

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

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## Scientific summary

### CBPS: health literacy and inequalities

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# 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.

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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