may include:

- those receiving the peer-support intervention
- their wider family/community
- those delivering the intervention, and
- people from the setting in which an intervention is delivered.

*Propositional statement* Involving PSs and/or peer-support participants as part of the team in the development of peer-support interventions leads to interventions being more relevant to participants needs, and creates a sense of ownership by those delivering and receiving the intervention.

Only a small number of the clusters reported active involvement of stakeholders in the design of programmes. Methods and levels of stakeholder involvement varied. The Diabetes Sharing Stories programme<sup>79</sup> and a project within the Healthy Living Older People cluster<sup>119</sup> reported using action research, whereas another project reported working with a stakeholder steering committee to guide the programme development process (Smoking in Ethnic Minorities). The Diabetes Sharing Stories cluster<sup>79</sup> described development of their programme using action research processes, working with staff who would deliver the peer-support programme (in this case, bilingual health advocates). The authors of the Diabetes Sharing Stories programme argued that action research led to 'progressively changing the focus of activity in response to participants' needs and priorities . . .<sup>79</sup> Similarly, authors from the Smoking Fag Ends cluster reported that support materials for the programme were developed by volunteers with the assistance of their participants,<sup>120</sup> whereas the authors from the Healthy Living Older People cluster reported that PSs were involved in developing the training manual for each peer educator. Within this cluster it was argued that: 'Success of the programme, from the point of view of the participants, was due to the content of the learning being chosen by the participants and not imposed by the facilitator'.<sup>121</sup>

Findings from the Diabetes Sharing Stories<sup>79</sup> and Healthy Living Older People clusters<sup>80</sup> suggest that involvement in the planning stages can engender a greater sense of ownership by those delivering and receiving the peer-support intervention, and this could be a factor in encouraging participants to continue their involvement with peer-support interventions. The authors of the nutritional programme for Aboriginal Australians also described that culturally appropriate and accessible interventions can be developed only through community control of the programme or extensive community consultation.<sup>122</sup>

Support for the proposition that involving stakeholders at an organisational level in the development of a peer-support intervention through regular updates and dialogue leads to the intervention being more easily embedded within existing service provision:

- Authors of the Diabetes Sharing Stories programme discussed how the project team engaged with the wider NHS organisation when developing and trialling the intervention. They provided regular updates within the governance and leadership structures of the Trust. They argued that this ensured that the peer-support intervention was welcomed as part of a multidisciplinary approach to diabetes care.<sup>79</sup> This would suggest that stakeholder involvement at an organisational level can lead to interventions being more easily accepted within mainstream provision. Building on this, data from the Advisory Network meetings suggested that building partnerships with other organisations can help to maximise the reach of peer-support programmes and can result in additional resources, expertise or facilities being made available for beneficiaries.
- When stakeholders are not involved, problems can be encountered in terms of embedding peer support into existing services. In the breastfeeding programmes, for example, HPs 'lacked confidence in their breastfeeding support and interpersonal skills'. As a result, 'They tended to resist or avoid engagement with the peer-support projects. . . . It becomes clear therefore that health professional's educational needs must be addressed concurrently with development of peer-support programmes'.<sup>123</sup>

#### Cultural needs assessment

# Component definition

Understanding the wider cultural context in which a programme would be delivered was discussed by several authors. Cultural context may include understanding local practices and cultural norms and beliefs, and organisational and community attitudes and values, barriers and facilitators to embedding the peer-support programme. Data from some of the clusters strongly suggested that programmes that were developed with cultural needs in mind aided the development of *trust*, which was central to the acceptance of the programme: 'It's about building the relationship, building the rapport and as soon as they see that okay this person is here for my benefit then they will start opening up. This is how our culture works'.<sup>124</sup>

*Propositional statement* When cultural needs assessments are conducted during the design stage, the design team are able to gain greater understanding of local practices and potential constraints to behaviour change that may lead to interventions that are better targeted to local needs.

For some of the clusters a cultural needs assessment was an explicit exercise. For example, within the breastfeeding cluster some project teams undertook local cultural needs assessments (including interviews with members of the community) to understand cultural beliefs relating to breastfeeding and in particular how they may impact upon the way in which the programme was delivered. Cultural assessments enabled teams to develop insight into how and why local practices had developed, and what constraints might exist in adapting and changing behaviour in line with the programme aims. For example, when exploring cultural beliefs within the Breastfeeding cluster, it was reported that 'the local community had very few breastfeeding role models and a bottle feeding culture predominates'.<sup>107</sup> Authors from the breastfeeding cluster reported that project teams that did not undertake cultural needs assessments came across difficulties during implementation stages. This suggests, in the context of the breastfeeding cluster, cultural needs assessments are an important initial aspect of the design process.

Authors of other clusters highlighted that needs assessment helped them to develop culturally appropriate materials, for example in programme participants' own language:

The sharing stories model was developed specifically to address the needs of limited English speakers with diabetes living in deprived inner city areas.<sup>125</sup>

... the curriculum was modified to address several cultural–linguistic barriers for the Latino community [and] written and delivered in the Spanish language appropriate for ... low literacy individuals. Communication style and values congruent with the Latino culture were also considered, including: familismo; collectivism; simpatía; personalismo; and respeto.<sup>126</sup>

*Propositional statement* When cultural needs are taken into consideration during the design stages of peer-support interventions, via formal or informal assessments, programmes are better aligned with community values, increasing the potential that they become embedded in social practice.

Addressing cultural needs helped to ensure that peer-support programmes worked with community values rather than against them. This increased the likelihood that programmes would become embedded within usual social contexts. Authors from the nutritional programme for the Healthy Eating Aboriginal Australians cluster argued that the cultural targeting of the course was considered crucial to its success.<sup>122</sup> The participants knew other students would be Aboriginal and cultural appropriateness was increased by using an Aboriginal teacher supported by Aboriginal health workers. Essentially, addressing cultural needs suggests a shift in power from a 'top-down' approach to providing interventions to a 'bottom-up' approach. This aligns with Nutbeam's assets-based model for HL.<sup>15,16</sup> For example, authors of the Diabetes Sharing Stories cluster explained how the intervention built on common cultural beliefs, attitudes and behaviours – rather than trying to 'remedy deficiencies',<sup>79</sup> whereas authors of the Breastfeeding cluster stated: 'Bottom up changes in the service model places emphasis upon understanding the local culture and implementing change in a creative, systemic and culturally sensitive way'.<sup>127</sup>

However, although accounting for cultural needs was a central element of many of the clusters, within the nutritional programme for the Healthy Eating Aboriginal Australians cluster the importance of tailoring programmes to individual needs was highlighted.<sup>122</sup> Although the programmes were designed to target a specific group (defined by ethnicity) and the recipes were designed with culturally appropriate foods in mind, individual barriers (such as the cost of healthy foods) were not always accounted for. The danger is that 'culturally sensitive' might mean that individually tailored is lost.

#### The peer-support programme setting

#### Component definition

The setting for delivery of the peer-support programme is closely linked to cultural needs assessment – understanding where a programme would ideally be delivered based on venues that were considered to be trustworthy/well used/credible/comfortable by the targeted recipients of the peer support.

*Propositional statement* When peer-support recipients trust the venue that is chosen, they are more likely to attend the programme.

There was some variation among the clusters concerning peer-support programme settings. Some programmes were bound by the institutional setting. For example, the Smoking in Schools programme was delivered within the school setting,<sup>128</sup> whereas the Breastfeeding cluster was delivered both within the hospital and in community settings, often via breastfeeding drop-in centres. It was argued that the most successful models of drop-in centre associated with the breastfeeding peer-support schemes were located in a venue 'that was both acceptable and accessible to the target group of women ... When the drop-in venues and times linked with other activities, for example a baby clinic, they were particularly

well attended'.<sup>123</sup> Authors of other clusters suggested that programmes worked most effectively in non-health, non-institutional settings. For example, for the Smoking Fag Ends cluster identified local venues based on travel links, indications that a venue was well used, and used this community intelligence to ensure that venues were often chosen 'where local people felt at home – usually in a non-health setting such as community centres, social clubs, pubs or churches'.<sup>120</sup> Venues were chosen with a view towards maximising opportunities for dialogue. Within the clusters, 'successful venues' were often identified as either places with which peer-support recipients were already familiar and utilised (e.g. a social club)<sup>79</sup> or places that encapsulated authority and credibility (e.g. a church setting, such as that used in Smoking in Ethnic Minorities): 'The church's acknowledged leadership role in the African American community and the trust that churches engender make churches promising venues for health-promotion programs'.<sup>129</sup>

Institutional settings present both advantages and disadvantages because they embody their own sets of norms about behaviour. For example, the taboo nature of smoking within religious communities may have actually prevented some potential participants from taking part: 'As articulated by the three pastors on the steering committee, strategies that included "acceptance of the sinner but not the sin" were critical to the successful implementation of the smoking-cessation programme. However, the negative perception concerning smoking may have been a barrier for recruitment and participation'.<sup>129</sup>

Despite the fact that smoking was not prohibited in some church settings, 'some church members were embarrassed by their smoking behaviour and others did not want to identify themselves as needing help. Some individuals did not wish to participate in programs that were developed and delivered by fellow church members'.<sup>129</sup>

Conversely, some settings do not support initiatives because they conflict with norms: 'Although most churches provide an excellent venue for health promotion, smoking as the target health problem was controversial, since in some denominations, such as the Baptist church, smoking is proscribed'.<sup>129</sup>

In some cases, however, use of an existing social setting may not increase participation because the activity is not seen to be congruent with the setting. Using gay bars to promote safer sex, for example, was not effective in the Glasgow Gay Men project, with the gay community in Glasgow 'representing a relatively closed social environment . . . Some men described the scene as being tribal, or based around clans or . . . families'.<sup>81</sup> Assumptions that pre-existing social settings will automatically contain cohesive groups need to be questioned because routine attendance at certain venues does not mean that people who attend are part of the same social group: 'Participant observation had shown that each venue had its own distinct regulars but also significant numbers of men travelled from one bar to the other throughout the evening reaping the benefits of each venue's happy hour, for example'.<sup>81</sup>

Settings not only embody their own norms, but also have particular routines that may or may not accommodate peer support. One smoking cessation programme was located in secondary schools, where support activities can be integrated with daily routines.<sup>128</sup> Conversely, settings that require activities to conform to existing routines – such as some of the breastfeeding programmes that were reviewed – can constrain the ability of PSs to gain access and implement support.<sup>127</sup>

# Logistical planning and project support

#### Component definition

Logistical planning and project support included consideration of the help needed with child care, travel expenses, language barriers, setting and organisational factors (such as attitudes, funding, resources, etc.). Logistical issues may be identified through formal cultural needs assessments or pilot work.

*Propositional statement* Greater participation is enabled when logistical barriers to attending a peer-support programme are identified and addressed during the initial design phase of the programme.

Participants attending the Advisory Network sessions spoke, at length, about the importance of addressing logistical barriers to peer support. Providing child care, paying travel expenses, holding sessions outside core working hours and facilitating access to free or subsidised courses or activities were all issues raised by Advisory Network members.

The nutritional programme for the Health Eating Aboriginal Australians cluster reported that the provision of free transport to the facility promoted attendance to the cooking course and enabled participants to make use of other health facilities at the primary care centre.<sup>122</sup>

When needs assessments were conducted, programme designers found that peer-support workers were needed who could offer support in native languages. Programmes that specifically tailored for individuals with limited English language reported increased participation.<sup>79</sup> In contrast, when local services did not accommodate language barriers limited uptake was reported, despite attempts by bilingual outreach workers who offered to accompany participants with limited English and translate for them.<sup>124</sup>

Organisational support was mentioned by authors of some clusters, as central to establishing programmes. For example, in the Diabetes Sharing Stories programme: '... most [bilingual health advocates] held low status positions in complex multiprofessional hierarchies and had neither the authority nor the resources to set up and run such groups ... for example an advocate might not be allowed to telephone a nurse without going through a manager'.<sup>79</sup>

The PSs were very dependent upon professional staff in the broader NHS context to 'buy in' to the initiatives, and 'in some cases there was palpable resistance from middle management to what was seen as a radical new service model'.<sup>79</sup> When there was a lack of support from management, it was difficult for groups to become embedded in the service model.

Similarly, the authors of the Breastfeeding cluster highlighted the importance of understanding the 'prevailing power structures' in order to manage institutional resistance to establishing peer-support programmes. Authors of the Breastfeeding cluster stated: 'Senior managers must anticipate resistance when staff see support programmes as a radical new service model. There is 'the need for continual reinforcement among health professionals of the potential benefits of a scheme ....'.<sup>108</sup>

This was addressed by liaison midwives working with colleagues to facilitate acceptance of the volunteers and reduce the potential for opposition from colleagues.

*Propositional statement* Aligning peer-support programmes with national policy and advertising campaigns maximises organisational support and helps programmes to become embedded within existing provision.

Aligning programmes with broader national policy initiatives and advertising campaigns was suggested as one way to ensure organisational support. For example, the Smoking in Schools cluster was endorsed by the Healthy Schools Programme.<sup>128</sup> As a result, schools were willing to engage in the trial. Similarly, the UK Feeding Initiative funded breastfeeding programmes to consolidate and expand as part of a national programme.<sup>123</sup> The Smoking Fag Ends cluster built on, and aligned its efforts with,

national activity to maximise marketing and recruitment to the programme: 'I remember a couple of years ago we got wind that nationally there was going to be a campaign which would be targeting mothers of young children . . . what we wanted to say locally was Fag Ends is here to help you if you want to give up smoking'.<sup>120</sup>

# Stage 1: summary and context-mechanism-outcomes for programme design

The propositional statements for the programme design stage, which are summarised in *Table 9*, were used to draft some of the emerging interactions between organisational context and mechanisms. It can be seen that some of the cross-cutting themes concerned organisational involvement with stakeholders, where engagement included partnership working and conducting a needs assessment.

Where these processes were used, engagement could lead to a feeling of collective ownership over the design process. CE therefore offered potential benefits during programme design. Our emerging theory for programme design is that when a wide range of stakeholders are involved in the design stage then partnership working may occur, resulting in collective ownership of the design process and more chance that the programme will become embedded in existing service provision. When a cultural needs assessment is conducted, there is increased understanding of local practices and constraints, leading to a better alignment of the intervention with community values and structures. The engagement process promotes more relevant and appropriate interventions that are better targeted to community needs.

It is important to note that multiple lines illustrating different pathways can be drawn between organisational context – for example, the organisation's willingness to engage – and the mechanisms of increased understanding of the community that is being targeted. For example, an organisation may not involve stakeholders in design at the earliest stages. This was demonstrated in the Breastfeeding cluster, for which the evaluator noted that those who neglected cultural needs assessment found that they had to go back and retrace their steps.<sup>131</sup> It is also possible that intermittent stakeholder involvement is adequate for ensuring relevance but that a lack of shared ownership due to limited contact during programme design has a knock-on effect at a later stage when stakeholders do not have enough buy-in to help with

Components of programme design	CMO configuration
Stakeholder involvement	Involving PSs and/or peer-support participants can lead to more relevant interventions and create a sense of ownership
	Involving stakeholders in the sponsor organisations, through regular updates and dialogue, can lead to the intervention being more easily embedded within existing services
Cultural needs assessment	When cultural needs assessments are conducted during the design stage of a peer-support programme, the design team are able to gain greater understanding of local practices and potential constraints to behaviour change, which may lead to interventions that are better targeted to local needs
	When cultural needs are taken into consideration during the design stages of peer-support interventions, via formal or informal assessments, programmes are better aligned with community values and structures, increasing the potential that they become embedded in social practice
Programme setting	When the peer-support venue chosen is one that the peer-support recipients trust then they will attend the programme
Logistical planning and project support	Greater participation is enabled when logistical barriers to attending a peer-support programme are identified and addressed during the initial design phase
	Aligning peer-support programmes with national policy and advertising campaigns can maximise organisational support, and help programmes to become embedded within existing provision

TABLE 9 Summary of CMO configurations for stage 1: designing the programme

recruiting peer-support workers or participants. The emerging CMO configurations (*Figure 15*) should therefore be read as a partial picture of the final theory. The findings from the programme design stage are compared with later stages of programme development, contributing to the final theory that is presented in *Chapter 6*.

# Stage 2: recruiting peer supporters

# Stage definition

The stage of recruitment includes how PSs are initially contacted and informed about the initiative, their characteristics, the barriers and facilitators to recruitment, the mechanism by which they were recruited, and whether or not remuneration and other incentives influenced recruitment and retention.

# Clarifying the role of the peer supporter when recruiting

# Component definition

Clarifying the role of the PSs includes providing some explanation to potential PSs about what the PSs are expected to learn and what they will be expected to do. The Advisory Network emphasised the importance of clearly defining the community health champion role from the beginning, including both 'what it is' and 'what it is not'. They explained that sharing this information during recruitment gave a clear indication of what would be expected, thereby helping people to make more informed decisions about becoming involved. Although the Advisory Network described this process in, for example, health champion programmes, only one published study reported on the process of orientating potential PSs through the use of a 'taster session', at which an overview of the programme expectations and the training process were provided before people decided to join up.<sup>79</sup>

# Barriers to recruitment

#### Component definition

Barriers to recruitment include personal barriers, such as perceived self-efficacy in terms of delivering peer support. There can also be community barriers such as discomfort with the proposed intervention or general distrust regarding the recruiting organisation.



FIGURE 15 Context-mechanism-outcome chain for the programme design stage.

*Propositional statement* Recruitment (and hence the subsequent success of the programme) may be less effective when potential peer supporters feel uncomfortable about the issues, condition, the prescribed approach to peer support or the objective of improved HL.

Some of our cluster studies noted that certain types of topic, for example breastfeeding and risky sexual behaviour, were particularly challenging for PSs to discuss. In the Glasgow Gay Men project 'emotional issues such as relationships' were considered difficult.<sup>81</sup> The challenges of discussing difficult topics, however, were not specifically related to recruitment in our studies, so there is little evidence directly supporting this statement.

#### Propositional statement Conflicting values within a community act as a barrier to recruitment.

Participant recruitment and participation may not work when the values of the institution hosting the intervention are in conflict with the health issue that is being addressed. For example, smoking is taboo to many church leaders, so potential participants – members of the congregation – are then embarrassed about their behaviour and do not want to identify themselves to the church leaders who are facilitating recruitment: 'However, the negative perception concerning smoking may have been a barrier for recruitment and participation. Some individuals did not wish to participate in programs that were developed and delivered by fellow church members'.<sup>129</sup>

Propositional statement Existing commitments may act as a barrier to recruitment.

The non-existence of a 'large pool of willing and qualified peer educators' was encountered in the nutrition in the elderly study.<sup>118</sup> Responses from participants suggested that they felt already overcommitted: 'Reasons given for unwillingness to participate included being too busy, family responsibilities, lack of transportation to carry out the work, planned vacations, and fear of burglary/ vandalism of their homes during the two two-day periods when they would have to be absent while attending the training workshops'.<sup>119</sup>

A community-based health promotion intervention using brief negotiation techniques to promote healthy eating and physical activity, based in a low socioeconomic area in the UK, also failed to recruit potential 'lifestyle helpers'.<sup>132</sup> The most common reason for withdrawing was reported to be competing workloads.

#### Reasons for becoming a peer supporter

#### Component definition

Reasons for becoming a peer supporter include both intrinsic and extrinsic motivations and rewards. Such rewards may relate to individual growth and development (e.g. in becoming more informed or assuming a more influential position within a community). They may also relate to altruism (i.e. in contributing to the community). Such altruism may be specific to a chosen community or, less conditional, to the community at large. Payment or other incentives may also influence decisions to become a PS.

*Propositional statement* Payment to peer supporters reduces the likelihood of programme failure without necessarily ensuring the likelihood of programme success.

There is evidence to suggest that the role of payment as a reason for becoming a peer is not a symmetrical one. Failure to pay peers may indeed act as a barrier to participation, as for the use of church-recruited lay health workers to promote physical activity and diet to prevent diabetes in the USA.<sup>133</sup> However, payment does not necessarily ensure the success of subsequent participation. The provision of payment specifically for participating in training may relate only to an increased likelihood of completion of training. For example, in schools the incentives for completion were a £10 voucher and certificate of achievement for PSs who completed the trial. PSs responded to their incentive and there was low attrition with most completing the trial.<sup>79</sup>

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Alternatively payment may relate to the core activity of engagement with others in implementing health promoting interventions. Payment of lay health workers for *both* training *and* subsequent leading of health promotion classes was considered a critical success factor in a study focused on the Latino community in Los Angeles.<sup>118</sup>

*Propositional statement* Non-monetary benefits for self and family (or the community more widely) are effective in recruiting peer supporters.

The idea of reciprocity – giving as getting something back – attracted people to the role of PS. Some PSs see their role as a way of contributing to their 'community'; however, they might define it as: 'Beneficiaries wanted to volunteer or 'give something back' to their community . . . some already had specific skills or activities in mind (such as walking, holistic therapies, writing, art, t'ai chi, yoga) others were just keen to try something new or get involved with an AB project' (AB, Altogether Better).<sup>113</sup>

Some participants visualise benefits from their own involvement in terms of access to information or to health programmes. For example:

The health champion involved in this case study wanted some support in getting himself and his family taking part in more regular activity and to encourage other taxi driving friends to become more active.<sup>113</sup>

A key attraction of becoming involved in a nutrition-related peer-led project was that they expected it to involve active learning for themselves – whether that related to the substantive content on nutrition or to the development of the skills required to run a food club.<sup>134</sup>

Most beneficiaries wanted to improve their own and their family's health and wanted information and practical support to adopt a healthier lifestyle.

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Others settle on peer support as a non-specific focus for a general need to engage in activity, whether or not it espouses CE as an explicit value.

*Propositional statement* Older citizens, specifically, have a particular motivation to volunteer in order to maintain an active life.

Peer-led interventions that recruited older PSs appeared to encounter fewer barriers to recruitment. These PSs also appeared to value being able to draw upon their experiences:

The would-be peer educators were highly motivated to engage in the project. Most of them actively sought structured activity in retirement, whether recreational, social or educational.<sup>126</sup>

[Potential peers] were not simply looking for activity in itself, but wished to be positively engaged by something worthwhile and slightly challenging, something not too onerous but nevertheless involving some commitment and carrying some responsibility.<sup>134</sup>

*Propositional statement* A feeling of being singled out for particular attention acts as a motivation to recruitment as a PS.

There was limited evidence in the published studies to suggest that pride in being chosen was a motivation for recruitment: 'PS felt pride in being nominated, "It was novel to miss school for the two training days and the follow up sessions" '.<sup>128</sup>

The Advisory Network, however, included several people who worked as PSs or who had taken on the role in the past before becoming paid health workers. They agreed that 'being valued to be part of it and being trusted to be part of it' was key to becoming a peer supporter (Advisory Network #11) (*Figure 16*).

*Propositional statement* Potential recruits may see involvement in peer support as offering access to social networks.

Social isolation was another important theme, which was extensively documented in Advisory Network discussions and in reports related to Advisory Network programmes. The primary motivation of many beneficiaries for taking part in Altogether Better projects was to meet new people and improve their social networks.<sup>113</sup>

# Recruitment process: who recruited peer supporters and how they were recruited?

# Component definition

The recruitment process includes the development of criteria for selecting peer educators, whether determined by demographic, social or personal characteristics, or a combination of these. The included studies covered a wide range of types of recruitment with variation in how PSs themselves were recruited and also in how they, themselves, might be further used to recruit more PSs or participants to the programmes. In some cases a researcher recruited PSs, for example in one study<sup>121</sup> a researcher encouraged members of the participant group who were willing to volunteer as peer educators (volunteer peer educator, VPE). These VPEs took on the role of instructors for their peer group.<sup>121</sup> In another model, community organisations/networks recruited PSs to act as Elderly Educators from a local Ageing Network and a high-rise apartment for the elderly.<sup>135</sup> Local HPs may also be used to recruit PSs.

Two midwives with an interest in BF [breastfeeding] were attached to the scheme as liaison midwives (LMs). Liaison midwives worked alongside community midwives and health visitors to recruit volunteers. Liaison midwives worked with colleagues to facilitate acceptance of the volunteers, reduce potential opposition from colleagues and provide access to new mothers.<sup>108</sup>

Alternatively other professionals may assume this recruitment role: 'Home economists assumed the responsibility for identifying potential peer educators. They contacted agencies and organizations that



FIGURE 16 Recruitment is a way of valuing and involving people (artwork: Sarah Smizz).

could identify prospective peer educators and then personally contacted suggested candidates, described the program, and elicited the candidates' interest ...'.<sup>119</sup>

Once PSs have initially been recruited they may, in turn, be used to recommend or indeed actively recruit additional supporters: It is 'exceedingly helpful' to select peer counsellors from recommendations made by other peer counsellors or supervisors.<sup>136</sup>

One programme described use of those who have been specifically trained for the role of recruitment:

Recruitment of participants was primarily conducted by trained recruiters, individuals familiar with the targeted Latino community. Eleven trained recruiters worked at community events, popular neighbourhood shopping centres, and within their own social networks to identify Latino smokers ...<sup>118</sup>

These later models are, of course, a short distance away from actively involving PSs in recruitment of participants for the initiatives themselves.

*Propositional statement* Appropriate methods for recruitment of PSs are determined by the cohesiveness of the community that is being targeted.

How PSs are recruited relates to the complexity of defining the community. In cases for which there appears to be a 'community of place', for example when venues such as churches (Healthy Body/Healthy Spirit) or schools (ASSIST) are a natural focus for recruitment. Recruitment in such cases focuses on identifying and recruiting individuals within the network who have credibility as a PS. In cases when the sense of community is more diffuse or less tangible – for example communities defined by demographics – recruitment becomes more complex as potential PSs within the community may not necessarily have relationships with the target group.

*Propositional statement* An inclusive recruitment process may be more credible than one in which there is less community involvement in the process.

In some cases existing organisations or networks may become the mechanism for recruitment. For example, breastfeeding project teams commissioned the La Leche League to provide their peer-support programme and, consequently, in developing a recruitment process for potential PSs.<sup>123</sup> Clearly, such an approach has advantages if the local programme can draw upon its experience and local connections for recruitment, but there may also be potential disadvantages depending on how the local organisation is perceived.

A community could be involved in determining the important characteristics for PSs and/or involved in the actual identification of them. There was some evidence to suggest that a more inclusive process may be required to support the credibility of the recruitment process and subsequent engagement with the community:

The Leicester Health Ambassadors said that the best way to recruit peer supporters is to invite everyone to join [instead of taking recommendations]. It's best to have no rules or limitations about who can join or what you have to do (e.g. not restricted by lack of literacy).

Advisory Network #3

All students in participating schools were asked to nominate those whom they judged to be influential, and the nominated students were asked if they were willing to take on the role of being a peer supporter.<sup>128</sup>

Propositional statement Recruitment is successful when a connection is established with potential PSs.

Many participants placed great importance on the value of 'word of mouth':

People are often frightened of taking part in something that is new to them – they wonder what is expected of me? ... People need to be able to find someone to ask questions of – what do you do, how did you get to do this?

Advisory Network #9

Such communication skills need to be augmented by interpersonal skills involving the positive building of connections:

You need to establish some sort of connection to people who might be interested in becoming peer supporters ... You need to find something in common when recruiting to make individuals feel welcome ... People are often unsure of themselves. To find a common connection is so important ... Building relationships, valuing the potential in others can be an asset that aids recruitment. Advisory Network #9

There were differing views as to whether or not the role was actively to encourage recruitment or simply to present it as an option and then to leave it with the potential recruitee to make up his/her own mind:

Recruitment works in the same way as peer support – when someone is interested in volunteering, give them info and opportunity to ask questions then let them make up their own mind . . . Positive word of mouth can be very effective, there can be better ways to recruit – other means can help people decide about the role and their own participation . . . such as raised awareness locally and citywide to ensure wide reach.

Advisory Network #9

#### What is a peer? Programme criteria for identifying appropriate peers

#### Component definition

Programme criteria for identifying appropriate peers includes the programme designer's definition of the important characteristics when recruiting peers, as well as practitioners' and beneficiaries' perspectives, on the characteristics that need to be sought during recruitment.

*Propositional statement* Criteria for what is meant by a peer need to be appropriate for the programme and context.

Although this may seem like an obvious point, there is no one way for recruitment that is always appropriate. There was evidence that when recruitment strategies were modified and moved away from CE, the process was less successful. For example the Glasgow Gay Men project<sup>81</sup> took the pragmatic step of recruiting and paying men and women to deliver the safer sex and health service messages.

The nature of such compromises may well determine the extent of the success or failure of the programme. Although the original recruitment model was followed initially:

.... This has implications for 'diffusion of innovation' because, although these people were certainly peers in that most were recruited in the bars, and were often recognizable to bar clientele, the 'popular people' model was not replicated exactly.<sup>81</sup>

The Healthy Eating 'Body and Soul' cluster revealed very prescriptive characteristics for recruitment, suggesting that educational and work experience 'qualifications' were being weighted more heavily than role in the community: 'Churches were asked to identify individuals, preferably with a college degree or a graduate-level education and a background in a "helping profession" '.<sup>137</sup>

Those who did not satisfy the initial requirements were screened for their ability to provide support:

... who were willing to attend a training lasting a day and a half, make two intervention calls with at least five church members, and undergo a tape recorded evaluation to determine if they met performance criteria. Volunteer advisors without the recommended education were allowed to attend the training and serve as advisors if they met the competency requirements.<sup>137</sup>

The Elderly Educator project<sup>135</sup> selected from interested applicants on the basis of interpersonal communication skills, further developing qualifications within the training programme:

[In] the Elderly Educator Method ... elderly persons who were used as teachers and as demonstrators in the colorectal cancer presentation ... talked to the participants as group before and after the slide-tape show ...<sup>135</sup>

The approach of selecting on qualifications and interpersonal skills worked for this programme, but may have worked less well when qualifications led the PS to use their professional rather than lay knowledge. For example, in the Aboriginal nutrition intervention,<sup>122</sup> the person providing peer support was actually employed at the technical college as a tutor, who was:

... supported by lay health workers who already had employed positions in these roles. So, although they were chosen because of their 'cultural roots' they had pre-existing roles and these may also have meant that they were no longer considered a 'peer' by the community they were supposed to support.<sup>122</sup>

# **Recruitment of participants**

# Component definition

Recruitment of participants can be done by the sponsoring organisation, the researchers who are setting up and evaluating the programme, partnership organisations, the PSs themselves, or any combination of the above. The recruitment process can influence the likelihood of a community engaging with a particular initiative, both in terms of the coverage of the initiative and in the subsequent quality of interactions. Programmes may have different underpinning rationales that determine appropriate recruitment, for example an initiative may seek to broaden the representation across all sectors of the community, it may identify a target community opportunistically or according to convenience or it may target those perceived to be at greatest risk (from the health problem) or seek to address perceived inequalities.

*Propositional statement* Barriers in recruitment of peer supporters are mirrored in barriers in engaging with participants.

Many barriers to recruitment of PSs are mirrored more widely in difficulties in recruiting participants more generally:

The negative perception concerning smoking may have been a barrier for recruitment and participation. Some church members were embarrassed by their smoking behaviour and others did not want to identify themselves as needing help.<sup>129</sup> However, where the same HB is viewed less judgementally, sharing ethnicity or religion may help to reinforce the success of the programme:

During observations, [outreach workers'] exchanges with potential clients were often initiated through outreach workers expressing their identity. Initial exchanges often involved shaking hands and using the religious expression 'Assalamu alaikum' ('Peace be with you'); thus immediately expressing their religious identity...<sup>124</sup>

#### Stage 2: summary and context-mechanism-outcomes for recruitment

The propositions for recruitment (*Table 10*) both build upon and add to the propositions that were identified at the stage of programme design.

For example, if a cultural needs assessment had been conducted during the programme, it could be assumed that the likelihood of discomfort with the prescribed approach to the intervention would be reduced. The type of interaction during recruitment appears to be important in terms of engaging in some sort of dialogue about roles and expectations, and establishing a connection with people. We propose that this interaction and the perceived acceptability of the intervention are weighed against intrinsic motivators. The quality of engagement, however, may help a person to reflect on internal motivators, as well as assess what sort of relationship they may be embarking on if they agree to participate (*Figure 17*).

Organisations recruited PSs in different ways – in some cases the PSs were recruited as being typical of their community, in other instances they were required to possess a specific educational level or interpersonal skills. The nature of the proposed intervention, the degree of acceptance for it, and the

Components of recruitment	CMO configuration
Defining the role of PSs	Clarifying expectations of the role enables people to make informed decisions about becoming PSs
Barriers to recruitment	Recruitment is less effective where potential PSs feel uncomfortable about the issues, condition, the prescribed approach to peer support or the objective of improved HL
	Conflicting values within a community act as a barrier
	Existing commitments may act as a barrier
Reasons for becoming a PS	Payment to PSs reduces the likelihood of programme failure without necessarily ensuring the likelihood of programme success
	Non-monetary benefits for self and family (or the community more widely) are effective in recruiting PSs
	Older citizens, specifically, are motivated in order to maintain an active life
	A feeling of being singled out for attention motivates people to join
	Monetary benefits are effective as a mechanism
	Potential recruits may see involvement as offering access to social networks
Recruitment process	Appropriate methods for recruitment of PSs are determined by the cohesiveness of the community that is being targeted
	An inclusive recruitment process will be more credible than one for which there is less community involvement in the process
	Recruitment is successful when a connection is established with those who are thinking of becoming involved
What is a peer?	Criteria for what is meant by a peer need to be appropriate for the programme and context
Recruitment of participants	Barriers in engaging PSs are mirrored in recruitment of participants

#### TABLE 10 Summary of CMO configurations for stage 2: recruiting PSs and participants



FIGURE 17 Context, mechanisms and outcomes for recruitment.

sensitivity and acceptability of the proposed health messages could either align, or conflict, with community and personal values. There was some evidence that concerns about being able to perform the task could be alleviated if people were given a clear idea of expectations for the role. Motivations for participating showed significant variation, from the intrinsic through to the extrinsic. Some form of recognition and pride in being asked to contribute appears to play a part in successful recruitment, as does a need to be engaged with others and involved in social networks.

# Stage 3: training peer supporters

#### Stage definition

This stage refers to all activities that take place in order to prepare, inform and equip PSs to fulfil their role. Training takes place prior to individuals undertaking their peer-support role. It does not include continuing professional development or ongoing support provided once PSs have begun their work.

# Clarifying expectations for participants in training

#### Component definition

The people who participated in training came from many walks of life. Some had positive experiences of training, whereas others had negative experiences that could cause concern about ability to understand the information and develop the skills.

*Propositional statement* When roles are clarified, anxiety about responsibilities is reduced and confidence in implementing the support programme increases.

In the Healthy Living Older People programme, PSs were quite anxious about the training workshops and their roles.<sup>119</sup> Roles were clarified in the initial session, where the programme emphasised that 'peer educators were not expected to become nutritionists nor try to learn enough about the subject to answer all the nutrition questions that could arise . . . This engendered expressions of relief from peer educators'.<sup>119</sup>

One of the breastfeeding projects noted that 'In the initial training, volunteers were taught to recognise limitations in their role and refer issues to HPs that they were not equipped to manage'.<sup>108</sup> Our Advisory Network agreed that role clarification was important to prevent PSs from overstepping boundaries, particularly in terms of providing technical information:

It's important to recognise the parameters of the role and check things out ... If I'm working in an area or way that I'm confident in, then I don't need health professionals – but it's important to have boundaries in terms of referring to them for specific questions.

Advisory Network #9

# Logistics of providing training

#### Component definition

This component refers to any practical arrangements needed to plan, organise and deliver training to PSs. It includes the duration and frequency of training but it does not include the content of training, such as the materials used, the information conveyed or the structure and format of the training.

Propositional statement Training is more effective when it is timed to fit with the recruitment of PSs.

The optimal timing of training was dependent on the pattern of recruitment of PSs. When PSs were recruited to the same programme over a period of time, it was important to design training that could be delivered on an ongoing basis. This meant that PSs were able to begin their training as soon as they were recruited, at a time when they were motivated to learn more about their role and its requirements: 'Programmes of education also needed to be organized on an ongoing "rolling" basis to ensure that new recruits were equipped with training at the time at which they were most motivated to join the scheme'.<sup>108</sup>

In other interventions, PSs were recruited at or around the same time. In this situation, training was required for the entire cohort as a preparatory stage prior to the start of the intervention: 'Professional health education experts led teams of trainers who trained these peer supporters for two days, at a venue off the school premises, to intervene in informal situations and encourage their peers not to smoke'.<sup>128</sup>

*Propositional statement* Training is more effective when it takes into account the personal needs of peer supporters.

It is crucial that the timing and location of the training are convenient for PSs and that any personal needs are accommodated to ensure that PSs could concentrate during training sessions. In some cases this means ensuring adequate provision is made for accompanying children: 'It was crucial that the times and format of the courses were flexible and that adequate provision was made for accompanying children'.<sup>123</sup> In another situation when PSs were adolescents it meant providing training at a venue with access to a safe outdoor space where they could exercise at break times, as well as providing healthy snack and drinks at meal times.

#### Increasing the value of training for peer supporters

#### Component definition

Peer supporters recognised and valued certain outcomes from their training. Identifying these outcomes, ensuring that they were achievable and highlighting their value to individuals was a positive way to improve motivation and commitment to the training provided. This component identifies outcomes of training that were valued by PSs.

*Propositional statement* PSs value training when they perceive it to be of personal benefit to themselves.

In most cases the outcomes of training that were particularly valued by PSs were those that were of benefit to the PSs themselves. For example, the opportunity to gain additional qualifications or credentials was viewed positively because of the potential to enhance future employment opportunities. PSs valued training when it gave them the opportunity to share their experiences and gain support from other PSs and to make and maintain friendships. Training that gave this opportunity enabled PSs to build their social networks and reduced their sense of social isolation. This helped to build confidence to provide peer support to others and maintain their own lifestyle changes. PSs also valued training which they felt developed their knowledge, skills and attitudes to enable them to help others and fulfil their role as PSs.

When it comes to training accreditation is an important motivator for many people.

Advisory Network #8

Peer supporters are more interested in training when they can clearly see how it will benefit them. Peer supporters value training when it leads to an additional qualification or accreditation and enhances their employability. They are also more likely to be interested in training when they can see clearly how the training will develop their knowledge, skills and attitudes to enable them to help others and fulfil their role.

Advisory Network #9

# Barriers to participating in training

#### Component definition

In some instances prospective PSs were limited in the extent to which they could participate in the training that was offered. This component highlights circumstances, situations or attitudes that negatively affected PSs' ability to benefit fully from the training provided.

*Propositional statement* Training that takes into account the preferences of individuals or groups encourages engagement and participation.

The Advisory Network recognised that prospective PSs may have had negative experiences of formal training. They suggested that the use of the word 'training' might have negative connotations for some individuals. It may be helpful to look at alternatives ways to improve the knowledge, skills and attitudes of PSs and thereby equip individuals to fulfil their peer-support role. Role play was one activity that was identified as something that PSs might find daunting.

Role playing is off putting for many people – needs to be in safe space with feedback from a trusted person.

Advisory Network #9

Don't call it role play, I've never been in a group where the mere mention didn't raise tensions immediately. Call it trying things out; imagine; what if? Show me how that might go;, etc. Advisory Network #9

# Training: identifying learning needs

#### Component definition

This component relates to formal and informal assessment of learning needs. In some situations a training needs assessment was conducted, either formally or informally, and findings were used to inform the development of the training programme. In other situations some form of training needs assessment was carried out at the preliminary stage of an existing training programme and the findings were used to enable those delivering the training to tailor or modify the programme to meet individual or group learning needs.

*Propositional statement* Training that is tailored to meet individual and group learning needs is perceived as more relevant by peer supporters.

Training needs analyses were carried out prior to, or, in some instances, at the start of, training. These were carried out both formally, using questionnaires,<sup>79</sup> (Advisory Network #8) and informally through discussion and reflection.<sup>125</sup> Conducting an assessment of PSs' learning needs meant that training could be developed or tailored to meet specific learning needs identified by participants, such as confidence and self-esteem (Advisory Network #8), as well as the goals of the programme (Advisory Network #8 and #9).

Bilingual health advocates were from diverse backgrounds with varying educational levels and required tailored training.<sup>79</sup>

Training needs to be relevant to the activity, knowledge and skills that people want.

Advisory Network #9

Tailoring the individual training sessions to the needs and pace of individuals and to make the best use of the group dynamics was felt to be helpful.

Advisory Network #8

In one pilot study, training was not tailored to groups in the study because of concerns about intervention fidelity. In this situation there was no flexibility to modify the training that was delivered according to a preprepared training manual. The pilot intervention was not successful and the authors suggest that a contributory factor may have been a lack of time for training, in combination with the fact that those providing training had been unable to prioritise the salient points because this would have meant deviating from the prescribed number of training package.<sup>138</sup>

#### Training: building on pre-existing knowledge, skills and attitudes

#### Component definition

This refers to situations for which training was designed or adapted to acknowledge and build on the current abilities of PSs. When this happened it created an environment in which PSs felt that their experiential knowledge was recognised and valued. This contributed to a sense of parity between PSs and the person or people providing the training, which, in turn, created a safe and open space in which to share ideas.

*Propositional statement* Training that is designed to build on the pre-existing abilities of PSs maintains PSs' self-esteem and confidence to deliver the intervention effectively.

Peer supporters' self-esteem was maintained when training was designed to recognise and build on their pre-existing attributes and to make use of their qualities and expertise (Advisory Network #8). This promoted their ability to function independently<sup>121</sup> and may also have increased their confidence to deliver the intervention and their sense of ownership of the intervention (Advisory Network #8).<sup>128</sup>

#### Training: cocreation of training materials

#### Component definition

Information about the planning of training found in the literature relates to the cocreation of training and materials used during training, that is the involvement and participation of PSs in the development or tailoring of training materials for specific individuals or groups.

*Propositional statement* When PSs contribute to the development of the training programme they have ownership of the process, which increases engagement with the intervention.

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When the researchers used an action research approach<sup>121</sup> to develop the content of the training programme they felt it created a stimulating environment for learning and fostered a sense of ownership in the process among PSs (*Figure 18*). Training that encouraged a sense of ownership felt relevant to the lives of PSs<sup>121</sup> and may have improved their motivation,<sup>79</sup> engagement and participation<sup>83,128</sup> in the intervention.

# Content of the training

#### Component definition

This refers to the knowledge, skills, attitudes or other attributes that were conveyed during the training activities.

*Propositional statement* Training that incorporates experiential learning gives PSs the skills and confidence to deliver the intervention.

Training was felt to be helpful when it realistically reflected the situations that PSs might face when implementing the intervention. This gave PSs the opportunity to anticipate situations that they might experience when delivering the intervention, and to rehearse their responses in a safe space.<sup>128</sup> Training that was delivered in an interactive, participatory and experiential manner<sup>139</sup> allowed PSs to practise and develop a range of skills on which to draw, and enabled PSs to relate the materials to real-life situations.<sup>135</sup> Conversely, training that did not give sufficient time or opportunities to practise skills was less successful.<sup>103</sup>

#### Stage 3: summary and context–mechanism–outcomes for training

The training stage has some themes that were similar to recruitment (*Table 11*), notably clarifying expectations and roles and recognising the needs of people who are going to take part. Although building on existing knowledge appears to be a new theme, it accords with the idea of building upon existing knowledge in the community when conducting needs assessments and developing appropriate recruitment strategies. Cocreation of training materials contains the concept of partnering with participants, and both cocreation and partnership were related to increased ownership. Although the idea of experiential learning appears to be new, it embodies the notion of drawing upon experiential knowledge with the outcome of enablement.

In the training stage (*Figure 19*), lines show that the activities of clarifying roles, identifying learning needs, building on existing knowledge, codesigning and experiential learning are activities that can trigger mechanisms depicted on the middle row. These mechanisms may have a cumulative effect, with the end result that PSs have increased confidence to engage with the intervention and to deliver it successfully.



FIGURE 18 Cocreating training encourages ownership (artwork: Sarah Smizz).

#### TABLE 11 Summary of CMO configurations for stage 3: training

Components of training	CMO configuration
Clarifying expectations for participants in the training	When roles are clarified, anxiety about responsibilities is reduced and confidence in implementing the support programme increases
Logistics of providing training	Training is more effective when it is timed to fit with the recruitment of PSs
	Training is more effective when it takes into account the personal needs of PSs
Increasing the value of training for PSs	PSs value training when they perceive it to be of personal benefit to themselves
Identifying learning needs and preferences	Training that takes into account the preferences of individuals/groups encourages engagement and participation
	Training that is tailored to meet individual and group learning needs is perceived as more relevant by PSs
Building on existing knowledge, skills and attitudes	Training that was designed to build on the pre-existing abilities of PSs maintained PSs' self-esteem and confidence to deliver the intervention effectively
Cocreation of training materials	When PSs contribute to the development of the training programme they have ownership of the process, which increases their engagement with the intervention
Content of the training	Training which incorporates experiential learning gives PSs the skills and confidence to deliver the intervention



FIGURE 19 Context, mechanisms and outcomes for training stage.

# Summary of organisational approaches to designing peer-support interventions

The cross-programme analysis of design, recruitment and training identified some patterns in terms of context, mechanisms and outcomes. In terms of context, organisations that adopted an inclusive approach by working with relevant stakeholders at the design stage were able to tap into experiential knowledge and codesign approaches to recruitment and training that increased the perceived relevance and appropriateness of the intervention. Partnership working in which organisational stakeholders interacted with PSs and participants in some cases facilitated health service ownership and increased the chances that the programme would be embedded within existing service provision. Engaging in dialogue with PSs, clarifying needs for the intervention and needs for training, reduced anxiety about expectations and ability to deliver on the role. There is a cross-cutting theme indicating that engagement at all stages increases successful design, recruitment and training.

The next chapter looks at if these activities, processes and mechanisms provided a firm foundation for implementation by exploring what actually happened when PSs tried to offer support to disadvantaged communities.

# **Chapter 5** Synthesising engagement between peer supporters and participants

# **About this chapter**

This chapter looks at the process of peer-support engagement with participants. Propositional statements for what worked (or did not work) were systematically compiled from a review of the implementation data across all of the programmes. Descriptions from the Advisory Network were integrated with data from the research papers. When positive statements were found, we deliberately looked to negative illustrations of the relationship in order to test the strength of the proposition. As with previous stage analysis, the leads for the stage extracted all data relevant to the stage and the draft statements were presented back to the team for review and identification of any relevant data that may have been missed. This process was iterative, with evolving statements being presented back to the Advisory Network for clarification. Agreement of the statements was reached via discussion.

The broader context in which PSs tried to implement their respective programmes is first outlined. The interplay between community norms and values and the relative homophily of PSs is explored in order to determine whether or not programme theory about recruiting PSs who would be perceived to be similar was successfully enacted. The interface between PSs and HPs is examined in order to determine if there was a relationship between interaction at the earlier stage of training and the nature of ongoing support for implementation. The nature of engagement with both the community and the supporting organisations influenced delivery of the service in both positive and negative ways. The actual process of delivering support is then reviewed in detail in order to identify the key components and principles of peer-support interventions that support increases in HL and corresponding decreases in health inequality. The relationships between organisational design and development of the programmes and successful implementation are established in the final section of the chapter, laying the groundwork for the emerging mid-range theory for CBPS.

# Stage 4: implementing peer support

#### Stage definition

Programme implementation begins after the initial training of the PS has been completed. The context surrounding implementation is influenced by the availability of ongoing support; peer–professional interface and community norms and values in relation to the proposed intervention; and community perceptions of the characteristics of PSs (*Figure 20*). Peer–professional interface and ongoing support influenced PSs' confidence about delivering the intervention, their autonomy and the process that they use when actually providing support. Interactions between context and the capabilities of PSs are first reviewed, before going on to describe how community attitudes and norms regarding the activities that are being promoted by PSs influenced the relative acceptability of the intervention. A detailed description of the multiple components of the actual support process is then provided.

#### Implementation



FIGURE 20 Elements affecting implementation of peer-support programmes.

#### How community norms and values affect implementation

#### Component definition

Communities can have negative attitudes towards certain behaviours (e.g. breastfeeding in public, alcohol consumption, smoking or drug use) and impose certain norms that make it difficult to provide support (e.g. stigmatising the discussion of safer sex). PSs must adapt accordingly.

*Propositional statement* When the condition or behaviour is seen negatively or stigmatised in society or in the community, this negativity acts as a barrier to participation.

Community attitudes may delay attempts to get people to participate in support services because participants might be afraid to come forward and discuss their situation. Some things are rarely discussed in the Gypsy and Traveller community. For example, the community views:

Post natal depression as a mental health problem. If you have mental health problems, you are vulnerable. There are fears that if you go to the doctor with depression, then social services will get involved and take the baby away.

Advisory Network #3

Health benefits, such as breastfeeding, also run the risk of being stigmatised:

Within such communities breastfeeding is commonly perceived and indeed experienced as a marginal activity, rarely seen and barely spoken about. Women within such communities are particularly vulnerable to a lack of confidence in their ability to breastfeed.<sup>123</sup>

*Propositional statement* Peer supporters act as role models who help participants overcome negative social attitudes and increase their willingness to take up healthy behaviours.

Modelling what to do and how to do it, in terms of improving health, can be done both in interventions with individuals/small groups and at the community level. When communities are hostile or resistant to accepting the behaviour, a 'mini environment' can be created via community centres, groups and classes that model the acceptability of the behaviour. When communities marginalise health promoting activities, PSs can provide positive role models that enable people to engage in the activity despite the fact that it is not a cultural norm. In the breastfeeding programmes there were numerous reports that women felt the peer-support schemes: supported them with exclusive breastfeeding and in continuing to breastfeed through situations that would otherwise have contributed to them ceasing to breastfeed.<sup>123</sup> The author went on to say, 'This constitutes a key route through which the local cultural norms may be shifted in that positive role models for breastfeeding in the community give other women confidence to initiate and continue breastfeeding'.<sup>123</sup>

Peer supporters also acted as positive role models when elderly people felt that discussions about colon cancer screening were a taboo topic. When 'many of the participants are afraid to even talk about cancer' [PSs] tell them, "We've had the test" and it makes it easier for them to do it'.<sup>135</sup>

*Propositional statement* When peer supporters embed their approach in routine community social events, participants feel less pressure to accept, and thus will consider, health messages.

Approaches that embed health messages involve introducing health issues, discussing them or offering health information when PSs fit their intervention into other events and activities where people are getting together to interact. For example, in Gypsy, Roma and Traveller communities: 'The best health events are those where health is just part of a bigger activity – a party or something else going on, it means the event doesn't preach to people, just gives them access to the information they need' (Advisory Network #3).

Members of the Advisory Network explained that embedding HL into wider activities allows people to 'feel that they are in control of the situation – which they can turn up if they want to, leave if they want'. If an uncomfortable topic is being discussed, people at these social events may find 'it's easier to listen to the information or try it out if other people are doing the same thing' (Advisory Network #3).

# Characteristics of peer supporters

# Component definition

The characteristics of PSs can contribute to perceived similarity between those who are giving and receiving support. This perception can help or hinder the chances of being accepted in the community, potentially impacting implementation of the programme. Assumptions about necessary characteristics should not be made; perceived similarity needs to be determined by conducting a cultural needs assessment and/or working closely with members of the community to identify the peer characteristics that will give credibility to the programme and engender trust.

*Propositional statement* Peer supporters who are recognised as community members and/or share similar challenges or characteristics are more accepted by the participants.

In one of the elderly-focused healthy living programmes, PSs of a similar age were recruited and 'the use of peer counsellors who were able to relate to problems caused by the ageing process helped establish and maintain empathic helping relationships'.<sup>140</sup> In this programme, age, combined with ability to share something of you, enabled trust. In fact, PSs were very clear that being near the same age as the participants was essential to the success of their role, saying it '... makes it much easier to relate to [the participants]... that was what made the whole thing work – being able to relate to them'.<sup>140</sup>

In programmes in which supporters were close to or embedded in the target community, PSs were more likely to be successful in their peer role: '... we found that those people who were well embedded in a

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community group, or who had undertaken the training as a staff volunteer, were more likely to report success with shaping a role as peer educator'.<sup>141</sup>

With PSs from outside the community, they need to establish credibility, either through their history of prior contact with the community or by establishing relationships. This may need to happen despite obvious similarities in ethnicity, age or gender. In Gypsy, Roma and Traveller groups, for example, a Gypsy from one area described how you need to establish your background as a starting point: 'When we meet people, we chat about our families and where we're from. Then they know who we are' (Advisory Network #3). If the connections are more tenuous and 'if we don't come from the same background, we chat about things we might have in common' (Advisory Network #3).

Interestingly, not being from the same community and having similar characteristics was not always a barrier.

In the Altogether Better research, what they identified was that people didn't necessarily have to live in that community or look exactly the same. But if they could identify something in common and feel like they were like-minded people then that would help with the connection. It's not as obvious as they're this age and they're this sex and they're this colour or they live in this place. It was more about like-mindedness and values and stuff. And I think it helps with the support if you are really different, cos some of the people I work with we're like worlds apart, we're different backgrounds, cultures, different languages. But when you get to speak to someone it's even easier to support them cos it's so interesting to listen to each other and to share your background, your experiences. It gives you a lot to talk about because it's kind of like a blank page and you're learning, they're learning from you and you're sharing things with each other. So that willingness to share part of yourself – you teach each other different things about your life and your experiences.

Advisory Network #11

Perceived similarity, therefore, acted as an initial entry point into the community but it appeared that similar characteristics could be either bolstered or undermined by the ability of the PSs to not only establish relationships, but also deal with differences. The process of discussion and sharing could reveal that underneath the obvious differences lay like-mindedness and many things in common (*Figure 21*).



FIGURE 21 Obvious differences may conceal like-mindedness (artwork: Sarah Smizz).

# Ongoing support for peer supporters

#### Component definition

Ongoing training and support consists of continued contact with either trainers or HPs after the initial training, aiming to enable PSs to implement what they learned. Support was delivered in various ways, via planned support sessions; telephone or face-to-face contact with HPs; debriefings with HPs; or learning sets. The aims of the ongoing training were to reinforce learning and provide updated information; ongoing support enabled PSs to obtain or check scientific and technical information, promote reflection and mutual problem-solving, and check implementation fidelity.

*Propositional statement* Providing opportunities to update knowledge and problem solve increases the ability of peer supporters to function effectively.

The review of breastfeeding programmes across England found that follow-up sessions including updates and problem-sharing was 'a vital form of ongoing support'.<sup>123</sup> The value of offering meetings to PSs to discuss any concerns and to reinforce information and promote implementation fidelity was also noted in the Smoking in Schools cluster.<sup>128</sup> In the Healthy Living Older People cluster, enabling peer educators to liaise with nutrition experts meant that educators 'had no trouble in saying they did not know the answer to nutrition questions ... [they] felt that the support provided was adequate for them to function effectively in the role delineated for them'.<sup>119</sup>

These support sessions not only allowed PSs to access the expertise of HPs, but also helped them to share experiences and to support each other:

Training and reinforcement sessions that covered communication and listening skills, how breastfeeding works, life with a breastfeed baby, being a peer supporter, and common breastfeeding problems increased knowledge about breastfeeding and confidence in talking to other mothers.<sup>107</sup>

In some programmes, peers decided to support each other by getting together informally or working together with participants, even although this was not a requirement of the programme.

*Propositional statement* Mutual support reduces isolation and anxiety as well as contributing to sustainability of the programme.

The role of 'PS' can be stressful, as noted by volunteers in Gypsy, Roma and Traveller communities, who said:

Relying on the peer supporter to respond to all needs at all hours can be stressful when peer supporters have their own family issues to deal with.

Advisory Network #8

And then they added:

There is a risk of burnout and some real questions about 'Who is supporting the peer supporters?' Advisory Network #8

In some situations, PSs helped each other. Members of our Advisory Network described how 'peers can be a good support to each other in their work, sharing knowledge skills and practice' (Advisory Network #9). Mutual support has the potential to increase the sustainability of peer support within an intervention:

In three instances the peer educators formed a two- or three-member team and worked together in conducting sessions . . . They gave very favorable accounts of this approach, saying that it reduced transportation problems and the anxiety associated with conducting a session.<sup>119</sup>

# Peer supporter-health professional interface

#### Component definition

This component refers to the dynamic between HPs and PSs (e.g. how PSs and HPs interact with each other, how they clarify roles and relationships between PSs and professionals, HPs' attitudes towards allowing PSs into the health setting, and the difference in knowledge about the HL topic) and how this affects peer support and the implementation of HL.

*Propositional statement* A hierarchical health professional–peer supporter interface impacts peer-supporters' confidence and ability to deliver interventions.

The Advisory Network felt that good relationships increase confidence:

There should be a good relationship between both peers and professionals so the peer-supporter workers feel they are making the right decisions and giving the correct advice.

Advisory Network #9

When relationships were enacted within a health service hierarchy, however, opportunities to develop trusting, working relationships between PSs and HPs were sometimes limited by attitudes about roles. For example, when HPs believed that PSs should work *for* them rather than *with* them, it was more difficult for PSs to work as potential agents of change in their local communities:

... [There was] little evidence to suggest that Health Professionals regarded the volunteers as colleagues with whom they might establish relationships of trust and equality ... More comfortable with the notion of peer supporters (volunteers) working for them, than with them ...<sup>108</sup>

Where the interface aims to control rather than enable interaction, peer supporters are limited in terms of working 'as potential agents of change in their communities'.<sup>108</sup>

When HPs are concerned about roles and professional territory, they may disengage or try to control the nature and extent of interaction. When PSs tried to access breastfeeding women in hospital, nurses acted as gatekeepers. PSs were not welcomed and facilitated into organisations by HPs, which led to them feeling 'alienated and marginalised'.<sup>123</sup>

Control was also apparent when HPs used support sessions as a 'debriefing' process, monitoring and checking to ensure that PS practice did not deviate from the initial training. Although breastfeeding support in one programme aimed to 'counterpoise the formal support available from HPs', the HPs structured the way that PSs contacted women by going 'round the ward to find appropriate women for Breastfriends to access'.<sup>108</sup>

These issues highlight the need to clarify peer–professional roles during the programme design stage, when programme developers can 'explain that PSs can free up the professional when they don't have time to explain things' (Advisory Network #9).

When discussion of roles was neglected:

Health professionals were unlikely to inform women about the peer supporters, and despite best efforts, the projects did not develop and expand.<sup>108</sup>

The author went on to report that:

Peer–professional relationships proved to be an area of potential conflict centering upon a lack of communication and understanding of each other's roles.<sup>109</sup>
#### Building relationships with participants

#### Component definition

The process of supporting participants included the following components: building a relationship; clarifying the peer-support role with participants; enabling participants to set realistic goals; tailoring health messages in response to needs and levels of understanding; signposting people to information and resources that will help them to meet their goals; helping people to negotiate interactions with providers and with health systems to explain needs and get what is needed; supporting participants in reflecting and making choices; and enabling people to set achievable goals. Each of the components is explained in this section, and the iterative nature of the support is presented via a model illustrating how peer support operates on individual, small group and community levels. There was unanimous agreement in the Advisory Network that the process of enabling participants to manage health and well-being was underpinned by relationships. Building relationships was described as a series of iterative steps that included sharing something of yourself; listening to their situation, concerns and needs; building rapport and trust; supporting participants' choices.

*Propositional statement* Sharing something of yourself establishes an equal relationship between peer supporter and participants.

Sharing something about yourself – finding something that you have in common – was an important first step because it signalled that PSs were willing to interact with people on an equal, social level. As one Advisory Network member said 'Socialising and building relationships should come first. This will help with tackling health issues' (Advisory Network #9). Through this interaction, PSs could get 'background information', which enabled them to build up a picture of the participants' situation, their concerns and their attitudes. Similarly, when elderly peer educators took the time to establish themselves as 'likeable, honest, and someone with whom the participants could identify', when they finally 'urged the participants to be a part of the colorectal screening, they were strong agents in influencing participation'.<sup>135</sup>

*Propositional statement* Active listening promotes critical reflection enabling participants to identify aspirations and capabilities.

In some programmes, active listening was explicitly described as a component of the intervention. Motivational interviewing, for example, was used in the Healthy Eating programmes and formed a component of Smoking Fag Ends,<sup>85,142</sup> whereas cognitive behavioural approaches were used by health trainers, who described it as a cyclical process of 'reflect and summarise and listen' in Advisory Network meetings (Advisory Network #2 and #3). Active listening 'put the client in control' of the interaction: 'Helping people to reflect on what they need, what they have, what they want to do is more important than telling them what to do' (Advisory Network #9).

*Propositional statement* Giving peer supporters the opportunity to tailor the intervention to the participants contributes to the success of the intervention.

Programmes that used PSs who were already known as influential peers meant that these PSs could use their tacit knowledge about how to influence others to promote and disseminate health messages. As a result, they produced tailored interventions that provided relevant support and information, which increased the chances that participants would find the approach acceptable. Tailoring the intervention can involve PSs, who are perceived to be members of the community and who share common experiences with the community, using their tacit knowledge to decide how best to influence community members:

Allowing the pastor and volunteers to tailor the basic interventions as well as the data collection techniques contributed greatly to the acceptance of the programme.<sup>129</sup>

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The author went on to say:

Sharing control . . . has led to creative, innovative, culturally sensitive interventions that are woven into the spiritual and social culture of the community.<sup>129</sup>

Accounts in the Smoking Fag Ends cluster also reported ex-smokers who achieved effectiveness without formality using their tacit knowledge:

We don't have a dogmatic approach. There are things that need to be done, but as long as we get those done, we're willing to work within whatever boundaries. We treat people as individuals.<sup>85</sup>

The Network pointed out that it is important to use relationships that you have built up and to respect people's feelings about the health information when planning health activities: 'You need to talk to them first about the best way to offer the information'. They agreed that planning takes time: 'You can't expect to just plan an event, shove people into a room, and get them to listen. You need to know the community – think about your target audience, what will attract them' (Advisory Network #3).

*Propositional statement* Health information must be offered opportunistically, when participants are interested and ready to receive it.

The Advisory Network describe opportunistic delivery as offering 'information when needed' – this 'might be tailored information in response to questions from a client' (Advisory Network #9). It is important to take cues from the participant, rather than imposing it upon them. 'Offer info and see if people respond and want it – don't just give them it regardless. We need to recognise opportunities but not impose where not wanted' (Advisory Network #9).

In the Healthy Living Older People cluster, the peer educators lived in the same site where the participants also resided, and they were encouraged to 'communicate this information informally to their fellow-residents': 'The peer educators in this study were already part of a social network system through which they could communicate information on heart disease prevention and serve as role models'.<sup>143</sup>

Being aware of when people are ready for information incorporates the idea of allowing people to control the pace of information. Rather than 'bombarding with information', our Advisory Network members felt that 'giving health information works best when there is no pressure to participate or to use it' (Advisory Network #3). This concept of seizing opportunities to impart information was also present in the two programmes that used Diffusion of Innovations approaches to spreading health messages about smoking and safer sex via popular opinion leaders, in school and bar settings during routine interaction.

*Propositional statement* Although participants' choices and decisions do not always align with what the programme is aiming for, supporting their choices enables the participant to feel empowered.

The Advisory Network explained that 'it is important to avoid telling people what to do – it's about facilitating them so they can make their own choices' (Advisory Network #7). Adopting an approach of do this, this and this is medical model and is not effective' (Advisory Network #9). 'Supporting people to make their own choices is essential for behaviour change' (Advisory Network #8).

*Propositional statement* When peer supporters help participants to identify small and realistic goals they achieve them.

Goal setting is described as a process through which participants identify challenges and constraints in terms of managing health and well-being, and, with the help of the PSs, develop a critical consciousness of what is realistic, given their abilities and the surrounding environment. The process of setting goals for health and well-being includes raising awareness of participants' personal situations, helping people reflect on what they have – and what they have lost or what has changed – and what they want to be able to do and aspire to be.

The Advisory Network described a process of supporting individual behaviour change, through which a 'person-centred approach' is taken to 'reframe information and make goals more achievable' using small steps (Advisory Network #2). 'Use simple steps: tackle one issue or barrier at a time and suggest things that fit into peoples' lifestyles and routines. "Quick wins" can aid motivation when tackling longer term health issues' (Advisory Network #8).

#### Delivering health messages

#### Component definition

Health information consists of facts about maintaining or improving health and well-being that are shared verbally, in written form, or through various media. Health information is often packaged in the form of a 'message' aimed to convince or persuade people to adopt a certain behaviour. Its potential impact can either be enhanced or diluted by when it is delivered, how it is delivered, and how relevant and appropriate it is in relation to participants' needs.

*Propositional statement* The content of the health message must be at the right level for the characteristics of participants and that using scientific and technical language impedes the process of turning abstract knowledge and instructions into practical understanding.

Peer supporters will be able to create rapport and trust when they 'speak the same language' as participants (both literally and metaphorically), and use everyday terms to discuss health.

The Diabetes Sharing Stories programme prioritised PSs who were fluent in the languages of the participants because 'poor immigrant patients may be unable to speak English fluently and may have low HL in their own language, both of which increase social distance, reduce communication and threaten trust between patient and health professional'.<sup>125</sup> The Smoking in Ethnic Minorities cluster found similar barriers to participation as a result of language:

There is a lot of motivated people out there who do want to quit and language is a problem ... because a lot of them are over the age of 35 and their English is pretty poor ... they're wary of going somewhere and not being able to speak English, understand even.<sup>124</sup>

Using common parlance – a similar vocabulary – was another tactic that PSs used to build rapport and trust.

In an attempt to dispel suspicions, [PSs] sometimes adapted their approach depending on the age and language spoken by the individual, for example, using 'street language' and 'buzz words' with younger smokers and addressing older smokers as 'uncle' to gain respect.<sup>124</sup>

... [clients] want real people, don't they? People they meet every day, on the same level, talking in everyday terms. Sometimes they get frightened of too much medical jargon. Most ... clients don't understand that.<sup>85</sup>

Similarly, in a socioeconomically disadvantaged population of elderly individuals, researchers found that when peers were encouraged to use 'everyday vernacular common to the region and the participants' ethnic origins' it contributed to the peers being strong agents in influencing HL practices, in this case colorectal cancer screening.<sup>135</sup>

Where programmes insisted on using scientific and technical terms to share information, it was more challenging to develop a relationship. A public health nurse said, 'I think [we] health care practitioners generally do have our own speakease. We communicate in a language that isn't always understandable'.<sup>35</sup>

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In some programmes, such as Healthy Eating, messages took the form of information giving, supported by practical demonstrations of cooking techniques and recipes. When giving information, particularly when participants have low literacy, PSs need to '... be ready to give visual information. Certainly when there is a language barrier, reading is a problem' (Advisory Network #9). Some programmes referred to the problems that people encounter with scientific information: 'Sometimes they get frightened of too much medical jargon. Most ... clients don't understand that ... they want real people, don't they? People they meet every day, on the same level, talking in everyday terms'.<sup>85</sup>

Tensions arose in several programmes, however, between workers' attitudes towards the type of health information that ought to be provided compared with views on what people actually wanted. In one of the breastfeeding programmes, a health centre co-ordinator insisted that women should be able to understand the reasoning behind advice given to them: 'These are certain things that need to be explained. You can't just leave it up to the fact that a doctor told you so'.<sup>35</sup> In contrast, a public health nurse suggested that mothers did not want the scientific justification for advice given to them: 'I find that a lot of the people that don't get a higher education don't want to hear that anyway. They don't want to know all the technical, the background; they don't really care how their body makes [breast milk]'.<sup>35</sup>

Orientating messages towards what concerns people or motivates them was an effective strategy for smoking cessation programmes. 'Messages were tailored to age and interests. For young men, particularly those interested in physical activity, the benefits of having a healthier lifestyle were emphasised.'<sup>124</sup> Smokers were also advised of the financial benefits of stopping smoking, for themselves and their family: 'The effects of smoking on the family were frequently discussed with smokers and also the wider community (typically non-smoking women) at various community events'.<sup>124</sup>

*Propositional statement* Peer supporters must facilitate critical reflection and dialogue so participants are enabled to turn abstract health facts into meaningful information.

In order to gain the best result from conveying effective health messages to the participants, health information needs to be sandwiched with opportunities for reflection, discussion and integration with personal experience. 'Instruction is great for technical skills but we learn most and best when we reflect on our experience. Some people want to read information, but discussion helps to understand better and to assimilate better' (Advisory Network #9).

Participants instinctively recognised the distinction between abstract knowledge (knowing that) which they felt they gained from health professionals and practical understanding (knowing how) which they felt they gained from sharing stories.<sup>125</sup>

#### Practical instrumental support

#### Component definition

Practical support – also referred to as instrumental or tangible support – is one type of social support discussed in the literature. In peer-support programmes, it comprises practical help that enables people to pursue their goals for health and well-being. Examples include taking participants to places when they do not have the confidence to go on their own; working together with participants to overcome barriers and solve problems; or offering financial or other tangible support during peer-support programmes.

*Propositional statement* Tangible, practical support helps people to interpret abstract knowledge and instructions (knowing that) into practical understanding (knowing how) through social modelling.

Showing people how to do things and doing things together may enable them to translate abstract instructions and information into practical knowledge and applied skills. For example, 'Doing things together (like cooking, shopping) helps people to understand information better' (Advisory Network #9).

The Advisory Network provided this description of practical support:

Along with the health trainer we supported M by referring her to a counsellor and going shopping with her, suggesting health foods and creating weekly meal plans for the family, also giving her tips on budgeting. We also booked her onto a cook and eat course so she has the skills and knowledge to continue cooking healthy food in the home.

Advisory Network #9

They also described direct support in the form of:

for example, paying for childcare or travel expenses to attend group; delivering exercise classes; or one to one support with healthy eating on a budget. Projects also linked with other organisations to provide indirect support through subsidised leisure centre membership; taster gym sessions; and access to health trainers or counsellors.

#### Advisory Network #8

There was agreement that you 'don't tell people what to do – do it with them' rather than 'giving abstract information through leaflets – show people – learning by doing' (Advisory Network #6). They described their healthy eating programmes as being instrumental because:

We did breakfast taster sessions . . . Some workers and clients eat breakfast here, so they could try what they wanted. We told them what was in it. In the cooking sessions we showed them how to make it. For learning nutrition, we read food labels and talk about the different ingredients. It shows them how to do a healthy shop.

#### Advisory Network #6

Practical support also took the form of helping people to negotiate unfamiliar systems:

In the Gypsy and Traveller communities, a lot of the time people don't have the confidence to try to sort it out for themselves. So they ask us to do it for them. They're afraid that they will look stupid or that they won't understand what they need to do.

#### Advisory Network #3

Another dimension of practical support is modelling what to do with participants. In addition to talking about breastfeeding, for example, 'seeing it happening' and 'getting consistent advice' increased women's confidence and 'helped women to make new friends and talk about other problems'.<sup>35</sup>

#### Social networks

#### Component definition

Social networks are used in several ways within peer-support programmes. PSs may explore how connected people are in terms of socialising with others, gaining a greater understanding of the degree of social isolation and how that may impact on health. PSs may capitalise on existing social networks, for example by using them to gain access to people in need, link people in need with others, and disseminate information. Alternatively, they may create new groups that come together for the express purpose of the health intervention.<sup>124</sup>

Propositional statement Reflecting on social connections helps people to expand their social networks.

Many programmes start with the assumption that it will be easy to get individuals to attend a peer-support group in their community. In actual fact, we need to be starting 'three steps before that' (Advisory Network #10) and consider how to get isolated people to the point where they feel comfortable in attending. Some Advisory Network members do this through an informal assessment through which they

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find out 'who are his social networks, peer support, circle of support, [who is] supporting each other' (Advisory Network #1 and #2). One paper in the Healthy Living Older People cluster also acknowledged the importance of reflecting on connections, saying:

The task of the peer counsellor is to help the client become aware of the extent of his current social network and to consider ways to expand the network ... the peer counsellor involves the client in developing a network chart to help the client visualize existing social networks ...<sup>141</sup>

*Propositional statement* Focusing on socialising and building social networks is a key step in the process of enabling people to learn how to achieve health and well-being.

Network members made the point at all network meetings that 'Being social is part of being healthy' (Advisory Network #9). There was consensus across all of the different network members that 'the social interaction is key' (Advisory Network #9) and people needed to be brought into a social environment as a first step in changing HB because 'socialising and building relationships should come first. This will help with tackling health issues' (Advisory Network #9).

When network members described peer support, they emphasised the importance of getting people involved in the first instance through social activities: 'The quality of socialising is important. Makes it fun!' (Advisory Network #9).

The importance of socialising came up in the cluster data for older people as well, as it played a role in reducing isolation and provided mutual encouragement for taking part in the health-related activities. In fact:

[PSs] found the majority of participants to be very positive [about] the social rather than health-related aspects of the scheme . . . [implying] that if this aspect was not easily accessible, then engagement in other aspects of the programme was affected.<sup>80</sup>

The authors of this study felt so strongly about the importance of socialising that they measured the success of the intervention in terms of whether or not people were willing to take part in an extended or related intervention to improve their health, reduce isolation and improve social engagement, and their findings were almost unanimously 'yes' (96%).<sup>80</sup> But the importance of socialising was echoed in other clusters, such as the Smoking Cessation community programme: 'Groups ... make new friends; get to know new people; and end up coming because the sessions offer social interaction'.<sup>120</sup>

Socialising is seen as a good way to introduce health because 'As you get older you don't want people to preach . . . It should be more of a social thing'.<sup>134</sup> The resistance to preaching was also noted as a key feature of the design in the Smoking Fag Ends project, in which those involved in developing the programme wanted to avoid the NHS messages exhorting them about the 'right' behaviour in terms of smoking.<sup>120</sup>

The approach taken by the Advisory Network members and some of the programmes was to put socialising first, with a view towards building in health messages when and where appropriate 'and if you can interest them in nutrition then you have had a good day'.<sup>134</sup>

This illustrates that health information needs to be built in to activities in which people would normally want to participate, rather than being a separate stand-alone activity where the focus is entirely on health. The focus needs to be on having fun:

Having fun and enjoyment are instrumental in sustaining behaviour change. If people can exercise together, swap tips on healthy eating or share their problems this is a positive step towards maintaining healthy lifestyles.

This Advisory Network member went on to say:

The value of the informal, social and friendship benefits of involvement . . . should not underestimated . . . Practical and fun activities can be an effective way of getting across positive health messages. Advisory Network #8

Establishing this 'unthreatening and social atmosphere in which participants could feel at home' was noted by all network members as an essential part of peer support – and reiterated in some clusters, as demonstrated by the Healthy Living Older People cluster:

It was clear from the [PSs'] interviews that a lot more activity and involvement went on than was apparent from the monitoring questionnaires – tea dances, socializing over tea and biscuits, social support.<sup>80</sup>

The social dimension was seen as very important to sustaining a food club .... The group that came along were enthusiastic and it was just a social event for them .... they put their best clothes on .... it was an outing for them.<sup>134</sup>

The Advisory Network noted that socialising was directly related to outcomes, stating that 'Health education is more persuasive and sticks in the mind if it is offered through socialisation' (Advisory Network #9).

The cluster data reinforced the links between a social approach and changes in health attitudes and behaviour, saying, 'People who enjoyed the experience were more likely to make positive changes or to feel they had changed positively'.<sup>80</sup>

## Summary of context-mechanism-outcomes for implementation

The analysis showed that PSs are challenged on the one hand to identify community norms and values, while interfacing with the supporting organisation (*Table 12*). When PSs truly have homophily, for example they embody the characteristics that are important to the community, then they have valuable experiential knowledge of community attitudes towards HBs and conditions (*Figure 22*).

The PSs will then be more readily accepted when trying to recruit participants and, after successful recruitment, they can build relationships. As relationships evolve, participants will look to them as role models who can demonstrate that it is possible and acceptable to try different HBs. However, the degree of organisational support during implementation has an effect on PSs' confidence to act autonomously in terms of using their experiential knowledge and effectively tailoring health messages to participant needs and readiness to act. When HPs – and their organisations – actively engage with PSs then the PSs, in turn, can actively engage in appropriate ways with participants (see *Figure 22*).

Thus the broader context – which is created during the process of programme design, recruitment and training – eventually affects the actual process of implementation.

The 'bicycle model' for peer support that was developed by the Advisory Network (see *Figure 9*) reflects the principles needed to create equitable relationships with participants but it also mirrors the need for equitable relationships during programme development. Several new concepts emerged or were clarified as a result of the Advisory Network explanation of a peer-support model about creating space for reflection and dialogue, participatory parity, promoting autonomy and control, and reciprocity.

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Components of implementation	CMO configurations
Community norms and values related to HB or condition	When the condition or behaviour is seen negatively or stigmatised in society or in the community, this negativity acts as a barrier to participation
	Embedding in routine community social events reduces pressure and inclines people to consider health messages
	When PSs act as role models they help participants overcome negative social attitudes and increase their willingness to take up healthy behaviours
Characteristics of PS	PSs who are recognised as community members and/or share similar challenges or characteristics are more accepted by the participants
Ongoing support for PS	Providing opportunities to update knowledge and problem solve increases the ability of PSs to function effectively
	Mutual support reduces isolation and anxiety, as well as contributing to sustainability of the programme
Peer-professional interface	A hierarchical HP–PS interface limits effective support and impacts upon PSs' confidence and ability to deliver interventions
Building relationships with participants	Sharing something of yourself establishes an equal relationship between PSs and participants
	Active listening promotes critical reflection, enabling participants to identify aspirations and capabilities
	Giving PSs the opportunity to tailor the intervention to the participants contributes to the success of the intervention
	Health information must be offered opportunistically, when participants are interested and ready to receive it
	Although participants' choices and decisions do not always align with what the programme is aiming for, supporting their choices enables the participant to feel empowered
	When PSs help participants to identify small and realistic goals, they achieve them.
Delivering health messages	The content of the health message must be at the right level for the characteristics of participants, and that using scientific and technical language impedes the process of turning abstract knowledge and instructions into practical understanding
	PSs must facilitate critical reflection and dialogue so that participants are enabled to turn abstract health facts into meaningful information
Practical instrumental support	Tangible practical support helps people interpret abstract knowledge and instructions into practical understanding through social modelling
Social networks	Reflecting on social connections helps people to expand their social networks
	Focusing on socialising and building social networks is a key step in the process of enabling people to learn how to achieve health and well-being

### TABLE 12 Summary of CMO configurations for stage 4: implementation



FIGURE 22 Contexts, mechanisms and outcomes for the implementation stage.

These concepts seemed particularly related to the concept of equity. Looking back to the stages of programme design, recruitment and training indicated that some of the same principles were embedded within CMO configurations. These included:

- Participatory parity At organisational level, the degree of stakeholder involvement and the type of involvement could be authoritarian, for example led by a single group of stakeholders within an organisation, who defined the intervention. Alternatively, involvement could be negotiated and shared by various members of the community during design, recruitment, training and implementation.
- Cultural awareness The degree of knowledge and understanding of cultural and social norms and challenges was manifested:
  - at programme design, by whether or not the programme undertook an initial cultural needs assessment
  - during recruitment, when a lack of understanding about attitudes towards providing peer support or working with the host organisation impeded recruitment
  - during training, when dialogue about roles reduced anxiety about relevance of the training and confidence in being able to carry out the role
  - during ongoing support, where dialogue and problem-solving further reinforced confidence and a relationship of parity between professionals and PSs, whereas lack of professional and organisational support reduced credibility of PSs and led to feelings of isolation and a lack of parity and reduced confidence in delivering the intervention.
- Recognition of experiential knowledge The value attached to experiential knowledge was manifested in whether or not partnerships were established with community organisations, how people were involved in developing recruitment strategies, the inclusion of PSs in the design of training materials, and the degree of autonomy given to PSs in delivering the intervention.
- Engagement in dialogue Opportunities for dialogue with the aim of collaborating on programme activities could occur during needs assessment, while clarifying roles of PSs and professionals when providing ongoing support and training, and when implementing support programmes with participants.

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These components reflected the degree of parity across organisational stakeholders, HPs, PSs and participants. We propose that these elements comprise an 'equity context' that reflects the ability of programmes and organisations to relate to beneficiaries – both PSs and participants – in a manner that demonstrates understanding of the challenges encountered by people in marginalised groups when faced with expectations to manage health and well-being. This equity context triggers mechanisms at all stages of development and implementation that influence the relative success or failure of CBPS programmes in reducing health inequalities.

## Testing the strength of the emerging relationships

Before going on to present the mid-range theory, the many different relationships between context, mechanism and outcome needed to be captured. Further, the relationship between organisational-level programme development and peer-support community-level implementation needed to be established. We looked at our propositions from three different vantage points and developed a graphic representation of the various pathways that peer-support interventions could take, given the different organisational and community contexts. Variations were illustrated using Rogers'<sup>144</sup> description of characteristics of complex interventions:

- *Alternative causal strands* Is it possible to represent the different pathways to achieving outcomes which can trigger different mechanisms?
- Recursive causality Can context-mechanism loops, which can reinforce or act as tipping points for disproportionate outcomes, be illustrated?
- Emergent outcomes Can outcomes that were not originally anticipated or planned for in the theory of change be identified?<sup>144</sup>

The graphic illustrations are presented in *Figure 14* for the stages of programme design, recruitment and training and *Figure 15* for implementation. The case of smoking cessation programmes is used to explain how to interpret the figures, illustrating how different causal strands can be responsible for success. In programmes in which the school was the organisational context, the students as stakeholders were not involved until the recruitment stage. No community needs assessment was conducted, and the training was not coproduced. Involving students in selecting peer leaders, however, created a sense of contributing to selecting credible leads. Further, allowing PSs to tailor the intervention by using their tacit knowledge of when and how to approach students gave them a sense of ownership over the intervention. Ongoing support from professionals bolstered confidence. Conversely, the Smoking Fag Ends programme represented a very different equity context where ongoing support from professionals was not perceived to be helpful and where support from health services organisations was perceived to undermine credibility of the programme. In this community context, the causal strands of community involvement in needs assessment, facilitating logistics, and use of experiential community knowledge to outreach were the influential causal strands.

The principle of recursive causality can also be seen in our programme data. In the case of the Diabetes Sharing Stories programme, early involvement of PSs in the design of the training materials explicitly used a discussion–reflection–action model reflecting the principles of education for empowerment and development of critical consciousness environmental barriers to self-management. The principles of partnerships during the training process led to partnership in terms of logistical management of the programme within the health service, which made PSs feel welcomed and included, facilitating opportunities for reflective dialogue and problem-solving with HPs who supported the programme.

As can be seen in *Figure 23*, programmes could experience any one of these causal strands reading down the figure, but they could compensate for problems with one strand by adopting a more inclusive approach at the next strand. Conversely, those that adopted more inclusive approaches at earlier strands could lose advantage if they reverted to less inclusiveness at the next stage.



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## Summary of synthesis process and results

The synthesis began by developing preliminary configurations of context and mechanism within each programme (see *Chapter 4*). In this chapter we have reported a cross-programme analysis to further clarify and expand on the relationships between contexts for designing peer-support programmes and the process of implementing peer support. This enabled identification of contextual patterns that were responsible for triggering mechanisms related to the development of equitable training and support for PSs, and enabling PSs to deliver interventions that were, in turn, equitable with participants. In *Chapter 6*, we describe the process for identifying candidate mid-range theory.

# Chapter 6 Results

## About this chapter

In this chapter we summarise the stages of the review and the information used in building the theory. A section is then devoted to explain the process of identifying potential theories. It is important to make this process transparent in order to justify the selection of one particular theory or the need to develop a 'hybrid' theory drawing upon various theoretical concepts. Theory is then presented for two levels of the intervention: (1) the 'implementing organisation' level, which includes the processes of design, recruitment and training; and (2) the 'implementers' level, which includes the PS process for identifying and supporting participants in developing HL. At both levels, we link the process to the outcome of reduced health inequalities for PSs and, subsequently, for their participants. The emerging theory is then tested to assess the goodness of fit with the data. The chapter concludes by presenting the theoretical relationship between peer support, HL and health inequalities.

### Stage summary and information flow

The results draw upon information from the index studies and 'kinship' studies (the programme cluster), papers on theory related to the index papers and practitioner knowledge and experience (*Figure 24*). We used these sources of information to:

- 1. develop within-programme theory
- 2. identify cross-programme patterns
- 3. link patterns to concepts of HL and health inequalities
- 4. produce a mid-range theory for the relationship between peer support, HL and health inequalities.

The process was iterative at several points. Related theories were first identified in the comprehensive search. Within-programme theories were compared with practitioner accounts to identify the potentially important components that could be mapped to community-based theories. The Advisory Network discussed theories related to social support, self-esteem, coproduction and empowerment, which were compared with CMO patterns in the programme literature and theories of social support, social learning, HL and health inequality. Searches were conducted to identify 'background papers' on potentially relevant theories and to gain a greater understanding of how their key concepts may be related to the emerging theory of the review.

## Identifying candidate theories

Before expanding on our theory for peer support and HL, some explanation is needed for the process of identifying candidate theories. In our review, we examined if peers who have experiential knowledge of a specific behaviour or stressor, and similar characteristics as the target population, can improve HL and reduce health inequalities. The programmes that we reviewed posited that having experiential knowledge enabled community-based PSs to act as credible 'senders' who could deliver relevant and appropriately targeted health messages while also enabling people to put them into practice. The provision of different types of support by an Advisory Network member in a community setting were visualised as contributing to the development of critical and interactive HL. The development of this literacy was further assumed to reduce health inequality by enabling people to make better-informed health choices and thereby improve their health situation.

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FIGURE 24 Information flow diagram.

The initial programme theory contains assumptions about using a person with a similar social position and social network connections can be instrumental in enabling people to maintain health and well-being. Although we identified programmes that offered CBPS, the theories of change underlying most of these programmes were at the level of individual behaviour change (see *Table 5*).<sup>90,94,97,145</sup> The health belief model, theory of planned behaviour, and social cognitive theory have been criticised for assuming that individuals have the ability to control and regulate HB, largely ignoring the barriers presented in the surrounding context.<sup>146</sup> Some of the programmes based their theory of change on more socially orientated frameworks that acknowledge some interaction and influence between the individual and the community,<sup>91,92,96</sup> and one programme used a theory explicitly related to CE.<sup>96</sup> Although our programmes described themselves as community based, their underlying theories implied that some were still orientated towards individuals. We therefore identified candidate theories that were more orientated towards community as the level of analysis, and looked at the programme data to explore goodness of fit.

We considered theories that were relevant to peer support in the first instance. Peer support has long been described as 'a method in search of a theory'<sup>4</sup> and a recent revisiting of the theoretical basis notes that the research still remains largely theoretical.<sup>148</sup> Simoni *et al.*<sup>148</sup> have mapped theoretical constructs to various types of peer-support interventions, for example education-based interventions; social support

interventions; interventions targeting social norms; targeting self-efficacy; and advocacy-based peer interventions. These theories contain some common elements that were present in our data. The first is the concept of homophily, where people believe that health messages are feasible because the behaviour change was achieved by someone that they perceive to be similar to them. Social support theories take this concept of homophily one step further, proposing that social role and status lends the PS credibility which facilitates ability to reach and be accepted by the target population. Homophily and credibility are diluted, however, when the information to be delivered is complex and the PS is a 'created' rather than a natural member of the social group. Our data concur with this observation, indicating that PSs who are challenged to deliver complex messages and who are unknown to the target group need more time to build credibility (*Figure 25*).

The idea that popular opinion leaders can use social networks to harness social and cultural capital was used in two of our programmes, but the process is dependent upon the relative cohesion of the system. The success of the intervention is mediated by the nature of engagement with the community and prior knowledge of the social system. Programme theory pointed to an interaction between homophily, the place of the PS in relation to the social network (known vs. unknown) and the cohesion of the social network.

Theories related to advocacy-based interventions focus on participatory learning for empowerment, which is one of the key principles of CE. Advocacy interventions using peer support target vulnerable, socially marginalised or stigmatised groups, as did our programmes. They promote connectedness to other people in order to help people to develop a critical understanding of the root causes of vulnerability. The participation and interaction gives people confidence, as well as strategies for tackling health. As this sort of interaction was described in several PS programmes, we compared advocacy theories to the concepts embedded in critical and interactive HL.

As noted in *Chapter 1* of this review, conceptual models for HL have proposed that interactive and critical literacy are needed to address health inequalities.<sup>16,149</sup> Interactive literacy involves development of the communication skills and social skills needed to derive meaning from information so that we can apply it. Critical literacy involves the use of both cognitive and social skills to critically assess the quality, relevance and appropriateness of health information to personal circumstances. A key aspect of critical literacy is developing the ability to exert greater control over situations. This control may be individual action or collective action aimed to address the social, environmental and economic determinants of health.<sup>16</sup> The process is akin to what is termed 'collective sense-making'. Collective sense-making is how we use our



FIGURE 25 Becoming part of a social network takes time (artwork: Sarah Smizz).

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identity, our experiences and our cultural belonging to make sense of an uncertain situation, alone and with other people, through retrospective reflection and dialogue. The process of describing a situation helps people to develop situational awareness, facilitating decision-making and enactment. The understanding that is constructed is used to take action.<sup>150</sup> Although both advocacy interventions and critical interactive HL interventions aim to develop critical understanding, we propose that the key difference is the positionality of the PS. On the one hand, PSs may focus on promoting individual literacy in a group setting. On the other hand PSs may deliberately facilitate active interface with the social structure that constrains health and well-being, encouraging groups to take collective action by advocating for the issues that they identify. The advocacy approach is more closely aligned with the recent reframing of HL as 'an issue of social justice',<sup>11</sup> with attention being paid to the ways in which societies and systems place unrealistic demands on individuals in terms of understanding what to do about health.

The relationship between interactive and critical HL and social justices originates in the concept of education for critical consciousness,<sup>20</sup> which was adopted in the 1980s as a new perspective on health education and community organisation.<sup>151</sup> The Freirian model of empowerment education is related to empowerment theory, which has been applied to individuals, cultures and communities as an approach in health education. In health education, empowerment theory is based on the assumptions that:

- people experiencing problems are the best placed to address them
- the knowledge that people already possess regarding their own values, needs and goals should be valued and used as the basis for change
- people bring experiential knowledge, skills and abilities to health issues, which should be recognised and used
- through participatory learning and use of the above assets, people can develop the resilience to become independent in addressing problems and making decisions.<sup>152</sup>

An assets-based approach to promoting resilience and empowerment was clearly described by the Advisory Network, and was manifested in programmes that used experiential knowledge at various stages of development and implementation (*Figure 26*).

We therefore explored if empowerment theory could be used as an explanatory model to explain the relationship between HL and health equity. Freire<sup>20</sup> proposes that there are two types of education relating to empowerment or the lack thereof: the 'banking' approach to education and the 'conscientisation' approach. When the banking concept is used in health education, the teacher takes the position of bestowing information upon 'those whom they consider to know nothing'. The idea that participants can bring experiential knowledge to their understanding of health and well-being remains largely unrecognised. 'Banking' assumes that information can be deposited within learners as if they are empty vessels waiting to receive it. The learner, as a repository, receives but rarely engages in dialogue and the learners accept their ignorance and 'never discover that they educate the teacher'.<sup>20</sup>



FIGURE 26 Assets-based approaches build resilience (artwork: Sarah Smizz).

Conversely, education for critical consciousness is based on dialogue leading to reflection and action. The learner is seen as an active agent who engages reflexively with the surrounding environment. The dialogical process starts with the posing of problems related to well-being. Discussion is co-operative as opposed to the teacher taking a superior role, with the aim of reflecting on obstacles to well-being and using a participatory group process to critically decipher the nature of the obstacles. The dialogue produces a critical consciousness of the factors outside of one's individual situation - environmental, political and social – that may constrain health, thereby shifting the emphasis from individual responsibility to collective reflection on what can be changed. The process of questioning, reflecting and learning together can represent either technical communication or transformative communication.<sup>153</sup> Technical communication focuses on the appropriate transfer of factual health information in a way that enables people to acquire skills for health. Showing women how to breastfeed and helping them to develop knowledge to solve problems with breastfeeding is an example of equipping women with the technical skills to continue to breastfeed. Transformative communication goes a step further, helping disadvantaged and marginalised communities to identify what they need, politically and economically, to maintain health and giving them the means to express their needs (enabling them to find a 'voice'), while creating receptive social environments that help them to take action. Campbell and Cornish<sup>153</sup> point out that technical communication focuses on transmitting meaningful knowledge, whereas transformative communication 'is a more politicised process, through which marginalised groups develop critical understandings of the political and economic roots of their vulnerability to ill-health, and the confidence and strategies for tackling them' (p. 848).

The Breastfeeding cluster in our analysis illustrated this spectrum, where supporters took the stance of didactically giving instructions, to transferring information appropriately and enabling women to acquire breastfeeding skills. In some cases, the social process in the support groups and the role of PS enabled women to point out the lack of public space for breastfeeding and the stigma associated with it, resulting in advocacy with agencies to promote and support the use of public space.

## Developing and testing the mid-range theory

Using the lens of empowerment education for critical consciousness, we developed a theory for explaining how peer support can promote HL and reduce health inequalities. The theory is presented here and applied to positive and negative cases drawn from our analysis to demonstrate goodness of fit.

We hypothesise that successful peer support occurs in organisational contexts where the system recognises and values the worth of experiential knowledge and gives parity to PSs in terms of deciding when, where and how to promote HL with disadvantaged and marginalised groups. Recognition and parity enable PSs to feel empowered in their role, and supported in terms of mediating the tensions between health expectations, local community norms and values, and development of capability. Further, they can bring a critical consciousness of the ways in which the surrounding environment either constrains or enables people to improve health, as well as skills for helping participants to look beyond immediate issues to their root causes and understand that in some cases the causes and solutions lie outside their individual behaviour or control.<sup>154</sup> Ability to mediate is greatly influenced by the surrounding organisational context. For peer support to be successful, the organisations responsible for setting up and maintaining the programmes need to establish relationships of parity with community organisations and PSs. Community needs assessment is an essential step in conceptualising the social and cultural norms of a community, as well as its composition and cohesiveness. Who participates in this conceptualisation is key to how problems are constructed and how solutions are shaped. Recognising and capitalising on experiential community knowledge demonstrates respect for community knowledge, which further promotes an equal dialogue between implementing organisations and implementers.

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In contexts when organisations valued community knowledge, programme design focused on identifying community stakeholders at the outset, developing a partnership, and conducting a cultural needs assessment. This initial engagement produced programme theories that were based on understanding of community norms, values, practices and constraints. Conversely, programmes that neglected cultural needs assessment experienced problems with implementation, and had to take a step back and increase engagement in order to make programmes relevant.<sup>123</sup> When recruiting PSs, organisations that consulted communities about appropriate peers and used communities to recruit appeared to identify appropriate and acceptable PSs. Conversely, organisations that did not use community-based approaches to recruiting identified PSs who were not known to local communities, leading to less successful participation, which may have been due to the lack of credibility of the PSs.

During the design and delivery of training, some organisations and HPs did not capitalise upon experiential knowledge or engage in coproduction. Where organisations maintained ownership and control over the content and delivery of health education, PSs were uncomfortable delivering some of the health messages. Conversely, in contexts where training materials and content were coproduced, PSs felt valued with a greater sense of ownership over the intervention and confidence to deliver health messages.

During implementation, when organisations allowed PSs to use their tacit knowledge of social norms and social approaches to well-being, PSs reported feelings of self-esteem, confidence and satisfaction with the programme. Conversely, when organisations monitored and controlled social networking activities, PSs felt unwelcome and lacked confidence in their role.

Supportive organisational contexts recognised the worth of the experiential knowledge that PS held about marginalised groups. This recognition led to a relinquishing of control, giving PSs the autonomy to tap into social networks to develop relationships with participants, use their judgement about appropriate times and places to deliver health messages, use a process of social learning and reflection, and tailor health messages to local norms and values. Recognition transformed interventions from those that merely targeted groups to receive health education messages, to interventions where PSs were empowered to tailor messages based on their knowledge and understanding of the individual's situation within the community and the broader society. When PSs were empowered to mediate, they were able to facilitate a social process through which participants were able to construct meaningful knowledge from health information and support each other in overcoming social barriers to changing HB.

# Relating theories of change to theories of action and engagement

The fit between empowerment education and successful peer support led us to revisit the different theories of change and theories of action in our respective peer-support programmes, and compare them to current models for CE. CBPS was situated at different points on Popay's model<sup>40</sup> of CE. The more controlling stance taken by some implementing organisations reflected a consultation approach, through which professionals exercised power in terms of shaping meaning and value, setting agendas and priorities, and decision-making. This approach represents a public health process of shaping issues so that particular ideas are considered, discussed and valued at the expense of others. The knock-on effect from unequal representation at the design stage is an agenda and priorities that may not reflect experiences of socially vulnerable groups. Decisions may be made about appropriate interventions that are based on insufficient recognition of identity. Furthermore, when relationships have not been established, a lack of dialogue may further perpetuate mis-recognition of ethnic, cultural, religious or geographical identities.<sup>155</sup> The end result, in terms of increasing HL and reducing health inequalities, is an antagonism in terms of health goals rather than an alignment of goals with recipients' perceptions of what is relevant to their everyday lives. Figure 27 compares the stages of designing and researching health inequalities interventions that were presented in a recent systematic review of CE,<sup>9</sup> using two different epistemological stances. We have characterised one of these stances as the epidemiological health systems perspective (in light green), where



FIGURE 27 Epidemiological and social approaches to designing health inequality interventions.

concern is triggered as a result of differentials in population health. We describe the alternative perspective as a community-based social perspective, in which concern is triggered by perceived unfairness in living conditions (in dark green).

The epidemiological perspective is triggered by morbidity and mortality statistics produced by health systems, which represent health inequality as an inequality in the mathematical sense.<sup>156</sup> In some cases, the focus remains on the problem of unequal numbers, for example greater proportions of poor glucose control and subsequent diabetic complications; low rates of colorectal cancer screening; low rates of HIV counselling and testing; and low rates of breastfeeding. The solution becomes provision of health information, with the assumption that using a peer to deliver messages will persuade people to comply. The valued outcomes focus on balancing the numbers, for example decreasing the proportion of people with poor glucose control, and increasing the rates of screening or breastfeeding.

Tones<sup>157</sup> characterises this as an authoritarian approach, through which ideological perspectives of HPs and researchers are used to select the theory of change and the methods for taking action to address the problem. When the authoritarian approach is used to design the intervention, PSs are seen as a vehicle to transmit the messages that have been deemed important by professionals. This theory of change was predominant in the review of experimental studies assessing effectiveness of CE to reduce inequalities in health [the CERI (Community Engagement to Reduce Inequalities)] review<sup>9</sup> (*Figure 28*).



**FIGURE 28** Theory of change for peer-delivered interventions. Reproduced with permission of the National Institute for Health Research Journals from O'Mara-Eves A, Brunton G, McDaid D, Olicer S, Kavanagh J, Jamal F, *et al.* Community engagement to reduce inequalities in health: a systematic review, meta-analysis and economic analysis. *Public Health Res* 2013;1(4).<sup>9</sup>

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When engagement with the community is the issue, experimental study design using authoritarian approaches risk missing the perspectives of those who need to be involved in the intervention. Incorrect assumptions lead to theories of change and action that do not reflect the reality of vulnerable groups, thereby producing equivocal or ineffective results (*Figure 29*). This was noted by our Advisory Network members:

My analogy of it is that it's almost that you've got a group of academics if you like sort of sat in one place building this brilliant mansion. But they're not talking to the people who it's there for, who are the concrete. So they've put their mansion on some sand and it sinks.

#### Advisory Network #11

In trials using CE, the views of stakeholders were primarily sought after HPs and health services had defined the problem. This contrasts with a community-based social perspective to designing interventions (*Figure 30*, in dark green). The involvement of communities is assumed to make the proposed intervention more appropriate and relevant.

This may be the case, but the point at which communities are involved may have a marked effect on whether the people receiving the intervention are seen as passive recipients or actors in the cocreation of the intervention. Implementing organisations who have adopted a community-based social perspective factor in experiential and cultural knowledge when defining the problem. This produces an intervention that is cocreated or controlled rather than just being altered, which may influence the outcomes. For example, some of our programmes included stakeholders in intervention design. One of our smoking cessation programmes was entirely community based and did not include any health service participation when designing their intervention, whereas our healthy nutrition and older people initiatives had community health service partnership at the design stage. Earlier involvement provides opportunities to look at the root causes of epidemiological disparity from the perspective of those with the condition, taking the surrounding context into account. The PS takes on the role of helping people to explore social barriers to managing health and well-being, including issues that may not fall within a traditional 'health' remit, such as social isolation or financial and housing issues. The solutions are social: facilitating participation in groups that will help people to make sense of their situation, building relationships that support people with a range of problems beyond immediate issues, such as breastfeeding or learning to cook healthy meals. Tones<sup>157</sup> describes this as a negotiated approach to theory-based health promotion. In contrast with the authoritarian approach, the ideological stance is to draw on CD theory to develop a



FIGURE 29 When stakeholders are not involved, programme evaluation may reflect false assumptions (artwork: Sarah Smizz).



FIGURE 30 Theory of change for patient/consumer involvement (adapted from O'Mara-Eves et al.9).

grounded understanding of the problem and generate solutions that include empowerment to take action. This approach was illustrated in the Smoking Fag Ends programme (*Box 5*).

The opposing perspectives are reproduced in research paradigms representing two different epistemological views. The epistemological difference between the models emerging from both the CERI review<sup>9</sup> and our realist synthesis is worthy of examination, because the different stances help to explain the challenges in determining effectiveness of CBPS interventions. When health services define the problem and largely design the intervention, the theories of change neglect the interaction between social structure and individual agency, presuming that behaviour can be bounded within causal chains that

#### BOX 5 Fag Ends case study

The Smoking Fag Ends cluster, which involved the community from the beginning in creating the peer-support programme, made the decision early on to avoid the use of health education materials that were branded by the NHS, as it was felt that they gave negative messages about smoking. By developing an own-branded programme, 'Fag Ends' was able to give users a sense of clear ownership, and the feeling that it was a service run 'by people like them' and not by HPs. It has not been unusual for individuals to turn up to sessions and ask for an exact match of support to that which helped a friend or relation stop: 'You helped our Julie give up. I don't want messages or lectures. I just want the same stuff you gave her and the same plan'. In terms of non-material gain, one of the key benefits of the programme is the community cohesion and ownership it creates. Groups choose the venues where sessions are held; make new friends; get to know new people; and end up coming because the sessions offer social interaction. To bolster this social element, the programme offers a 'recommend a friend' card, which encourages individuals to spread the word and bring their friends or family along. In some cases, people who have guit smoking continue to attend the sessions because of the company and social element that they offer. Such attendance is encouraged, as it provides groups with positive, relevant role models from within their own community. Advice, support and treatment from a layperson may remove existing social barriers in the community and increase the chance of a successful period of abstinence. Having the services based in the community has also encouraged many members to attend through word-of-mouth recommendations from their friends. The strong social networks have been used to the programme's advantage, for if one person stops smoking it can have a domino effect through their immediate community.

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'enclose human actions in a set of actions that appear determined, predictable and modifiable'.<sup>158</sup> This sort of design produced programmes that were unable to engage or that triggered negative mechanisms in both PSs and participants. Conversely, those that used interactive and engaged processes for intervention design coproduced causal chains and triggered positive mechanisms in stakeholders that extended through recruitment and training to implementers. In this intervention design, PSs were empowered to reconfigure 'existing social networks' by creating or supporting forums through which people can discuss and act upon conditions that shape their health.<sup>158</sup>

## Relating engagement in intervention design to health literacy

We further tested the relationship between engagement in the design and delivery of the intervention to HL by classifying programmes according to whether they embodied authoritative research designs or negotiated research designs. In some cases, programmes had examples of both approaches (breastfeeding and healthy nutrition), so both pathways were traced. The HL outcomes proposed in Nutbeam's model<sup>15</sup> (see *Chapter 1*), and further articulated in a recent conceptual analysis of HL,<sup>19</sup> were plotted to the research approaches by programme. In several programmes, a RCT design used predetermined approaches that limited involvement in tailoring of information and education. In the Healthy Eating Middlesbrough trial, for example, limited involvement translated into problems recruiting local peers and, as a result, the college students who were recruited were unable to engage with local communities effectively.<sup>132</sup>

One Smoking in Ethnic Minorities programme referred people to cessation programmes that did not tailor communication to people with English as a second language.<sup>124</sup> As a result, attempts to quit smoking were diluted by poor attendance at appointments.

Some of the Breastfeeding programmes described interactions that were characterised by a 'reductionist style or approach which involved information and advice being given in a dogmatic and or didactic style'<sup>127</sup> which led to problems in understanding information and having the confidence to put it into practice.<sup>33</sup>

Although the smoking example showed some increase in knowledge of risks as evidenced by attempts to quit, the lack of involvement and subsequent lack of engagement reduced participation and ultimately resulted in negative outcomes. The reductionist approach to breastfeeding information was associated with what was described as a 'disconnected presence' and associated with lack of confidence and motivation to change behaviour.<sup>127</sup>

A lack of engagement in determining appropriate health messages also constrained the tailoring of communication. This was evidenced by PSs who struggled with complicated health messages,<sup>103</sup> and who also struggled with sensitive messages that potentially contradicted social norms (HIV Safer Sex). Interventions that had less interaction with PSs or the community to identify appropriate messages were unable to report an increase in decisions to try the behaviour. In the case of HIV, ambivalence about communicating safer sex messages was related to a lack of diffusion of the messages across a social network.

There appear to be two levels of advocacy: individual and collective. Individual advocacy was manifested as becoming capable of interacting differently to get needs met. As a result of participation in a breastfeeding support group, for example, one mother became more confident and was able to challenge her doctor about health information: 'Before I used to take everything [the HPs said] as gospel. If the doctor said it, then it must be right. Then I figured out [he was giving me incorrect information] so I actually told him he was talking out his arse'.<sup>108</sup> Social organisation and advocacy are not precisely defined by Nutbeam,<sup>15</sup> who notes that further empirical work is needed to operationalise his proposed outcomes. We therefore defined social organisation according to what was reported in the programmes: as the ability of groups to choose and participate in group activities that would promote health. We defined social

advocacy as the ability of a group to collectively take action to improve an aspect of the surrounding environment, social structure or health system. This was evidenced in breastfeeding in terms of challenging norms in public spaces. For example, in the North American study<sup>33</sup> the co-ordinator of a community-based prenatal nutrition programme enabled a breastfeeding mother who was asked not to breastfeed in a local restaurant to discuss her experience with other mothers. Discussion led to organising a protest through letter writing and a boycott of the restaurant, which led the restaurant to respect women's rights to breastfeed in a public place. As noted by the co-ordinator, 'Everybody has a responsibility I guess to inform the community about the benefits and about workplace and about going to wherever, shopping or to a restaurant, that you have the right to breastfeed your baby'.<sup>33</sup>

Greater control over situations maps to the concept of empowerment (Box 6).

Empowerment can be conceived as a continuum on which the PS starts by enabling an individual to take personal action and connecting them, via signposting and activities, to interact with groups (see *Figure 9*). According to Laverack<sup>159</sup> community empowerment begins to develop when individuals and groups work with community organisations to address inequality. These organisations can form partnerships with the aim of taking social and political action. The programmes targeted social networks, for example small mutual groups or community groups in the first instance to build individual and collective assets. In some cases, people, organisations of social advocacy with the aim of increase control over situations. In fewer cases, there were indications of social advocacy with the aim of increasing fairness of the organisation or surrounding environment with a view towards obtaining social justice.

The process of negotiating interventions is related to the concept of cultural literacy which is described as 'the ability to recognise and use collective beliefs, customs, world-view and social identity in order to interpret and act on health information'.<sup>49</sup> Cultural literacy can work on three different but related levels: it influences organisational ability to engage with communities; PSs' ability to communicate with participants, and participants' ability to become critically conscious of how beliefs, customs and social identity influence their ability to adopt healthier lifestyles.

The importance of drawing upon beliefs, customs and world views manifested itself across the programme stages. The Network's description of the process of cocreating interventions maps to Freire's notion of education as a partnership<sup>20</sup> and the principles of adult learning (which focus on respect for the learner's needs), valuing previous experiential knowledge, and using scaffolding to add additional knowledge and skills on to what is already known.<sup>21,24,26</sup> The end result is collective ownership:

The way that they will learn is by receiving some of the information and training but also it's the experience of creating it. So together you sort of see everybody as part of the solution don't you. They're experts in their lives and their experience. They bring something into the room, they [each] bring another set of knowledge and those people together can create it. You know it's that ownership and shared purpose which is really important in health I think.

Advisory Network #11

#### BOX 6 Definitions of empowerment

Community empowerment '... a social-action process that promotes the participation of people, organisations and communities towards the goals of increased individual and community control, political efficacy, improved quality of life and social justice.'

Wallerstein N. Powerlessness, empowerment, and health: implications for health promotion programs. Am J Health Promot 1992;**6**:197–205.

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When these principles are used, a condition of parity is created through which experiential knowledge is valued and seen as equal to the 'expert' knowledge of researchers and HPs. Negotiated approaches to designing peer-support programmes demonstrate how power differentials in society can be equalised through engagement. Conversely, authoritarian approaches exhibit a lack of awareness and these 'top-down' designs contain several risks: (1) allocating insufficient time to the development of relationships that will produce the understanding needed to design culturally appropriate programmes; (2) disregard of the importance of experiential community-based knowledge in designing and delivering peer-support programmes; and (3) inability to recognise that health-care professionals unconsciously adopt a position of social elite in terms of class and values,<sup>160</sup> which manifests itself as an unwillingness to cede control for the design and delivery of programmes to those who may know best. Therefore, on a health systems level, the sponsor organisations and HPs need to be skilled at establishing an 'equity context' in order to promote CBPS programmes.

We define equity context as a context in which organisations prioritise the importance of health inequalities in policy and funding; community challenges and needs are recognised; people are ready to investigate root causes of poor health and well-being; the sponsor allows adequate time for development of relationships and connections; experiential cultural knowledge is valued; there is awareness of the importance of sharing power and control; collective beliefs, customs, world views and social identity are acknowledged and actively used in programme planning and implementation (cultural literacy); PSs are enabled to use their experiential knowledge to decide how to promote HL; and emergent outcomes are seen to be an essential part of the evaluation.

The relationship between an equity context and subsequent mechanisms and outcomes is presented in *Figure 31*.

Equity contexts trigger a range of mechanisms that contribute to or hinder the abilities of the programme to reduce health inequalities. When the implementing organisations were able to recognise the importance of creating an equity context, there was greater participation of PSs in the development of the programme, which built the individual assets of the PSs to produce more relevant materials and interventions. The outcomes emerging from organisation/CE in designing the intervention carried over to the actual implementation of the support programmes, for which PSs were encouraged to use their tacit knowledge and exercise their own judgement in terms of how, when and where to approach participants. In other words, the PSs became empowered. This in turn increased community participation and the development of community assets (Figure 32). When PSs are allowed to use their experiential knowledge of collective beliefs and world views (cultural literacy), they are able to create an equity context where control is handed over to the participant to decide what they would like to be able to do. The handing over of control is achieved by sharing information about commonalities and differences – recognising each other's social identity and establishing a relationship of parity. The relinquishing of the authority of the 'teacher' is achieved through a process of active listening and dialogue, through which reflection is encouraged and participants' expert knowledge about their own situations and challenges is respected. Emergent outcomes such as motivation, readiness to consider a change, achievement of small goals and increased confidence are celebrated as important and essential parts of the process of developing HL. With increased control over one's situation comes increased empowerment of participants, through which individuals are able to interact in groups to gather and analyse information in terms of its relevance, as well as critically observing how people in similar situations cope with adversity. This interactive and critical social process produces socially generated knowledge that is directly related to individual and collective HL outcomes. We describe the PS role as one of 'bridging participation' to describe situations in which PSs helped individuals to make initial connections and to expand their social networks.

EQUITY CONTEXT	PROCESSES A	PROCESSES AND MECHANISMS	EMERGENT OUTCOMES
Acknowledging and valuing experiential knowledge	PSs use their experiential community knowledge and interpersonal skills to do outreach	U Community members perceive peers to be credible and acceptable	Willingness to participate in peer-support programme
		- O	
Recognition versus misrecognition of	HPs provide ongoing support including problem-posing and problem-solving	R PSs feel that they are given credibility by professionals T Perceived increase in social status	Autonomy and control for PSs
community challenges and needs	Organisational involvement in providing logistical support (publicity; venues; resources) HPs facilitate	T PSs feel that their role is supported and they are given credibility by the organisation	Increase in self-esteem
	access to participants		
Organisational awareness of the		- Z	Collective ownership over training process
importance of sharing power and	Provision of interactive, pragmatic training with opportunities to practise skills and problem-solve	PSs feel confident to deliver support	
control			Relevant training based on
	Professional/peer involvement in drawing upon experiential knowledge to develop training	C PSs feel valued for their experience and knowledge	experiential knowledge of participants
Organisational readiness to investigate root causes of poor health		х <b>)</b> — н	
and well-being	Professionals/community are involved in recruiting PSs	People feel that their opinion is valued	PSs have credibility and are acceptable to community
		) ш	
Importance of health inequalities	stakenolger involvement in formulating solutions	Solutions appropriate and acceptable to community	
prioritised in policy, funding, protected time	Stakeholder involvement in problem-shaping and identification of social networks		Increased knowledge and
	Community/cultural needs assessment is conducted	Recognition and valuing of community knowledge	of inequity
FIGURE 31 How equity co	FIGURE 31 How equity context triggers mechanisms and produces emergent outcomes.	comes.	

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## Linking health inequalities to mid-range theory

After identifying principles of equity in the programme contexts, we moved on to developing the mid-range theory for the relationship between CBPS, HL and health inequalities. Research on health inequalities was scoped to identify literature that was related to the equity concepts emerging from the programme theory, such as establishing parity and trust, valuing experiential knowledge, the significance of social networks in developing capability, social organisation and collective advocacy.

The most developed theory so far has been produced from an extensive synthesis of the international literature conducted by Wilkinson *et al.*<sup>161</sup> in their seminal work *The Spirit Level*. In order to understand how health inequalities are created, Wilkinson *et al.*<sup>161</sup> make the case that we need to start by considering social status on individual and community levels, noting that in their research 'social status and friendship have kept cropping up together, limited inextricably as a pair of opposites'.<sup>161</sup> In our review, there was a set of data related to the importance of socialising and social networks (see *Chapter 5*). On an individual level, people tend to choose friends from those they perceive to be near-equals. This is the principle of homophily (the tendency to develop socially significant ties with people who are perceived to be similar to oneself), which is one of the foundations of peer support. These friendship ties are characterised by recognising the needs of others; sharing problems; reciprocity; and co-operation (*Figure 33*).

Involvement in friendships gives people a sense of social identity and raises their perceptions of their own social status because they feel valued by others. Sharing resources – whether it be food, experiences, or knowledge – creates a sense of common identity and interdependence as a group. Trust in others is created along with a belief that one is part of a system of shared values. Participation in the group fosters further community connections and protects health. Using Wilkinson *et al.*'s<sup>161</sup> conception of social status and health, we could posit that the participants in our programmes could have perceived themselves to be of lower social status in comparison with other people as a result of age, socioeconomic status, religion, ethnicity or sexual orientation. When faced with threats to health status or changes in health status, people who are socially vulnerable fear that they will be exposed to negative social evaluations of both their health condition and their ability to cope with it. This certainly fits with our data, which indicated that elderly people were anxious about attending for colorectal cancer screening; young mothers were nervous about meeting expectations for breastfeeding; and smokers feared negative social judgements. Although being exposed to social evaluation in a health context is an occurrence that is experienced by everyone,



FIGURE 33 Reciprocity contributes to a sense of worth and social identity (artwork: Sarah Smizz).

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those who are most socially vulnerable are least equipped to deal with negative judgements. When disadvantaged and vulnerable people are subsequently faced with incomprehensible or unachievable health messages, they experience shame at not being able to understand or master the task. Shame is the most fundamental of our social emotions, where feelings of stupidity, insecurity and inadequacy are internalised along with a fear of being exposed as incompetent and being embarrassed.<sup>162,163</sup>

People in this position are caught in a cycle of low HL, admitting a lack of understanding risks, triggering a chain of negative judgement and, subsequently, lower self-esteem. The way out of this conundrum is via social interaction, as suggested by Wilkinson *et al.*<sup>161</sup> but the biggest barrier is becoming connected (*Figure 34*). Members of our Advisory Network noted that 'we actually have to start three steps further back than just starting the programme because it takes, there's a hidden kind of work to finding people in the first place' (Advisory Network #11). Getting people to the first interaction takes a lot of (often unrecognised and unfunded) support.

The GP [general practitioner] or somebody will say go down to the social café Monday at 10 o'clock. And the stories the [clients] tell us about the anxiety that's caused them! Very often it is quite daunting and they've spent a week worrying about it. So we'll be at the surgery and walk them down to try to bridge the gap. Then first impressions when they come in are quite important, in establishing a relationship and a role. If it's not done right, people will disappear and all the work can be undone. Advisory Network #11

These barriers exist in our society for many reasons, but, as Wilkinson *et al.*<sup>161</sup> note, part of it is related to disconnectedness in what were formerly more cohesive communities.

People's sense of identity use to be embedded in the community to which they belonged, in people's real knowledge of each other, but now it is cast adrift in the anonymity of mass society . . . As a result, who we are, identity itself, is endlessly open to question.<sup>161</sup>

The PS in this circumstance can act as the initial catalyst, by sharing something of themselves, establishing a connection and developing enough trust with the participant to ensure ongoing participation. As participants begin to trust PSs, they are increasingly drawn into group situations in which they have the opportunity to share mutual problems with other people. The emotional and affirmational support received confirms that others struggle with the same issues, thereby reducing their concerns about being the only



FIGURE 34 Practical support is needed to get people connected (artwork: Sarah Smizz).

one who is feeling unable to cope. The group recognises the needs of the individual and responds by enabling them to critically reflect on their situation and select feasible goals. The process of identifying what one wants to be able to do, and develop the capabilities to do it, leads to a sense of control and autonomy. The outcome is the opposite of shame, for example pride in becoming more competent, in being able to critically understand and act to maintain health. This process occurs when a group has high levels of security and trust, which appeared to occur in some of the programmes included in this review. The Diabetes Sharing Stories programme, for example, enabled people to collectively make sense of health information and to support each other to take action. The Advisory Network noted that the Health Champion programme contained numerous case studies of the ability of group support to re-engage people in society and promote health.<sup>113</sup>

Fear of vulnerability is countered by group support, and affirmation enables people to deal with negative social evaluations. CBPS – when it is supported within an equity context and creates an equity context – is therefore the catalyst that can change a system of social relations from one of unequal to equal status (*Figure 35*).

Peer support that promotes group interaction and social networking therefore offers the potential to enable people to better deal with health and health systems, empowering them to gain individual and collective control over health and reduce inequality. Our final diagram presents the mid-range theory for the interaction between CBPS, HL and health inequalities (*Figure 36*).

Low social status can be internalised by socially vulnerable groups, leading to a sense of exclusion and social isolation. In our programmes, where people were brought into contact with others who shared similar challenges the group process enabled people to deal with health. It needs to be noted, however, that the ways in which social networks and participation in society mediate perceived social status was not the explicit aim of the peer-support research but seemed rather to be an underlying mechanism. Our search for research, which explicitly links social networks and self-management of health, identified a review by Vassilev *et al.*<sup>164</sup> calling for more investigation of these links. The authors noted that research focuses primarily on individual networks and what they describe as affective networks. Individual networks place the individual in the centre of what are essentially a web of dyadic relationships with family members and friends. This conceptualisation of networks in health is predominant, which aligns with the predominant framing of health issues as issues of individual behaviour. Research using the primarily HP–individual focus is not particularly relevant for CBPS programmes, but research on groups who function as affective communities is quite relevant. Affective community networks can be pre-existing cohesive groupings comprising a combination of family, religion, ethnicity and/or locality. Alternatively, they can be



FIGURE 35 An equity context enables coproduction of peer-support interventions (artwork: Sarah Smizz).

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FIGURE 36 How CBPS increases HL and reduces health inequalities: mid-range theory.

recently formed groups that emerge as a result of a specific intervention or a local initiative. In a peer-support context, the PS may enter a pre-existing group – such as, for example, the diabetes group – and propose a new intervention or focus, such as sharing stories about coping with the condition. The PS can also try to form a group, which occurred in many of the breastfeeding interventions. The lines between pre-existing and recently formed groups are blurred, as in some cases the initial attempts to recruit are taken over by word of mouth, with the result that the group comprises people who already know each other but have come together for a different reason than their previous connections. This happened, for example, in the Healthy Eating Aboriginal Australians intervention. There is evidence from the Vassilev *et al.* review<sup>164</sup> that emerging groups may be related to better health outcomes but the authors note that research is needed on how social networks actually enable people to make sense of health and how the interaction shapes their health practices and discourse. We include the discussion of the potential of social networks in improving social status here, because the link between peer support and reduction in health inequalities is the most tenuous in our mid-range theory. Although the Advisory Network certainly confirmed the power and importance of networks, the published programme data had far less detail on how perceptions of social status were equalised as a result of participation in networks.

## Summary of the chapter

In this chapter, a mid-range theory for peer support and HL was identified by relating the concepts of empowerment education with the relatively new concepts of interactive and critical HL. We first examined how peer-support research has been based on two different epistemologies represented by an authoritarian compared with a negotiated stance to intervention design and evaluation. The authoritarian approach limited ability to use principles of empowerment education in peer support, whereas the negotiated approach fostered a process in which cocreation of the programme empowered both PSs and participants. We compared this process to the concept of cultural literacy, making the point that recognising and using collective beliefs, customs, world views and social identity is key to developing relevant and appropriate HL interventions. The cultural literacy contexts of the respective programmes was then examined, and from this we posited that implementing organisations that embody an equity context are best placed to establish peer-support programmes that have the potential to reduce health inequalities. Key concepts related to a health inequality context – specifically perceived social status, exclusion, social isolation and fear of negative evaluation – were then mapped to the programme data to determine whether peer-support interventions have the potential to reduce health inequality. Because the programme evaluations did not specifically assess these concepts, we looked at how the benefits of social networks in our data were related to reduction of social isolation, inclusion, and ability to take action despite potentially negative evaluation. Conceptually, it appears that peer-support programmes that enable the development of effective social networks in communities have the potential to reduce health inequalities.

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# Chapter 7 Discussion

n this chapter we start by summarising the findings, and discussing the strength of the evidence. We critically review how the evidence was constructed from the perspective of approaches to theory development. The mid-range theory is then compared with related literature to situate the theory to the existing body of knowledge.

## **Summary of findings**

Our review aimed to answer two broad questions on the relationship between peer support, HL and health inequalities:

- *Research question 1* What approaches to CE are most effective in promoting peer support, to which people and in what circumstances?
- *Research question 2* How does CBPS impact on understanding of existing health information and use of health information and health services to improve health and reduce health inequalities?

Addressing these two questions in turn:

## Research question 1: what approaches to community engagement are most effective in promoting peer support, to which people and in what circumstances?

The approaches to engagement varied by stage of programme design and implementation. At one end of the engagement spectrum, there were organisations that took an informing approach characterised by using researcher and policy-maker views of what would work to develop the theory of change. The theory of action for these programmes, as a result, used strategies for recruitment and methods for training that were prescribed by the host organisation with limited community consultation. During implementation, PSs subsequently felt limited in terms of using their tacit and experiential knowledge, although this was actually supposed to be the active ingredient of the intervention. Programmes that appeared to have the more prescriptive approach, however, still 'worked' in some cases. Closer examination reveals that there were positive mechanisms, such as demonstrating respect for the knowledge of PSs, manifested in willingness to allow them to use their community-based experience to tap into existing networks and create new networks. Thus higher degrees of initial control over the programme were moderated when organisational sponsors and professionals supported a more collaborative model of implementation. At the other end of the spectrum were programmes that embodied a philosophy of active CE from the outset. It is tempting to assume that these programmes would be consistently successful, but examples indicate that degree of control and autonomy is again the tipping mechanism. Programmes that reverted to a more controlling stance, for example when community-based recruitment failed, experienced less success in finding PSs from the community. Similarly, programmes that appeared to offer interactive training could still experience problems when ongoing support and supervision was perceived to be too prescriptive.

Therefore, on a health systems level the sponsor organisations and HPs need to be skilled at establishing and sustaining an equity context in order to promote CBPS programmes. We define an equity context as a context in which organisations prioritise the importance of health inequalities in policy and funding; community challenges and needs are recognised; people are ready to investigate root causes of poor health and well-being; the sponsor allows adequate time for development of relationships and connections; experiential cultural knowledge is valued; there is awareness of the importance of sharing power and control; collective beliefs, customs, world views and social identity are acknowledged and actively used in programme planning and implementation (cultural literacy); PSs are given control of how, when and where to deliver the intervention; and emergent outcomes are used to inform and modify the intervention.

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## Research question 2: how does community-based peer-support impact on understanding of existing health information and use of health information and health services to improve health and reduce health inequalities?

At the implementation level, maintaining an equity context is also instrumental in enabling participants to understand information and use health services. Recruiting participants was based on the principle of homophily – the assumption that perceived similarities with PSs would foster relationships of trust. Perceived similarities may provide a window of opportunity when first establishing a connection but homophily alone is not enough to establish trust. PSs need to be skilled in establishing equitable relationships with participants who promote a dialogue of active and critical reflection on the root causes of poor health and well-being. The ability to establish positive relationships is, however, challenged by negative attitudes towards the HB in question. PSs therefore need time to develop relationships with communities, because in cases where there is fear of being judged and a lack of readiness to consider change repeated contact may be needed to motivate and sustain engagement (*Figure 37*).

Successful peer-support programmes have the potential to reduce health inequalities by changing perceptions of social status. They do this by creating a common bond with disadvantaged and vulnerable individuals or groups, promoting social interaction and sharing of problems and experiential knowledge. This dialogue among equals promotes participatory parity and encourages the formation or strengthening of social groups. The individual's perception of his/her own social status improves from being included in a group and the loss of social identity that he/she may have experienced as a result of their low social status is restored. As this bond develops, people come to trust the group and reflect critically on their circumstances, their aspirations and their capabilities. Anxieties about being evaluated negatively for their health condition or inability to manage HB are mediated by affirmational and instrumental support from the group. People become more confident – both individually and collectively – to consider behaviour changes. Practical and informational support enable them to select goals that they are capable of achieving, and success with small changes increases confidence and motivation to negotiate and self-manage health.

Groups that are enabled to take control of their own situations can collectively change social norms and practices themselves and within their social and community networks. The ability to assess the scale of the change across the wider community was limited by the fact that most of the evaluations occurred in the early stages of programme implementation. The studies did not aim to collect evidence on the relationship between HL and engagement in social action for health.



FIGURE 37 Peer supporters must consider readiness to consider health (artwork: Sarah Smizz).

## Strengths and limitations of the review

In realist synthesis the strength of evidence is not only judged against the original data, but also by the methods used to develop theory. In this review a cross-section of topics related to health inequalities in socially disadvantaged groups was used to increase opportunities to find disconfirming cases.<sup>165</sup> Initial bias in case selection was reduced by conducting a comprehensive search for literature, and selecting topic areas with a substantive number of publications. Depth within each health topic was maximised by developing strategies for cluster searching, which produced sets of articles related to a single study.<sup>64</sup> In some cases this produced a larger data set, and in all cases it maximised opportunities to identify and develop within-programme theory. As noted in *Chapter 2*, however, the reporting of linkages between mechanisms and outcomes was incomplete. This meant that configuration was required in order to hypothesise what the associations might be. Several types of triangulation<sup>166</sup> were used to lend rigour to the analysis, including:

- Data triangulation Different health topics and disadvantaged populations were included.
- Investigator triangulation Each health topics was analysed by a different team member; analysis was cross-checked by other team members.
- Theory triangulation The concepts in cited theories were extracted and compared for similarity and difference; related theories were tested for goodness of fit.
- Methodological triangulation The source data included peer reviewed quantitative and qualitative studies, unpublished evaluation reports, training documents, and comparison with the experiences of members of our Advisory Network.

#### Data triangulation

In realist review, explicit sampling decisions are made based on relevance and richness of the available studies, as well as the policy brief. We focused on UK studies in the first instance, which enabled us to review how CBPS is conceptualised in a UK context. We included topics focusing on key themes in the Marmot report to address health inequalities,<sup>86</sup> for example health risks; developing healthy and sustainable places and communities; and strengthening the role and impact of health prevention. We chose to use a sampling for maximum diversity approach, including a wide range of topics, and populations encompassing the equality strands of age, ethnicity, faith/religion, gender and sexual orientation in order to identify potential patterns for peer support. This diversity allowed data triangulation. However, the approach risks the production of a UK-centric viewpoint on peer-support interventions. We compensated for this by including programmes located in North America, and returning to the literature after synthesis to identify whether or not studies conducted in other countries had produced different findings.

#### Investigator triangulation

As our review sampled the literature rather than aggregating it, the issue of bias must be addressed. The team comprised a range of backgrounds including experience in conducting systematic reviews of effectiveness; qualitative evidence synthesis; mixed-methods reviews; qualitative research; realist evaluation and synthesis; community-based participatory research; and health promotion. The range of disciplines included information science, nursing, public health, health psychology and sociology. The members of our Advisory Network had experience of delivering peer support in all of the health topics covered in the review, and their backgrounds included untrained volunteer PSs, trained CHWs, and HPs who had been trained in community-based approaches to peer support. In addition, several members had themselves been recipients of peer support before moving on to a PS role. Both PSs and supervisors/managers of peer-support programmes were included in the Advisory Network, as well as people who had authored some of the programme reports. We feel that the diverse perspectives strengthened the review process in terms of reflexivity, because different participants questioned each other's stance on what was known and how we constructed the knowledge.

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### Theory triangulation

Theory was initially identified from the stated programme theory. There was little similarity between the stated theories, which included theories for individual behaviour change, adult education and community activation. We therefore took a grounded approach to developing theory, by identifying key concepts in the data and developing causal strands. The strength of the causal strands was tested by exploring if there was a match across positive and negative dimensions of the CMO configurations, and by looking at if programmes demonstrated recursive causality.<sup>144</sup> Where positive CMO strands were identified in a programme stage, negative examples were also present. The CMO configurations were further tested and refined via cross-programme analysis. Recursive causality was demonstrated, in that programmes that experienced more than one negative strand had less chance of being successful, while those that experienced more positive strands demonstrated a cumulative effect that appeared to be associated with positive intermediate outcomes.

The review used an approach which has been described by Denzin and Lincoln<sup>167</sup> as 'bricolage' to configure the data and develop the programme theory.<sup>167</sup> Bricolage is an approach to research that represents a critical approach to inquiry incorporating multiple perspectives, multiple theories and multiple methodological approaches.<sup>168,169</sup> In a systematic review, it can add rigour, complexity, richness, breadth and depth – particularly when the review encompasses both gualitative and guantitative research designs. As we wanted to include both culturally supported and empirically tested interventions in the review, critical bricolage was useful in terms of exploring how different perspectives of community-based versus community-placed interventions shaped the programme design and the knowledge generated. As our aim was to discover the relationship between peer support and health inequality by drawing upon both culturally supported and empirically tested interventions, critical bricolage was also appropriate because it is 'dedicated to questioning and learning from the excluded'.<sup>168</sup> The inclusion of Network perspectives and different types of study design gave opportunities for discovering experiential knowledge, which is often missing in dominant research narratives.<sup>169</sup> For our review, moving between qualitative, quantitative and practitioner accounts of peer support enabled us to identify how peer-support interventions are socially constructed in relation to their surrounding context, and to explore how ideological stances affected the equity of interventions. The use of controlled trial studies in a realist review poses the challenge of constructing causal strands when the phenomenon of interest has been removed from its surrounding context. The context therefore has to be extracted from using multiple methods because the entities 'are often removed from the context that shaped them, the processes of which they are a part, the relationships and connections that structure their being in the world<sup>169</sup> (p. 74). Multiple analytical methods were used that included qualitative thematic analysis and constant comparison of programme theories in the first instance, moving on to methods used in theory-driven evaluation to construct the programme theory. The mid-range theory was developed using methods for theory construction found in the social sciences, by 'deconstructing' the theories that programmes claimed to be using into their constituent concepts, identifying the common components, and combining these with the constructs emerging from the grounded analysis to construct a hybrid theory.<sup>88</sup>

Although this methodological approach seemed justifiable on multiple fronts, the potential weaknesses of the review and the strategies used to redress these should be considered. These include:

- conceptually insecure definitions for CBPS, HL and a lack of explicit links between peer support for marginalised groups and health inequalities
- the challenge of linking stated outcomes to the (often more valued) intermediate outcomes that focused on process
- the data available, the quality of reporting context, mechanism and implementation
- the lack of explicitly stated theory particularly theories of change
- the use of theories aimed at individual-level behaviour change for community-based interventions.

Systematic reviews of effectiveness commonly start by constructing an operational definition for the components of an intervention and the primary and secondary outcomes. Our search on CBPS produced
few articles that explicitly investigated peer support from a CE perspective. Instead, we were presented with a range of articles that labelled peer support as 'community based' but constructing an operational definition was challenged by very different epistemological stances. The type of CE encompassed a spectrum from minimal engagement across programme stages to maximum involvement and coproduction throughout. 'Community based', therefore, could mean that outsiders placed a programme within a community setting. However, it could also mean that the community itself decided upon the need to create a programme that was either led or cocreated with insider involvement. This epistemological tension between 'community placed' and 'community based' was recently outlined in an Institute of Medicine report commissioned for the express purpose of developing a framework for community-based prevention strategies and wellness programmes.<sup>170</sup> Community-based programmes are usually designed by academic researchers who design a programme by involving members of the affected communities at various stages to helping the planning, development, implementation and/or evaluation of the initiative.<sup>171</sup> The involvement can be at various levels, ranging from being invited to contribute input to conceding that the community should take the lead in deciding on the most appropriate approach. Community-placed programmes, on the other hand, lack engagement at key stages of programme design and development, trying to generate community support after the intervention has been decided or introduced into the community.170

Articles containing peer-support interventions mainly defined HL as health education or health promotion, and measures for health inequality were not explicit. As a result, we had to do conceptual analysis within the review for each of our three constructs.

In our review, community-based programmes that engaged at the level of consultation could not be easily split from those programmes that engaged at the level of coproduction, because the degree of community involvement and level of engagement varied by stage within programmes. The variation was greatest when programmes identified emergent negative outcomes and retraced key developmental steps – such as conducting cultural needs assessment – to improve relevance. We tried to compensate for internal variations in engagement by analysing the process across programme stages. Assumptions about culturally appropriate interventions were tested through our Advisory Network, where there was explicit discussion about the different approaches to designing programmes using an authoritarian stance compared with a negotiated stance.

Most systematic reviews use the primary and secondary outcomes identified during scoping to construct a definition of outcomes for the review. Our included studies defined outcomes as uptake of health promoting/risk reducing behaviour, change in lifestyle, increased uptake of a health service, improved well-being and quality of life, weight loss, improved self-management, and ability to maintain behaviour change. Our proposed intermediate outcome was an improvement in HL and our proposed primary outcome was a reduction in health inequality. The review was challenged by the fact that outcomes for interactive and critical HL are still being operationalised. We clarified outcome definitions by using descriptions from the Advisory Network, discussion papers and conceptual analyses of HL published during our review.<sup>19,172</sup> The review revealed a set of emergent process outcomes, which we refer to as intermediate outcomes. In many cases these were not included as part of the original study design as phenomena worthy of measurement; however, the pattern across different programmes indicated that these needed to be acknowledged as antecedents or pre-conditions for achieving health-related outcomes. The intermediate outcomes included helping people to connect with each other; establishing friendship networks; and getting people to participate in dialogue and mutual reflection to critically construct socially generated knowledge. The importance of these process outcomes – which are broader than just health – is noted by the Institute of Medicine report,<sup>170</sup> as well as in many health models.<sup>173,174</sup> Our finding that empowering people to take social action for health was not researched in peer-support programmes echoes the findings of a systematic review of community-based participatory research, which found that of 60 included studies only four included the aim of increasing community capacity or engendering empowerment as a major outcome.<sup>175</sup>

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It is important to note that our search identified those publications that identified themselves as focusing primarily on peer support as the intervention, but this ignores a broader set of CD studies that focus on community networks, community initiatives and community advocacy. In these interventions it is likely that peer support is one of the main components, but not identified as such, although it may be key in social advocacy for health.<sup>176</sup>

Several studies – particularly the quantitative studies – lacked rich description of how peer-support programmes were established or implemented. There was a noted lack of information on mechanisms in some clusters, while others provided rich description of participant attitudes and context. We tried to get a more complete description of how contexts interacted with mechanisms to influence the trajectory of interventions by identifying sibling articles on the same project, or same topic, that were produced by the same authors. Cluster searching not only produced articles by the same authors, but also in some cases enabled us to map the development of programme theory within a body of work over time. Although this allowed us to accumulate evidence from multiple related sources, we noted that none of the articles discussed unintended or negative consequences of peer support. We sought views from the Advisory Network, who were of the view that peer support triggered potentially negative experiences if it was offered before people were ready to take advantage of it.

One of the characteristics of realist synthesis is stakeholder involvement. Stakeholders are topic experts who have input into negotiating the review topic, defining the scope of the review, informing tool development, increasing understanding of how things actually work, 'validating' emerging findings, and shaping the presentation of the review findings to support dissemination.<sup>59,62</sup> The extent of stakeholder involvement varies across different reviews but usually involves periodic meetings at key stages of the review process.<sup>177,178</sup> Our Advisory Network differed from other stakeholder groups because the Advisory Network was large (120 participants). The composition of the Advisory Network ranged from experienced CHWs to volunteers with 1–2 years' experience in providing peer support. We aimed for a diverse range of practitioners rather than limiting to 'topic experts', which enabled us to relate programme theory to culturally appropriate programme interventions. This was an appropriate approach for identifying culturally appropriate interventions. The Advisory Network meant that there were varying degrees of engagement. Some gave input at a particular stage, while others participated at all stages.

Reviewers are generally advised to identify candidate theories early on in the process and use these theories as a conceptual framework for data extraction. The included studies cited a wide range of theories, indicating different epistemological approaches to peer support. We wanted to compare the relative effectiveness of these different approaches, so adopted a grounded approach, directly developing theory by extracting it from our articles and working with practitioners in our Advisory Network to more directly link practice with theory. The emerging theory was then compared with other theories in social science literature. Developing candidate theories at a later stage in the review instead of using mid-range theory to shape the process at the outset has been defended when the review contains multiple open-ended questions.<sup>59,60</sup>

#### Review findings in the context of the broader literature

There are as yet no published reviews for CBPS to promote critical and interactive HL. Related reviews and syntheses have been recently conducted, however, on perceptions of peer-support<sup>3</sup> adaptation of health promotion interventions for ethnic groups,<sup>118</sup> the role of social networks in enabling self-care,<sup>164</sup> the role of CHWs,<sup>179</sup> and power and empowerment in health promotion.<sup>159</sup> The findings from each review, as well as relevant citations within the reviews, were examined in relation to our findings for stages of programme development and implementation and the mid-range theory for peer support.

#### Programme design findings

The CERI review<sup>9</sup> included 143 peer- or lay-delivered intervention studies and nine process evaluations conducted alongside trials explaining why things may or may not have worked in peer- or lay-delivered interventions. Two process evaluations in the CERI review concluded that the process of consultation and collaboration at the design stage influences the planning and delivery of the intervention.<sup>180,181</sup>

A qualitative study within a RCT noted lack of engagement with community groups, which affected recruitment. In some of the included studies, PSs were unprepared when they encountered cultural differences, and language barriers compromised success.<sup>182</sup>

A peer-support review of interventions for breastfeeding found that poor attendance was related to issues with local services, transport and safety. The implementers were unaware of these issues until women's views were sought retrospectively – after design of the intervention. In contrast, an intervention with prospective community involvement experienced good attendance.<sup>183</sup>

The Liu *et al.* review,<sup>118</sup> which contained 173 reports of adapted health promotion interventions, confirmed that collaboration was of great importance with both local and respected leaders, as well as ethnic-specific institutions and professional organisations.

One of the process evaluations noted the importance of developing a strong and trusting relationship between academic and community partners.<sup>184</sup>

In Kane *et al.*'s realist synthesis of CHWs,<sup>179</sup> the authors observed that power differentials between professionals and workers can either be addressed through relationship building or neglected at the expense of trust.

Laverack<sup>159</sup> found that participation in framing and assessing the problem is still a major shortcoming of health promotion programmes and lack of involvement at this stage is related to failure to achieve programme aims. Negative outcomes are associated with interventions that do not address participants' unmet needs, which was similar to our finding that developing understanding of, and addressing, needs is vital to programme success.<sup>179</sup>

Interventions cannot be selected without a thorough exploration of community norms, as well as 'the socio-cultural context and constraints that operate within a given community. Without this socio-cultural knowledge any intervention may "fall at the first hurdle" due to contradictory cultural beliefs and/or constraints upon families in taking up or implementing designated changes'.<sup>131</sup>

#### **Recruitment findings**

Andersen *et al.*<sup>185</sup> examined recruitment, retention and activity of volunteers promoting mammography use in rural communities. They report that recruitment to such activity was not untypical of other volunteer initiatives but remarked that 'special efforts may be required to retain volunteers ... and to encourage their activity'. Utilising informal networks that are ethnically and culturally appropriate to promote the programme was recommended by Liu *et al.*<sup>118</sup> Selecting or electing CHWs from within the beneficiary community engendered a sense of being valued in the workers and was related to positive outcomes.<sup>179</sup> Conversely, being selected from people outside the community led to an absence of relatedness and affected CHWs' motivation. Poorly defined roles for CHWs were associated with a lack of involvement and motivation, as well as causing confusion and negative outcomes.<sup>179</sup>

#### Training and ongoing support

- Training materials and a delivery approach that are based on cultural norms and values, including approaches such as storytelling, can contribute to intervention success.<sup>186</sup>
- Three process evaluations noted the importance of ongoing training and support.<sup>179,187–189</sup> When combined with supervision and staff meetings, the support can reduce turnover and contribute to success.<sup>188</sup> Pragmatic training and on the job mentoring is associated with feelings of increased self-esteem in CHWs.<sup>179</sup> Local health system supervision and mentoring added credibility to the role, as well as a perception of increased social status.<sup>179</sup>
- This is similar to our findings that ongoing support in the form of additional training, and individual or group supervision contributed to PS satisfaction and confidence when successfully delivered, and undermined confidence when it was not offered in a supportive way. Our Advisory Network members related how being included in health service provision triggered feelings of being valued, being able to make a contribution and 'feeling that you are part of something' (*Figure 38*).

#### Content and delivery of the intervention

The CERI review found that a 'community-specific, completely administered programme content appears to be an important process influencing CE initiatives'.<sup>9,186,190</sup>

One process evaluation alongside a trial found that the proposed approach to the intervention may not be acceptable to the workers who are going to deliver it. They recommended a more holistic approach to health, which focuses on self-esteem.<sup>191</sup>

This accords with Laverack's observation<sup>159</sup> that holistic approaches to exploring upstream community-identified problems enables people to identify their own needs and produce more locally acceptable solutions.

Creating or cocreating material using expert opinion and members of the target population can increase relevance and acceptability. Including participants 'ensures that the themes are relevant, allows the material to present the health issue from the point of view of the learners, carries the authenticity of the learner/authors, and can lead to further involvement. Most importantly, this level of involvement serves to reaffirm the vital role of learner as activist'.<sup>192</sup> Matching content to the population's social and cultural



FIGURE 38 Opportunities to contribute to increase connectedness (artwork: Sarah Smizz).

values, and ensuring that the intervention goals and outcomes are culturally appropriate for participants are key when working with ethnic groups. Materials need to be in the target population's language, and reflect the way that language is used in terms of concepts and vocabulary.<sup>118</sup>

Accessibility of the programme was defined differently across the reviews. Geographical location and timing influenced reach and participation in several of the trials included in the CERI review.<sup>9,186,190</sup> Location needs to be considered, however, in relation to how the programme defines 'community'. Where community is defined geographically as simply a place where people live, placing a programme in the middle of that place will not necessarily increase reach. Similarly, placement in a demographically targeted area, for example placement of smoking cessation programmes in a Pakistani community, may not increase participation if the demographic group is heterogeneous and disconnected. Locating the nexus of social relations appears to be most important.<sup>193</sup>

A qualitative evaluation of a RCT mentioned that interventions focused on individuals at the neglect of social networks.<sup>182</sup> The importance of social networks was noted in a breastfeeding systematic review, in which the benefits listed by the women included opportunities for social contact, to talk about problems, and to make friends.<sup>183</sup> Similar social contexts and value systems facilitate rapport,<sup>3</sup> which reflects the finding in our review that shared values are as important as perceived. The ethnicity review noted the importance of encouraging social support and including social support affected participation and retention.<sup>83</sup>

There appears to be some interest in exploring the connections between membership in social networks, social stigma, change in perceived social status and improvements in self-efficacy that could impact on health inequalities.<sup>194</sup> However, a recent conceptual review of the importance of social networks in managing long-term and chronic disease noted that although people perceive these networks to be beneficial, they are rarely the focus of interest in health research.<sup>164</sup> The persistent focus on individual interventions has been noted in breastfeeding, where a 2012 review found that in 30 research articles and four reviews published between 2000 and 2008, the majority of peer-support programmes for breastfeeding literature have concluded that interventions need to focus on 'the centrality of relationships'.<sup>131</sup> Community locales need to be defined by first identifying people who possess membership to a group, common symbol systems, shared values and norms, shared needs and shared emotional connections.<sup>195</sup> Once the community is located by finding the social interactions, the placement of the programme can be aligned with where those interactions normally take place.

The number of sessions and the amount of time spent with participants were both listed as influential factors in the CERI review.<sup>9,189,196</sup> However, the definition of 'intensity' as a proxy for relationships with PSs may mask the dynamics of the interaction. The need for a specific type of encounter should be considered in tandem with the topic being addressed and the type of support needed. A qualitative synthesis of breastfeeding included in our review<sup>127</sup> noted that the quality of the time spent with participants was a more important factor than the amount of time. This was described as having an 'authentic presence', through which women felt that the supporter could 'be there' for them. For some health issues, the number of encounters may not be a meaningful indicator of relationships. Conversely, where the PS is engaged with new social networks or discussing sensitive topics, the number of encounters, the duration and the period of time may be very important. This was noted in the HIV Safer Sex programme, through which participants who spoke with peer educators on several occasions were more likely to consider changing their risk behaviour.<sup>81</sup> Similarly, a narrative synthesis noted the need for high-intensity interventions

over a longer period of time when the aim is to promote interactive and critical HL.<sup>197</sup> The importance of 'time' was echoed by the Advisory Network, whose members said:

A lot of time was needed to build relationships which was particularly critical when interventions were targeting groups who were more marginalised. An example was the peer led interventions with gypsy and traveller communities. 'It takes time to get to know each other and trust that your experiences will be portrayed respectfully.' The development of the intervention tool (video) took nearly two years to complete, but this was in part due to the long time invested in building relationships 'but it was worthwhile taking the 2 years. People wouldn't have felt comfortable to talk any sooner'.

Advisory Network #3

Participants expressed fear of their experiences not being treated respectfully. They needed time to be sure that the 'implementers' could be trusted and were people with whom they could identify. A rapport needed to develop, again only possible with time spent together.

Characteristics of peers were considered in several of the reviews. There was some agreement that suggested that community members providing interventions need a similar ethnicity and life history; empathy; tenacity; problem-solving skills; a direct, honest, non-judgemental manner; belief in participants' worth despite their history; and previous experience working with high-risk populations.<sup>83,188,189</sup>

Peer support had the 'potential to replicate power dynamics' if the helper assumes a position of superior knowledge, but the potential imbalance can be levelled 'through the development of egalitarian, affective relationships'.<sup>3</sup>

#### Creating an equity context

The observation that organisations and interventions need to level differences in power relations when working with communities was made by several reviews.<sup>3,118</sup> Issues of power and control between supporting organisations and those delivering the intervention were mentioned in Ritchie *et al.*,<sup>191</sup> who noted that a lack of flexibility in the organisation could hinder delivery of the intervention. Laverack<sup>159</sup> explains the tension by pointing out that governmental organisations and government-funded non-governmental organisations are usually responsible for delivering health promotion programmes, and these organisations are accountable to bureaucracies that may be 'chained to traditional ways of thinking and acting, which inhibit the effective inclusion of empowering approaches'<sup>159</sup> (p. 134). An extensive review of maternal and child health/family planning programmes found that organisational structures that provide opportunities for collaboration and support across all stakeholders can be instrumental in meeting programme goals.<sup>198</sup>

The Liu *et al.*<sup>118</sup> review of tailoring interventions for ethnic groups found that addressing discrimination and mistrust, and involving local leaders at all stages of programme development and design affects ability to recruit, relevance of materials, appropriateness of the delivery, and participation. The findings produced from this review were similar in many respects to the equity context that emerged from our realist synthesis (*Figure 39*).

The Embuldeniya *et al.* review<sup>3</sup> found that participants associated changes in outlook, knowledge and behaviour with increased empowerment. The process of empowerment was defined as involvement in 'setting and achieving goals, gaining information, receiving advice, sharing experiences, and making connections with fellow peers, providers and others in the community', with the end result being 'acquiring confidence and ability to cope, take control of one's disease and change one's outlook'.<sup>3</sup> A review of the effectiveness of empowerment interventions was commissioned in 2006 by the



**FIGURE 39** Programme Theory of Adapted Health Promotion Interventions. Reproduced with permission of NIHR Journals from Liu JJ, Davidson E, Bhopal RS, White M, Johnson MRD, Netto G, *et al.* Adapting health promotion interventions to meet the needs of ethnic minority groups: mixed-methods evidence synthesis. *Health Technol Assess* 2012;**16**(44).<sup>118</sup>

Health Evidence Network, and this has recently been used to conduct a rapid review of empowerment in relation to peer support.<sup>115</sup> Both of these reviews iterate the key concepts related to empowerment that were identified in our analysis, and note that the effects of empowerment can be experienced not only by recipients of an intervention, but also by those providing the support:

- improved self-efficacy and self-esteem
- greater sense of control
- increased knowledge and awareness
- behaviour change
- a greater sense of community, broadened social networks and social support.

Empowerment is related to participation, in the sense that individuals who participate in discussion and activities with like-minded people may develop trusting relationships, thereby allowing them to share difficult and stressful situations and obtain ideas for successful coping.<sup>199</sup>

## **Chapter 8** Conclusions and recommendations

#### **Conclusions from the realist synthesis**

From the synthesis, we conclude that CBPS is likely to be effective when the surrounding context, for example the people and the organisations that are designing and developing the programme allow adequate time for engagement in the processes of:

- identifying community and cultural needs
- using learning from the needs assessment to design appropriate strategies for recruitment and training
- involving local people in the recruitment process
- building on experiential knowledge to codesign training materials
- using empowerment education approaches to deliver the training
- promoting partnerships between PSs, community organisations and HPs to facilitate embedding of the programme within existing health services and community activities
- providing ongoing support that focuses on problem-solving to PSs, enabling them to develop capabilities in delivering the intervention
- allowing PSs to exercise autonomy and control over the tailoring and delivery of the intervention.

We further conclude that CBPS is likely to promote the development of HL when PSs are given time to:

- engage with community members and develop enough rapport to get them involved in social networks
- facilitate social networks to enable community members to create new and further enhance existing relationships that incorporate dialogue, critical reflection, and development of critical consciousness related to the social determinants of health
- allow participants to be in control of identifying what they would like to do to address health and other issues, as well as taking action to develop capabilities.

Many of the conclusions are not new – the Advisory Network noted that the principles of effective engagement have been previously identified in a plethora of documents, reports, workbooks, and general guidance on best practice in CE (e.g. see UK resources, such as Community Engagement Toolbox, www.community-toolbox.org/; Urban Forum and National Association for Volunteer and Community Assistance (NAVCA) 2009, *Developing your Comprehensive Community Engagement Strategy: A Comprehensive Guide for Local Strategic Partnerships*, www.navca.org.uk/; Communities Scotland 31 July 2009, National Standards for Community Engagement, www.scotland.gov.uk/; Community Places 2012 Community Planning Toolkit, www.communityplanningtoolkit.org/).

What is surprising is that these principles are not being used when designing and researching peer-support interventions that focus on working with disadvantaged and vulnerable groups to address social determinants of health. HPs continue to base interventions on the provision of professionally determined information instead of taking a relational perspective to developing socially generated knowledge and understanding via interaction and communication. The equity context surrounding the intervention needs to be considered an integral part of the programme design.

#### Recommendations

We have several recommendations related to the above conclusions. The first four recommendations relate to the design of peer-support interventions. Where the aim of the intervention is to reduce health inequalities, attention needs to be paid to the fact that the design and conduct of the intervention can replicate unequal power relations. Conditions of disparity compromise the relevance and uptake of the intervention, potentially disempowering PSs and participants alike.

#### Recommendations for programme managers

#### Recommendation 1: peer-support interventions need to be designed and conducted using existing principles of good practice for community engagement

This seems like an obvious recommendation, but the lack of CE at some stages of programme design and implementation indicates a low level of awareness about guidance for CE (*Figure 40*).

The findings from the various sources used in this review agreed that adequate time is needed to establish relationships with community partners, as well as establishing relationships between PSs and communities. The health system continues to maintain a hopeful focus on achieving short-term clinical effects despite the fact that researchers evaluating community initiatives have pointed out that the time periods expected to achieve behaviour change are very unrealistic.<sup>200</sup> These expectations for a quick result place unrealistic expectations on programmes to produce evidence for what are termed 'primary outcomes' within a period of time that is usually < 2 years. When the evidence is not produced within this time period, there is a risk that potentially effective community-based programmes will be discontinued. The Advisory Network agreed that a recommendation was needed about the amount of time needed for good community-based programmes to develop:

I don't think [commissioners] invest the time in learning the politics of what really matters. This is innovation, this is a different way of doing things and most of the commissioners are thinking in the short term [while peer-support programmes are] beneficial in the long term. The NHS can't innovate because they're short term, it's short term commissioning, leaders are thinking short term and innovation takes a long time to you know to show the results of there's a fundamental issue here. Having commissioners lined up, being made to listen to conversation like this would be a way to, a way to bridging that gap.

Advisory Network #11



FIGURE 40 Professionals need to use existing CE guidance (artwork: Sarah Smizz).

## Recommendation 2: interventions need to be funded for sufficient lengths of time – at least 3 years – to enable the collection of data on both intermediate and higher order impact outcomes

Attention also needs to be paid to the process of coconstructing peer-support interventions. For years, it has been acknowledged in the field of health promotion that a didactic approach to health promotion is not effective.<sup>201</sup> Despite this recognition, principles of adult education appear to be inconsistently supported during intervention design, and incompletely reported in publications.

#### Recommendation 3: organisations that are funding the design of peer-support interventions need to ensure that peer-support interventions are coconstructed, using experiential knowledge and based on theories of adult education

In community-based interventions, the outcomes given primacy need to be intermediate outcomes of process. These intermediate outcomes of initial engagement, relationship building, creation of a secure and trusting environment in which to question social and environmental barriers to maintaining health are the antecedents to realising the longer-term outcomes of, for example, increases in physical activity, healthier food choices, weight loss and better control of blood glucose levels. There are now several studies that recognise that research designs that simply aim to monitor changes in individual behaviour are at risk of misinterpreting success. Quantitative designs need to acknowledge the significance of the wider context of CD.<sup>202</sup> Further, many of the outcomes that are currently used in programmes that are labelled 'community based' appear to be related to theories of individual behaviour change.

## Recommendation 4: community-based peer-support programmes need to be based on theories of community development and social networks

In terms of health inequalities, there appears to be an important and under-researched connection between perception of social status and poor HL. Participation and membership in social networks appears to improve perceived social status, with the potential to promote development of capabilities and reduce health inequalities. The relationship between these constructs needs further articulation and evaluation.

#### **Recommendations for researchers**

# Recommendation 5: community-based peer-support interventions need to include measures of social process as well as measures of health outcomes, which enable the evaluation to place the findings within the wider community context

Although possible measures of social process were identified in qualitative discussion of the various clusters, none of the clusters operationalised measures of social process (*Figure 41*). There is scope for a conceptual review that identifies and produces a taxonomy of shorter-term social process outcomes.

## Recommendation 6: the constructs of critical and interactive health literacy, and the relationship between health literacy and the development of capabilities, need further research

The ways in which peer support promotes capabilities related to HL has yet to be researched. Conceptual models, such as that of Sorensen *et al.*,<sup>19</sup> should be applied to establish whether or not the concepts of 'access', 'appraise', and 'apply' are useful in terms of assessing development of capabilities.

#### Recommendation 7: community-based peer-support programmes need to investigate the conditions that enable people to make the transition from mutual small group support to cohesive social networks to community advocacy for better environmental and social conditions that promote health

There is a significant research gap in terms of exploring how peer support relates to the constructs of social organisation and advocacy, and engagement in social action for health. The outcomes of increasing community capacity and engendering empowerment are also neglected in the peer support and HL research.



FIGURE 41 Inequality is related to the degree of social support (artwork: Sarah Smizz).

#### Implications for policy-makers and commissioners

Before implementing CBPS programmes, policy-makers need to:

- explore the local equity context including, exploration of whether past relationships with communities were perceived to be relationships of parity or inequality
- determine if the sponsoring organisations are equipped with the community-based engagement skills needed for coproduction of peer-support programmes
- identify evaluators with the skills to use a mixed-methods approach to evaluating both the social process and the health outcomes
- allow adequate and protected time for the development of trust and relationships across providers and community groups
- include community groups in both implementation and evaluation.

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#### **Contributions of authors**

**Janet Harris**, Senior Lecturer, designed the review, wrote the protocol, extracted the data, analysed the programme stages, contributed to writing the report and takes responsibility for the overall integrity of the report.

**Jane Springett**, Professor of Health Promotion, designed the review, wrote the protocol, extracted the data and contributed to writing the report.

**Liz Croot**, Research Fellow, designed the review, wrote the protocol, extracted the data, analysed the programme stages and contributed to writing the report.

**Andrew Booth**, Reader in Evidence Based Information Practice, designed the review, wrote the protocol, extracted the data, analysed the programme stages, and contributed to writing the report.

**Fiona Campbell**, Research Fellow, designed the review, wrote the protocol, extracted the data and contributed to writing the report. Fiona Campbell also analysed cross-cutting themes, which contributed to all stages of analysis. Analysis was checked by all members of the team.

**Jill Thompson**, Lecturer, extracted the data, analysed the programme stages and contributed to writing the report.

**Elizabeth Goyder**, Professor of Public Health, designed the review, reviewed the protocol and extracted the data.

Patrice Van Cleemput, Research Fellow, designed the review, wrote the protocol and extracted the data.

**Emma Wilkins**, Research Fellow, extracted the data, analysed the programme stages and contributed to writing the report.

**Yajing Yang**, Graduate Research Assistant, extracted the data, analysed the programme stages and contributed to writing the report.

All authors contributed to determining which research should be included.

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## Appendix 1 Abstract sift sheet

Ref. ID	Abstract	Research or evaluation	Peer support	HL
		INCLUDE – systematic review	INCLUDE – buddy	INCLUDE – explicit literacy
		INCLUDE – RCT	INCLUDE – champion	INCLUDE – health education/ health promotion
		INCLUDE – other quantitative research	INCLUDE – coach	INCLUDE – health information
		INCLUDE – qualitative research	INCLUDE – CHW	EXCLUDE – no HL
		INCLUDE – evaluation	INCLUDE – counsellor	UNSURE – refer
		INCLUDE – models and theories	INCLUDE – health activist	
		EXCLUDE – narrative review	INCLUDE – health trainer	
		EXCLUDE – descriptive article	INCLUDE – lay/health advocate	
		EXCLUDE – others	INCLUDE – link worker	
		UNSURE – refer	INCLUDE – mentor	
			INCLUDE – navigator	
			INCLUDE – peer educator	
			INCLUDE – promotora	
			INCLUDE – support group	
			INCLUDE – volunteer	
			INCLUDE – other	
			EXCLUDE – no peer support	
			UNSURE – refer	

CE	Country	Population	Special topics	Memos/notes
INCLUDE – CE	USA	Black and ethnic minorities	Virtual communities	
EXCLUDE – no CE	UK	Indigenous populations	Recruitment	
EXCLUDE – participatory research as topic	Canada	Children and adolescents	Training	
EXCLUDE – professional education in CE as topic	Australia	Poor		
UNSURE – probable (get full paper)	Africa	Mothers		
UNSURE – possible (refer)	Asia	Women		
	Europe	Pregnant women		
	Central America	Elderly		
	South America	Chronic disease		
	Other	STD/AIDS		
		Alcohol/drugs/ smoking		
		Men		
		Oral health/dentistry		
		Diabetes		
		Other health		

## Appendix 2 Case studies for each cluster

#### **Cluster: Breastfeeding**

Project identifier: Breastfeeding

**Topic:** Uptake and continuation of breastfeeding

Location: UK

Dates covered: October 1990 to 2012

#### **Overview**

An evaluation of the UK Infant Feeding Initiative that covered 79 projects, of which 26 were peer-support breastfeeding programmes (Dykes<sup>123</sup>).

#### **Objectives**

The aim of the evaluation was to assess if infant feeding projects were successful in increasing the uptake and continuation of breastfeeding; synthesise the key challenges and findings; and make recommendations on how best to promote breastfeeding and support mothers in socially excluded communities who choose to breastfeed. The review of peer-support programmes focused on the challenges of implementing programmes successfully.

#### **Theoretical models**

Dennis's conceptual model of peer support<sup>1</sup> in a health-care context was used to describe the ultimate aim of peer support, but the evaluation itself aimed to contribute to the development of programme theory related to the process of establishing peer-support programmes. Seven common challenges were noted:

- *Cultural awareness* Conducting some form of local analysis and needs assessment enabled the programme to be based on the needs of the local culture and the knowledge of local people.
- *Building on existing infrastructure* As a continuation of the needs assessment, identifying existing and related initiatives and linking with them is key.
- Comprehensive planning That includes all key stakeholders, including community members.
- Engaging PSs Creating a training model that provides ongoing support, and that focuses on empowerment by encouraging communities to value their own capacity.
- *Peer–professional interface* Aim to maintain clear ongoing dialogue between PSs and HPs to ensure understanding of the complementary nature of the roles; give PSs 'foreground' responsibility for facilitation with recourse to professionals as 'background' support.
- Marketing the programme Needs to include ongoing publicity within the community.
- *Supportive infrastructure* Spanning the hospital–community interface and including multiple access points at accessible venues across the community.

The evaluation noted that women in socially excluded groups in cultures where breastfeeding is marginalised have negative expectations of breastfeeding, low confidence, and experience embarrassment about breastfeeding in public. Those groups in most need of support are least visible to the health system.

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#### **Target population**

Women post-partum in socially excluded communities who may be considering breastfeeding.

#### Intervention

Peer-support interventions focused on identifying mothers post-partum who were considering breastfeeding, engaging them in an exchange of information and support, and helping them to problem-solve when encountering challenges with breastfeeding.

Peer-support workers with experience of breastfeeding were engaged, with the help of HPs, to approach women in hospital and community settings and explore their interest in receiving information and support around breastfeeding. Contacts could be made via HPs, who acted as gatekeepers in hospital settings, via midwife liaisons in the community or community nurses. In some projects, peer-support workers also engaged informally, using their local social networks to find women through family and friends.

Women received support while still in hospital, and/or attended group sessions that were held at local community venues, such as places where antenatal classes were being held or well baby clinics. They were offered tips and support on how to breastfeed, as well as discussions about common problems and how to resolve them. The women in the groups also supported each other in terms of wider issues concerning parenting and breastfeeding in public settings and the acceptability of breastfeeding to friends and family.

#### Peer supporter: recruitment

Peer supporters were recruited by community organisations, community midwives and nurses.

#### Peer supporter: training

Peer supporters were offered a short course facilitated by qualified members from one of the voluntary breastfeeding organisations or by HPs.

#### **Evaluation**

Action research or qualitative evaluation for developmental studies; some attempts to collect before-and-after data.

#### Quantitative outcomes

Projects were at the capacity-building and developmental stage at the time of evaluation, which precluded definitive statements about causal relationship between the interventions and breastfeeding outcomes. However, there was a positive trend in most projects towards increased continuation of breastfeeding.

#### Main themes and propositional statements

When the condition or behaviour is seen negatively or stigmatised in society or in the community, this negativity may act as a barrier to participation.

Peer supporters may act as role models who help participants overcome negative social attitudes and increase their willingness to take up healthy behaviours.

A setting's appropriateness, acceptability, and accessibility can create a sense of security that may increase programme attendance or participation.

Providing opportunities to update knowledge and problem solve increases ability to function effectively.

The HP–PS interface impacts PSs' confidence and ability to deliver interventions.

Lack of communication and misunderstanding of each other's roles can be a potential source of conflict for HPs and PSs; this can be minimised when HPs are fully informed of the scheme and involved in providing some form of education and training.

When HPs lack confidence in their own knowledge and skills, they tend to resist or avoid engagement in the projects, adopting a gatekeeping role that makes PSs feel unwelcome.

Health information needs to be offered opportunistically, when participants are interested and ready to receive it.

'Where the interface aims to control rather than enable interaction, peer supporters are limited in terms of working 'as potential agents of change in their communities' (Curtis *et al.* 2007).

#### Antecedent

Dykes F. Infant Feeding Initiative: A Report Evaluating the Breastfeeding Practice Projects 1999–2002. London: Department of Health: 2003.

#### Descendant

Dykes F, Flacking R. Encouraging breastfeeding: a relational perspective. Early Hum Dev 2010;86:733-6.<sup>131</sup>

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9196 Condon L, Ingram J. Increasing support for breastfeeding: what can Children's Centres do? *Health Soc Care Commun* 2011;**19**:617–25.<sup>78</sup>

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14798 Gillis DE. *Exploring Dimensions of Health Literacy: A Case Study of Interventions to Promote and Support Breastfeeding*. PhD thesis. Nottingham: University of Nottingham; 2009.<sup>35</sup>

312 Schmeid V, Beake S, Sheehan A, McCourt C, Dykes F. Women's perceptions and experiences of breastfeeding support: a metasynthesis. *Birth* 2011;**38**:49–60.

2464 Smale M, Renfrew M, Marshall JL, Spiby H. Turning policy into practice: more difficult than it seems. The case of breastfeeding education. *Matern Child Nutr* 2006;**2**:103–13.

#### Reference

Dennis C-L. Peer support within a health care context: a concept analysis. *Int J Nurs Stud* 2003;**40**:321–32.<sup>1</sup>

#### **Cluster: Diabetes**

Project identifier: Diabetes Sharing Stories

Topic: Diabetes

Location: Newham, London

Dates covered: Recruitment ran from November 2006 to January 2008

#### Overview

Bilingual health advocate-led groups with minority ethnic groups for diabetes education and support. The groups used informal sharing of personal stories as the 'intervention' core components of the Sharing Stories intervention: spontaneous, informal without imposed format; facilitated non-directively by a non-clinical professional or volunteer trained in sharing stories; and clinical input in a response mode to stories shared by participants.

#### **Objective**

To explore the impact of sharing stories peer-support intervention on diabetes self-management in minority ethnic populations.

#### Theoretical models

Anthropological perspective (shared values and meanings that embed individual behaviour within a cultural group).

Developing critical HL.

#### Target population

Minority ethnic groups with diabetes, living in a socioeconomically deprived borough of London.

#### Intervention

Sharing Stories.

#### Peer educator: recruitment

A cohort of bilingual health advocates, already working in diabetes care.

#### Peer educator: training

Learning set style (social construction of knowledge) based on stories of clients. Provided training in basic diabetes knowledge but also included support, development of the individual (i.e. self-esteem and professional identity) and consideration of the process of learning as well as content.

#### **Evaluation**

Randomised controlled trial.

#### Quantitative outcomes

United Kingdom Prospective Diabetes Study (UKPDS) coronary risk score, HbA<sub>1C</sub> (glycated haemoglobin), cholesterol, systolic blood pressure and total well-being score – no significant impact for any of these.

Patient enablement score showed significant difference between intervention and control, suggesting that patients felt better able to understand and manage their diabetes as a result of the Sharing Stories intervention.

#### Main themes and propositional statements

When individuals with diabetes come together to participate in the Sharing Stories initiative they are given the space to develop collective accounts and shared meaning and values, rather than focusing on individual beliefs and behaviour and can develop practical 'knowing how' knowledge.

When an intervention is specifically tailored to the client group, in this case Asian diabetics from a socioeconomically disadvantaged suburb, mechanisms to build social capital can lead to greater participant attendance.

When intervention is held in community settings, participants are familiar with the setting, often leading to high attendance levels.

When intervention is delivered informally by a non-clinical lead, allowing for spontaneity and group-directed discussion, invariably diabetes issues are covered.

When intervention is delivered informally by non-clinical lead, allowing for group-directed discussion, key health topics can be missed reducing impact of intervention on clinical outcomes.

#### Antecedent

14950 Greenhalgh T, Helman C, Chowdbury AM. Health beliefs and folk models of diabetes in British Bangladeshis: a qualitative study. *BMJ* 1998;**316**:978–83.

#### Descendants

None identified.

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14953 Greenhalgh T, Campbell-Richards D, Vijayaraghavan S, Collard A, Malik F, Griffin M, *et al.* New models of self-management education for minority ethnic groups: pilot randomised trial of a story-sharing intervention. *J Health Serv Res Policy* 2011;**16**:28–36.

#### **Cluster: Healthy Eating Aboriginal Australians**

Project identifier: Healthy Eating					
Topic: Aboriginal Australians healthy eating					
Location: Australia					
Dates covered: 2002–8					

#### **Overview**

Current dietary patterns in Aboriginal communities are often high in fat and carbohydrates and low in fruit and vegetables, and there is usually little access to traditional food. Aboriginal people experience marked socioeconomic disadvantage compared with other Australians. A cooking course for Aboriginal people with diabetes and their families was designed by the Aboriginal Medical Services Western Sydney, a large Aboriginal community-controlled primary health service governed by an elected board of community representatives.

#### **Objective**

The intervention aimed to promote healthful eating through improved nutrition knowledge and cooking skills.

#### Theoretical model

None was described.

#### **Target population**

The target population was Aboriginal people living in the disadvantaged outer suburbs of Sydney. The course was designed for people with diabetes and their families.

#### Intervention

Qualitative evaluation of a series of cooking courses was run in partnership with an Institute of Technical and Further Education (TAFE), a major provider of vocational education. Each course consisted of 18 weekly classes of 4 hours' duration; a course was held every 6 months and 11 courses were held in total. The classes were based on a TAFE hospitality cooking skills curriculum modified to promote healthful eating on a budget. Simple health messages regarding diet and lifestyle were promoted during formal and informal class discussions. The health benefits of limiting takeaway food and soft drinks; increasing fruit and vegetable intake; and decreasing sugar, salt and fat intake were reinforced. Each class concluded with the students eating what they had cooked and they took home food for their families to taste.

#### Peer educator: recruitment

The TAFE nutrition teacher was an Aboriginal woman from the local community. She was assisted by Aboriginal health workers, who provided transport for students to the health centre, and health screening and education during some classes. Students were encouraged to access medical care while at the classes, and to take breaks to attend consultations in concurrent general practitioner (GP), diabetes education or podiatrist clinics.

#### Peer educator: training

There did not appear to be any additional training provided. The trainer was already a teacher at the Institute and her skills as a nutrition teacher were used in her role as a peer educator. Some of the participants described themselves as adopting a role as a 'peer educator' following the course, and passing on some of the messages they had been given.

#### **Evaluation**

A qualitative evaluation of the course was undertaken by the medical centre chronic care team, comprising two Aboriginal health workers and a GP. The team had been involved in the development, cultural supervision, and implementation of the course since its inception. Data were collected through semistructured, in-depth interviews with 23 former cooking course students in 2007–8. Purposive sampling was used to select these study participants for maximal variation of age, sex, attendance records and viewpoints, using the research team's knowledge of the course attendees.

#### Quantitative outcomes

No quantitative data were reported but participants described weight loss, improved well-being and greater motivation for other lifestyle changes, such as smoking cessation and increased physical activity as a result of participating in the course. Most participants felt that they had adopted more healthful eating behaviours, using a wider range of vegetables, using more low-fat cooking techniques, hygienic food preparation, salad preparation and improved ability to shop for healthful food because of a better understanding of food labels.

#### Main themes and propositional statements

Good relationships between the peer participants were important. The opportunity to have a meal together at the end of the class was important in maintaining commitment to the course.

This intervention worked well at recruitment of peers and of participation. This was a result of relationships developing between peers.

Peers will not necessarily promote behaviour change. Other factors may also influence HBs, and cultural norms may be stronger influences than peer influence.

Peer support engages the community when appointed peer leaders are recognised as members of that community.

Health information needs to be responsive to cultural norms, but also taking into account barriers that 'peers' may encounter to making behaviour changes.

A dimension of effective peer-support interventions are ones that build social and informational networks between and within communities.

Antecedents None identified.

**Descendants** None identified.

#### **Cluster references**

Abbott PA, Davison J, Moore L, Rubinstein R. Barriers and enhancers to dietary behaviour change for Aboriginal people attending a diabetes cooking course. *Health Promot J Aust* 2010;**21**:33–8.

14997 Abbott PA, Davison JE, Moore LF, Rubinstein R. Effective nutrition education for Aboriginal Australians: lessons from a diabetes cooking course. *J Nutr Educ Behav* 2012;**44**:55–9.<sup>122</sup>
# **Cluster: Healthy Eating 'Body and Soul'**

Project identifier: Healthy Eating 'Body and Soul'
Topic: Church-based healthy nutrition
Location: America
Dates covered: 2004–5

#### **Overview**

The 'Body and Soul' programme was a church-based health promotion campaign targeting the African American population. The intervention included the following components: church-wide nutrition activities, including a kick-off, and at least three church-wide project events; self-help materials that include a cook book and nutrition video; and at least one policy or environmental change and peer counselling calls using motivational interviewing by trained lay church members.

#### **Objectives**

A number of wellness programmes developed specifically for African American churches have been implemented, with the goal of empowering members to eat five to nine servings of fruits and vegetables every day. Additionally, to reduce the salt, sugar and fat content of their diets.

#### Theoretical models

'Body and Soul'.

Ecological model and motivational interviewing principles.

#### Target population

African American people were selected because of the need to address the health disparities that exist in both cancer incidence and mortality among African Americans compared with white populations within the USA. Churches were the focus because of their importance within African American communities as a resource for spiritual guidance and social–emotional and tangible support. In addition, churches provide an opportunity to reach a large number of community members for health promotion activities.

#### Intervention

'Body and Soul'.

Church-wide nutrition activities, self-help materials, motivational interviewing by volunteer advisors or control.

#### Peer educator: recruitment

Trained volunteer advisors were selected by the pastors. They were selected because of unique situations. They were people who had challenges in their lives and had overcome them. They had family members who had chronic diseases or they had health problems themselves. They could speak with conviction on the values of the health messages they were giving. They were also people who were leaders in their community and could motivate people to action.

#### Peer educator: training

Potential volunteer advisors were recruited and invited to attend one of eight training sessions held in three regional areas. Training was conducted by experienced university staff, generally over a single weekend. The training provided general skills in asking open-ended questions and reflective listening,

as well as specific strategies to elicit discussion about fruit and vegetable intake. A semistructured protocol was developed and role played during the course of the training. At the end of the training, participants were audio-taped, conducting a simulated encounter with another trainee, using the semistructured protocol.

#### Evaluation

The study was a randomised effectiveness trial. A total of 16 churches (eight interventions and eight comparisons) were randomised. One comparison church dropped out, leaving 15 churches completing the baseline and follow-up surveys. Churches were pair matched based on size, socioeconomic status, and whether rural or urban setting before being randomised. The primary outcome for the study was fruit and vegetable intake, assessed by food frequency questionnaires at baseline and at a 6-month follow-up.

#### Quantitative outcomes

Intervention group increased fruit and vegetable intake compared with the control participants (p < 0.5). Post-test differences were 0.7 and 1.4 servings for the two-item and 17-item fruit and vegetable frequency measures, respectively. Statistically significant positive changes in fat intake, motivation to eat fruit and vegetables, social support, and efficacy to eat fruit and vegetables were also observed.

#### Main themes and propositional statements

Careful attention to partnership development and building trust.

Crucial to the development of trust is the issue of sustainability of relationship. The long-term nature of peer-support intervention may be an important aspect of effective peer-support interventions.

Efforts to understand the cultural/social context through extensive formative research and involvement of key informants/advisors.

An intervention strategy that incorporates the sociocultural environment and can be delivered at least in part by the community.

#### Antecedents

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Campbell MK, Motsinger BM, Ingram A, Jewell D, Makarushka C, Beatty B, *et al.* The North Carolina Black Churches United for Better Health project: intervention and process evaluation. *Health Educ Behav* 2000;**27**:241–53.

Resnicow K, Coleman-Wallace D, Jackson A, Digirolamo A, Odom E, Wang T, *et al.* Dietary change through Black Churches: baseline results and program description of the Eat for Life Trial. *J Cancer Educ* 2000;**15**:156–63.

Resnicow K, Jackson A, Wang T, Dudley W, Baranowski T. A motivational interviewing intervention to increase fruit and vegetable intake through black churches: results of the Eat for the Life Trial. *Am J Public Health* 2001;**91**:1686–83.

#### Descendants

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Peregrin T. Cooking with soul: a look into faith-based wellness programs. *J Am Diet Assoc* 2006;**106**:1016–20.

# **Cluster: Healthy Eating Middlesbrough**

#### Project identifier: Healthy Eating

Topic: Community-based health promotion on dietary intake, physical activity levels and weight outcomes

Location: Middlesbrough, UK

Dates covered: 2008

#### **Overview**

The increasing prevalence of obesity in the UK general population is a major public health concern. Many conventional health promotion interventions targeting unhealthy diets and low levels of physical activity continue to be based upon traditional advice-giving approaches. The approach used motivational interviewing a brief negotiation for eliciting behaviour change by helping clients to explore and resolve ambivalence.

#### **Objective**

The present study aimed to assess the effectiveness of a brief face-to-face health promotion intervention using brief negotiation techniques compared with standard advice-giving techniques, delivered in a community setting to promote healthy diets and levels of physical activity.

#### Theoretical models

The study was underpinned by two psychological models of HB change: the theory of planned behaviour and social cognitive theory.

#### Target population

Adults living in low socioeconomic areas of Middlesbrough (UK).

#### Intervention

A key component of the health promotion intervention was a community challenge (a pledge to improve elements of dietary intake and physical activity habits over a 1-year period). All participants were asked to make two specific pledges from three general themes: decrease dietary fat intake, increase fruit and vegetable intake; and increase moderate- to vigorous-intensity physical activity levels. A population internet-based version of the intervention called 'Get a Better Life' was targeted at all those living in Middlesbrough and surrounding areas, and was managed by the local newspaper. Participants were recruited to the study by members of the research team via schools, workplaces, community centres, Shopmobility, newspaper articles and a health event held at Teesside University. Consultations with a lifestyle helper were arranged by the research team. The majority of the consultations took place in the 'Life Store' (a health service drop-in centre located in Middlesbrough town centre) but some also took place in participants' homes, at Teesside University or at local community centres/venues. After the consultation with the lifestyle helper, baseline data were collected by a member of the research team. Intervention consultations took approximately 30–45 minutes to deliver and control consultations approximately 15–30 minutes.

### Peer educator: recruitment

Lifestyle helpers were recruited to deliver the intervention. Potential lifestyle helpers employed by the local health authority were invited to participate in the study by an invitation letter or e-mail from their respective line managers. Also, a number of local community and voluntary organisations were contacted and asked to invite their members (both paid and unpaid to act as community champions).

#### Peer educator: training

Lifestyle helpers attended a half-day training session: either an intervention or a control session, depending on the location in which that individual worked. The response to invitations was lower than anticipated. The lifestyle helpers were trained in the process of recruiting participants (consent procedure, making pledges, contract signing) with either additional training on motivational interviewing/brief negotiation techniques (intervention group) or no additional training (control group). The intervention training sessions covered techniques such as reflective listening; understanding the client's motivation; resisting the righting reflex; exploring readiness to behaviour change as a tool for change talk; and exploring ambivalence.

#### **Evaluation**

This intervention was evaluated using a parallel group pre–post design using randomised matched groups. Six public health localities within the local health authority of Middlesbrough were included in the study. Control and intervention groups were matched on Index of Deprivation scores. Outcomes were measured at baseline, and at 6 and 12 months.

#### Quantitative outcomes

As well as difficulty in recruiting lifestyle helpers, none of those who were recruited managed to successfully recruit participants to the study over the first 2-month period allocated for participant recruitment, and withdrew from the study. The most common reason for withdrawing was reported to be competing workloads, particularly for those employed by the local health authority.

No significant differences in change in diet or physical activity behaviours, or in black and minority ethnic participants, were observed between the intervention and control groups. The control group had a significantly greater decrease in waist circumference at 12 months than the intervention group.

#### Main themes and propositional statements

Effective peer support is characterised by the building of relationships in which there is a sense of trust. The absence of relationship characterised by trust is a barrier to effective peer-support interventions.

Peer-support interventions are enhanced when there are opportunities for positive relationships to develop between peers and/or peer leaders. When they are absent, peer-support interventions are less likely to lead to improved HL.

Peer-support interventions appear to be more acceptable and to engage members of the community when the PSs themselves have time to contribute towards the design of the (intervention) and to the training of peers. Failing to involve them in the design of the intervention may lead to non-engagement by PSs.

Relationships between peers are key to CBPS interventions. Their absence will render the intervention ineffective. Its presence does not guarantee success. Healthy behaviours and HL may be influenced by factors outside of the control of individuals. This is particularly true of interventions that involve families and are influenced by resource availability, such as nutritional behaviours.

Antecedent

None was identified.

#### Descendant

15003 Hillier FC, Batterham AM, Nixon CA, Crayton AM, Pedley CL, Summerbell CD. A community-based health promotion intervention using brief negotiation techniques and a pledge on dietary intake, physical activity levels and weight outcomes: lessons learnt from an exploratory trial. *Public Health Nutr* 2011; **15**:1446–55.<sup>132</sup>

#### **Cluster reference**

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# **Cluster: Healthy Living Older People**

Project identifier: Healthy Living Older People

Topic: Promoting nutrition and healthy lifestyles in older people

Location: North East England; West Midlands, England

Dates covered: 2006-8

#### **Overview**

This case study looks at evaluations of two interventions that promote healthy nutrition (Hyland *et al.*<sup>134</sup>) and healthy living (Holland *et al.*<sup>80</sup>) in older populations from lower socioeconomic backgrounds.

#### **Objective**

To evaluate the effectiveness of peer group organisers ('Older People's Champions') in the outcomes of a health improvement programme (Holland *et al.*<sup>80</sup>).

To evaluate the use of peer educators in nutrition interventions with older people (Hyland et al.<sup>134</sup>).

#### **Theoretical models**

None identified.

#### Target population

People aged 50+ years who live in a multiethnic area that was formerly an industrial and mining district and has a lower-than-UK-average life expectancy (Holland *et al.*<sup>80</sup>).

People aged 60+ years who are living in sheltered accommodation housing schemes in socially disadvantaged areas (Hyland *et al.*<sup>134</sup>).

#### Intervention

The programme comprised several interventions that aimed to improve the fitness and health of older people using an incentivised 'Healthy Passport Scheme' that offered various tasks including, but not limited to, home accidents assessments, vaccinations, stopping smoking, healthy eating, exercise, and an energy-efficiency home check. Older People's Champions, who were known locally, were recruited to support participants when needed as part of a wider role in the community (Holland *et al.*<sup>80</sup>).

A 20-week, 2-hours per week 'food club' led by peer educators focused on practical food preparation and building healthy eating knowledge (Hyland *et al.*<sup>134</sup>).

#### Peer educator: recruitment

Recruitment was not described but Older People's Champions were locally known to participants and some were participating in the scheme themselves (Holland *et al.*<sup>80</sup>).

Non-HPs over the age of 60 with an interest in food and health and access to a car were recruited through flyers and in the local newspaper. Peers would be paid a set wage just above the UK national minimum wage rate (Hyland *et al.*<sup>134</sup>).

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#### Peer educator: training

Training of the Older People's Champions was not described (Holland et al.<sup>80</sup>).

Peer educators took part in 13 weeks of training, leading to a nutrition skills certificate related to the National Vocational Qualification in Nutrition Skills. The training had been designed for community nutrition assistants. Emphasis was placed on topics that were relevant to the nutrition of older people, such as eating on a low income, and issues of access and food availability. The training made clear the objective to foster an inclusive, collaborative and facilitatory interactive style within the food club (Hyland *et al.*<sup>134</sup>).

#### Evaluation

Qualitative evaluation of the 'Healthy Passport' when achieving 15 points, and at 30 points of the follow-up form, through telephone interviews by the independent evaluators, to assess the positive and negative issues about the programme (Holland *et al.*<sup>80</sup>).

Evaluation of the project included a qualitative investigation into the perspectives of those recruited, trained and employed as peer educators (Hyland *et al.*<sup>134</sup>).

#### Quantitative/qualitative outcomes

The Healthy Passport led to many participants changing their behaviour with reference to diet, exercise changes and the take-up of influenza vaccinations. The points achieved did not associate with reports of behaviour change – this was more a function of enjoyment of the scheme. The role of the Older People's Champions was strongly confirmed in terms of significant associations of the presence of their support with enjoyment and successful change (Holland *et al.*<sup>80</sup>).

Peer educators demonstrated that they could absorb the key elements of the training and make the intervention experience accessible to a largely neglected population. The key lesson, however, is that, from the outset, training needs to be more flexibly tailored to the specific needs of those undergoing it, and must also more realistically reflect the likely conditions of implementation (Hyland *et al.*<sup>134</sup>).

#### Main themes and propositional statements

Non-monetary benefits for self and family (or the community more widely) may be effective in recruiting PSs.

Older citizens, specifically, may have a particular motivation to volunteer in order to maintain an active life.

Training that was tailored to meet individual and group learning needs was more likely to be perceived as relevant by PSs.

Training that incorporated experiential learning gave PSs the skills and confidence to deliver the intervention.

Focusing on socialising and building social networks is a key step in the process of enabling people to learn how to achieve health and well-being.

#### Antecedents

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#### Descendants

None identified.

#### **Cluster references**

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14938 Seymour JE, Almack K, Kennedy S, Froggatt K. Peer education for advance care planning: volunteers' perspectives on training and community engagement activities. *Health Expect* 2013;**16**:43–55.<sup>141</sup>

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## **Cluster: HIV Safer Sex**

Project identifier: HIV Safer Sex

Topic: Sexual health behaviour and uptake of HIV services

Location: Glasgow, Scotland

Dates covered: October 1997 to June 1998

#### **Overview**

The Gay Men's Task Force (GMTF) was a community-level intervention to promote sexual health among gay men in Glasgow. It ran for 9 months, between October 1997 and June 1998. The GMTF comprised three elements: (1) a peer education programme operating in gay bars; (2) gay-specific sexual health services, located in both hospital and community centre locations; and (3) a telephone 'hotline'.

#### **Objective**

To evaluate peer education in terms of the wider sexual health needs of homosexual men, focusing on the potential role of peer educators as health outreach workers, with the aim of increasing the visibility and use of sexual health services.

#### **Theoretical models**

Programme drew on a Diffusion of Innovations model, whereby popular opinion leaders engaged in conversation with other homosexual men to promote HIV risk reduction. According to this model, behaviour change initially adopted and endorsed by the opinion leaders gradually diffuses throughout the population.

The model is believed to be well suited to community-level HIV prevention campaigns that typically require the initiation, diffusion, and long-term maintenance of behaviour change.

#### Target population

Men who have sex with men who frequent Glasgow's gay bars.

#### Intervention

Peer educators wore distinctive uniforms (T-shirts, jackets, bags) and, on entering the bars, would distribute GMTF leaflets on sexual health and behavioural issues, and then approach men to discuss both these and wider issues along with advocating sexual health service uptake.

A contact involved a conversation between a peer educator and a customer in the bar, through which issues raised by both would be discussed and further leaflets distributed if required.

Resultant discussions covered a wide range of health-related topics, such as hepatitis B vaccination and HIV testing. These discussions did mainly reflect the content of the leaflets, but other issues related to sexually transmitted infections, condoms and lubricants were also raised.

#### Peer educator: recruitment

Recruiting and retaining peer educators proved to be more difficult than originally envisaged. Problems in recruiting enough peer educators resulted in people being recruited from local gay organisations and being paid for their time.

#### Peer educator: training

Peer educators were trained in communication skills and specified message delivery, using role play. Training did not include scripted conversations, as used in the US-based study upon which the intervention was modelled (Kelly *et al.*).

#### **Evaluation**

During the intervention, 42 peer educators contacted 1484 men in Glasgow's gay bars, and a wide range of psychosocial and sexual health issues were discussed. The genitourinary medicine (GUM) service was used by 506 men across each of its locations, including 332 new clients who had not used the service before the intervention. The hotline was less well used, with only 45 'genuine' calls in the first 6 months of the intervention. It was terminated after this period.

The GMTF succeeded in contacting large numbers of gay men in Glasgow to discuss sexual health issues. Many gay men used gay-specific GUM projects to access a wide range of services.

#### Quantitative outcome

During the 9-month intervention (October 1997 to June 1998) the peer educators reported 1484 contacts with men in all of Glasgow's gay bars.

#### Main themes and propositional statements

Peer support is more effective when there is a positive relationship between the PS and the peers.

Building up of relationships and trust may be more difficult in more sensitive areas.

Peer support may not be effective when the training programme does not allow sufficient time for information transfer, skills practice and development to enable PSs to effectively carry out their roles.

Working as a PS may improve confidence and self-esteem.

If training allows PSs to recognise and build on their pre-existing knowledge and skills it may increase their confidence to deliver the intervention and their sense of ownership of the intervention.

Training is more effective when it is tailored to the individual needs of PSs.

Peer-supporter training is more effective when it enables PSs to develop the practical skills that they will need to deliver the intervention.

Popular people or opinion leaders may not be regarded as peers.

Distinguishing PSs from normal clientele may have a negative effect.

When PSs have control over the intervention they are able to use their contextual/tacit knowledge (as a peer) to optimise their chances of a positive outcome.

When PSs have autonomy in the way they deliver the intervention they may privilege some aspects of the intervention over others, which may mean that the intervention is not as successful as it could be.

#### Antecedents

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#### Descendants

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14985 Flowers P, Hart G, Marriott C. Constructing sexual health: gay men and 'risk' in the context of a public sex environment. *J Health Psychol* 1999;**4**:483–95.

14979 Flowers P, Frankis J, Hart G. Evidence and the Evaluation of a Community-level Intervention: Researching the Gay Men's Task Force Initiative. In Watson J, Platt S, editors. *Researching Health Promotion*. London: Routledge: 2000. pp. 102–24.

14984 Flowers P, Marriott C, Hart G. The bars, the bogs, and the bushes: the impact of locale on sexual cultures. *Cult Health Sex* 2000;**2**:69–86.

3929 Flowers P, Hart GJ, Williamson LM, Frankis JS, Der GJ. Does bar-based, peer-led sexual health promotion have a community-level effect amongst gay men in Scotland? *Int J STD AIDS* 2002;**13**:102–8.<sup>81</sup>

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3984 Williamson LM, Hart GJ, Flowers P, Frankis JS, Der GJ. The Gay Men's Task Force: the impact of peer education on the sexual health behaviour of homosexual men in Glasgow. *Sex Transm Infect* 2001;**77**:427–32.

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3375 Kelly JA. Popular opinion leaders and HIV prevention peer education: resolving discrepant findings, and implications for the development of effective community programmes. *AIDS Care* 2004;**16**:139–50.

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# **Cluster: Smoking Fag Ends**

Project identifier: Smoking Fag Ends

Topic: Smoking cessation

Location: North West England (Liverpool and Knowsley)

Dates covered: 1994–2012

#### **Overview**

A service composed entirely of lay advisers, which grew out of a self-help group comprising ex-smokers who acted as volunteers to help others quit smoking. By 1997, it had become an active arm of the Roy Castle Lung Cancer Foundation. The service then combined a telephone helpline with group and individual one-to-one counselling.

Subsequently, the service was commissioned by Liverpool Primary Care Trust (PCT) to deliver smoking cessation services. The successful model was later expanded to Knowsley, Cheshire. It represents a community-based initiative with a social, rather than medical, model.

#### **Objectives**

The intervention aimed to achieve the following behavioural goals:

- target group to use the community smoking cessation service
- target group to quit and stay quit.

#### Theoretical model

Some aspects of the approach follow accepted theoretical or scientifically 'known', such as the popular but highly structured Prochaska and DiClementi (1982) model and motivational interviewing, both of which are included in the add-on training that advisers can receive. However, the model as it evolved did not consciously draw on these theories, even although it reflects aspects of them.

#### Target population

Targeted age groups with the highest smoking prevalence: females 35–45 years and males 40–55 years.

#### Intervention

Offers support tailored to each individual, including:

- Drop-in support: moral support and practical help at sessions at the same times every week, so that people can choose to drop in to any session whenever they want and see an advisor.
- Group sessions: led by trained advisors, these sessions are friendly, informal gatherings in familiar community settings.
- One-to-one support: private sessions with an advisor to discuss smoking habits and the sort of strategies that are likely to help.
- Telephone helpline: open Monday to Friday from 9.30 a.m. through to 8.00 p.m. to give advice, discuss strategies or just help someone through a craving (available across Merseyside).
- Text support.
- Free NRT.

#### Peer educator: recruitment

Staff are recruited from local communities and are therefore able to build contacts, networks and credibility.

#### Peer educator: training

The core of the training is a shadowing scheme through which potential advisers learn the instinctive art of the empathetic supportive and choice-centred approach (experiential learning). They also subsequently receive formal instruction through the Diploma in Smoking Cessation from the National Respiratory Training Centre, as well as a whole range of other short courses on different models and approaches to smoking cessation (propositional learning). This gives them the credibility of certification and a range of potential skills to draw on while remaining true to the original Fag Ends principles.

Advisors also receive training in motivational interviewing, group work facilitation, working one to one, presentation skills, smoking and cannabis issues, smoking and mental health issues, specific training on pharmacological interventions for smoking cessation, basic counselling skills, listening skills, and training in deaf awareness.

#### **Evaluation**

Data from the Stop Smoking Service demonstrate that the number of 4-week smoking quitters in Knowsley has increased significantly, and that targets for adult stop smoking services have been significantly exceeded.

#### Quantitative outcomes

In Knowsley, the number of successful 4-week quitters has increased over the life of the programme. As well as these successful quits, referral rates to the service are high.

At face value it is expensive 'per quitter' but expenditure per quitter is likely to be less than the cost of care 'per smoker' over their life time.

#### Main themes and propositional statements

Peer support is more likely to be effective when it includes speaking the 'same language'.

Peer support is more likely to be credible if PSs have positive experiences of success with the condition.

PSs are less likely to be distrusted or mistrusted through being perceived as a representative of 'system'.

The success of peer support is not so much in the creation of social networks but more in their exploitation of, and access to, existing social networks – PSs can navigate them.

Peer support may provide an alternative 'view' of community, i.e. from within but different outcome.

Peer support is more likely to be effective when it emphasises personal choice.

Building up trust takes time. PSs may have time to build up trust, whereas HPs may not have time to build up trust.

Sustainability of a peer-support service is not always attributable to continuity of membership. It may be offered by structures and clear message relating to access – offer facility to drop in.

If training allows PSs to recognise and build on their pre-existing knowledge and skills then it may increase their confidence to deliver the intervention and their sense of ownership of the intervention.

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Peer-support training is more likely to be successful when it enables PSs to develop the practical skills that they will need to deliver the intervention.

When PSs have control over the intervention they are able to use their contextual/tacit knowledge (as a peer) to optimise their chances of a positive outcome.

When PSs have autonomy in the way in which they deliver the intervention they may privilege some aspects of the intervention over others, which may mean that the intervention is not as successful as it could be.

PSs will operate more effectively in a place belonging to the community, not to a health service. The environment should be 'non-health and non-institutional'.

#### Antecedents

None – community initiated.

#### Descendants

None, although it has spread from Liverpool to Knowsley (see above).

#### **Cluster references**

15010 Bauld L, Ferguson J, McEwen A, Hiscock R. Evaluation of a drop-in rolling – group model of support to stop smoking. *Addiction* 2012;**107**:1687–95.

15011 Owens C. Increasing people's chances of success in smoking cessation. Nurs Times 2003;99:30.

15012 Owens CL. Making Stop Smoking Support More Widely Available in the Community. In *The 13th World Conference on Tobacco or Health*, Washington DC, USA, 12–15 July 2006.

14492 Owens C, Springett J. The Roy Castle Fag Ends Stop Smoking Service: a successful client-led approach to smoking cessation. *J Smoking Cessation* 2006;**1**:13–18.<sup>139</sup>

6251 Springett J, Owens C, Callaghan J. The challenge of combining 'lay' knowledge with 'evidence-based' practice in health promotion: Fag Ends Smoking Cessation Service. *Crit Public Health* 2007;**17**:243–56.<sup>85</sup>

#### References

Bauld L, Bell K, McCullough L, Richardson L, Greaves L. The effectiveness of NHS smoking cessation services: a systematic review. *J Public Health* 2010;**31**:71–82.

Prochaska JO, DiClemente, Carlo C. Transtheoretical therapy: towards a more integrative model of change. *Psychother* 1982;**19**:276–88.

South J, Woodall J. Planning and Evaluating Health Promotion in Settings. In Scriven A, Hodgkins M, editors. *Health Promotion Settings: Principles and Practice*. London: Sage; 2011. pp. 69–86.

South J, Meah A, Branney PE. 'Think differently and be prepared to demonstrate trust': findings from public hearings, England, on supporting lay people in public health roles. *Health Promot Int* 2012;**27**:284–94.

# **Cluster: Smoking in Ethnic Minorities**

**Project identifier:** Smoking in Ethnic Minorities

**Topic:** Promoting smoking cessation in ethnic minorities

Locations: Birmingham, UK

**Dates covered:** 2009–2011

#### **Overview**

This is a study in which trained community outreach workers served as PSs to improve access to English smoking cessation services offered by NHS services among Bangladeshi and Pakistani male smokers in the UK. Interventions include randomising geographical areas and delivery of outreach worker-based services to promote participants' utilisation of NHS smoking cessation services.

#### **Objective**

Using peer support to increase uptake of smoking cessation services and tailor services to meet the needs of Bangladeshi and Pakistani male smokers in the UK.

#### **Theoretical models**

None identified.

#### Target population (more specific, e.g. low-income)

Bangladeshi and Pakistani male smokers in Birmingham, UK.

#### **Interventions**

In the 12-month trial, community outreach workers identified potential participants on the streets in health services premises, in local businesses and at community events by promoting cessation services using word of mouth. Outreach workers referred identified smokers (participants) to existing clinics for smoking cessation services or provided cessation support themselves (Begh *et al.*<sup>124</sup>).

#### Peer supporter: recruitment

Peer supporters were recruited based on their ethnicity (two Bangladeshi PSs and two Pakistani PSs), language (speaks the same language as the participants) and experiences of being Stop Smoking Service advisors (one Bangladeshi PS and one Pakistani PS).

#### Peer supporter: training

The training was delivered by accredited NHS trainers and members of the research team. Training included role playing, communication skills development, general health promotion, how to deliver behavioural support and medication management for smoking cessation, and sessions on cultural diversity to understand the range of cultural-related beliefs, practices and experiences that may be of norms for the ethnic minority smokers (warned against the dangers of stereotyping, e.g. on the basis of ethnic origin, language or age).

#### **Evaluation**

#### Quantitative

The effectiveness of the smoking cessation services was measured by a RCT.

#### Qualitative

The researchers conducted ongoing process evaluation at regular intervals during the 12-month trial. The evaluation was to explore how the outreach workers' role and approach changed over time when having challenges in delivering the intervention to the ethnic minorities, their overall performance and impact on the public, and reflections on working in the team. The programme was evaluated based on outreach workers' weekly diaries, as well as participant observation and conducting focus groups and interviews with the outreach workers. The first focus group was conducted before the outreach workers started delivering the interventions, followed by four further focus groups carried out every 2–3 months. Interviews with the outreach workers, the Stop Smoking Service managers and the specialist Stop Smoking Service advisor were carried out at the end of the study.

#### Quantitative outcomes

More participants had attempted to quit with NHS services in intervention areas compared with control areas [rate ratio (RR) 1.32, 95% confidence interval (CI) 1.03 to 1.69]. There appeared to be a small increase in the number of 4-week abstinent smokers in intervention areas (RR 1.30, 95% CI 0.82 to 2.06). However, the NHS service users in intervention areas tended to be less likely to attend weekly appointments than those in control areas.

#### Main themes and propositional statements

Involving PSs and/or peer-support participants as part of the team in the development of peer-support interventions can lead to interventions being more relevant to participants needs, and create a sense of ownership by those delivering and receiving the intervention.

When cultural needs assessments are conducted during the design stage of a peer-support programme, the design team are able to gain greater understanding of local practices and potential constraints to behaviour change, which may lead to interventions that are better targeted to local needs.

When cultural needs are taken into consideration during the design stages of peer-support interventions, via formal or informal assessments, programmes are more likely to work within existing structures, increasing the potential that they will become embedded in social practice.

When the peer-support venue chosen is one that the peer-support recipients trust then they are more likely to attend the programme.

If logistical barriers to attending a peer-support programme are identified and addressed during the initial design phase of the programme this enables greater participation.

Pre-existing roles within a community may act as a barrier to recruitment.

Giving PSs the opportunity to tailor the intervention to the participants contributes to the success of the intervention.

The content of the health message needs to be at the right level for the characteristics of participants. Using scientific and technical language impedes the process of turning abstract knowledge and instructions into practical understanding.

#### Antecedents

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14943 Woodruff SI, Talavera GA, Elder JP. Evaluation of a culturally appropriate smoking cessation intervention for Latinos. *Tob Control* 2002;**11**:361–7.<sup>126</sup>

#### Descendants

None identified.

#### **Cluster references**

14940 Begh RA, Aveyard P, Upton P, Bhopal RS, White M, Amos A, *et al.* Study protocol: promoting smoking cessation in Pakistani and Bangladeshi men in the UK: pilot cluster randomised controlled trial of trained community outreach workers. *Trials* 2009;**10**:71.

180 Begh RA, Aveyard P, Upton P, Bhopal RS, White M, Amos A, *et al.* Experiences of outreach workers in promoting smoking cessation to Bangladeshi and Pakistani men: longitudinal qualitative evaluation. *BMC Public Health* 2011;**11**:452.<sup>124</sup>

110 Begh RA, Aveyard P, Upton P, Bhopal RS, White M, Amos A, *et al.* Promoting smoking cessation in Pakistani and Bangladeshi men in the UK: pilot cluster randomised controlled trial of trained community outreach workers. *Trials* 2011;**12**:197.<sup>84</sup>

14945 Malchodi CS, Oncken C, Dornelas EA, Caramanica L, Gregonis E, Curry SL. The effects of peer counseling on smoking cessation and reduction. *Obstet Gynaecol* 2003;**101**:504–10.

## **Cluster: Smoking in Schools**

**Project identifier:** Smoking in Schools [including ASSIST, TAP and CASE (Cannabis And Smoking Education) studies]

Topic: School-based, peer-led intervention for smoking prevention

Location: 59 schools in England and Wales

Dates covered: September 2001 to May 2004

#### **Overview**

This cluster was made up of 11 papers originating from the ASSIST study. Additional papers that were included related to two feasibility studies that were based on the ASSIST project ,and which also carried out school-based, peer-led intervention studies to reduce the risk of harmful HBs, including cannabis smoking (CASE) and binge drinking (TAP).

#### **Objective**

To design, implement and evaluate a peer-led intervention to reduce smoking among secondary school students. Descendants included in this cluster aimed to reduce the risk of cannabis smoking (Welsh 2009; Welsh and Munro 2009;<sup>138</sup> Munro and Bloor 2010) and binge drinking (Hasan *et al.*<sup>103</sup>) among secondary school students.

#### Theoretical model

Diffusion of Innovations theory (Rogers 1983<sup>109</sup>).

#### Target population

Students aged 12-13 years (UK, Year 8).

#### Intervention

A 10-week period during which PSs undertook informal conversations about smoking with their peers and logged a record of these conversations in a simple diary.

#### Peer educator: recruitment

Completion of a questionnaire by all students aged 12–13 years to nominate influential peers. The 17.5% of students with the most nominations were invited to a recruitment meeting.

#### Peer educator: training

Two-day training event held out of school and facilitated by a team of external trainers. The training aimed to:

- provide information about the short-term risks of smoking and the benefits of remaining smoke free
- develop communication skills, including co-operation and negotiation, ways of giving and receiving information and conflict resolution
- enhance students' personal development, including their confidence and self-esteem, empathy and sensitivity to others, assertiveness, decision-making and prioritising skills.

Methods to achieve this included participatory activities, student-led research, small group work, discussion and games. Feasibility studies used similar models of training, with one study (Welsh 2009; Welsh and Munro;<sup>138</sup> Munro and Bloor) also testing a 3-day training period to cover prevention of cannabis smoking in addition to cigarettes. This study was concerned with intervention fidelity, and training was delivered uniformly with as little deviation as possible from the training manual used. This was in contrast with the ASSIST training, which was designed to be tailored to individual students and groups.

### **Evaluation**

#### ASSIST

Data were gathered at baseline, immediately after the intervention, at 1-year follow-up and at 2-year follow-up. Data were gathered using a questionnaire, including a standard set of questions about smoking behaviour designed for young people and a saliva sample to test for cotinine concentrations. These were used to assess the amount of misreporting rather than to correct self-reported data.

#### CASE

Survey about smoking behaviour and saliva samples collected at baseline, immediately post intervention and at 3 months post intervention.

#### TAP

Self-completion questionnaire about drinking frequency at 6 months post intervention.

#### Quantitative outcomes

#### ASSIST

The primary outcome was the prevalence of smoking in the last week in the year group of the school.

Smoking prevalence was lower in intervention than in control schools at all three follow-up points after adjustment for baseline differences.

The odds ratios (ORs) of being a smoker in intervention compared with control group were:

- at 1 year: 0.77 (95% CI 0.59 to 0.99)
- at 2 years: 0.85 (95% CI 0.72 to 1.01) (not significant).

There was a 22% reduction in the odds of being a regular smoker in an intervention school compared with a control school.

No differential effect was evident according to sex, PS status or deprivation. A more pronounced effect was evident in schools in South Wales valleys [OR 0.58 (95% CI 0.36 to 0.93)].

#### CASE

The intervention had no effect on the intention to smoke cannabis.

#### TAP

There was no evidence that the intervention had a beneficial effect on the primary outcome measure.

#### Main themes and propositional statements

Peer support works when there is congruence between the methods for recruitment and the requirements of the intervention programme theory.

Training for PSs works when it capitalises on their pre-existing knowledge and skills and is tailored to their individual needs.

Peer-support training works when it reflects the situations that PSs will encounter.

Peer support works when PSs have time to contribute to training and to the intervention.

Peer support works when the target community recognise the PSs as peers.

Peer-support interventions work when all stakeholders are committed to their success.

Peer-support interventions work when they are incorporated into settings that already encompass a certain sort of predefined roles and relationships (e.g. schools).

Peer-support interventions work in naturalistic settings in which interventions are incorporated into naturally occurring social processes.

Access to ongoing information and affirmational support gives PSs the confidence to deliver accurate intervention over time.

Peer support works when PSs have some discretion and autonomy over the way in which they deliver the intervention.

Peer support works when there is a positive relationship between the PS and the peers (trust and a sense that the person is believable/credible).

#### Antecedents

Rogers EM. Diffusion of Innovations. New York, NY: Simon and Schuster; 2010.<sup>109</sup>

#### Descendants

15015 Hasan M, Moore L, Chalder M. Feasibility study for an evaluation of a schools-based peer-led intervention to reduce pupil problem drinking: The 'Teenage Alcohol Project' (TAP). *Alcohol Educ Res Counc Alcohol Insight* 2005.<sup>103</sup>

15019 Welsh S. Preventing Smoking and Cannabis Use in Secondary Schools: The CASE and CASE + Programme Manual 2007/2008. Glasgow: Centre for Drug Misuse Research; 2009.

15020 Welsh S, Munro A. Delivering peer education within a research study: tensions between research and practice. *J Youth Work* 2009;**2**:25–38.<sup>138</sup>

#### **Cluster references**

6895 Audrey S, Cordall K, Moore L, Cohen D, Campbell R. The development and implementation of a peer-led intervention to prevent smoking among secondary school students using their established social networks. *Health Educ J* 2004;**63**:266–84.<sup>128</sup>

2668 Audrey S, Holliday J, Campbell R. It's good to talk: adolescent perspectives of an informal, peer-led intervention to reduce smoking. *Soc Sci Med* 2006;**63**:320–34.

15013 Audrey S, Holliday J, Parry-Langdon N, Campbell R. Meeting the challenges of implementing process evaluation within randomised controlled trials: the example of ASSIST (A Stop Smoking in Schools Trial). *Health Educ Res* 2006;**21**:366–77.

6048 Audrey S, Holliday J, Campbell R. Commitment and compatibility: teachers' perspectives on the implementation of an effective school-based, peer-led smoking intervention. *Health Educ J* 2008;**67**:74–90.

15014 Bloor M, Frankland J, Langdon NP, Robinson M, Allerston S, Catherine A, et al. A controlled evaluation of an intensive, peer-led, schools-based, anti-smoking programme. *Health Educ J* 1999;**58**:17–25.

1670 Campbell R, Starkey F, Holliday J, Audrey S, Bloor M, Parry-Langdon N, *et al.* An informal school-based peer-led intervention for smoking prevention in adolescence (ASSIST): a cluster randomised trial. *Lancet* 2008;**371**:1595–602.<sup>83</sup>

5690 Holliday J, Audrey S, Moore L, Parry-Langdon N, Campbell R. High fidelity? How should we consider variations in the delivery of school-based health promotion interventions? *Health Educ J* 2009;**68**:44–62.

15016 Munro A, Bloor M. Process evaluation: the new miracle ingredient in public health research? *Qual Res* 2010;**10**:699–713.

15018 Starkey F, Moore L, Campbell R, Sidaway M, Bloor M. Rationale, design and conduct of a comprehensive evaluation of a school-based peer-led anti-smoking intervention in the UK: the ASSIST cluster randomised trial. *BMC Public Health* 2005;**5**:43.

15017 Starkey F, Audrey S, Holliday J, Moore L, Campbell R. Identifying influential young people to undertake effective peer-led health promotion: the example of A Stop Smoking In Schools Trial (ASSIST). *Health Educ Res* 2009;**24**:977–88.<sup>67</sup>

# **Appendix 3** Study characteristics: data extraction tool

# **Programme design and theory**

Category	Study ID	Study type	Theoretical framework	Codesign of peer-support intervention	Time period for intervention
Name of cluster		Action research; systematic review; etc.	Yes: type of theoretical	Codesigned with input from PSs?	Weeks?
			framework	Input from clients	Months?
				or communities?	Any research on sustainability?

# Peer selection and training

Type of peer	Peer-support role	Peer recruitment and selection	Characteristics of peers	Peer training and support	Reimbursement/ incentives for peers?
Local men; people from local community	Lay worker; CHW; health advocate; health activist; health trainer; health	How recruited and selected?	What were deemed to be important	Type of training offered?	Type of reimbursement (financial yes/no;
able to relate to common concerns; ex-smokers from low-income communities	champion; buddy; mentor; coach; counsellor; peer educator; promotora	Who did the recruitment and selection?	characteristics? Was there a match or mismatch with clients?	Who offered and how delivered?	to cover costs of participation; salaried)

## Intervention

Who are peers targeting?	Peer-support intervention	Formal or informal peer support	Group or individual peer-support	Effects of peer-support on HL
Adolescents; older people; pregnant women; women	Activities that peers use to engage with	How are participants involved – are they referred by providers?	Delivered one to one?	Functional, critical, interactive HL mentioned?
(not pregnant); men; ethnic minorities; lesbian, qay, bisexual;	participants and promote HL	Found by peers?	Small group? Both?	Explicit assessment of how peer-support contributed to HL?
sex workers; students; prisoners; low-income groups		Self-referred?		Discussion of relationship between peer-support and HL?

# Relationships between community engagement, health literacy and peer support

CE process described	CE process not described but referenced	Effects of CE on HL	Effects of CE on peer-support	Peer-support + CE = HL connections made?	What worked for whom and why?	What didn't work for whom and why?
NO or if YES = extract information on process	Give references	NO or if YES = describe effects	NO or if YES = describe effects	NO or if YES = describe connections	Link back to theoretical framework, if one was given	Link back to theoretical framework, if one was given

# Identification of articles on the same programme, related programmes, useful background articles or articles related to programme theory

Literature review or multiple studies

Useful references

# **Appendix 4** Outcomes chaining for programmes

 $S_{ee}$  Appendix 2 for details of references for each cluster.)

Cluster focus	Theory of change	Context	Intervention characteristics	Mechanisms triggered	Outcomes
Breastfeeding	Peer support in a health-care context offering emotional, affirmational, instrumental and informational support can enable women to initiate and continue breastfeeding	UK Infant Feeding Initiative established in 1999 to jump-start 79 projects aiming to support breastfeeding women in socially excluded communities Projects developed capacity	Characteristics varied in different localities but included, conducting community and cultural needs assessment to determine community attitudes and concerns; establishing a new programme or linking/	HPs motivated to participate because they knew they would have to deliver on the policy ideal Promoted discussion about breastfeeding	Increased knowledge about breastfeeding (KPS) Increased women's confidence in talking to other mothers (C) Enabled people to draw on a
		for producing culturally sustainable and sensitive changes that would promote initiation and duration of breastfeeding Related projects occurring within the same policy	emaigammating with existing programmes; setting up support groups for mothers; using PSs who had experiences of breastfeeding; providing concurrent training for HPs	Enabled women to be less isolated after birth Enabled women to feel that they were 'on common ground' and feel like they belonged; talking about breastfeeding, 'seeing it	range of information and experience and learn for themselves (AE) Helped women to make new friends and talk about other problems (AE)
		environment, although receiving funding from other sources Programmes described a high level of hostility to		happening' and getting consistent advice Women felt more 'normal' about breastfeeding	Support groups were able to challenge social norms (Adv) PSs felt able to breastfeed 'anywhere now, in the park or on a bench in the town' (HB)
		breastfeeding in the local community Women did not get much support from family or friends		'Being there' in a facilitative rather than controlling role conveyed to the woman that the supporter is available for her when needed in the	Mothers generally felt that they breastfed for longer than originally stated (HB)
		on breastfeeding of parenting. HPs did not feel comfortable in talking to mothers about breastfeeding		hospital setting or at home	Not possible to demonstrate consistent trend in initiation and uptake because most projects were at an early stage and other concurrent breastfeeding initiatives (HO)

Limited Eaglich cooperativ		INTECHALINE UNDER COMPACT IN THE INTERNATION OF THE INTERNATIO	Outcomes
anthropological perspective: anthropological perspective: use peer support, taking an use peer support to create an open dialogic space where knowledge can be framed and reframed through narrative and interpretation and interpretation and interpretation and interpretation shiph and outcome poor language may increase social distance, reduce social distance, reduce communication and threaten trust between patient and HP group will promote development of HL	Bilingual health advocates with no clinical background, known to the community Fluent in one or more of five languages common to the population Community venues with groups that already had wide attendance Spontaneous, informal and without imposed format Facilitated non-directively by a non-clinical professional or volunteer trained in sharing stories Clinical input in a response mode to stories shared by participants	Providing a forum in which participants can negotiate the meaning of knowledge and prompting action Building on beliefs, attitudes and behaviours, already existing in the culture, which promote good diabetes control, prevent complications address practical barriers to positive HBs Informal stories (such as gossip or hearsay) told by an equal status peer (as opposed to status beer (as opposed to status beer (as opposed to status beer a trigger for behaviour change	The Sharing Stories intervention was significantly better attended than structured diabetes self-management in nurse-led groups (AE) A key outcome of the group in the eyes of the participants was 'knowing what to do about diabetes' (KPS) Practical knowledge – 'knowing how' (C) Led to greater patient enablement than structured diabetes self-management in nurse-led groups (C) Positive in terms of attendance but no impact on clinical outcome
vi la		communication and threaten trust between patient and HP	sourd rustance, reduce communication and threaten trust between patient and HP Spontaneous, informal and without imposed format Facilitated non-directively by a non-clinical professional or volunteer trained in sharing stories Clinical input in a response mode to stories shared by participants

Intervention characteristics Mechanisms triggered

Healthy Eating (contains three examples: Aboriginal Australians, 'Body and Soul' and Middlesbrough)					
1. Aboriginal Australians	None described for Aboriginal Australians	The target population was Aboriginal people living in the disadvantaged outer suburbs of Sydney. The course was designed for people with diabetes and their families There is evidence that dietary patterns in Aboriginal communities are often high in fat and carbohydrates and low in fruit and vegetables, and there is usually little access to traditional food Aboriginal people also access diabetes and nutrition education less than other Australians Aboriginal people experience marked socioeconomic disadvantage compared with other Australians	The 'peer' was Aboriginal and from the local community – a nutrition teacher Recruitment via posters, advertisements on local Aboriginal radio station and word of mouth Aboriginal health workers transported people to the course Cooking course offered for people with diabetes or at high risk of developing diabetes. Students sat down together to eat what they home for their families Simple health messages regarding diet and lifestyle were promoted during formal and informal dass discussions	Informal small group activities triggered social learning Participants thought that confining the eligibility was inappropriate and that future courses should be available to all members of the local Aboriginal community Important barriers were the higher cost of healthful food, their own food preferences and medical problems, such as poor oral health and depression Families not included in the course Recipes were not a good match with lifestyle. They would have preferred simpler food, more meat dishes and match with lifestyle or children or	Increased knowledge and understanding of how to read and use recipes, measure ingredients, follow television cooking shows (KPS) Very few reported using recipes from the course, which were considered to have too many ingredients to be practical or affordable (AE) Enabled to make healthier choices while buying and preparing food (C) Other positive health changes attributed to attendance: greater motivation for other lifestyle changes, such as smoking cessation and increased physical activity (C); improved diabetes self-management (HB); weight loss (HO)
				large families	

Theory of change

Cluster focus	Theory of change	Context	Intervention characteristics	Mechanisms triggered	Outcomes
2. 'Body and Soul'	Ecological model and motivational interviewing principles	African Americans were selected because of the need to address the health disparities that exist in both cancer incidence and mortality among African Americans compared with white populations within the USA Churches were the focus because of their importance within African American communities as a resource for spiritual guidance and social-emotional and tangible support. In addition, churches provide an opportunity to reach a large number of community members for health promotion activities Several wellness programmes developed specifically for African American churches have been implemented with the goal of empowering members to eat five to nine servings of fruit and vegetables every day. Also to reduce the salt, sugar and fat	The 'Body and Soul' programme was a church-based health promotion campaign targeting the African American population. The intervention included the following components: church-wide nutrition church-wide project events; self-help materials that include a cook book and nutrition video; at least three change; and peer counselling calls using a motivational interviewing by trained lay church members	Pastoral leadership is vital to the success of the programme. When the pastor participates in the design of the programme it indicates the importance he places on healthy eating. The church community places trust in the pastor and historically there is a general mistrust of larger institutions The programme has many components, and a variety of educational activies that introduce the many ways fruit and vegetables can be included in peoples diets. The variety of approaches means that the needs of the different groups within the church are met The whole church commits itself to a healthy-eating policy, so it influences the types of foods that are served at church leaders more healthy options Influential church leaders are recruited to be peer counsellors. Only those meeting 'competency criteria' following training were able	Intervention group increased fruit and vegetable intake compared with the control participants (KPS) Statistically significant positive changes in fat intake (HB), motivation to eat fruit and vegetables (AE), social support (AE) and efficacy to eat fruit and vegetables (C) were also observed
				to work as peer counsellors	

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Cluster focus	Theory of change	Context	Intervention characteristics	Mechanisms triggered	Outcomes
3. Middlesbrough	The theory of planned behaviour and social cognitive theory These theoretical models overlap considerably as they both assume that behaviour change is goal directed, and moderated by a person's beliefs, perceptions and expectations about HB in different social and environmental contexts Several individual intervention strategies with evidence of effectiveness were incorporated into each brief intervention. It was hypothesised that if an individual makes a pledge they have displayed their behaviour. The only other variable thet directly influences behaviour, the only other variable thet directly influences behaviour. The intervention using brief negotiation techniques incorporates strategies that aim to increase control	Adults living in low socioeconomic areas of Middlesbrough (UK) Lifestyle helpers were recruited to deliver the intervention. Potential lifestyle helpers employed by the local health authority were invited to participate in the study by an invitation letter or e-mail from their respective line managers. Also, local community and voluntary organisations were contacted and asked to invite their members (both paid and unpaid to act as community champions) Peer educator – training: lifestyle helpers attended a half-day training session, either an intervention or a control session, depending on the location in which that individual worked. The response to invitations was lower than anticipated. The lifestyle helpers were trained in the process of recruiting participants (consent procedure, making pledges, contract signing) with either additional training on motivational interviewing, brief negotiation techniques	A key component of the health promotion intervention was a community challenge (a pledge to improve elements of dietary intake and physical activity habits over a 1-year period). All participants were asked to make two specific pledges, from three general themes: decrease dietary fat intake; increase fruit and vegetable intake; and increase moderate to vigorous intensity physical activity levels. A population internet- based version of the intervention called 'Get a Better Life', was targeted at all of those living in Middlesbrough and the surrounding areas, and was managed by the local newspaper. Participants were recruited to the study by members of the research team via schools, workplaces, community centres. Shopmobility, newspaper articles and a health event held at Teesside University Consultations with a lifestyle helper were arranged by the research team. The majority of the consultations took place in the 'Life Store'	Despite efforts to inform the 'community' about the intervention – it was not able to recruit lifestyle helpers as intended and had to use undergraduate students to deliver the intervention. The study was not described as having been designed in partnership with the community. The 'lifestyle' helpers were not identified by the community. The 'community' was linked by living in a poor socioeconomic neighbourhood. In the UK context this may not be sufficient to create a sense of being in a 'community'	As well as difficulty in recruiting lifestyle helpers, of those that were recruited, none managed to successfully recruit participants to the study over the first 2-month period allocated for participant recruitment, and withdrew from the study. The most common reason for withdrawing was reported to be competing workloads, particularly for those employed by the local health authority. No significant differences in diet or physical activity behaviours were observed between the intervention and control groups in black and minority ethnic, communities between the intervention and control groups, were observed. The control group had a significantly greater decrease in waist circumference at 12 months
		brief negotiation techniques	place in the 'Life Store'		

CIUSTER TOCUS	Ineory of change	Context	Intervention characteristics Mechanisms triggered	Mechanisms triggered	Outcomes	
		(intervention group) or no	(a health service drop-in			
		additional training (control	centre located in			
		group). The intervention	Middlesbrough town centre)			
		training sessions covered	but some also took place in			
		techniques such as reflective	participants' homes, at			
		listening; understanding	Teesside University or at local			
		client's motivation; resisting	community centres/venues			
		the righting reflex; exploring				
		readiness to behaviour	After the consultation with			
		change as a tool for change	the lifestyle helper, baseline			
		talk; and exploring	data were collected by a			
		ambivalence	member of the research			
			team. Intervention			
			consultations took			
			approximately 30–45 minutes			
			to deliver and control			
			consultations approximately			
			15–30 minutes			

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Cluster focus	Theory of change	Context	Intervention characteristics	Mechanisms triggered	Outcomes/conclusions <sup>a</sup>
HIV Safer Sex	Based on Diffusion of Innovations Model Selection of popular opinion leaders will ensure the appropriateness and acceptability of health messages. The health messages will be passed on from the opinion leaders to other people, who will accept and diffuse the messages across the community, spreading effects to a wider group as people converse and interact with each other	Aimed to use community to identify opinion leaders, but this was not successful so project leads had to adopt alternative means of recruitment. One-third of men surveyed at the 7-month follow-up report some form of contact with the peer educator, indicating that PEs were able to interact with the surrounding context	Peer educators wore distinctive uniforms (T-shirts, jackets, bags with project badges and logos) Targeting gay bars in Glasgow Deliver messages about risks associated with hepatitis B and HIV and encourage testing Discuss safer sex Diffuse messages across the gay community	Peer educators were not recognisable as popular opinion leaders. Rather than 'diffusion of innovation', peer educators were advertising available service provision Building up a relationship is more effective than casual contact in terms of relative impact of peer educators on clients Peer educators reported it was easier to talk about sexual health than safer sex behaviour, and this may account for the failure of the intervention to effect sexual behaviour change	Individual effects as a result of talking to peer educators: Awareness of risks of unsafe sex (KPS) 49% had thought about their sexual behaviour (AE) and 26% reported changing their sexual behaviour (HB) Increased uptake of hepatitis B vaccination and HIV testing (HB) Men who reported talking to peer educators more than once were more likely than non-contact men to report each of the sexual health measures, except for more recent HIV tests (AE) Community-level effects not demonstrated in terms of diffusing the innovation (Adv)

Cluster forus	Theory of change	Context	Intervention characteristics	Machanisms trindered	Outromes/conclusions <sup>a</sup>
Healthy Living	Carkhuff's helping model,	People aged 50+ years	Peer champions of similar age	Peers and participants are all	Increased knowledge of
	stages of:	that was formerly an industrial	known locally, delivering	much easier to relate to [the	
	<i>Empathy:</i> understanding	and mining district and has a lower-than-UK average life	interventions that promote healthy nutrition and healthy	participants] that was what made the whole thing work'	Increased knowledge of disease (KPS)
	another person's state,	expectancy; people aged	living	, , ,	
	condition, frame of	60+ years who are living in	3 2 3 3	Development of rapport and	Significant improvement in
	reterence, point of view	sheltered accommodation bouising schemes in socially	Improve the fitness and health of older neonle using incentives	trust	quality of life (AE)
	Respect: responses that	disadvantaged areas	to various tasks including, but	Peers served as role models and	Improved perception of social
	convey caring for someone	)	not limited to, home accidents	convinced participants that they	support (AE) and perceived
	and believing in their		assessments, vaccinations,	would be able to achieve	self-efficacy (C)
	capacity to do something		stopping smoking, healthy	difficult tasks, such as colorectal	
	about their situation		eating, exercise, and an energy-	cancer screening	Behaviour with reference to
			erriciency nome check		ulet, exercise criariges and
	Concreteness: moving from		-	Alleviates suspicion about the	the take-up of influenza
	abstractions to specifics		Outreach including door-to-	programme and addresses	vaccinations (HB)
	-		nool colliger		-
	Genuineness: being real;		-		Increased physical activity
	responding authentically		Peer support emphasises the	Involvement in a community	time, truit and vegetables
	:		client's strengths and abilities	group provides socially isolated	intake and take-up of
	Immediacy: discussing		to cope with the situation and	seniors with a social network of	vaccinations and eyesight tests
	what is going on between		helps the client realise that the	peer relationships, which act as	(HB)
	supporter/supported		problematic situation can be	a natural support system	
			changed		Increased participation rates in
			- - - - - - - - - - - - - - - - - - -	Enjoyment of the programme	cancer screening (HB)
	discrepancies between		Socially isolated clients are		:
	words, feelings, actions –		encouraged to become	People were willing to take part	Improved engagement with
	an invitation to reflect		involved in a community group	in an extended or related	society, social support and
	Salf-disclosure.			Intervention to Intprove ment boalth radius isolation and	
	volunteering personal			improve social engagement	
	intormation in accordance with the helpee's concerns				

Cluster focus The	Theory of change	Context	Intervention characteristics	Mechanisms triggered	Outcomes/conclusions <sup>a</sup>
Smoking In Ethnic Minorities	None identified	Smoking cessation offered in the following contexts: (1) a community church-based setting, in which the intervention was codesigned with support from the church and (2) a community-based intervention in the Pakistani and Bangladeshi communities	Researchers became involved in the activities of the church pastors and church volunteers (peers) were given the opportunity to influence (tailor/ individualise) the programme's delivery and data collection process Outreach workers shared the same ethnicity and/or religion. They emphasised that they were there to specifically help Pakistani and Bangladeshi communities Enlistment of community organisations Outreach worker refers people to a third-party smoking cessation programme Messages about benefits of smoking cessation were tailored to age, interests and concerns about the likely health impact of smoking Benefits included effects on family, fitness and finance Services were provided at fixed times, in another language, in an unfamiliar setting that had a formal and impersonal atmosphere	Volunteer peers and church pastors trust and accept the researchers Acceptance/support of the programme by smokers Outreach workers are present/ visible (publicity), display community in the community on a regular basis and interact with community members (in culturally appropriate ways). Such displays of communality offered reassurance and facilitated communication Outreach workers formed relationships and developed trust with some in the community offered reassurance and facilitated communication Outreach workers formed relationships and developed trust with some in the community Community Community Community Community organisations hecame demotivated when it was found that there were no financial incentives. Young people reluctant to disclose smoking status to organisations that may know them and their families Referral is not part of the cutreach worker Language barrier creates an intimidating atmosphere, weariness about lack of understanding	People lacked interest in stopping smoking (AE) Some enrolled people accepted referrals out of politeness (AE) Although the outreach workers, relatively few attended the cessation service (AE); therefore there were no data on changes to knowledge or personal skills (KPS) Service users in intervention areas were less likely to succeed in stopping smoking than those in the control areas (C)

Cluster focus	Theory of change	Context	Intervention characteristics	Mechanisms triggered	Outcomes/conclusions <sup>a</sup>
Smoking Fag Ends	None explicitly used, although the programme model does map to motivational interviewing and stages of change	A service composed entirely of lay advisers, which grew out of a self-help group comprising ex-smokers who acted as volunteers to help others quit smoking. By 1997, it had become an active arm of the Roy Castle Lung Cancer Foundation. The service then combined a telephone helpline with group and individual one-to-one counselling Subsequently, the service was commissioned by Liverpool PCT to deliver smoking cessation services. The successful model was later expanded to Knowsley, Cheshire. It represents a community-based initiative with a social, rather than medical, model	Service runs 'drop-in' groups at venues that are used by local people Peer support offered by former smokers who successfully completed the programme. Some people who have quit smoking continue to attend sessions because of company and the social element that they offer Flexible, holistic, socially driven model, focusing on positive approach, enabling individual to feel empowered to take control of his/her smoking for him-/herself Service customised for each individual, based on initial needs assessment session	Variety/quantity of locations that individuals can access (same time, same place) every week, so people can just drop in at location whenever they want Social attendance from ex-smokers (AE) provides groups with positive, relevant role models from within their own community (KPS) Positive messages encourage smokers and by seeing people 'like them' who have managed to quit, individuals gain boost in confidence Self-esteem remains intact and/or is enhanced	Take-up rate increased from 80% in 2001/2 through 94–95–96% in 2004–5 (HB) Smoking cessation at 4 weeks (self-report or CO monitor) as proportion of quit attempts; 57% of clients successfully abstained for four consecutive weeks (C) At least 70% validated using CO monitor. Average of 32% of clients (between 2001 and 2004) who achieved 4-week quit remained smoke free at 52 weeks (HO) Smoking cessation at 52 weeks (self-report or CO monitor) as proportion of quit attempts over 4 years: minimum 45% of clients referred to Quit in any 52-week period (HO)
Smoking in Schools	Diffusion of Innovations	Students asked to nominate others in their year group on basis that they are influential Off-site training provided with a high teacher-student ratio of 1:15	PSs undertook informal PSs undertook informal conversations about smoking with their peers, sharing information about the dangers of smoking an role modelling non-smoking or stopping smoking behaviour PSs use tacit knowledge to decide when, where and how to talk to friends about smoking	Asking students rather than school staff to name influential students seemed to aid the credibility of the PSs with their peer group (KPS), thus enhancing the intervention's effectiveness May have been able to influence friends but may also have missed opportunities	Achieved the specified target of 15% of year group to be recruited as PSs (AE) 99% of students who completed the training went on to be PSs and 84% of these handed in a completed diary at the end of the programme (AE) Smoking prevalence was lower in intervention than in control schools at all three follow-up points after adjustment for baseline differences (HB, HO)

heory of change Context Intervention characteristics Mechanisms triggered Outcomes/conclusions <sup>a</sup>	s above As above Informal conversations using pupils about alcohol and sersible drinking in everyday conversations Ds felt able to talk to othe pupils about alcohol and sersible drinking in everyday conversations Cuccessful recruitment 15.3%   Rany PSs reported that they provide that they referred Many PSs reported that they provide the provide provide they provide th	Adv, engagement in social action/advocacy for health; AE, active engagement in health decision-making; C, developed knowledge and capability; CO, carbon monoxide; HB, changed health behaviours and practices; HO, improved health outcomes; KPS, knowledge and personal skills development; RCFE, Roy Castle Fag Ends (community stop smoking service providing
Theory of change	As above	it in social action/advoca s and practices; HO, imp
Cluster focus	Alcohol Reduction in Schools	Adv, engagement in social action/advocacy for her health behaviours and practices; HO, improved he

# **Appendix 5** Data extraction template for programme stages

Stage	Propositional statements: the concept (or variable) described by the data	Constructs: higher level, more abstract description
Stage 0: programme theory development		
How to find programme theory (which is often implied rather than explicitly stated)		
Look for mechanisms that are expected to solve the problem, by finding statements about:		
1. Problem formulation: Why was this seen to be a problem?		
2. Goals of the programme or intervention: How will the programme address the problem?		
3. What mechanisms were expected to solve the problem? Why were they expected to work?		
4. Link the mechanisms that were expected to solve the		
problem with the stated goals of the programme as propositional statements <sup>102</sup>		
The programme theory is presented here by cluster to facilitate comparison across the cluster topics		
The initial programme theory can then be compared with 'What actually happened in terms of		

#### Stage 1: designing the programme

problem resolutions?'

Cluster data describing the following components:

- Stakeholder involvement Who was involved in design, at what level, who was left out?
- Logistical planning and project support Including finding appropriate locations, times, resources; organisational support for people to set up and maintain projects
- Cultural needs assessment A process of eliciting cultural beliefs and social norms related to the situation and behaviour; development of understanding of current practices and the context with which people have to deal when considering a change in behaviour; identification of key influences that may affect the success of the programme or intervention

Propositional statements: the concept (or variable) described by the data

Constructs: higher level, more abstract description

#### Stage 2: recruiting PSs

Cluster data describing the following components:

- Defining the role of the PSs when recruiting
- Barriers to recruitment, such as attitudes about providing peer support, or lack of trust in the recruiting organisation
- Reasons for becoming a peer
- Recruitment process: Who recruited and how were they recruited?
- What is a peer? Programme criterion for identifying appropriate peers

#### Stage 3: training and providing ongoing support

Cluster data describing the following components:

Training and support are combined because some articles did not draw a line between them. This stage includes:

- Logistics of providing training Time, place, frequency, etc.
- Motivations Motivations for attending training
- Training needs assessment Assessment of current KSA; activities that aimed to identify what people needed in terms of knowledge, skills and support
- Cocreation of training materials How the training needs assessment was used to identify what the content of the training should be; how trainers used training needs assessment to create tailored materials; how peers participated in developing training materials
- Delivery of training Didactic; interactive; hands on with opportunities to apply new skills
- Ongoing support includes Continuing professional development sessions; access to HPs for help with scientific and technical information; regular meetings, debriefings on difficult cases; learning sets that promote reflection and mutual problem-solving
- Supporting the supporters Situations in which peers have an unmet need for support; situations in which peers informally or formally support each other, either through cofacilitation or through debriefing

KSA, knowledge, skills, attitudes.

Propositional statements: the Constructs: higher concept (or variable) described level, more abstract Stage by the data description

#### Stage 4: implementation

#### Cluster data describing the following components:

Community attitudes and norms regarding the activities that are being promoted by PSs

- Peer-professional interface Managing the peer-professional relationship; how peers and professionals interact with each other; attitudes towards allowing PSs into the health setting; attitudes towards allowing PSs to take on the support role; allowing control and autonomy in terms of delivering the support
- Setting Accessibility of the setting for peers and participants; appropriateness of setting; safety
- Making connections How peers find people; how they engage them in the first stages
- Aspirations Raising awareness of personal situations; helping people reflect on what they have – and what they have lost or what has changed, what they want to be able to do and be
- Supporting choices Respecting the choices made by people, even if they are not the choices for which the programme or intervention is aiming. Respecting that it is most important to let the person be in control of deciding what they want to try to achieve
- Goal setting Identifying challenges and constraints; developing a critical consciousness of what is realistic given abilities and the surrounding environment. Enabling people to turn aspirations into small, achievable goals
- Signposting to information and resources Helping people become aware of the information, activities and types of support that they can access
- Negotiating systems Helping clients and patients to understand how health systems and other institutions and systems are set up; how to navigate around them; how to interact and communicate with people in various systems to explain your needs and get what you need
- Social networks Exploring existing social networks; assessing social isolation; enabling people to expand their current network or create new ones
- Practical instrumental support Taking people to places when they have not got the confidence to go on their own; offering financial or other tangible support
- Health messages Delivering health information that is relevant, at the right time and which is understandable and appropriate in response to client needs

Propositional statements: the concept (or variable) described by the data

Constructs: higher level, more abstract description

- Learning by observation social modelling How peers can act as role models, both for individuals and for shifting community norms
- Reflecting on progress Helping people with setbacks and problems with achieving their goals; monitoring progress
- Collective sense-making How we use our identity, our experiences and our cultural belonging to make sense of an ambiguous situation, alone and with other people through retrospective reflection and dialogue. The process describing a situation enables people to develop situational awareness and understanding when they are in uncertain situations, facilitating decision-making and enactment. The dialogue helps people to make sense of abstract information and its relevance to their situation. The understanding that is constructed (by individuals, a group, a community, an organisation, a society) is a cue to taking action (Weick<sup>150</sup>)
- Empowerment The capacity to make choices and transform those choices into desired actions and outcomes (World Bank: http://web.worldbank.org/ WBSITE/EXTERNAL/TOPICS/EXTPOVERTY/ EXTEMPOWERMENT/0, contentMDK:20245753~ pagePK:210058~piPK:210062~theSitePK: 486411,00.html (accessed 2 December 2014)

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