People in Public Health - a study of approaches to develop and support people in public health roles

Report for the National Institute for Health Research Service Delivery and Organisation programme

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The Report

1 Introduction

'People in Public Health' is a study about approaches to develop and support lay people in public health roles. The use of participatory approaches in public health programmes, both in national and international contexts, is well established and seen as necessary to deliver sustainable improvements in public health (Bracht and Tsouros, 1990; Rifkin *et al.*, 2000; World Health Organization, 2002). Indeed a central argument in the Wanless reviews was that a 'fully engaged scenario' with high levels of public engagement in health would result in lower levels of public expenditure and better health outcomes (Wanless, 2002; Wanless, 2004). Government policy supports greater community engagement in health as a means of addressing public health priorities and tackling health inequalities (Department of Health, 2003). The health agenda on community involvement resonates with arguments for citizen empowerment and greater democratisation of services, not only in the NHS but across the public sector, in national agencies and local authorities (Campbell *et al.,* 2008).

Recent national guidance on community engagement noted the wide variety of approaches, indicating that those approaches based on higher levels of participation and greater community control were more likely to lead to increased health and social outcomes[1] (National Institute for Health and Clinical Effectiveness, 2008). There was a recommendation to recruit what were termed 'agents of change' in communities who become involved 'to plan, design and deliver health promotion activities and to help address the wider social determinants of health' by taking on roles such as peer educators, health champions or neighbourhood wardens (National Institute for Health and Clinical Effectiveness, 2008:28). The concept of empowerment, the process of individuals and communities being enabled to undertake local action to effect change, is seen as core to health promotion (Tones and Tilford, 2001; World Health Organization, 1986; Wallerstein, 2006). Government policy on community empowerment advocates increased citizen involvement in planning and running services (Secretary of State for Communities and Local Government, 2008) and this agenda is linked to the personalisation of health and social services and patient and public involvement (Department of Health, 2005b; Department of Health, 2006; Secretary of State for Health, 2006). More evidence is required,

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[1] Drawing on Popay's framework (2006 cited in NICE, 2008: 8).

however, about effective mechanisms for lay engagement and how public services can best enhance, support and sustain community involvement.

1.1 Lay health workers and public health

This study is concerned with a particular type of community engagement, where lay people take on roles in the delivery of public health programmes. Lay health workers are regarded as a valuable asset in health systems as they can act as a bridge between communities and public services (Nemcek and Sabatier, 2003). It is argued that such approaches are able to enhance natural social support and improve information flows between services and individuals (Dennis, 2003; Rhodes et al., 2007). Lay knowledge and expertise may complement or indeed challenge the expertise provided through professionals or through academic research (Popay et al., 1998; Entwistle et al., 1998). Peer based approaches have been used across a variety of settings, including schools, prisons, and workplaces, and with a range of population groups (Cuijpers, 2002; Mellanby et al., 2000; Farrant and Levenson, 2002; Shiner, 1999; Sloane and Zimmer, 1993; Hainsworth and Barlow, 2003; Fairbank et al., 2000; Buller et al., 1999). Community health workers are an established feature of health systems in low and middle income countries and are routinely involved in treatment and preventive activities (Abbatt, 2005; Hongoro and McPake, 2004). In North America, lay health workers are used extensively within public health programmes, particularly where these are targeted on the under-served populations (Jackson and Parks, 1997; Ramirez-Valles and Uris Brown, 2003).

The situation in the UK is less clear and there is a confusing array of terminology to contend with. Current public health practice in England encompasses a diversity of approaches including peer education, befriending schemes, link workers, community health educator programmes, health advocates, community health champions and health promotion projects supported by volunteers (see Table 1). In addition, examples of lay engagement in the delivery of public health activity have emerged through different national initiatives, such as Sure Starts (Attree, 2004) and Walking for Health (Natural England, 2009; The Countryside Agency, 2005). Interest in lay-led approaches has been further stimulated through two flagship programmes, the Expert Patient Programme (Department of Health, 2001a) and the National Health Trainer Initiative (Department of Health, 2004).

Public health services can be involved in a number of ways through: directly developing and implementing programmes; commissioning other agencies, including third sector organisations; providing specialist public health guidance and support; and capacity building and partnership working in community-based initiatives. Little is known, however, about the role of practitioners in developing and supporting these programmes and what approaches work best.

Table 1.Examples of public health programmes involving lay workers

Public health programmes involving lay workers within Bradford & Airedale teaching PCT in 2007
- Pathways to Action – training for community health activists   'Healthwise' tutors running groups around physical activity and health topics   - Health apprenticeship schemes   - Health trainers   - Breastfeeding peer support   - Asian outreach workers   - Buddy schemes around HIV/AIDS   - Voluntary walk leaders   - Community coaches   - Lay workers running food co-ops & cook and eat sessions   - Healthy Living Centres   - Sure Starts/Children's Centres

1.2 Study rationale

The National Institute of Health Research (NIHR) Service Delivery and Organisation (SDO) public health research programme was initiated in 2007 and public/community engagement is one of four work areas (Peckham *et al.*, 2008). An earlier Home Office review on community engagement (Rogers and Robinson, 2004:52) recommended more research to investigate both: 'issues around people's willingness and capacity to become active citizens and issues around the willingness and capacity of public bodies to make best use of active citizens'. Identified research gaps included what sort of skills and support were needed, particularly to enable the participation of groups deemed hard-to-reach.

Given the wide application of lay health worker programmes and the development of practice in the UK, it was identified that more needed to be known about the acceptability and adaptability of these approaches in different social contexts. A number of international reviews of community health workers were available, some relating primarily to developing countries (Lewin *et al.*, 2005; Nemcek and Sabatier, 2003; Rhodes *et al.*, 2007; World Health Organization, 2007), but there had been no synthesis of UK public health practice. Furthermore, there were identified gaps in knowledge about the qualities, experience and skills of lay people taking up public health roles and the provision of education and support by public health services. Additional questions around recruitment and career

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progression were linked to workforce development, one of the other research areas in the SDO public health programme.

1.3 Aims and objectives

The 'People in Public Health' study sought both to provide a synthesis of evidence in a complex area of public health practice and to determine how public health services can best develop and support lay people involved in delivering public health programmes. The broad aims of the study were:

- To improve understanding of valid approaches to identifying, developing and supporting lay people who take on public health roles in community public health activities
- To undertake research on public perspectives regarding the acceptability and value of lay people in public health roles
- To aid public health commissioning and planning by identifying elements of good practice and how these might be applied to different contexts.

A series of specific research objectives were identified relating to different elements of the study:

- To undertake a scoping study on approaches to involving lay people in public health roles through a literature review and a review of current practice
- To present a critical analysis of models of involving lay people in public health roles including defining different dimensions of 'lay' and providing clarity over the core elements of different models
- To investigate how public health services currently recruit, develop, manage and support lay people in public health roles
- To identify factors affecting the development, effectiveness and sustainability of services/programmes which seek to involve lay people in public health roles
- To examine the perspectives of community members with experience of public health services/programmes delivered or led by lay people

- To produce a planning matrix bringing together key evidence and guidance to assist public health services commission, develop and support programmes involving lay people in public health roles

- To make recommendations for further research and evaluation of service models.

It was intended that the study would generate improved understanding of the nature and application of lay roles within the context of the English public health system. Policy makers and those involved in public health

commissioning and practice would therefore have improved access to appropriate evidence to aid planning, management and delivery.

1.4 Scope of the study

The scope of the study was necessarily broad, due to the diversity of public health practice and the need to take an inductive approach to identifying models. Nonetheless, there was a need to define the boundaries of the study in order to focus the enquiry and avoid unnecessary duplication of results. The study has examined lay roles in the context of public health programmes, interventions and services. The assumption was that health services have a role in recruiting, training and supporting lay workers. This placed true natural helpers, individuals embedded within social networks who undertake support activities and disseminate lay knowledge as part of their daily life (Dennis, 2003; Eng *et al.*, 1997), outside the scope of the study. It is recognised, however, that community networks and informal systems of self help and social support are key determinants of health (Wilkinson and Marmot, 2003) and that the actions of many community volunteers make an invaluable contribution to the health of individuals and communities.

The evident challenge of defining lay roles and coping with both diversity of practice and contested terminology led the adoption of a working definition of a lay health worker, adapted from a Cochrane review (Lewin *et al.*, 2005)[2]:

"Individuals carrying out a public health function, trained or supported in some way in the context of the intervention, and having no formal professional or paraprofessional certificated or degree/tertiary education."

This definition was felt to be broad enough to encompass different types of roles and activities, but was not circumscribed by the concept of volunteering as there was anecdotal evidence from UK practice, and from the review by Lewin *et al.*, that some programmes utilised payments. It was noted that alternative definitions highlighted the relationship between the lay person and their community, for example, the World Health Organization (2007) definition states that community health workers should be selected by their own communities, but since this aspect was identified as a potential area for investigation (see Swider, 2002; South *et al.*, 2007), it was not included in the working definition.

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[2]Lewin *et al.*'s (2005) review focused on lay workers in primary health and community care as opposed to public health. The authors define lay health workers as any health worker (1) carrying out the functions related to healthcare delivery (2) trained in some way in the context of the intervention (3) having no formal professional or paraprofessional certificated or degreed (sic) tertiary education.

North American literature refers to the concept of paraprofessionals where lay workers become professionalized and fully integrated into the health system (Eng *et al.*, 1997). While the distinctions between different types of roles are finely drawn, approaches involving employment within health services are more likely to be associated with extensive training and supervision, and therefore were not included in the study. The roles of non-clinical professionals and others who have some involvement in public health as part of their employment were also excluded because these groups are already considered part of the public health workforce (Department of Health, 2001b). While the national health trainer programme is predicated on the notion of lay advice and support, it is the subject of other research programmes and was therefore considered outside the scope of 'People in Public Health'.

Public health activity is multi-disciplinary in nature, so in order to reflect the key areas of public health action in England and to set realistic limits for the literature review, this study focused on the Choosing Health priorities (Department of Health, 2004). It was recognised that there are parallel fields of work where health and social programmes utilise lay workers, for example, in peer support of parenting (for example see Aboud, 2007; Artaraz and Thurston, 2006; Oakley *et al.*, 2002) or in management of long term conditions (for example see American Association of Diabetes, 2003; Bakski *et al.*, 2008; Brown *et al.*, 2007; Griffiths *et al.*, 2007). These areas evidently contribute to public health but were not included in the scope of the study. School based interventions were also excluded as it would have required a more extensive study to research the issues around involving children and young people. Notwithstanding the evident links between lay roles in programme delivery and wider community engagement processes, it was deemed that patient and public involvement, participatory research and other forms of collective participation in service planning and development were outside the scope of this study.

In summary, while adopting an inductive approach to scope the range of possible models, the primary focus of this study has been on lay people with no professional education or background, who take on identified public health roles and are supported by professionals in the context of a public health intervention, programme or service. The Choosing Health priorities (Department of Health, 2004) provided an additional framework for the study.

1.5 Study design

The choice of methodology was informed by the nature of the study topic, which is inherently complex and characterised by the lack of a unifying

terminology. An inductive approach was taken in order to be able to interrogate the notion of lay roles and other contested concepts, and to examine the boundaries of practice. There was an aspiration to bring greater clarity and deepen understanding of these approaches and furthermore to ensure that the research results were relevant and applicable to current public health practice. The conceptual framework for the study therefore drew on a broad notion of public health evidence that seeks to incorporate different sources of evidence including practice based evidence and lay perspectives (McQueen, 2001; Raphael, 2000). The study design was based primarily on qualitative methodology and involved the triangulation of both data sources and methods (Patton, 2002), gathering existing experiential knowledge, public perspectives and published literature, to provide a comprehensive picture of the main service delivery and organisational issues (Figure 1). This was informed by (Rada *et al.*, 1999)'s model of evidence based purchasing of health promotion with its four domains: scientific; organizational; socio-cultural; and health promotion.

Figure 1.   Study design – triangulation of evidence
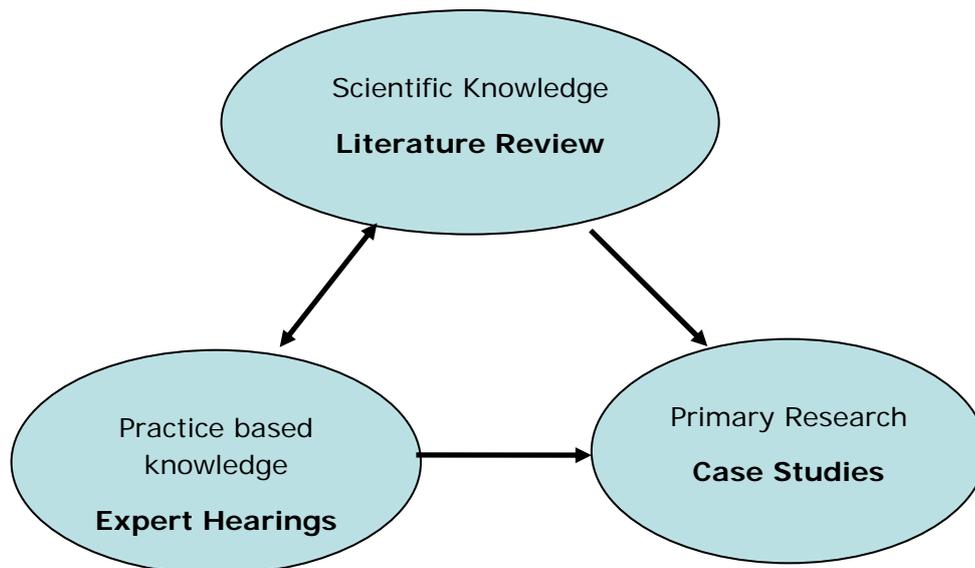
The study was conducted in two distinct phases over a 27 month period, 2007-9. Both phases of the study received NHS ethical approval from Leeds West Research Ethics Committee. A synopsis of the main methods is provided below, while further description of the methodology, methods and sampling is covered in later sections of the report.

Phase 1 Scoping study

A scoping study was undertaken to identify the range and types of lay roles and how public health services supported this type of engagement. The scoping study had three linked elements:

1. A comprehensive literature review of lay engagement in public health roles to identify emerging models of lay roles and thematic issues for service delivery and organisation.

2. A series of expert hearings where key informants with relevant experience and expertise presented evidence. The expert hearings were based on deliberative methods in order to explore different perspectives and stimulate debate on contested issues.

3. Liaison with practice through the establishment of a Register of Interest and a small number of site visits to gain first hand information about current practice.

The different sources of evidence in Phase 1 allowed some triangulation of findings, and also further sources of evidence to be identified. Phase 1 identified different models in public health practice and led to the selection of case studies for Phase 2.

Phase 2 Case studies

Phase 2 entailed primary research to investigate service delivery and organisational issues and gain consumer perspectives on lay roles. Five case studies of public health programmes/projects were undertaken with each case reflecting a different model of practice and target population. The case studies gathered in-depth qualitative information from different stakeholder groups including public health commissioners, practitioners, partner organisations, lay workers, volunteers and service users.

At the end of the study, findings from Phase 1 and 2 were brought together and the main issues for policy, practice and research were summarised. These findings will be used to develop guidance for those planning and implementing public health programmes involving lay workers.

The study was undertaken as a partnership between Leeds Metropolitan University, NHS Bradford and Airedale and the Regional Public Health Group, Government Office, Yorkshire and Humber. Representatives from these partners were fully involved in the development of the study proposal, as part of the study steering and advisory groups, and in the expert hearings. Overall the study design and choice of research methods enabled the research team to maximise dialogue with the public health field and to

draw on different sources of evidence thereby enhancing the validity of the results. As part of the study protocol, a website and searchable database of published research, projects and contacts in England was established in order to promote shared learning and aid further dissemination of research.

1.6 Structure of the report

Prior to presenting results from both phases of the study, a background chapter gives a brief overview of relevant themes in public health policy and practice. In the following sections, each element of the study is reported separately with a full description of research methods, sampling and analysis followed by presentation of the results. The literature review is reported in sections 3-6; expert hearings in sections 7 & 8 and then a brief section describing liaison with practice. Section 10 provides a full discussion about the results from Phase 1 with some critique of the limitations of the scoping study and the emerging themes. Sections 11-14 present the methods and results from the case studies undertaken in Phase 2. Section 15 contains a description and evaluation of the processes of public involvement and reports on some of the themes to emerge. The final two sections provide a synthesis of the study findings and recommendations for public health practice and research.

2 Background

Any investigation of the lay roles requires some consideration of the wider public health function in order to understand how a lay workforce fits within current practice. This section therefore provides a brief overview of the public health system, workforce structures and key settings. An identified need to address capacity issues in public health in order to achieve health targets (Department of Health, 2005a) has been accompanied by a strong governmental drive to encourage and support volunteering within a broader notion of citizenship (Blunkett, 2003; Secretary of State for Communities and Local Government, 2008). The section goes on to highlight relevant research on the contribution of volunteering, where issues relate to lay involvement in public health.

2.1 The public health system

There is wide acceptance of the multi-disciplinary nature of public health practice, there are, however, challenges in terms of achieving clarity over the diversity of roles in practice (Abbott *et al.*, 2005). A preliminary scoping study conducted for the SDO public health programme was used as a framework for understanding the role of communities and lay people within the current public health system (Hunter, 2007). Hunter points to the lack of a unifying set of values in public health and confusion about who is included in the public health workforce. Any study of lay roles, therefore, needs to take account of the context for public health practice where shifting definitions and realignment of professional roles, boundaries and organisational structures are the norm. Hunter (2007) goes on to argue that the notion of a public health system composed of different facets and resources, developed initially by the US Institute of Medicine, provides a useful conceptual model.

The notion of a multi-sectoral public health system, drawing in different resources and skills, is one that has resonance with arguments for greater community and lay engagement in health (Rifkin *et al.*, 2000; World Health Organization, 2002). The significance of communities as agents within the public health system has been emphasised in all the major public health policy documents from Saving Lives: Our Healthier Nation onwards (Department of Health, 2001c; Department of Health, 2003; Department of Health, 2004; Department of Health, 2005a; Secretary of State for Health, 1999). In Tackling Health Inequalities, A Programme for Action (Department of Health, 2003:45), the opportunity to build practical links with

communities and local services through use of lay health workers is noted. Local government policy in England has promoted greater community empowerment, with an emphasis on increased community capacity and individual learning, in order to build stronger, more cohesive communities and better quality services (Communities and Local Government, 2007; HM Government, 2008; Secretary of State for Communities and Local Government, 2008). Local authorities, as well as having direct responsibilities for public health, have a role in supporting community participation as a way of improving services and neighbourhoods.

Commonly there is a distinction made between communities of place and identity, although both can be seen as interdependent (Campbell *et al.*, 2008). In the context of this study, there is also an important distinction to be made between lay people within communities, whose participation may fluctuate across a range from community leadership to non-participation (Taylor, 2003) and community organisations and groups. The Voluntary and Community Sector (VCS) has a significant place in the public health system and a key role in promoting access and bridging the gap between statutory services and communities (HM Treasury, 2002) but the balance of lay-professional interests, paid and unpaid staff, will vary between organisations (Hogg, 1999).

2.2 Public health workforce

Given the nature of public health practice, there are questions about how the lay contribution complements a workforce located across various statutory and non-statutory organisations. The Chief Medical Officer's Project to Strengthen the Public Health Function (Department of Health, 2001b) proposed a tripartite division of the public health workforce:

- People with a role in public health in addition to their mainstream work, for example, teachers or housing officers

- Public health practitioners whose role is focused on public health working with groups, communities and individuals, for example, health visitors or community development workers

- Public health consultants and specialists working at a strategic level, managing public health programmes.

The Public Health Skills and Career Framework describes the skills, knowledge and competencies of nine levels of public health practice, matched to the NHS career framework (Public Health Resource Unit and Skills for Health, 2008). Critically, the framework extends the tripartite division to encompass lay workers and others without professional training

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(see Table 2). Levels 1 and 2 include examples of volunteer roles as well as public health roles carried out within unskilled or semi skilled work. The National Occupational Standards for Community Development (Paulo, 2002) offer an alternative skills based framework for community work[3].

Table 2.Public Health Skills and Career Framework Levels 1-3

	Level	**Examples**
Level 1	Has little previous knowledge, skills or experience in public health. May undertake specific public health activities under direction.	Volunteer workers – e.g. breastfeeding
Level 2	Has gained basic level public health knowledge through training and/or development. May undertake a range of public health activities under guidance.	Peer educator, lay health worker. Classroom assistant, refuse worker.
Level 3	May carry out a range of public health activities under supervision. May assist in training others and could have responsibility for resources used by others.	Community food worker, health trainer, dog warden, stop smoking advisor.

(Source: Public Health Resource Unit and Skills for Health, 2008:9 & 75)

The Public Health Skills and Career Framework is built on the concept of career progression, with accumulation of knowledge and skills through the different levels. There is policy support for the notion of a skills escalator, whereby individuals without professional training can enter the health workforce at different points and go on to develop a health career (Department of Health, Undated). The Royal Society of Public Health provide health improvement courses for Levels 1 and 2 that fit within a qualification pathway (Royal Society for Public Health, 2009).[4]

2.3 Health Trainers

One major development in public health practice has been the emergence of Health Trainers, a new cadre of public health worker (Department of Health, 2004). The primary role of Health Trainers is to provide personal support to help people make and maintain healthy lifestyle choices. The original concept was based on lay people with local knowledge promoting health,

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[3] At the time of the study the National Occupational Standards for Community Development were being revised and a consultation on the standards was taking place.
[4] Level 1- RSPH Health awareness
Level 2- RSPH – Understanding health improvement
Level 3 – City Guilds Certificate for health trainers

signalling a shift from 'advice from on high to support from next door' (Department of Health, 2004:106). The health trainer programme, introduced first through early adopter sites, then through Spearhead PCTs, was seen as both a mechanism for addressing health inequalities and as a solution to the problem of capacity in public health as the programme was intended to draw in unemployed or unqualified individuals into the public health workforce (Department of Health, 2005a). In 2008, the Department of Health announced that Health Trainers would be complemented by a 'network of health champions' who would help increase uptake in different communities (Department of Health, 2008a:68).

Although outside the scope of this study, the introduction of Health Trainers has undoubtedly stimulated interest in the value of lay health workers. Visram and Drinkwater (2005) assert that while Health Trainers are a new initiative, there is a body of evidence around the effectiveness of similar roles such as peer educators, lay health advisors and bilingual advocates. An evaluation of an early adopter scheme found that Health Trainers were able to provide a bridging role between services and communities, and brought qualities as non-professionals, able to offer empathy and support to people in their own or similar communities (South *et al.*, 2007).

Health Trainers operate at Level 3 of the Public Health Skills and Career Framework (Table 2) and there is an accredited training scheme (City & Guilds, 2007). Wilkinson *et al.* (2007) in their review of health trainer activity in 2005, noted the considerable diversity in the development and management of schemes ranging from volunteer based programmes through to the integration of health trainer roles within an existing workforce, although the most common model was the use of a single employment structure with paid workers. There is some evidence that Health Trainers are being successfully recruited from target communities (Smith *et al.*, 2008).

2.4 Lay roles in primary care

The Alma-Ata declaration 1978 (World Health Organization, 1978) envisaged the active participation of communities as an essential part of primary health care. Community health workers recruited from local communities, and undertaking both preventive and basic healthcare activities, are part of local health systems in many low and middle income countries and are seen to offer a mechanism to widen access to healthcare services (Hongoro and McPake, 2004). There is some evidence of the effectiveness of community health worker programmes, for example in uptake of immunisation, but evidence is not extensive in part due to the challenges of evaluating impact and the variation in programmes (Abbatt, 2005; Lewin *et al.*, 2005; World Health Organization, 2007). The World Health Organization review drew attention to the necessity for good

management, training and support for community health workers and the importance of programmes being 'driven, owned by and firmly embedded in communities themselves' (World Health Organization, 2007:9).

Community health worker programmes have evidently not taken root in the UK health system, where primary care is predominately based on a medical rather than social model of health, with less emphasis on public health functions (Busby *et al.*, 1999; Peckham and Exworthy, 2003). There is some evidence of the use of linkworkers to bridge the gap between communities and primary care services, typically working with minority ethnic communities (Gillam and Levenson, 1999).

The introduction of the Expert Patient Programme in 2001, as part of the patient and public involvement reforms, was undoubtedly a significant development within primary care (Department of Health, 2001a; Secretary of State for Health, 2000). The Expert Patient Programme (EPP) was based on the notion of lay tutors delivering a structured training course around self management to people with long term conditions through primary care organisations. Kennedy *et al.* (2005) argue that the EPP has a public health dimension because it takes a strategic approach to integrating self care support in the NHS, aims to broaden the NHS workforce and furthermore 'can been seen as an attempt by the welfare state to bridge the gap between different models of delivering informal and professional health care.' (p.432). Despite high level support for the programme, the early results from the national evaluation indicated that aspects of implementation were problematic, and the programme struggled to recruit tutors from certain disadvantaged groups.

Overall participatory approaches within primary care in England are underdeveloped and there are recognised challenges to changing mainstream practice and incorporating a public health perspective (Busby *et al.*, 1999; Peckham *et al.*, 1998). The context, therefore, for the development of a lay workforce delivering on the public health agenda remains very different from many international contexts where prevention and primary care are more often linked to community action.

2.5 Volunteering

Voluntary action has always been a feature of civil society in the UK, and currently there is wide recognition of the value of volunteering not only in terms of alternative service provision, but more critically as an expression of active citizenship and a key mechanism for empowering individuals and communities (Dingle and Heath, 2001; Ware and Todd, 2002). There is an extensive literature on volunteering, and because of its relevance to this study an overview of the major themes is provided here.

In terms of definitions of volunteering, the potential difficulty of distinguishing volunteering from other social actions is apparent. The Commission for the Compact (2005:4), the national code between the voluntary sector and government defines volunteering as:

"*an activity that involves spending time, unpaid, doing something that aims to benefit the environment or individuals or groups other than (or in addition to) close relatives.*"

Wilson (2000: 215), in a review of volunteering, describes it as 'part of a cluster of helping behaviours, entailing more commitment than spontaneous assistance but narrower in scope than the care provided to family and friends'. He distinguishes between volunteering, where a public good is being produced, and participation within a voluntary organisation, which entails the consumption of that public good. The extent to which volunteering is defined by the lack of remuneration is debatable; while the Compact provides an unequivocal statement on volunteering as unpaid activity (The Commission for the Compact, 2005), a study of voluntary activity in a deprived community, found that there was a blurring of boundaries between paid and unpaid work (Hardill, 2006).

Research indicates that there are a range of explanations for volunteering relating to individual motivations, including altruism, rational choice around the costs and benefits, and the influence of social context, including family ties (Wilson, 2000). Volunteers themselves report a range of motivations; the national survey 'Helping Out' found that the most common reason for volunteering was to help people (53%) and only 7% indicated that it was to help their career (Low *et al.*, 2008). Brooks (2002) found that there were three main stances relating to 'keeping busy', 'doing your duty' and 'a personal turning point'.

The Commission for the Compact (2005) describes volunteering existing within a spectrum of involvement where people may participate in volunteering in different ways and at different stages of their lives. Low *et al.* (2008) found that 59% of respondents were involved in formal volunteering over the past 12 months, with 39% regularly volunteering. In general, women were more likely to volunteer than men, and in organisations associated with health or disability (26% compared with 17%), but the trend was reversed for sport and exercise (16% compared to 30%). Just under a quarter (23%) of those volunteering did so through the public sector organisations. Hawkins and Restall (2006) identify 101 separate volunteer roles in health and social care, including benefits advice, befriending, peer educators and walking companions.

Improving the volunteer experience and encouraging wider participation in volunteering are concerns highlighted in a number of documents (Department of Health, 2008b; Gaskin, 2003; Hawkins and Restall, 2006). There are recognised barriers to participation, for example, research carried out with five groups under represented in volunteering (young people, older people, disabled, Black and Minority Ethnic groups (BME) and unemployed) found that the main barriers were related to the image and culture of volunteering, and also to practical barriers and difficulties (Niyazi and National Centre of Volunteering, 1996).

The benefits of volunteering can be categorised into individual, both to volunteers and those they assist, and societal, in terms of the impact on organisations and communities. A recent systematic review of volunteering in health provides strong evidence that the act of volunteering is beneficial (Casiday *et al.*, 2008). Positive outcomes for volunteers included:

- Improved health and wellbeing - self rated health status, life satisfaction and quality of life
- Adoption of healthy lifestyles
- Improved mental health - impact on depression, stress and emotional exhaustion
- Increased self esteem and self–efficacy
- Increased ability to carry out activities of daily living
- Social outcomes - improved family functioning, social support and interaction.

The psychosocial benefits to volunteers engaged in peer support were noted, although the authors commented that the boundaries between peer and client were not always clear. The review examined the impact of different types of volunteering in health (direct care, non-direct care, education, prevention, patient representation and self help) and found some evidence on impact to service users but cautioned that it was difficult to generalise due to the diversity of activities represented in the studies reviewed. In terms of wider benefits, volunteering, through mutual aid and reciprocity, can lead to the strengthening of community networks, thereby building social capital (Bolton, Undated). The improved dissemination of information within communities is significant (Dingle and Heath, 2001) and social support may have greater effect on health and healthcare behaviour if it is provided by peers (Cooper *et al.*, 1999). The contribution of volunteering to promoting health and wellbeing and to reaching marginalised communities was highlighted in a recent Department of Health consultation (Department of Health, 2008b). Overall volunteering can be seen to be making a significant contribution to civic life and more pertinently to health and wellbeing.

2.6 Summary

In summary, this section has provided a review of major themes relating to lay roles in public health. Within the current social and policy context there is recognition of the value of the lay contribution within the public health system. Aspirations to enhance and support greater lay engagement are reflected in the development of innovative health programmes and in the promotion of volunteering as essential feature of civic life. With the exception of the Health Trainer programme, lay health workers are not part of mainstream health services, but the map of public health practice is changing and there is an emphasis on broadening the workforce. In scoping lay roles in public health, there needs to be an understanding of both formal frameworks for the development of this workforce, while at the same time acknowledging the wider issues around the motivations, benefits and support systems for volunteering.

3 Literature review methods

Phase 1 of the research comprised a scoping study drawing on both scientific and experiential evidence to obtain a comprehensive picture of the main approaches to lay engagement in public health roles and relevant organisational factors. The literature review formed a major element of this phase and was conducted prior to the expert hearings. The primary purpose was to discover all of the relevant published and grey literature and provide a map of research, with a particular focus on process issues. A critical analysis of public health roles, including defining different dimensions of lay, was then undertaken and service delivery and organisational issues were scoped. This section describes the methodological approach and the literature review methods, while results from the mapping are presented in the following section.

3.1 Scoping review methodology

The literature review was conducted as a systematic scoping review. Scoping reviews are useful for determining the size and nature of the evidence base available on relatively unexplored topics, and have been particularly informative in topic areas that cross traditional discipline boundaries (Centre for Reviews and Dissemination, 2004; King *et al.*, 2002; NHS Centre for Reviews and Dissemination, 1999). They can be used to identify gaps in the literature and make recommendations for further research (Centre for Reviews and Dissemination, 2009). It was agreed from the outset that a traditional systematic review would not be appropriate as the topic area of interest was very broad, and the study was not exploring rigidly defined questions.

Systematic scoping reviews involve a comprehensive and systematic search of published and grey literature, with attempts to locate unpublished studies, and differ from a full systematic review as there is no attempt to synthesise the evidence. The search often has fewer restrictions than searches in a full systematic review, yielding a high volume of hits. The processes for screening the results of the literature search and selecting studies are the same as for a full systematic review that is double screening and checking between at least two reviewers, with a system for resolving differences. The process of study selection is, however, more likely to be an iterative process with inclusion criteria being refined as familiarity with the literature increases. A consultation stage is sometimes included.

Data extraction differs from a full systematic review: in a scoping review a number of categories are defined after discussion and each selected paper is

assessed against these categories, but detailed data extraction does not take place. This categorisation is essential for producing the final map of the literature, but also for pragmatic reasons as a scoping review has many more included studies than a full systematic review. Validity assessment is not undertaken beyond recording study design. Data synthesis involves use of a database to explore population and overlap of categories, and the production of a 'map' which can take the form of tables and/ or text and shows where research has been undertaken, where there are gaps in the literature and where there may be sufficient literature to make a full systematic review worthwhile (Arksey and O'Malley, 2005).

3.2 Literature review methods

Consistent with systematic scoping review methods, the literature search was broad in order to ensure that the full range of approaches were mapped. The scope of the study, described in section 1, provided a clear framework with a working definition of a lay health worker. In order to meet the study objectives, and to discriminate between other forms of lay engagement and informal self help, literature included in the review needed to report on public health programmes or interventions that involved lay workers or volunteers in delivery.

Detailed inclusion criteria were developed (Appendix 1). An iterative approach was taken to refining these criteria, including discussion at a full steering group meeting after the pilot stage of title and abstract screening, and development of diagrams and tables of what should be included and excluded from the review. Following several rounds of discussion, some uncertainty remained over whether studies of certain groups of participants or interventions should be included or excluded. It was decided to classify these as 'Borderline' and, while not including them in the review, provide a breakdown of studies included in this category.

3.2.1 Inclusion criteria

Types of studies

Studies of any design that evaluated or presented primary data on the engagement of lay people in public health roles were eligible for inclusion in the scoping review.

Types of participants

Studies of individuals carrying out a public health function, trained or supported in some way in the context of the intervention were eligible for inclusion in the review. In line with Lewin *et al.* (2005) definition,

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participants would not require or receive formal professional or paraprofessional certificated or degree/ tertiary education to undertake the role. The review also included studies or other publications of any lay-led approaches to public health activities, such as advocacy roles. Studies of peer education in schools and studies of children under the age of 16 were excluded, as these have been reviewed previously (Cuijpers, 2002; Mellanby *et al.*, 2000) and were outside the scope of the study. Studies where a public health function was performed as an extension to an existing professional role, for example, housing officers, were excluded.

Types of intervention/ activity

Studies of activities defined as public health, health promotion or health improvement in the UK context (Hunter, 2007) were included in the review. In order to set limits to the review, the primary focus was on interventions or programmes that aimed to reduce health inequalities or addressed the Choosing Health priorities (Department of Health, 2004). These are:

- Reducing the number of people who smoke
- Reducing obesity and improving diet and nutrition
- Increasing exercise
- Encouraging sensible drinking
- Improving sexual health
- Improving mental health.

Papers about generic lay roles were also eligible for inclusion if activities were within holistic (horizontal) health promotion or public health programmes with explicit health goals (Tones and Green, 2004).

Studies where the primary role related to care, treatment or service use, such as encouraging people to go for screening, antenatal and postnatal interventions, occupational health, and carer support, were not eligible for inclusion, but were recorded as borderline on the screening database, so that they could be retrieved for further analysis if required. In line with the agreed scope of the study, other forms of community engagement, such as lay people on advisory boards or participatory needs assessments, were also excluded. Studies of community outreach workers and other job titles which could be lay or professional were only included if it was clear that the role was fulfilled by lay people. Papers on volunteering were included if they contained useful information relating to service issues. A full list of included, excluded and borderline categories is provided in Appendix 1.

Types of outcome measures

As this was a scoping review (not a systematic review of effectiveness), all outcomes reported were included. Outcomes were categorised as service (training/ organisational), uptake or effectiveness.

3.2.2 Search strategy

The literature search drew on academic and grey literature and web based resources. The following electronic databases were searched for publications from 1992 to November 2007 (these search dates were chosen to provide a manageable volume of data):

- MEDLINE/ PubMED
- ASSIA
- CINAHL
- ERIC
- LISA
- Social Services Abstracts
- Sociological Abstracts
- Worldwide Political Science Abstracts
- PsycLIT
- NHS Economic Evaluations database
- The Cochrane Library
- NICE (HDA/ HealthPromis database)
- CSA Social Sciences
- Web of Science
- IDOX

Key **search terms** included: lay train* or lay educat* or peer train* or peer educat* or community health activist* or lay support * or peer support* or link work* or community health educator* or community health trainer* or health advoca*. Search strategies were tailored to each database. See Appendix 2 for details of search terms used.

Reference lists of retrieved articles and relevant websites, such as the World Health Organization, Sport England, Joseph Rowntree Foundation and King's Fund, were searched. A full list of websites accessed is given in Appendix 3. National and international experts were contacted to ask if they were aware of any other relevant studies. In addition, there were formal links with the research team conducting the HTA (Health Technology Assessment) evidence synthesis (07/26/03) that examined the effectiveness and cost-effectiveness, equity and acceptability of health-related lifestyle adviser role.

Appropriate academic and practice mailing lists (for example, public-health@jiscmail) were contacted to ask people to submit any published or unpublished research. Respondents were asked to register interest in the study and a database of contacts was maintained. Further details about liaison with practice and the Register of Interest is given in section 9.

3.2.3 Study selection

Two researchers screened titles and abstracts retrieved from electronic searches against the inclusion criteria, after piloting the process on a small number of records. If there were any disagreements that could not be resolved by discussion the full publication was obtained. One researcher screened retrieved publications against the inclusion criteria, using a standardised form, and decisions were checked by a second researcher. Any disagreements that could not be resolved by discussion were taken to a third researcher.

3.2.4 Data extraction

A data extraction form was developed, based on the study objectives and an initial analysis of examples of eligible papers. The form was piloted on a small number of studies, by two researchers working independently, to ensure a consistent approach to data extraction. The data extraction form was developed synchronously with a Microsoft Access database and included the following fields:

- Coder
- Bibliographic details
- Keywords
- Country of Origin
- Study Design
- Whether there is a clear definition of lay worker role
- Description of lay worker role:
- Type of primary role and/or main activity
- Whether lay person is recruited from target group
- Whether lay person is paid
- Educational level of lay person
- Comments on lay role/characteristics
- Intervention approach (individual or community; targeted or generic[5])

[5] Based on Visram and Drinkwater's (2005) categorisation of health trainer approaches: targeted community; generic community; targeted individual; generic individual.

- Choosing Health priority
- Setting
- Target Groups
- Comments on intervention approach and methods
- Whether there is information relating to service issues
- Organisations involved
- Extent of role of professionals/Health services
- Whether there are data on recruitment
- Whether lay person receives training
- Comments on training issues
- Whether there are data on experiences of lay person in role
- Whether there are data on experiences of service users/beneficiaries
- Comments on SDO/recruitment issues
- Whether there are data on organisational outcomes
- Comparison groups with other types of delivery
- Whether uptake outcomes are reported
- Whether effectiveness outcomes are reported
- Overall effectiveness outcome
- Comments on outcomes

As this was a scoping review, the aim was to provide a map of the literature rather than going into detail about each included study. Validity assessment was not undertaken.

3.2.5 Data analysis and synthesis

The findings of the review were summarised narratively. In the first instance, the literature was mapped, grouping papers using categories in the data extraction process. Areas where there were multiple papers, or alternatively, limited research were noted.

Further data analysis was undertaken as part of the scoping review process in order to develop a critical analysis of models in public health practice and to review service and organisational aspects. This part of the review adopted an inductive approach to analysis. Publications were initially grouped with the aim of identifying the main models appropriate to current UK practice. Within these groupings, studies were sub-grouped by health focus. The data extraction process included qualitative comments of themes in papers. Key papers, defined as papers with extensive primary data or in-depth discussion of conceptual or process issues, were identified through this process. One researcher then undertook an initial analysis of the definitions of 'lay' and models of approaches to involving lay people. Service

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delivery and organisational issues were summarised narratively. An iterative process, involving other members of the research team, was used to test and refine emerging explanations, until data saturation occurred.

In order to promote better access to evidence, and to ensure transparency in the review process, an electronic searchable database of included studies, with data extraction categorisation, was made publicly available on the People in Public Health website in September 2009: https://piph.leedsmet.ac.uk/main/litreview.htm.

4 Literature mapping

4.1 Literature search results

The literature searches found 16204 hits when duplicate references were excluded (Figure 2). An additional 103 references were identified from other sources: web searches (48); authors' personal libraries (33); reference lists (8); expert hearings (5); register of interest (5); hand searches of journals (3); and direct from first author (1). A total of 582 papers were ordered in full, 315 references were identified as 'borderline' at the titles and abstracts stage and 15410 were excluded at this stage.

Figure 2. Study selection process

Potentially relevant papers identified and screened for retrieval (n=16204)

15410 papers excluded
315 papers 'borderline'

103 papers from additional sources:
Web searches (48)
Authors' personal libraries (33)
Reference lists (8)
Expert hearings (5)
Register of interest (5)
Hand searches (3)
Direct from 1st author (1)

582 papers retrieved for more detailed evaluation

142 papers excluded:
    77 not transferable to UK
    23 not enough information on lay role
    46 did not meet inclusion criteria

51 'borderline'
122 'background'
43 unobtainable

Papers included in the scoping review (n=224)

After full publications were retrieved and checked against the inclusion criteria, 224 were included in the review, a further 51 were identified as 'borderline', and 122 were categorised as containing useful background information, though were not included in the review.

Of the 142 papers that were excluded at the full paper stage: 46 did not meet the inclusion criteria, 77 were judged not to be transferable to the UK setting, the majority reporting on interventions in low income countries, and 23 did not contain enough information about the lay role to be useful (see Appendix 4 for a list of excluded studies). Forty-three potentially relevant papers were unobtainable at the time of writing (see Appendix 5 for a list of these papers).

4.2 Borderline papers

There were 366 papers which, at the titles and abstracts or at the full paper stage, fell into categories deemed by the research team to be 'uncertain' in terms of inclusion in or exclusion from the review. Table 3 gives a breakdown of borderline studies by category, with more detail given in Appendix 6. The largest category was long term conditions or illness, followed by children and schools, outreach workers, occupational or workplace interventions, parenting, screening and maternity. Some studies fell into more than one category.

Table 3.Breakdown of borderline studies by category

Borderline category	Number of papers
Long term condition or illness	100
Children and young people	50
Schools	33
Outreach workers	27
Workplace/ occupational	28
Parenting	28
Miscellaneous: Models	16
Screening (not health inequalities or sexual health)	13
Maternity	12
Miscellaneous: Health inequalities	10
Miscellaneous: process issues	9
Community researchers only	7

Community development/ health workers	9
Carer support	5
Miscellaneous: Communities	4
Miscellaneous: Older people	4
Mental health with unclear definition	5
Access to services (not health inequalities)	3
Miscellaneous: Indigenous medical practices	3
Secondary prevention	2
Homelessness	1
Lay people on advisory board/ panel only	1
Healthcare setting	1
Miscellaneous: Generic health promotion intervention	1
Miscellaneous: Volunteering	1

4.3 Included papers

In total, 224 papers were included in the review (Appendix 7). The majority of these (130) were from North America, while 62 were from the UK and 31 from other countries: Australia (2); China (4); Brazil (2); Ghana (2); Mexico (2); Hong Kong (2); Netherlands (2); and one each from Bangladesh, Cameroon, India, Hungary, Ireland, Pakistan, Senegal, Solomon Islands, South Africa, Sweden, Uganda and Vietnam. Four were multi-country.

Of the included studies, 173 (43 from the UK) reported primary research. Forty-seven were commentary or discussion papers[6], nine were reviews, nine were published reports, four were theoretical or conceptual papers, one was a policy document and two were other types of papers.

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[6] Commentary and discussion papers were included if they contained important information about service-relevant issues or models of lay engagement.

Figure 3.   Type of publications represented in included papers
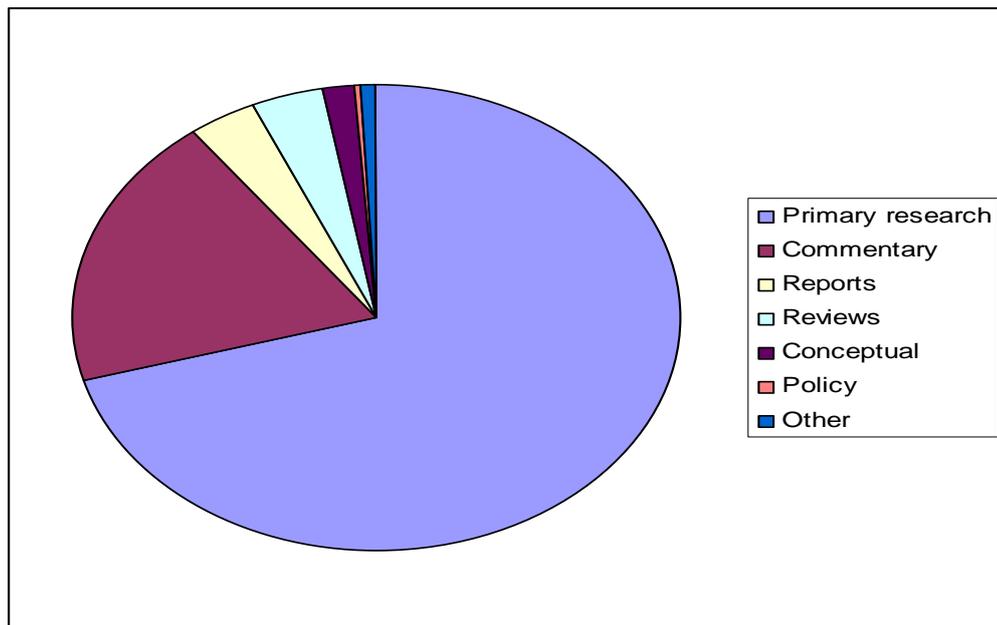
Six of the included studies were systematic reviews, (Rhodes *et al.*, 2007, Fairbank *et al.*, 2000; Casiday *et al.*, 2008; de Oliveira *et al.*, 2001; Lewin *et al.*, 2005; Swider, 2002). Twenty were randomised controlled trials (RCTs), 20 were non-randomised controlled trials, 55 were qualitative research, five were one group before/ after (pre/ post) studies, one was a (UK) cost-effectiveness study, ten were case studies, five were literature reviews, 63 were other evaluations[7], and 67 were other designs or were not studies.

Appendix 8 presents a table of all included studies with breakdown of country, type of paper, design, definition of lay worker role, process issues, organisational outcomes, uptake outcomes, effectiveness outcomes, split by Choosing Health priority. An electronic searchable database with details of included papers is available through the study website:

https://piph.leedsmet.ac.uk/main/litreview.htm.

4.3.1 Interventions

In terms of **health focus**, ten papers looked at smoking reduction or cessation, no papers looked at alcohol use, 51 at diet, nutrition or obesity

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[7] Studies were classed as evaluations where they reported on an evaluation of an intervention or service but there was no obvious study design, such as RCT.

interventions, 69 at sexual health, 44 at interventions designed to tackle inequalities, 29 at generic health promotion interventions, nine at exercise or activity, one at mental health, and 32 at other topics. Some papers fell into more than one category.

In the UK, one study looked at smoking cessation, 21 at improving diet or reducing obesity, 12 at sexual health, seven at health inequalities, three at generic health promotion, three at exercise or physical activity, and one at mental health. No papers looked at alcohol.

Figure 4.   Health focus of included papers
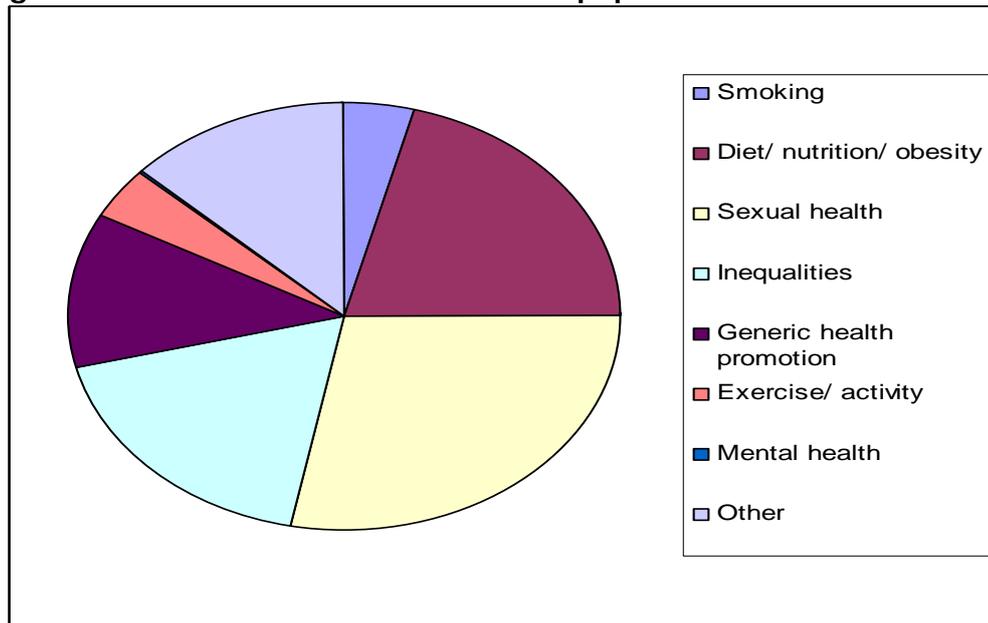
A breakdown of intervention approaches used in included studies is given in Table 4. Some studies fell into more than one category. The majority of included studies were of targeted rather than generic interventions (Visram and Drinkwater, 2005). Forty-six included papers (eight from the UK) compared delivery of interventions by lay people to other routes or types of delivery.

Table 4. Intervention approach represented in included papers

Intervention approach	Number of studies
Working with individuals - targeted/ specific intervention	135
Working with individuals - general health promotion/ public health intervention	5
Working with groups – targeted/ specific intervention	112
Working with groups – general health promotion/ public health intervention	3
Working with communities – targeted/ specific intervention	35
Working with communities – general health promotion/ public health intervention	12

The majority of included papers (140) reported on interventions that were set in the community; six papers reported on interventions set in prisons, four on interventions in workplaces, four on interventions in rural settings, three on interventions in health service settings and 14 on interventions in other settings. Fifty three papers did not report settings. In the UK, where setting was reported, 41 papers were based in community settings, one in a workplace setting and one in a rural setting.

Women were the most common target group (Table 5), followed by black or minority ethnic groups, disadvantaged populations[8], parents, and young people and adolescents. Most studies targeted people in more than one category. Forty studies did not give details of targeted groups or the category was not applicable.

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[8] Here 'disadvantaged' refers to populations experiencing socioeconomic deprivation, by geographic location, indices of multiple deprivation or similar measures, or to populations with obvious needs related to inequalities

Table 5.Target groups represented in included papers

Target group	Number of studies
Women	71
Black/ minority ethnic	45
Disadvantaged	40
Parents	36
Young people/ adolescents	28
Older people	23
Lesbian/ gay/ bisexual	20
Men	14
Drug users	13
Health problems	7
Prisoners	5
Language barriers	4
Healthy people	3
Sex workers	2
Carers	2
Homeless	1
Asylum seekers	1
Physically disabled	1

4.3.2 Lay workers

Of the 138 papers that provided a clear definition of the lay worker role, the most frequently used terms were: lay health advisers or advisors; peer educators, volunteers, community health workers and peer supporters. See Table 6 for a breakdown of lay worker terms. In the UK, the most frequently used terms were volunteers, peer educators and peer supporters.

Lay workers were recruited from the target group in 73 (53%) of these 138 papers. Thirty of the papers reported that the lay workers were paid, six reported other incentives, 15 stated that lay workers were unpaid, 12 reported that both paid and unpaid lay workers were involved and 75 did not report whether lay workers were paid.

Information about the educational level of the lay workers was given in 29 studies. Of these, one recruited people with an educational level of primary

or none; four at secondary level; three at tertiary level and 21 at mixed levels.

Table 6.Lay roles described in included papers

Description of role	Number of papers	Countries
Lay health adviser/ advisor	25	USA (24); Netherlands (1)
Peer educators	25	USA (10); UK (6); China (2); Uganda; Vietnam; Sweden, Netherlands; India; Hungary; Ghana; Australia
Volunteers	14	UK (7); USA (4); China; Hong Kong; Canada
Community health workers	10	USA (7); UK, Mexico, Brazil
Peer support/ supporters	10	UK (5); Canada (3); USA (2)
Community health advisors	5	USA
Peer counsellors	5	USA (2), UK, Hong Kong, Bangladesh
Popular opinion leaders	5	USA (3); UK(2)
Promoters	4	USA
Community health advocates	3	USA (2); UK
Lay health educators	2	USA
Linkworkers	2	UK
Peer health advocates	2	USA
Outreach workers	2	USA
Village health workers	2	USA
Abuela educators	1	USA
Activators	1	Australia
Activity friends	1	UK
Breastfeeding support workers	1	UK
Camp health aide (lay health promoter)	1	USA
Community health educators	1	UK
Community nutrition assistants	1	UK
Female health workers	1	Pakistan
Grandmothers	1	Senegal
Latino health advocates	1	USA
Lay educators	1	USA
Lay food and health workers	1	UK
Lay health workers	1	South Africa
Peer coach	1	UK
Peer outreach workers	1	India
Peer volunteer	1	Canada
Community mobilisers, Relais, Middlemen	1	Cameroon
Support workers	1	UK
Vendors	1	UK
Voluntary lay leaders	1	UK
Young Latino Promontora (YLP)	1	USA

4.3.3 Service delivery and organisational issues

Data on service delivery and organisation issues were presented in 151 of the included studies (31 from the UK). Fifty eight studies (11 from the UK) reported organisational outcomes. Most studies (211) reported effectiveness outcomes. 94 (25 from the UK) reported uptake outcomes for lay workers, target groups or both.

The literature was dominated by studies of interventions involving health services and academic organisations (Table 7). Many of the studies involved more than one organisation, although nine involved only academic organisations and 25 involved only health services. The role of health professionals or services (Table 8) was primarily supervision & management, or commissioning/funding where reported. Surprisingly few studies reported involving health professionals in providing specialist guidance or training, advocacy, provision of services or supporting services. This may be partly due to many studies not specifying the roles of health professionals, and partly due to some health professionals also holding an academic role.

Table 7.Type of organisations represented in included papers

Organisations involved	Number of studies
Health service	101
Academic	95
Community or voluntary	62
Local authority	28
Non government organisation	21
Employer	1
No information	55

Table 8. Role of health professionals/services within included papers

Extent of role of health professionals/ service	Number of studies
Supervision and management	62
Commissioning/ funding	58
Specialist guidance or training	13
Advocacy	7
Direct provision of services	4
Supporting services	4
No information	71

In relation to the experiences of lay workers, 72 included papers (19 from the UK) contained data on the experience of lay workers. 101 included papers (17 from the UK) contained data on recruitment of lay people and only 35 included papers (7 from the UK) contained information about whether the lay person received training. Only 57 included papers (16 from the UK) contained data on the experience of service users.

4.4   Summary

The literature search and mapping identified a relatively large volume of literature looking at lay workers, as is consistent with a systematic scoping review. Many studies reporting on lay roles were classified as borderline because the focus of the intervention was deemed to be outside the scope of the study, however, these studies may contain relevant data for public health. Out of the 224 publications included on the review, 62 were from the UK but only 43 of these reported primary research. In terms of interventions, the mapping found a range of target groups and topic areas represented across included studies, but this was not spread evenly. Critically many different descriptions of lay worker roles were used but educational level and training of lay workers was poorly reported. Overall the results from the mapping indicated that literature on lay workers within public health programmes is diverse, with a moderate amount of studies looking at service delivery and organisational issues.

5 Literature review findings - lay roles

5.1 Definitions

The search revealed a plethora of terms used to encapsulate the range of roles, activities and contexts which the study is concerned with exploring. Over 70 lay descriptors were identified which ranged from variations of the term 'peer' in the UK, to more consistent use of the prefix 'lay' in the US, where lay involvement in health is particularly well established. A full list of descriptors identified through the review is presented in Appendix 9.

Very few of the papers provided detailed definitions or problematised understandings of what 'lay' or 'peer' mean in the context of health, and there was little data to indicate whether the absence of remuneration was a prerequisite for such interventions. Some of the terms described more ambiguous concepts which can be applicable in either lay or professional contexts; examples include 'outreach worker', 'community health worker', and 'community development worker'.

5.1.1 Peer

In the UK there is a preference toward interventions in which 'peerness' is the focus: peer supporters, peer educators, peer coaches, peer volunteers, peer counsellors, peer support workers, peer health coaches, and peer health workers (Shiner, 1999). From the literature review, it appears that there has been a growth of peer-based interventions in the UK over the last two decades, especially those working with teenagers and young adults, with particular emphasis on interventions concerned with HIV/AIDS, sexual health and drugs. Indeed, a 1994 report of the Ministerial Drugs Task Force in Scotland noted the potential of peer education 'to enhance the ability of young people to provide each other with accurate information on health and other issues' (cited in Parkin and McKeganey, 2000:293). There have, however, been challenges to the uncritical acceptance of the efficacy of peer-based approaches (Frankham, 1998). Among these challenges is the fact that the term 'peer' itself provokes contestation.

Dennis (2003) highlights the Oxford English Dictionary (OED) definition of 'peer' as 'a person who is equal in ability, standing, rank or value', while a 'peer group' is 'a group of people of the same age and status'. An examination of the literature indicates that many projects premised upon peer education or support have been reported in the relative absence of any reflection on the dimensions of 'peerness' to which they are assumed to

appeal. Age is more often deemed to be the principal constituent, particularly amongst interventions targeted at young people but also provides the basis of a peer intervention aimed at preventing falls among older people reported by Allen (2004). Shiner (1999:558) asserts that while clear definitions of what 'peer' means have remained elusive, 'age does not constitute a master status that overrides all other possible sources of identity'. Indeed, by illustration of three different peer-education interventions undertaken by drugs prevention teams, Shiner suggests that a narrow focus on age alone can ignore important, and often conflicting, dimensions of ethnicity, sexuality, social class and gender which also contribute to identity formation. This point is reinforced by Latkin *et al.* (2004) who point out that the assumed homogeneity of social groups can be a potential pitfall in peer education since it can ignore the existence of subcultures with cultural groupings.

5.1.2   Lay

The OED defines 'lay' as 'not having professional qualifications or expert knowledge'. The literature search revealed that the prefix was commonplace in North America and in particular the US, where lay-led or lay-delivered programmes have been used to address health inequalities since the 1970s. Here, 'lay health advisor' (LHA) is a commonly used descriptor, but variations include: lay health worker (or promotora), lay health promoter and lay health educators. Indeed, Eng and Young (1992) identify 31 alternative terms for 'lay health advisors' in the US literature alone. Additionally, the present review found in use: lay [breastfeeding] counsellor, lay carer, lay home visitor, lay health leader, lay health volunteer and lay navigator. Rather than absence of professional qualifications, Rhodes *et al.* (2007) in reporting on lay health advisor interventions among Hispanic and Latino populations in the US, emphasise the existence of lay expertise. They state that LHAs:

"*...are part of the communities in which they work, ethnically, socioeconomically, and experientially; possess an intimate understanding of community social networks, strengths, and health needs; understand what is meaningful to those communities; communicate in a similar language; and recognise and incorporate culture (e.g. cultural identity, spiritual coping, traditional health practices) to promote health and health outcomes within their communities.*" (Rhodes *et al.* 2007:418).

In a similar vein, according to Israel (1985), LHAs are:

"*Lay people to whom others naturally turn for advice, emotional support, and tangible aid. They provide informal, spontaneous assistance, which is so*

much a part of everyday life that its value is often not recognised." (cited in Eng and Young, 1992: 26).

Role variation exists even within the specific descriptor of LHA. Eng *et al.* (1997: 415) identify what they describe as a continuum of informal to formal helping, with natural helpers at one end of the continuum, and paraprofessionals at the other. The latter, they point out, are extenders of the service delivery system, carrying out tasks that would normally be undertaken by practitioners, demonstrating an acceptable level of standardised competencies and are often paid by the employing agency. Elsewhere (Eng and Smith, 1995; Dennis, 2003), it is argued that when lay people or peers become professionalised, 'their talents and accountability to the target population are shifted to the healthcare system, diminishing their role in mobilising a community to ensure the health system's responsibility for meeting needs' (Eng and Smith, 1995: 24). Conversely, at the informal end of the continuum, natural helpers are neither employed by, nor have to meet any qualifications set by an agency, but rather their qualifications are set by the community. They are specific individuals who have a reputation in their communities for good judgement, sound advice, a caring ear and for being discrete (Eng *et al.*, 1997: 415). Somewhere along the continuum exists a whole range of lay activity, which will be illustrated below. Importantly, Kennedy *et al.* (2008a: 205) suggest that the choice of term used to describe lay workers appears to be of little importance, but rather 'attention to the role definitions and the social and cultural contexts in which lay helping takes place is more helpful in defining the various roles and responsibilities associated with lay involvement'.

5.2 Justification for lay roles

The literature review found that rationales and motivations for the development of lay or peer roles within public health were presented at different levels. These were grouped into four main justifications: the potential to reach and communicate with hard-to-reach groups; the potential to mobilise community resources; the mechanisms by which lay workers can offer support to their intended beneficiaries; and the broader benefits for lay workers themselves.

5.2.1 Reach, access and communication

Frankham (1998: 179) reports that peer education has been characterised as 'a radical approach with clear cut benefits for reaching constituencies who have been impervious to personal and social education of more 'traditional' forms'. Consequently, arguments have been made regarding the need to capitalise on the susceptibility of young people, for example, being influenced by their peer groups, and there is an assumption that young people are 'ready-made experts in communicating with their peers' (Frankham, 1998: 180) and are likely to engage with more empowering and

participatory methods than adults. However, given the many dimensions against which 'peers' can be matched, it is clear, as both Frankham (1998) and Shiner (1999) note, that this process can be less straightforward than it appears.

Hart (1998) suggests a further rationale for peer-based interventions based on the tendency of individuals to share the attitudes and opinions of people they choose to socialise with or to whom they are attracted in some aspect of their lives. Because of the psychosocial context in which individuals form opinions, they may be more willing to act upon the lead given by respected others (Hart, 1998:87). The 'Popular Opinion Leader' (POL) approach, evidenced in the sexual health literature in the US (Fernandez *et al.*, 2003; Kelly, 2004; Kelly *et al.*, 1992), provides a pertinent example here. While Kelly (2004:141) argues that 'peer-education' is an ill-defined, generic concept, the POL approach represents a very specific, theoretically-based type of peer-based programme. The model is premised upon Roger's (1983) diffusion of innovation theory, and works on the basis that behaviour change can be initiated within a population and will then be diffused to others, providing that enough popular individuals, who are themselves members of the target population, are seen to have adopted and endorsed behaviour change. Opinion leaders, whose views, attitudes and behaviour can influence others because of their social standing, therefore influence changes in behavioural norms, which in the case of HIV-prevention for gay men, for example, includes condom use and avoidance of high-risk sexual activities (Kelly, 2004).

Kelly (2004) argues that key to the success of this model in promoting sexual behaviour change among gay men is the need to identify, recruit and train enough POLs, both to reflect adequately the different subcultures of the target population, and to achieve a 'critical mass' of people to establish new norms and behaviours within the target population. Additionally, Kelly observes, the messages delivered should not simply reflect 'AIDS education', but should 'specifically target critical, theory-based psychosocial determinants of behaviour change that are relevant for the population' (2004:142), which can be endorsed during the POLs naturally occurring conversations with friends and acquaintances. The aim of the model, ultimately, is to establish something comparable to a social movement with enough momentum to establish and sustain safer sexual behaviour as a new social norm.

5.2.2 Mobilisation of community resources

In a period during which increasing emphasis is being placed on promoting active citizenship and the revitalisation of communities, lay involvement in health is viewed as a positive example of co-ordinated activity in which people are seen to be 'generously donating their time and effort to their

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local community, and with the best of altruistic motives - the improvement of health' (Hart, 1998:87). Typically responding to issues concerning health inequalities, community organising interventions are associated with, for example, Sure Start initiatives (Attree, 2004) and other programmes which mobilise community resources (Kennedy *et al.*, 1999). Some of the best examples can be evidenced in US literature (see Baker *et al.*, 1997, Earp *et al.*, 1997; Eng, 1993; Kim *et al.*, 2005; McQuiston *et al.*, 2001).

An example of an intervention which has its roots in theories of social organising is North Carolina Breast Cancer Screening Programme (NCBCSP), a key component of which is the Save Our Sisters Project. The intervention was developed in response to a disparity in the use of screening services among older African American women in rural areas, leading to increased mortality amongst this population group. A 10-year study co-ordinated by the University of North Carolina was undertaken (Altpeter *et al.*, 1999; Bishop *et al.*, 2002; Earp *et al.*, 1997; Eng, 1993, Eng *et al.*, 1997; Eng and Smith, 1995; Eng and Young, 1992; Flax and Earp, 1999). The NCBCSP approach is theoretically driven and premised upon a combination of the social-ecological theory of health promotion, and principles for institutionalising health programmes (Altpeter *et al.*, 1998). Thus, at one level it is recognised that there is a need to target different stakeholders, from individuals and their social networks through to policymakers, in order that the necessary linkages can be made between women in rural areas and the various agencies which serve them. On another level, locality development is used to build community capacity to improve quality of life. Altpeter *et al.* (1998) point out that when social or community-based workers act as 'coaches', they can support community members' efforts at organising themselves, including providing opportunities for training and skills development. Finally, complementing lay-based activities, professionals then identify and integrate the needs of these most marginalised communities in the appropriate planning and development of services. In the NCBCSP, a three-pronged approach was employed, with the Save Our Sisters Project forming the basis of the OutReach component, and drawing upon an extensive network of older African American women volunteers to provide information about breast-cancer and screening and social support around mammography through their social networks.

5.2.3 Lay roles as a support mechanism

Lay or peer interventions can be seen in a variety of contexts and in response to what Dennis (2003) describes as different 'stressors'. These can be transitional or life-course stressors, such as those linked to motherhood or bereavement, or chronic or acute situational stressors resulting from changes in long-term health. Additionally, the 'prompt' may be health promotion. Dennis (2003) suggests that all lay/peer interventions involve emotional, information and appraisal support, in differing degrees, producing a range of effects for both the lay worker and the intended

beneficiaries. For example, being provided with opportunities to feel part of a social network can have a direct impact in: decreasing social isolation and feelings of loneliness, thus promoting positive mental health; encouraging help-seeking behaviours and deterring maladaptive practices; increasing motivation to improve health; providing information and signposting to additional sources of help (Dennis, 2003:326-327; Neuberger, 2008). Another effect that lay roles can have is helping to buffer or 'protect individuals from potentially harmful influences of stressful events' (Dennis, 2003:327) or determine their responses to such events by providing opportunities for cognitive appraisal of the situation or stressor. Similarly, lay people/peers may also have a mediating effect in helping people of similar backgrounds and experiences to assess their own capacity to deal with situations by example.

5.2.4 Benefits to lay workers

The literature abounds with examples of perceived benefits of lay activity for participants. These include building social resources, improvements in self-esteem, empowerment and enabling people to feel that they are making a contribution (Black and Living, 2004; Casiday *et al.*, 2008; Curtis *et al.*, 2007, Dennis, 2002a; Downing *et al.*, 1999; McGlone *et al.*, 1999; Raine, 2003; Ramirez-Valles and Uris Brown, 2003; Rodriguez *et al.*, 2003; The Countryside Agency, 2005; Weeks *et al.*, 2006). Participation can act as a catalyst for personal development and result in individuals going on to pursue other training opportunities and gain subsequent employment (Attree, 2004; Neuberger, 2008; Raine, 2003). Lay activity can be particularly beneficial for prisoners who volunteer since it can play a role in preventing re-offending and, additionally, can improve self-worth, provide meaningful use of time and give a sense of purpose (Farrant and Levenson, 2002). Ramirez-Valles and Uris Brown (2003) also note that in the context of community involvement around HIV/AIDS, volunteers report improved self-efficacy concerning condom use.

5.3 A method to deliver an intervention, or an intervention itself?

The review identified different approaches to lay-led delivery. At one end of the scale, lay people are used to deliver an intervention or health promotion message, while at the other end are projects in which lay people are the intervention, for example, developing capacity within their communities. While there was, on the whole, a dearth of critical discussion regarding these distinctions, Shiner (1999) draws attention to the aims and methods of an intervention and the way in which lay people are involved, making a distinction between '(peer) development' and '(peer) delivery'. Speaking specifically of peer education, Shiner points out that this is viewed, primarily, as a method of delivery, ignoring the nature of the relationship

which peer workers might have with a project. For Shiner, activities which are based in formal settings, rely upon and reinforce existing professional expertise, and focus on communicating key messages, largely fall into the category of 'peer delivery'. However, those projects which entrust participants with decision-making power, enabling them to contribute to the development of an intervention and its implementation via participation on advisory/steering groups or research teams, thereby creating a sense of ownership and investment, can be described as having a 'peer development' focus. This type of approach tends to focus on additional potential outcomes, such as personal growth and skills development for lay workers, who are seen as an inherent part of the intervention itself.

5.4 Dimensions of role

The data extraction process categorised studies across a number of dimensions relating to interventions, lay workers and their roles. Additionally, qualitative review of studies revealed a range of other, less straightforward, dimensions which complicate efforts to map the ways in which lay people are involved in public health. These include motivating factors for lay people and the organisations who work with them, the relationship that lay people have with services, the focus of the intervention, the type of expertise which lay people bring and whether lay people are working within or simply providing access to a community. Table 9 illustrates the complexity involved in mapping and understanding interventions involving lay people.

Table 9.Core dimensions of interventions involving lay workers

Key role dimensions	
- Health Priority - Target population - Core and subsidiary roles - Working with individuals, groups or community - Paid, unpaid or other incentives - Why do lay people get involved in public health? - What expertise/knowledge is it that lay people are valued for: experiential, cultural, linguistic, embodied? - Who benefits	- Lay person identified and recruited by community or organisation? - Motivation of organisation for involving lay people: economic, intellectual or emotional (Hart, 1998) - Is lay person giving access to community or working within it? - Are lay people the intervention or are they delivering it? - Is the intervention based on natural or created links? - What is the relationship between lay workers and service organisations?

Why lay people get involved

The literature review identified a number of reasons for lay people to take on public health roles (see Wilson, 2000). A recent consultation with health and social care volunteers undertaken by Baroness Neuberger (2008) discusses motivations and indicates that people often get involved in this type of volunteering because they want to 'give something back' or to help people in their communities. Some people want to do something positive to help others as a result of their own experiences of, for example, giving up smoking or want to make a contribution around specific health concern, HIV/AIDS being a good example. It is also an opportunity to meet new people, perhaps in similar circumstances, either experiencing social isolation, or facing a particular health issue. Others specifically see it as an opportunity to acquire skills and training which can lead to employment and further education.

Payments/incentives

It should not be assumed that all people engaging in lay roles do so on a voluntary basis. Indeed, the literature illustrates that lay workers are also paid on a sessional basis (Allen, 2004; Ingram *et al.*, 2005; Leaman *et al.*, 1997), have their out of pocket expenses, such as travel and telephone costs, reimbursed (Scott and Mostyn, 2003), or are offered other incentives. For example, in a New York-based sexual health intervention targeting low-income women, peer educators were expected to work 20 hours a week in return for a weekly stipend of $100, a figure which would not jeopardise their public assistance support (Freudenberg *et al.*, 1994:122). Another US study reports that community health advisors were offered $50 on completion of six out of the eight training sessions, and then a further $10 to attend post-training monthly meetings (Hinton *et al.*, 2005). In a study targeting HIV-prevention education at gay men using London gyms, £100 towards gym memberships was offered (Elford *et al.*, 2002b). Reporting a Lay Health Advisor (LHA) intervention in the US, Plescia *et al.* (2006) discuss how a decision was made about paying LHAs. While some members of the community coalition overseeing the project felt that payment would inhibit the potential for capacity building, others suggested that it was important to compensate for the risks associated with outreach work.

Why organisations involve lay people

Reasons why service organisations choose interventions involving lay people also varied. Increased service capacity is an important motivation. Kennedy *et al.'s* (2008a) study of lay workers involved in community-based food initiatives indicates that the role of lay food and health workers in the NHS is typically to provide a cost-effective solution to relieving dieticians' caseloads. There is a distinction between whether a service is simply trying to secure access to 'hard-to-reach' communities or target populations (see Kennedy *et al.*, 2008b) or to achieve a more meaningful multi-lateral exchange of knowledge and expertise (illustrated by some of case studies presented by Levenson and Gillam, 1998). In the US literature in particular, much has been written about the role that lay people can play in providing a 'bridge' or link between the formal service delivery system and communities' informal social support systems (Eng *et al.*, 1997; Eng and Young, 1992). Hinton *et al.* (2005), however, point out in relation to community health workers in the Deep South Network for Cancer Control, these workers 'are not trained to substitute for professionals, but rather act as counterparts to assist healthcare providers and other professionals in their mission to improve health and social conditions in ways these traditional providers are not able to provide' (2005:26). Beam and Tessaro (1994:78) also note that where an intervention is agency-based, the lay activities may, in fact, be directed at 'maintaining and strengthening the current system instead of trying to negotiate a more efficient system of access through outreach activities or organising communities to find their own solutions'. As the discussions in the following chapter will illustrate in

more detail, the ways in which lay workers are identified, recruited and subsequently trained represent key dimensions of difference, particularly in terms of their accountability. Those interventions which exclude the community from selection and recruitment processes are more likely to be concerned with securing access to, rather than working with, communities to improve services.

Type of expertise

A further consideration concerns the type of expertise professionals are seeking to engage by drawing upon lay knowledge. Some interventions draw upon experiential or embodied knowledge, such as experience of living in similar social conditions, or familiarity with a particular health concern and examples include peer-based drug interventions and breastfeeding peer support. Meanwhile, other interventions rely on lay people's cultural knowledge. This is particularly salient for interventions targeting Black and Minority Ethnic (BME) populations, especially where language barriers exist, but is equally relevant in terms of reaching, for example, the gay community and its various subcultures. A King's Fund report indicates that, in spite of the important role that linkworkers can play in facilitating the relationship between health professionals and communities whose first language is not English, there is evidence to suggest that these language skills are undervalued by the NHS, and this is reflected in the pay and status of bilingual Linkworkers (Levenson and Gillam, 1998:35).

Activities and roles

A number of different roles and associated activities emerge within the literature. For example, a systematic review of Lay Health Advisor interventions among Hispanic/Latino populations in the US undertaken by Rhodes *et al.* (2007) found six primary roles for LHAs. These include: supporting participant recruitment and data collection, serving as health advisors and referral sources, distributing materials, being role models, advocating on behalf of community members, and serving as co-researchers in participatory research methods. Reporting on the roles of Linkworkers in the UK, Levenson and Gillam (1998:10) include: interpreter, cultural ambassador, outreach worker, advocate, patient's representative, social supporter, health advisor/educator, health promoter, lay health worker, source of feedback to NHS planners and providers, route for communication on consultation, educator of health professionals, community change agent, counsellor and messenger. Some of these roles are also more complex than they initially appear. For example, Faulkner (2005) points out that while 'social support' is a commonly identified role, it is also ill-defined and used as something of an 'umbrella' term, encompassing a range of dimensions. Drawing upon Langford *et al.*'s (1997) concept analysis, Faulkner concludes that social support relates to one or more any combination of four broad components: appraisal, emotional, instrumental and informational.

Evidently, a complex range of roles emerge depending on the context, health priority, population group, mechanism and focus of the intervention, but these can broadly be categorised into core and subsidiary roles.

Core roles include:

- facilitating access to communities, particularly those deemed 'hard-to-reach'
- providing information regarding health education
- providing direct services or activities (from walking activities to new patient checks)
- social support
- access to or signposting services.

Depending on the intervention and context, other roles can include:

- advocacy
- informal counselling
- cultural mediation
- training and skills development
- help with improving community and collective resources.

Different activities will vary depending on the focus of the intervention. For example, some may be concerned with instigating behaviour change at an individual level around specific targets or health priorities, for example peer based HIV prevention, and the role may focus primarily on providing information specific to that health priority. On the other hand, for some community-based projects, the emphasis is often on cascading information through social networks and, by providing appraisal support, empowering people to instigate wider changes within their lives which extend beyond the domain of health. Within such contexts the role of the lay worker is not simply to provide information, but incorporates a whole range of activities with a much broader focus.

The UK breastfeeding literature is particularly interesting since it reveals very different emphases within one health priority, where differing foci can impact upon the training provided and the way that the role of the lay worker is conceptualised. In reporting on NHS breastfeeding peer support programmes in Scotland, Britten *et al.* (2006) note that the emphasis is with the mechanics of breastfeeding and problem solving, as training is based upon the UNICEF Baby Friendly Initiative training for health professionals. By contrast, it is noted that in England, training emphasises the role of listener and confidence-builder. Thus, in Scotland, training has

not tended to prioritise the importance of exploring personal breastfeeding experiences or developing communication skills of peer workers. Such skills could enable peer supporters to be distinguished from health professionals, perhaps enabling mothers to perceive them as more accessible (Britten *et al.*, 2006:19), whereas in the Scottish model, peers are characterised less as 'equal' to other mothers, and more as extensions of the health service.

Relative autonomy or service-linked?

Another important dimension is that lay roles may vary depending on the relationship between the lay worker and health professionals. For example, activities which tend to be informal, community-based and relatively autonomous from formal structures are less likely to encounter the type of monitoring and evaluation associated with the service delivery objectives agreed in more formal settings, where discourses around evidenced-based practice predominate. Again, peer support for breastfeeding provides a useful illustration. The literature indicates that professionals are more likely to endorse peer-based activity and make referrals if they are seen to reinforce service-identified objectives and not to transgress role boundaries. Indeed, in a study discussing the peer-professional interface in a community-based breastfeeding project in Doncaster, Curtis *et al.* (2007:154) conclude that:

"*the potential for conflict between health professionals and volunteers may well be greatest when the volunteers feel constrained by the expectations imposed upon them by a project and when health professionals interact with volunteers on the basis of assumptions derived from those expectations.*"

Although the level of professional or organisational control is something which can change both ways, the 'Fag Ends' smoking cessation service, reported by Springett *et al.* (2007) provides a pertinent example of an intervention which began autonomously but has subsequently been mainstreamed. Originally a self-help group born out of an Everton-based community development project in 1997, Fag Ends was a service composed entirely of voluntary lay advisers who were ex-smokers wanting to help others to quit smoking. Its approach to smoking cessation predates current government guidelines. By 1997, it had become embraced by the Roy Castle Lung Cancer Foundation (RCLCF). This development led to a telephone help-line, alongside group and one-to-one counselling. Two years later, it had become the main smoking cessation service for Liverpool and the volunteers paid employees of the RCLCF. In order to qualify for government funding, however, the service had to adapt its original community-based approach to conform to national guidelines despite its proven success records and acceptability in the community.

Springett *et al.* (2007:252-253) point out that 'Fag Ends derives its evidence base for the way it works from its service users, whose needs and requirements have driven the service', but this has had to be developed to accommodate 'centrally driven implementation advice and performance- and target-driven public management' concerns (2007:252-253). What has resulted is a 'hybrid' approach integrating national guidance with experience of what had already been proven to work. Having started out as 'natural helpers', Fag Ends' lay advisors now find themselves at the paraprofessional end of the continuum.

5.5 Common models

In terms of the health issues targeted by lay/peer interventions reported in the literature, these covered a broad range of concerns, varying by geographical region, but a large proportion of papers focused on sexual health, breastfeeding and health inequalities. Table 10 provides details of health priorities addressed, descriptors used and examples of related studies and outputs. From the data extraction and analysis process, it was possible to identify a number of common models that can be implemented in response to different health issues and in different contexts. Each of these models are discussed in turn and an illustrative case study provided. It is important to note that it is not always possible to make sharp distinctions between these models since key dimensions of one model may also feature in another, but there are issues of focus or delivery which ensure their distinctiveness.

Table 10.   Examples of lay workers in practice

Health Priority	Descriptor	Target Population	Studies/Outputs
Sexual Health	Community Health Agents Inmate peer educator Lay Counsellors Lay Health Advisor Peer Educator Peer health advocates Peer informant Peer Leader Popular Opinion Leader Volunteer	Underprivileged urban women (Brazil) Prisoners (US) General (Ghana) African-American women Men who have sex with men (UK) Young people (Sweden; US) Lesbian/Bisexual women(US) Prisoners US; (UK) Male sex workers (UK) Women prisoners (US) Drug users Young people (UK) Young people (UK) Men who have sex with men (US) General population (US) Latino men who have sex with men (US) Men who have sex with men (UK)	(Barbosa *et al*, 1998) (Grinstead *et al*, 1999) (Baiden *et al*, 2007) (Thomas *et al*, 1998) (Elford *et al.*, 2002a, Elford *et al.*, 2002b, Flowers *et al*, 2002, Williamson *et al*, 2001) (Anderson, 1995, Feudo *et al*, 1998), (Stevens, 1994) (Boudin *et al*, 1999, Farrant and Levenson, 2002) (Ziersch *et al*, 2000) (Boudin *et al*, 1999) (Dickson-Gomez *et al*, 2006) (Ford and Inman, 1992) (Ochieng, 2003) (Fernandez *et al*, 2003, Kelly, 2004, Kelly *et al*, 1992) (Caceres *et al*, 2007) (Somerville *et al*, 2006) (French *et al*, 2000)
Breastfeeding	Breastfeeding supporter Lay Supporter Peer/Personal Coach Peer Counsellor Peer Supporter Peer Support Volunteer Peer Volunteer Support Worker Volunteer	Mothers (UK) Mothers (Bangladesh; USA) Mothers (Canada) Bangladeshi Mothers (UK) Mothers (UK)	(Hoddinott *et al*, 2006a, Hoddinott *et al*, 2006b, Ingram *et al.*, 2005, Raine, 2003) (Fairbank *et al*, 2000, Haider *et al*, 2002, Schafer *et al*, 1998) (Scott and Mostyn, 2003, Dennis *et al*, 2002, Dennis, 2003) (Britten *et al*, 2006, Battersby and Sabin, 2002, Ahmed *et al*, 2006) (Curtis *et al*, 2007, Watt *et al*, 2006)
Health Inequalities	Bi-lingual health advocate Buddy/Listener/ Peer Supporter Community health worker Lay Health Advisor Lay Health Worker Village Health Worker Peer Educator	South Asian communities (UK) Prisoners (UK; Australia) Various (US) African American breast-cancer screening (US) Latino/Hispanic communities US) Vietnamese Women (US) BME communities (US) South Asian communities (UK)	(Greenhalgh *et al*, 2005) (Devilly *et al*, .2005, Farrant and Levenson, 2002) (Andrews *et al*, 2004, Kash *et al*, 2007, Kuhajda *et al.*, 2006, Love *et al*, 1997) (Bishop *et al*, 2002, Earp *et al*, 1997, Eng, 1993, Eng and Smith, 1995, Flax and Earp, 1999) (Baker *et al*, 1997, McQuiston and Uribe, 2001, Rhodes *et al*, 2007) (Lam *et al*, 2003) (Schulz *et al*, 1997) (Farooqi and Bhavsar, 2001)
Smoking Cessation	Buddy Community health advisors/worker s Lay advisor Peer Educator	Pregnant adolescent smokers (US) BME communities (US) All smokers (UK) Roma Gypsies (Hungary)	(Albrecht *et al*, 1998) (Andrews *et al*, 2007, Rodriguez *et al*, 2003, Woodruff *et al*, 2002) (Springett *et al*, 2007) (Szilagyi, 2002), 2002

Nutrition/Diet	Community food worker Community Nutrition Assistant Community Nutrition Worker Grandmothers Lay Health Community Worker Peer Educator	Low income groups (UK) Low income groups (UK) Low income groups (US) Young mothers (Senegal) Latino communities (US) Female college students (US) Hispanic communities (US) Low income groups (US) Older men (US)	(Kennedy *et al*, 2008a) (Kennedy *et al*, 1999) (Leaman *et al*, 1997) (Aubel *et al*, 2001) (Navarro *et al*, 2000) (Kunkel *et al*, 2001) (Taylor *et al*, 2001) (Anliker and Damron, 1999) (Lynde, 1992)
Physical Activity	Activators Lay Volunteer Peer Educators	Older adults (Australia) 40-70 yr olds (UK) Older adults Netherlands)	(Jones and Owen, 1998) (Lamb *et al*, 2002) (Westhoff and Hopman-Rock, 2002)
Mental Health	Listener Community Mentor	Prisoners (UK) Older people (UK)	(Farrant and Levenson, 2002) (Goodenough, 2007)
Drugs	Big Issue vendor Buddy Outreach worker Peer educator Peer health advocates Peer outreach educators Peer volunteer The Crew	Homeless drug users (UK) Prisoners (UK) Drug users (US) Drug users (UK) Drug users (US) Drug users (US) Young people (UK) Various (UK) Young people (UK)	(Hunter and Power, 2002) (Farrant and Levenson, 2002) (Andersen *et al* 1998) (Craine and *et al*, 2006) Weeks *et al*, 2006 (Latkin *et al*, 2004) (Shiner, 1999) (Hunter *et al*, 1997) (Skelton, 1998)
Alcohol	Peer health educator	College Students (US)	(Adams *et al*, 2006)

5.5.1 Peer education

Peer education is a common model used in the context of sexual health, health inequalities, smoking cessation, nutrition, physical activity and drugs, and in relation to a range of target groups. To varying degrees, it features as a *method* in all models. In each of the priority areas listed, the principal focus of the peer education model appears to be on communicating information which could effect behaviour change. In the studies listed in Table 10, the dimensions of 'peer' which these interventions appeal to is understood to refer to age, sexuality, ethnic or cultural background, occupation and income levels. In some cases, for example in the context of drug users or prisoners, it also refers to particular types of experiential knowledge. Box 1 provides an example of peer education targeted at homeless drug-users.

Box 1. Big Issue vendors as peer educators: reducing drug-related harm

Hunter and Power (2002) report on a feasibility study for a peer-education initiative aimed at reducing drug-related harm among homeless people. Employing action research methods that involved *Big Issue* vendors in identifying the health promotion priorities of homeless people, the intervention was premised on arguments that peer education in this context offers greater access to and credibility within the target population than health professionals, and also enables effective use of informal networks (Turner and Shepherd, 1999). Having carried out research with *Big Issue* sellers at sites in Brighton, London and the West Midlands, two NHS drugs workers designed a one-off training session, lasting approximately four hours, which they then delivered to 15 *Big Issue* vendors at the magazine's offices. The emphasis of the training was to provide information regarding HIV and hepatitis, prevention of injection-related injury, prevention and dealing with overdose. Vendors were paid £35 for attending, to cover lost earnings. Six weeks after training, they were invited back for a follow-up interview. While vendors reported wanting to find out more about Hepatitis C, for example, a common motivating factor was the money and it was felt that the intervention would not be feasible unless lost earnings from vending were reimbursed.

Clearly, vendors were recruited as peer educators because of the very specific embodied experience of homelessness, its risks and dangers which they shared with the target population. However, Hunter and Power report conflict between lay and professional expertise. Indeed, 'while their nursing background was significant in establishing expertise, the trainers had to accept that participants were knowledgeable about drug use and potential risk (and) often a contradiction existed between trainers' advice and vendors' experience' (Hunter and Power, 2002:61). Additionally, vendors were sceptical about the extent to which their 'peer' status would actually make a difference in terms of encouraging people to listen or accept harm reduction advice. Follow-up interviews with 13 of the 15 vendors who attended the training session highlighted that a one-off session was inadequate as retention of accurate knowledge from the session was patchy. They also revealed that it was often difficult to engage in 'peer education activity' spontaneously.

5.5.2 Peer support

Experiential knowledge was also the core dimension of the peer support model, largely found in the breastfeeding literature, but the smoking cessation intervention reported by Springett *et al.* (2007) provides another example. It should be noted that peer support was also found to be a core dimension within other models, lay health advisors being a pertinent example. Box 2 provides an example of peer support in prisons.

Box 2. Peer support: prison 'Listener' or 'Buddy' schemes

In the first national study of volunteering and active citizenship in prisons in England and Wales reported by Farrant and Levenson (2002), it was revealed that in 2001 there were 103 'Listener' or 'Buddy' schemes in operation in the 82 prisons which took part in the study, including all the high security and open prisons. Prison Listener schemes are 'based on the belief that Samaritan principles of confidential and sympathetic listening can be applied formally within the prison setting' (Farrant and Levenson, 2002:9). Listeners are prisoners who are trained and supported by the Samaritans to befriend those who feel vulnerable or suicidal. The first scheme was established in Swansea in 1991 and within three years, the record of self-harm was reported to have halved Davies (1991) reported in Farrant and Levenson (2002:9).The service that Listeners provide is believed to play a crucial role in reducing the distress caused by imprisonment, particularly for those who are suicidal. Clearly, then, they are perceived to be performing a buffering role. Farrant and Levenson report that a number of prisons provide special crisis or care suites where vulnerable prisoners can spend time with a Listener away from a normal cell. It is unclear as to whether Listeners received any form of incentive, but at one prison, it was reported that Listeners had declined an offer of payment to 'preserve the independence' of the service they offered (Farrant and Levenson, 2002:10).

Schemes were largely viewed as positive, although some cynicism was reported Farrant and Levenson (2002). For example, some prisoners felt that their role was not taken seriously by prison staff, and staff at one prison believed that the scheme was being used to distribute drugs within the prison Prisoners were motivated to get involved because of their own experiences of having felt suicidal and because it helped them put their own lives into perspective.

5.5.3 Popular Opinion Leaders

As previously discussed, the POL model is seen as distinct from peer education since it is a very specific type of theoretically-driven peer education based upon diffusion of innovation theory and has been primarily developed in the context of sexual health/HIV prevention. Box 3 provides an example in practice of how the original model, developed for use among gay men, was applied to an intervention with a particular group of at-risk women in the US. As with the bridging (Lay Health Advisor) model, the POL model relies upon the social networks of lay workers.

Box 3. Using the POL model among poor, urban minority women in the US

Responding to a shift in the epidemiology of HIV in the US which has placed poor, minority women, in particular, at increased risk via heterosexual transmission, Kelly and his colleagues launched another series of experiments to test whether the POL model would be successful in creating behavioural change amongst this population (Fernandez *et al.* 2003). The model was adapted following a survey of 671 women living in 10 inner-city, low income housing developments in five US cities and a randomised controlled trial was conducted involving 18 low-income housing developments in five cities. These were divided equally into intervention and control communities. Baseline and 12-month follow-up interviews were carried out with 690 women. Women who were identified as popular by their peers in each of the intervention communities were trained to plan and conduct HIV-risk reduction workshops and ongoing community events. While little change was observed in the control communities, it was reported that there was a 25 per cent reduction in unprotected intercourse and a 56 per cent increase in the frequency of condom use in the intervention group.

5.5.4 *Community organising*

The primary focus of the community organising model is on mobilising community resources and building capacity within a given community. Projects falling into this category emphasise the community-based nature of the intervention. Unlike other models which can also utilise community organising methods, this model is distinctive because it does not rely on social networks. Indeed, lay workers can operate within communities which are parallel, but are not their own, providing that they can relate to issues of relevance to that community. Examples of this model can be found through community nutrition interventions and Box 4 provides an example of a Bolton-based project.

Box 4. A community organising model: dietetic helpers in the community

The Bolton Community Nutrition Assistants Project was developed by a community dietetics team with a reputation for employing innovative approaches to promoting healthier food and nutrition. Food Health Advisers (FHAs) worked predominantly in disadvantaged areas to increase the use of services among hard-to-reach groups. The aim was not to provide nutrition information, but to help people to overcome the barriers to eating healthily. The project reported by Kennedy *et al.* (1999) involved recruiting and training a network of lay people as Community Nutrition Assistants (CNAs) to work in their own neighbourhoods. Their task was to 'explore and act on the food and health needs of local communities,

particularly those in disadvantaged areas, using the principles of community development' (Kennedy *et al.*, 1999:504).

Nine lay people completed the training and started working in their communities under the supervision of the FHAs. Results show that after one year, the CNAs were making four times as many contacts as the FHAs. Their flexible working hours and proximity within the community meant that they were more accessible and enabled them to access homeless people and hostels for young mothers for example.

Incorporating elements of social and appraisal support, typical activities included: assisting individuals in interpreting dietary advice from their GP; advising on shopping or cooking tips to adopt a low-fat diet; helping communities to establish food co-operatives in areas where access to fruit and vegetables is limited, and supporting parent groups in campaigning for healthier school tuck shops (Kennedy *et al.*, 1999:507). The role does have elements of peer support and, to some extent, it can be said that CNAs fulfil a bridging role between the community and traditional services. It is their significant role in mobilising community resources and empowering local communities to take control of their own health which illustrates features of the community organising model.

5.5.5 Bridging model – lay health advisors

While, the LHA model can also be identified as a community organising model, it is premised upon developing the supportive roles that some people termed 'natural helpers', naturally find themselves fulfilling within their communities. Also known as community health workers, these workers are perceived to be:

"*Uniquely skilled to serve as bridges between community members and healthcare services because they live in the communities in which they work, understand what is meaningful, and communicate in the language of the people in their communities. They know the cultural buffers, such as cultural identity, spiritual coping, and traditional health practices that can help community members cope with stress and promote positive health outcomes. A critical asset of programmes that engage community health workers is that they build on already existing community network ties that contribute to the acceptance and sustainability of effective community programmes.*" (American Association of Diabetes, 2003:821).

Typically, the bridging model appears in US literature concerning health inequalities since many target communities are underserved. The North Carolina Breast Cancer Screening Programme, discussed earlier, is an example of LHA study whose results have been widely published. Another example, illustrated in Box 5, is the Lay Health Worker Outreach Programme used to promote breast and cervical cancer screening among Vietnamese-American women.

Box 5. Lay Health Workers: linking communities to services

The Lay Health Worker Outreach (LHWO) Programme reported by Lam *et al.* (2003) was born out of a collaboration between a community coalition in Santa Clara County, California, and a University of California (San Francisco) Vietnamese Community Health Project, the aim of which was to increase cervical cancer screening among Vietnamese women, who have the highest rates of the disease than any other ethnic group in the US (Lam *et al.*, 2003:516).

The community coalition selected five partner agencies. The aim was that each agency would select an LHWO co-ordinator and 10 lay health workers (LHWs), who would receive a $1,500 stipend. These women had to be over 18, Vietnamese-American, residents of Santa Clara County, 'compassionate, dedicated, personable and willing to learn' (Lam *et al.*, 2003:518). As with lay workers in the NCBCSP, these LHWs were would then be required to recruit a further 20 women from their social networks; a gift or $30 would be offered as an incentive by partner agencies.

Lam *et al.* (2003) report findings from work undertaken with the first two partners, both non-profit health and social service agencies. Having recruited and trained the required number of women to become LHWs and women from their social networks (n = 200), these were randomised into two equal groups. One received only media education concerning cervical cancer and screening, and the other received this and information from the LHW via group discussions lasting between 90 and 120 minutes. Results indicate that among those women receiving the intervention via LHWs, there was a 14.8 per cent increase in PAP screening and 47.8 per cent of those who had never been screened reported attendance compared with only 2.5 per cent of women who received only media education (Lam *et al.*, 2003:520).

In this example, lay people were not simply being used to enable health services to access an underserved or hard-to-reach community, but rather their cultural knowledge and, more importantly, their ability to communicate in the same language as the target group enabled them to provide a valuable bridge between the health system and a community at risk. In this context, not only do LHWs represent a bridge, but they also

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> play a literal role in translating messages from one group to another.

An interesting variation of the bridging model can be found in Baker *et al.* (1997). Discussing a pilot for a collaborative intervention aimed at Latino communities, the authors state that:

"*In working with both the community and the health and human service providers, the advocates sought to <u>build a bridge</u> that the two parties could use, not to be that bridge between them – that is, they did not want effective interactions between the two groups to be dependent on their participation.*" (Baker *et al.*, 1997:500 [emphasis added]).

Overall, the five case studies provided here do not offer straightforward examples of interventions that neatly fall into each of the model types, but rather illustrate their complexity in practice. They illuminate how key dimensions of an intervention will be determined by a range of factors, including the context, health priority, focus and a range of other dimensions in greater or lesser degrees. Such factors include motivations, incentives and relationships with formal health services. One example which provides a good illustration of the difficulties wrought in trying to attribute an intervention to a specific model is that of Community Health Educators (CHEs). Although the CHE initiative draws upon Rogers's (1983) diffusion of innovation theory, a study of social networks among CHEs undertaken by Chiu and West (2004) suggests that these workers are not simply popular opinion leaders but, rather, their reliance on social networks has meant that CHEs have increasingly become valued as change agents. Indeed, those of Chiu and West's participants who had been active CHEs for some time were reported to have been more likely to perceive 'themselves as bridges or links between health organisations and their communities' (Chiu and West, 2004:10). This suggests that CHEs represent a hybrid of key dimensions of two models: the theoretical underpinnings of the POL model, with the bridging model in practice. The application of the models in different contexts is now considered below, with reference to the mapping results.

5.6 Lay workers in practice contexts

International

Seven of the 31 included papers originating from outside the UK or North America dealt with HIV/AIDS and two focused on nutrition, one of which contained learning which could be transferable to the UK since it dealt with breastfeeding peer counsellors in Bangladesh (Haider *et al.*, 2002). Four papers focused on dimensions of peer education and support, others drew

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on social and family networks or specifically on the bridging, community/lay health worker model (Daniels *et al.*, 2005; Wayland, 2002). Given the healthcare context, it was not surprising that some papers reported the activity of NGOs, particularly in mobilising community resources, and also that lay workers were involved in delivering primary care (Barzgar *et al.*, 1997; Chevalier *et al.*, 1993).

North America

While both the nature of the healthcare system and differences in demography make it difficult to transfer some of the models which have been established successfully in the US to the UK, nonetheless there is potential for valuable learning. Of the 130 papers originating from North America, 38 focused on black and minority population groups, and many of these related to screening. Given the barriers to access to healthcare for low income and minority groups in the US, this focus is perhaps unsurprising. Indeed, 73 papers discussed the role of community health or lay health workers in bridging the gap between marginalised communities and formal services. However, based upon their survey of 197 agencies employing community healthcare workers (CHWs) in North California, Love *et al.* (1997), point out that these workers serve in a variety of capacities, from volunteers, to frontline healthcare professionals, and that 'there is no agreed-on set of skills for these health workers, nor is their a clear definition of their role' (1997:510).

In terms of emphasis, the key dimension was either peer education or peer support in 57 papers, including the POL studies. Forty one papers focused on sexual health, but unlike UK studies, these addressed a wider target population, including intravenous drug users, young people and minority groups. As with UK papers, it seems to be the case that interventions in which peer education or support are the focus tend to be more prescriptive and service linked, while those which rely on social networks perhaps have more autonomy. However, as the discussion in section 6 will illustrate, being selected by and working in the community does not in itself always denote autonomy from service organisations. Indeed, by virtue of having to provide a bridge to these services can mean that there are expectations around service delivery objectives which can undermine the 'natural helping' dimension of these roles.

UK

Sixty-two documents reporting on the UK were included in the review, including a number of useful discussion papers (for example, Frankham, 1998; Hart, 1998; Parkin and McKeganey, 2000; Shiner, 1999; Turner, 1999; Turner and Shepherd, 1999). The majority of papers containing primary research reported on breastfeeding (16) and sexual health

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interventions (15). Although models may overlap in terms of their dimensions, peer education (HIV, sexual health and drugs) and peer support (breastfeeding, smoking cessation, suicide-prevention among prisoners) models tended to dominate the UK literature.

It was difficult to identify, from the UK literature, evidence of what could be categorised as the bridging model. Perhaps the closest example is represented by Linkworkers in primary care (Gillam and Levenson, 1999; Khanchandani and Gillam, 1999) and bilingual health advocates involved in diabetes education (Greenhalgh *et al.*, 2005). In both these cases, however, the workers appear to be aligned with a service delivery model, for example, working in medical practices.

Examples of community organising models, such as those linked to initiatives like Sure Start (Attree, 2004), tended to be absent in the formal literature and were largely excluded because the emphasis was usually on children and parenting, which was outside the scope of this review.

Academics have attempted to formally replicate the Popular Opinion Leader model to target gay men with sexual health messages in Glasgow (Flowers *et al.*, 2002; Hart, 1998; Hart *et al.*, 2004; Williamson *et al.*, 2001) and London (Elford *et al.*, 2004; Elford *et al.*, 2002b), both with limited success. In both cases, Kelly *et al.*'s (1992) original model was adapted, rather than adhered to faithfully. Differences in context, failure to recruit and retain adequate numbers of POLs, budget constraints and the absence of sustained training are all attributed to the failure. Consequently, Flowers *et al.* (2002) have admitted that rather than diffusion of innovation, their peer educators were advertising available service provision.

5.7 Summary

Clearly, lay or peer helping is a complex terrain, not least because the terms 'peer' and 'lay' remain ill-defined categories in this context and, therefore, difficult to conceptualise. Key questions, such as what dimensions of peer are being drawn upon and who decides who is lay, emerge as salient issues. While there are some useful analytical frameworks which provide starting points to understand the conceptual 'messiness', none capture the range of overlapping, and sometimes competing, dimensions which have been outlined above. Visram and Drinkwater (2005)'s framework for the categorisation of Health Trainer programmes is useful for exploring dimensions of context and health priority, but these dimensions do not account for the complexity of issues that have been highlighted in the literature review. Lay activity also needs to be contextualised in terms of factors relating to individual and organisational motivations, relationship with services, and the focus of the intervention. The complexity of

relationships, at both the lay-professional interface and between lay workers and communities, is critical to understanding interventions and roles yet evades easy categorisation. Drawing upon qualitative work concerning community-based food initiatives in England, Kennedy *et al.* (2008b) provide a conceptual model for lay food and health worker roles which builds upon Eng *et al.*'s (1997) continuum, acknowledging the interaction with and influence from health professionals. Overall the literature review illustrates the challenges of both attempting to identify models, and trying to categorise lay interventions in practice accordingly.

6 Literature review findings – development and support

The range of interventions, health priorities and delivery contexts addressed within the literature was extremely diverse. As part of the systematic scoping review, data extraction covered matters relating to service delivery and organisation. This included recruitment, training and development, support and sustainability, professional involvement, experiences of lay workers and those of the target population. Fewer than 70 documents contained discussions on any of these matters in any depth, most focusing instead on outcomes. Of these, 43 studies contained primary data on organisational issues. This section summarises key themes concerning the development and support of lay workers.

6.1 Recruitment

Identification and recruitment of lay workers tended to be mentioned only in passing in many of the papers. Very few provided any detail of the recruitment rationale, and even fewer included a critical evaluation of the recruitment process and its challenges. Analysis of papers revealed considerable variation in approaches to recruitment and these are discussed below in relation to health priority.

Breastfeeding

Within the breastfeeding literature, examples from both the UK and Canada report efforts to recruit participants via the distribution of flyers, newspaper advertisements and word-of-mouth (Dennis *et al.*, 2002; Watt *et al.*, 2006). It is worth noting that in the UK-study undertaken by Watt *et al.* (2006), the mail-out produced little success and 14 of the original 39 volunteers who completed the training dropped out due to changing personal and family circumstances.

Recruitment criteria set by professionals were highlighted in various studies. In Dennis *et al.*'s (2002) Canadian study, potential peer supporters were required to have previous breastfeeding experience of at least six months duration and a 'positive breastfeeding attitude' (Dennis *et al.* 2002:22). In a North London-based study, volunteers were required to be mothers, living locally, be able to speak and write in English and commit to the project for at least nine months (Watt *et al.* 2006:716). The self-selection basis of these interventions contrasts with the findings of Britten *et al.*'s (2006) review of nine Scottish breastfeeding support groups. While similar criteria

applied in terms of breastfeeding experience and locality to the target area, volunteers were also often vetted for criminal record, mental health and alcohol or drugs problems (Britten *et al*. 2006). The authors note that only two areas advertised publicly for volunteers but in other programmes they tended to be identified by health professionals from within their existing networks. Given the earlier discussion concerning the different emphases of training for breastfeeding 'peer support' in England and Scotland (the latter being more focused toward peer education), the level of professional involvement in recruitment is perhaps not surprising.

Sexual Health

The literature revealed some interesting examples of recruitment which were very specific to sexual health and particular target populations, namely gay men. For example, the Popular Opinion Leader (POL) interventions reported initially by Kelly *et al*. (1992) in the US, and then replicated in the UK by Elford *et al*. (2002b) and Flowers *et al*. (2002), engaged a very specific strategy which involved recruiting directly from the target sites. In the Kelly *et al*. (1992) study, these were gay clubs in three intervention cities. Bartenders, familiar with the club scene, were trained to observe people in the club over a one-week period. Their brief was to identify individuals who were most popular among gay men, that is, those who greeted and were greeted most frequently and were sought out for advice by gay male friends (Kelly *et al*. 1992:1484). Those men receiving nominations by more than one bartender were recruited for training. The number of POLs recruited per city averaged 7 per cent of the total number of men active in the city's gay club scene. This number was necessary to achieve the 'critical mass' required as a core element of the model. No data were reported regarding any challenges in this process.

In the UK, the context of the Elford *et al.* study (Elford *et al*. 2004; Elford *et al*. 2002b) was London gyms frequented by gay men. Here, gym managers were asked to identify potential peer educators according to 'agreed selection criteria by observing regular users at their gym over a period of one week' (Elford *et al*. 2002b:353). In line with the theoretical model, those selected were required to be popular, well-known, good communicators and belong to a social network. Criteria for the latter included age, ethnicity and the time of day they used the gym. Sexuality and gender were not considered to be issues. Potential peer educators would then be approached by a member of the research team. The Elford *et al*. study did not replicate the positive outcomes of the original Kelly *et al*. model and this is believed, in part, to be attributable to its failure in recruiting adequate numbers of POLs to achieve a critical mass. Indeed, although 144 people were originally identified by gym managers, only 27 trained and remained peer educators for the duration of the intervention, representing only 1.3 per cent of the target population. This was in spite of being offered £100 toward gym memberships as an incentive. Elford *et al*.

(2004:153) report that the 20 per cent retention rate was attributable to factors such as lack of time, lack of interest and lack of confidence on the part of peer educators.

The issue of recruitment is identified as problematic by Hart *et al.* (2004) in their response to Kelly's (2004) criticism of the methods employed when they attempted to replicate the POL method in gay bars in Glasgow. Initially people were invited to volunteer on the basis of being well known and liked on the gay scene. This approach secured the interest of only six volunteers. A decision was then made to pay 'volunteers', which accelerated the number to 42, all now being paid for their time. As Hart *et al.* (2004:161) observe, most peer educators were not recruited on the basis of their being popular or well liked, meaning that, in combination with their failure to recruit adequate numbers, the study failed to replicate two of the nine core elements of Kelly *et al.* (1992) original POL model.

In the context of sexual health interventions targeted at drug users in the US, Andersen *et al.* (1998) and Weeks *et al.* (2006) highlight the importance of recruiting lay workers who could relate to the issues faced by the target population. Hiring of former drug users was therefore deemed to be vital to the success of the programme reported by Andersen *et al.* (1998) as they can empathise with clients, but also recognise denial and manipulation: 'I've been on both sides of the fence. I know the games people play and I know what to notice' (outreach worker, quoted in Andersen *et al.* 1998:26). Hansen *et al.* (2005) also report a pilot breast and cervical cancer screening intervention programme for Latino women through which *promotoras* (lay health educators) were recruited on the basis that they had experience of breast cancer.

Community-based interventions

Not surprisingly, those interventions that are community-based are more likely to involve a wider network of stakeholders in the recruitment of lay people. Some of the best evidence comes from the US, where the bridging or lay health advisor (LHA) model is well established. Discussing the Community Health Educator Program (CHEP), Jackson and Parks (1997) indicate that identifying true 'natural helpers' is a lengthy process, taking at least three to six months. These people, it is argued, must 'embody the combination of social, cultural, ethnic, environmental, and communication values, norms and beliefs of the target population' (Jackson and Parks, 1997:420). Staff are reported to have publicised the programme in the community and solicited names of people who might be suitable to fit the LHA role through face-to-face contact with individuals, particularly those in key occupations such as ministers, storekeepers, teachers, barbers and beauticians, and through informal groups and service organisations. The

more times a person's name appeared on the list of nominees, the more likely it was that they would be identified as a true lay advisor.

Reporting on a lay health advisor intervention targeting migrant Latina farm-workers, Watkins *et al.* (1994) describe the 'reputational' method used to recruit female lay workers. This involved project staff carrying out open-ended interviews with clinic and other outreach staff, including existing LHAs, and asking for the names of Latina women who were thought to have leadership ability, empathic and caring attitudes, an interest in learning more about their and their children's health and an understanding of the importance of sharing knowledge with friends and family. Project staff then initiated contact with identified women since: 'migrant women generally are not orientated toward being self-seeking… Although they did not seek out the opportunity to be an LHA, they took advantage of the program when offered' (Watkins *et al.* 1994:78).

Publications concerning the Save Our Sisters outreach project (part of the North Carolina Breast Cancer Screening Programme described earlier), also report the involvement of the community in the identification of older, African-American women as LHAs (Altpeter *et al.* 1999; Altpeter *et al.* 1998; Bishop *et al.* 2002; Earp *et al.* 1997; Eng, 1993; Eng and Smith, 1995; Eng and Young, 1992). Via the programme's Community Outreach Specialists (COS), members of the five Local Advisory Groups (set up to ensure community representation in the development of the project) and focus groups, a list of women felt to be natural helpers was generated. Eng (1993) reports that 23 potential LHAs were identified from the focus groups alone and Eng and Smith (1995) report that the Community Advisory Groups recommended that a pyramid strategy be used for identifying LHAs. This involved holding a 'house party', to which each member would bring two women with the characteristics of a LHA. These women would then bring another two women to a second house party and so on, until four of these events had been held. This approach led to the identification of 125 potential LHAs.

Bishop *et al.* (2002) shed more light on the complexity of the recruitment and selection process. Interviews with the COS revealed that the sampling criteria had not been strictly adhered to, some admitting that they had chosen to approach women that they knew well, as opposed to those who were natural helpers. It is suggested that this might have occurred due to anxiety on the part of recruiters concerning recruitment targets, as they had been told that they needed to identify twice as many women as were needed to account for non-attendance. Consequently, women were invited who would not, in fact, have made good LHAs. Additionally, some potential LHAs brought friends and family members to the training, and other women attended who had not been invited. Others were reported to have felt left out and so decided to stop by, just to see what was going on. A further

problem was that among those women who had been recommended by the Local Advisory Groups, there were some who were not guaranteed to have appropriate LHA qualities. Interviews with the COS indicate that they would have liked to have had more face-to-face contact to enable them to screen out women who did not appear to be natural helpers, or who would not be well-suited for the position.

Prisons

Recruitment in the context of the prison setting requires particular care. Farrant and Levenson (2002) point out that the recruitment process should not be based solely on staff selection. Indeed, prisoners should also be involved and Devilly *et al.* (2005) suggest that strategies for establishing nominations should be devised which could include advertising via posters, leaflets and local bulletins around the prison. Devilly *et al.* (2005:233) also suggest that while the main criteria for selection should be willingness and ability of the nominee to positively influence the behaviour of their peers, they should also be representative of, and influential with, the various subcultures in the prison population. In terms of retention, both Farrant and Levenson (2002) and Devilly *et al.* (2005) point out that the turnover of prisoners can be problematic as prisoners are often moved on as soon as their training is completed. This was noted to be a particular problem in lower security prisons in the UK. Conversely, all high security, or dispersal, prisons had Listener or Buddy schemes. In part this reflects a more stable prison population, but also recognition of a need for such schemes for prisoners who may have particular problems concerning the nature of their offence and length of the sentence (Farrant and Levenson, 2002).

6.2 Training

Many papers made reference to training, although few discussed it in any great detail. There was minimal data on the education levels of lay workers and few papers included any reflections by lay people participating in the training. The length and content of reported training varied considerably. In some training programmes, for example, the emphasis was on providing information concerning the health topic or message that the intervention would address, in others it was on the personal, social and communicative skills required to work with user groups, and many combined both training components. Those that emphasised personal, social and communication issues were more likely to be interactive in nature, providing participants with opportunities for role play. Some programmes, particularly those with significant service involvement, included training regarding confidentiality, record keeping and monitoring.

Interesting variations include the training provided to male escorts acting as peer educators, reported by Ziersch *et al.* (2000). Here, half of the two day

training programme was dedicated to exploring personal growth, and communication and negotiation skills, assumed to be an empowering strategy for peer educators themselves. Another is Kennedy *et al.*'s (1999) study of Community Nutrition Assistants who were trained to be 'nutrition facilitators, not nutrition experts' (Kennedy *et al.* 1999:504). Thirty hours training was provided over 10 weeks, leading to an NVQ Level 2. In addition to information about nutrition, this also included sessions on working in multi-cultural communities, working with groups and individuals, and communication skills. In an example of what can be described as peer development, as opposed to peer delivery, Shiner (1999) discusses a West Yorkshire drugs prevention project in which peer educators were empowered by being encouraged to identify their own training needs and to negotiate with external trainers. This led to young people working toward NVQ Level 2 in Community Work Training for Volunteers.

Greenhalgh *et al.*'s (2005)'s study of bi-lingual health advocates working around diabetes in the Bangladeshi community reported on training needs. Results from a pre-training questionnaire showed that, although these lay workers dealt with very large numbers of clients with diabetes, few had any training in diabetes and none had been trained in patient education. They also rated their knowledge and confidence in dealing with diabetes as poor. Consequently, a three-hour 'taster' session was run to enable advocates to identify their learning needs in relation to diabetes and group support, leading to the development and refinement of learning objectives and a syllabus. This involved 10 more formal, structured sessions, covering different themes. Learning was facilitated through the sharing of stories about clients in small groups and 'good' examples were fed back to the larger group. This enabled participants to reflect on clients' unmet needs and professional support needs. It was these 'stories', rather than text book information that formed the basis of learning (Greenhalgh *et al.* 2005:629).

The variation in approaches to training existing within one type of intervention, or even within the same model of training, is further explored in relation to breastfeeding peer support and the POL model.

Breastfeeding

Britten *et al.*'s (2006) review of nine breastfeeding support groups in Scotland reports that while one programme offered no training, others ranged from a minimum of 12 hours delivered over six sessions, to 24 hours delivered over five sessions. Some programmes used recognised training models, but there were still variations in delivery. For example, the UNICEF Baby Friendly training was delivered over 12, 16 and 21 hours in different programmes.

Variation in the intensity and content of training is also reflected in other breastfeeding literature. For example, in a breastfeeding peer support

intervention in Canada (Dennis, 2002b; Dennis *et al.* 2002) volunteers were only required to take part in a two and a half hour orientation session. The aim of this session was to develop their telephone support and referral skills, role-playing and the verification of problem solving skills (Dennis *et al.* 2002:22). Clearly, the emphasis here is with preparing women for the method of delivery, rather than education. Despite the potential limitations of a single short session, Dennis (2002b:173) reports that 93.3 per cent of participants felt that the orientation session had adequately prepared them for their role, many enjoying the opportunity to meet with other women, although 83.3 per cent said that they would have liked opportunities for ongoing educational sessions. It is worth noting that volunteers were given a 43-page handbook, outlining a range of information, including professional services available for referral, volunteer role description and tips for effective telephone support.

The relative low intensity of this orientation session is contrasted to a breastfeeding support intervention in Bangladesh, reported by Haider *et al.* (2002). Here, one of the authors, alongside the breastfeeding supervisors, provided 40 hours training over 10 days. Combining lectures and interactive discussions, training focused on providing information concerning aspects of breastfeeding and nutrition. The health education component was complemented by a skills development component that provided trainees with opportunities to develop and practice skills required for listening to and supporting mothers and to help build their confidence.

In the UK, the 'Babes' breastfeeding supporters reported in Ingram *et al.* (2005) undertook a training course designed by two La Leche League counsellors and an Association of Breastfeeding Mothers trainee counsellor, which ran for two hours a week over six weeks. As with the example from Bangladesh, communication and listening skills and overcoming common breastfeeding problems featured as key elements of this training programme. While Curtis *et al.*'s (2007) study of a breastfeeding peer support initiative targeting young women in one area of Doncaster does not provide any detail of the 20 hour, classroom-based training programme, which was co-delivered by a National Childbirth Trust tutor, a midwife academic and liaison tutors, the authors note that volunteers were offered ongoing opportunities to enhance their learning and skills development as additional training was delivered at monthly sessions. While the authors note that this was also accomplished via ongoing telephone support provided by the tutor and weekly attendance with liaison midwives at a community-based, drop-in breastfeeding session, it could be argued that these activities constitute support, rather than training. Reporting on the 'Worldly Wise Project' , a Sheffield-based Sure Start initiative, Battersby and Sabin (2002) demonstrate how the training provided within this breastfeeding support intervention was located within the formal delivery system, with the two workers being employed by the Sure Start.

The most detailed description of training provided around breastfeeding peer support can be found in Watt *et al*. (2006). This training programme was 54 hours in length and delivered over a three-week period. The paper provides details of group sizes, length of sessions and a programme summary. Unlike some of the other examples presented above, listening and communications skills seem to be less of a feature in this training programme, emphasising, instead, a wide range of nutritional information, from breastfeeding, to weaning and feeding a toddler. Additional features are boundary issues, child protection, confidentiality and record keeping. It is possible that this range of topics reflects the fact that training was delivered by people from a range of organisations and with different backgrounds, but also the original intention had been to seek external accreditation for the training programme 'to aide the volunteers in seeking future employment or further education' (Watt *et al.* 2006:719). This was not achieved as a result of the complex bureaucratic procedures. This was the only breastfeeding support intervention that appeared to have a planned outcome to develop its volunteers.

Sexual Health

The papers by Kelly (2004) and Elford *et al*. (2004), in which they engage in a dialogue regarding the process of implementing the POL model, explore how variations in training and the method of delivery can impact on outcomes for lay people. Elford *et al*. used the 'Opinion leader HIV prevention training manual' written and supplied by Kelly when they were at the planning stage for their study. This manual emphasises skills-building, and Elford *et al*. (2004) report that developing communication skills a core element of the training provided in the study. Participants were given opportunities to 'actively participate in the discourse around risk-reduction, HIV testing [and] risk within relationships' (Elford *et al*. 2004:155).

Having opportunities to engage with, and practice negotiating with, such discourses are central to Kelly's model, necessitating ongoing contact between trainees and those supporting them. Consequently, the training provided in the Kelly *et al*. (1992) study was delivered in two-hour sessions over five weeks. During these sessions, participants were taught about the characteristics of effective health communication messages and POLs repeatedly role played examples of conversations they might have with friends and acquaintances in everyday life (Kelly, 2004). It is reported that participants in both studies felt discomfort in discussing AIDS and explicit aspects of safer sex and perhaps felt more comfortable sticking to basic education. Kelly (2004), however, reports that the use of group techniques, including the provision of 'exemplar' conversations and multiple opportunities to role play and gain feedback from the group, helped them to develop the skills required to communicate effectively in their POL role, and also enabled them to overcome the initial discomfort. The weekly format is reported to have enabled POLs to plan and set goals for talking with others

in between sessions, practice conversations in real life (see also Hansen *et al.* 2005), and report back and share learning with other POLs at each session. In contrast, the training provided by Elford *et al.* was delivered as a one-day session as participants were unable to commit to multiple training sessions. Had it been delivered over two sessions, as was originally intended, the authors suggest that they would have encountered even more problems with recruitment. The impact of this decision was that their POLs did not have the opportunities to practice conversations, feedback and learn from each other.

Another interesting example from the US is reported by McQuiston *et al.* (2001). Here, a 7-week, 21-hour culture specific, community-based programme was delivered in Spanish to Mexican lay health advisors. Unlike HIV prevention training programmes which focus simply on behaviour change, this was based upon the principles of empowering participatory education and applied an ecological framework to disease aetiology (McQuiston *et al.* 2001:278). The research team developed the training curriculum using a partnership approach which involved both observing and listening to members of the target immigrant Mexican population in North Carolina. Engaging a number of learning styles to accommodate different learning needs, including those with low literacy, the programme addressed issues such as the functions and role of LHAs, how to raise sensitive topics, self-awareness of personal feelings and beliefs concerning HIV/AIDS and planning for their involvement in the community. As with the POL intervention reported by Kelly (2004), participants had the opportunity to practice their roles in between training sessions and to share their experiences with the group, which facilitated both a group approach to problem solving and provided support (McQuiston *et al.* 2001:281-282).

Accreditation

In their study of linkworkers in primary care, Levenson and Gillam (1998) note the absence of a widely accepted, accredited national course, and this is illustrated through the variety of accredited training reported in the examples above. Levenson and Gillam point out that linkworkers often find themselves in a difficult position, since their lack of training may reinforce the perception among professional colleagues that they are under-trained lay people, lacking professional status and respect. These challenges were also reported in Love *et al.* (1997)'s survey of healthcare providers using community health workers in Northern California. Paradoxically, with training, lay workers run the risk of being alienated from their communities of origin (Levenson and Gillam, 1998:39). Additionally, Hunter and Power (2002) feasibility study using *Big Issue* sellers as peer educators provides an example of the tensions that can arise when the theoretical content of training conflicts with experiential knowledge learned through lived experience.

Reporting on training for community health workers (CHWs) in the US, (Love *et al.* 2004) argue that given the increased demand for CHWs to contribute to the healthcare workforce, education and training must be developed toward standardised competencies and assessment tools which, at the same time, value what is at the heart of their effectiveness: 'their roots in and knowledge of their communities' (Love *et al.*, 2004:420). The approach which these authors used in delivering their training programme was performance-based and drew upon popular education pedagogy (see Farquhar *et al.*, 2005). Through this approach, students who lack conventional academic skills could be assessed by non-traditional means which enabled them to demonstrate competency in necessary skills. Additionally, Love *et al.* (2004) note that popular education because it draws upon students' life experiences as an educational tool, deeply engages them, thereby improving the retention of students from underserved communities, where most CHWs are both needed and work. In doing this, it is believed that students are enabled to increase their understanding of the social and political determinants of health, knowledge which is essential to their work in their communities.

6.3 Support and sustainability

Research concerning support and sustainability was sparse. However, a recent systematic review of volunteering commissioned by Volunteering England (Casiday *et al.*, 2008) reports that contextual factors, including how well volunteers are trained, managed and supported are critical factors in establishing positive outcomes. Elsewhere in the literature it was indicated that there is a need both for regular and effective communication with professionals and opportunities for lay workers to meet and share experiences (Attree, 2004), which also has the effect of helping to forge a sense of group identity and ownership over the interventions (Freudenberg *et al.*, 1994:124). A summary of local health walks evaluations (The Countryside Agency, 2005:35) indicates that following the termination of funding streams, a number of successful schemes have emerged which are run and administered by volunteers with little input from statutory organisations.

Conversely, Zuvekas *et al.* (1999) point out that lay people may never have had experiences of working in a professional environment and may require particular supervision and guidance with regard to, for example, using the telephone to speak with clients. Ashery (1993) also notes some of the issues which may emerge in dealing with 'non-traditional' employees who are not used to working in a structured environment, for example, outreach workers targeting 'street addicts' with HIV/AIDS education. Supervision of these workers is reported to require recognition and accommodation of their indigenous and/or recovering status. Although retention of such workers can be particularly problematic, Weeks *et al.* (2006:551) report that in their study which recruited active drug users as peer health advocates, it was

'unexpectedly high': 80 per cent completing the first phase of the training, 50.8 per cent of which went onto complete the full training programme.

In the UK, Elford *et al.* (2004), Elford *et al.* (2002b) underestimated the level of support required by peer educators to support them in their activities. This involved monthly meetings at the gyms where they were based, along with telephone and email support. Given peer educators' reported lack of confidence with raising sensitive issues concerning certain aspects of HIV/ AIDS and sexual behaviour, the need for ongoing support is unsurprising.

Leaman *et al.*'s (1997) study of the Ontario Community Nutrition Worker Project provides an interesting example of the impact of variation in support within one programme. The community nutrition workers (CNWs) were recruited by various community agencies involved in the inter-sectoral steering committee governing the project. Funded from a state Ministry for Health grant, CNWs were paid $10 per hour, childcare and transportation costs were covered by the grant, and the recruiting agency was responsible for supervising and supporting them. Initially, some agency contacts worked closely in helping CNWs establish their activities within their communities, while others expected their CNWs to work independently. Almost one third of CNWs who took part in the research reported feeling unsupported. The research findings indicate that positive support can make a difference in what can be very challenging roles.

A further issue for consideration, particularly with regard to those workers involved in a bridging role, is that of governance, raised by Levenson and Gillam (1998). They point out that there is lack of clarity as to where management responsibility for linkworkers should lie: within the NHS management system, or with an independent body? Reporting on one London-based project, they note that workers in this context perceived themselves to be health workers, but not working for the hospital, which caused problems for the hospital staff, who were unclear as to how linkworkers fitted into the hospital hierarchy, thereby reducing staff control (Levenson and Gillam, 1998:41).

While the availability of adequate support is likely to be an important contributor to the sustainability of an intervention, there is little discussion within the literature concerning retention of workers. There are some suggestions that lack of time and changing personal circumstances can affect people's decisions to withdraw from activities (Craine *et al.*, 2006; Elford *et al.*, 2002b; Hunter *et al.*, 1997), however, as discussed earlier, the absence of remuneration may also be a factor. For example, lay people reported in some North American literature simply could not afford to continue in a voluntary or poorly paid capacity (see Leaman *et al.*, 1997; Schulz *et al.*, 1997).

6.4 Professional involvement

In general, the nature and extent of professional involvement in lay or peer interventions is not explored in-depth within the literature. Where there is discussion, this has tended to focus on boundaries and roles.

Boundaries and roles

Kennedy *et al.*'s (2008b) study of lay food and health workers (LFHWs) in15 community-based food initiatives in England highlights clear roles, expectations and supervision arrangements:

"*LFHWs here were seen as part of a wider multi-disciplinary team, working under the strict supervision and guidance of a dietician, to assist with more practical aspects of the dietician's caseload.*" (e.g. supporting clients to adopt healthier weaning practices by demonstrating or discussing healthy options) (Kennedy *et al.*, 2008b:220).

In this study, the politics of naming was also of importance since lay workers objected to being referred to as 'assistants' when 'we don't assist anybody', yet health professionals were cautious about their being referred to as 'nutritionists'. This dilemma is summarised in the following interview excerpt:

"*I would say that one of the other problems we come up against is how they are viewed, are they viewed as dieticians or are they viewed as our assistants, and that's been an issue. What their title is and how that is shortened and how they are introduced in the community. If it's shortened to community nutritionist it would give the impression of them being more qualified than they are.*" (Health Professional, quoted in Kennedy *et al.*, 2008a:203).

Dykes (2005), in her survey of 26 peer support infant feeding projects, highlights the 'peer-professional interface' as an important challenge, centring on lack of communication and understanding of each other's roles. One of the interventions included in Dykes' survey was the Doncaster-based, 'Breastfriends' project, and Curtis *et al.* (2007) report specifically on the peer-professional interface within this project. Health professionals contributing to the study acknowledged that there were benefits to peer supporters' involvement, such as the easing of their own workloads and being able to improve their own practice by learning from peer supporters. Nonetheless, the authors acknowledge that not all health professionals

exhibit positive attitudes and behaviours in supporting peer interventions. While training is reported to teach breastfeeding peer supporters to acknowledge the boundaries of their knowledge and role (Curtis *et al.*, 2007; Stremler and Lovera, 2004; Watt *et al.*, 2006), this remains a sensitive interpretive process. Curtis *et al.*, (2007:152) report that health professionals praised volunteers who 'know their boundaries' and also commented on others who were perceived as 'muscling in' or 'overstepping the mark'.

Curtis *et al.* (2007) also report that health professionals discussed 'gate-keeping' activities which controlled volunteers' access to pregnant and new mothers on the wards, in addition to 'debriefing', which enabled them to maintain their surveillance over volunteers' activities. This stance had not gone unnoticed by volunteers, who used language such as 'ownership' and 'territorial' when referring to their relationship with health visitors (Curtis *et al.*, 2007:153). Some health professionals suggested that some of their colleagues perhaps felt 'threatened' by the thought of having to 'relinquish the power that being a professional gives them' (Curtis *et al.*, 2007:153). Conversely, Faulkner (2005) reporting the role of volunteers in providing social support in healthcare settings, found that hospital staff supported the role of volunteers precisely because they were appeared more approachable.

Neuberger's (2008) report on volunteering in the public sector, focusing specifically on health and social care, acknowledges that the activities of lay people or volunteers have precipitated debate among the trade unions since these could be perceived as threatening for staff in paid roles. Although the national trade union position is generally supportive of volunteer roles, providing that they do not perform duties which are in the job descriptions of paid staff (Neuberger, 2008:17), Neuberger acknowledges that volunteers continue to face resistance locally, particularly in hospital settings.

Commitment

The commitment of professionals to an intervention can hinge on adherence to boundaries, but is also relative to the extent to which it is embedded within a service. Speaking of Linkworkers, Levenson and Gillam (1998:42) observe that the more embedded a scheme is within the NHS hierarchy, the more likely it is that it will be accepted by health professionals. Conversely, the more autonomous it is, the less likely it is to be accepted, but this may increase both its remit and its accountability to the community. Prisons provide another pertinent example as the commitment and perceived relationship of the governor and staff can have a significant impact upon whether a Listener or Buddy scheme is accepted by prisoners and staff alike. Farrant and Levenson (2002:9-10) give an example of one scheme

were prisoners felt that their role was not being taken seriously by staff and that they were being asked to 'babysit' prisoners who were not suicidal, and another where the scheme was said to be 'run by officers'. Although technically outside the inclusion criteria for the review, Brown *et al*. (2007)[9] highlight some interesting issues regarding challenging relationships between lay educators and professionals in the context of a research study comparing the use of lay educators with primary care nurses in the delivery of asthma self-management education.

Cost

It has been suggested that lay roles offer a 'cheap' and attractive option to commissioners and Hart (1998:87) raises the question of why pay full-time staff when it is possible to 'employ' lay people on a voluntary basis with, perhaps, only an outlay for expenses. This was also a concern identified in the Neuberger (2008) consultation, and moreover, Leaman *et al*. (1997) report that tensions can arise when lay, sessional staff are being paid at a higher hourly rate than salaried staff members. Process evaluations indicate that interventions which rely on lay people for delivery do not represent a cheap option since many, and particularly those which are complex in nature, require significant organisational input in terms of providing training and ongoing support to lay people, regardless of their level of ownership. For example, Elford *et al*. (2002b) estimate that over the course of their 18-month POL intervention, 16.4 hours per week were required from members of the health promotion team to provide training and ongoing support to peer educators. This is the equivalent of a full time member of staff working 2.5 days a week on the project, and did not include the peer educators' or gym managers' time.

Risk

Risk was an issue which did not generally arise in the literature. Three papers discussed interventions in the US where lay people were working in high risk contexts (HIV-prevention outreach work with IV-drug users) where workers might be at risk of arrest (Andersen *et al*., 1998, Dickson-Gomez *et al*., 2003), or in physical danger (Dickson-Gomez *et al*., 2006). Only one (Canadian) paper mentioned insurance (Dahl, 1997), and one other discussed factors relating to explicitly to risk[10]. Faulkner (2005) presents two case studies of social support provided by volunteers. He acknowledges that because volunteers are not trained counsellors, there are potential risks in their delivering appraisal and informational support. These include potentially being confronted with emotional issues they find difficult to manage, and the risk of providing inaccurate or inappropriate information to

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[9] Included in the scoping review because in depth discussion of relevant service delivery and organisational issues
[10] Included in the scoping review because in-depth discussion of relevant service delivery and organisational issues

patients because they lack understanding about diagnoses and prognoses. He suggests that it is important that volunteers are aware of their limitations and seek appropriate professional support when needed and he notes that volunteers in a primary care intervention were reported to have taken part in a two-week training course encompassing rudimentary counselling skills and an overview of useful community-based services (Faulkner, 2005:43).

A web-search as part of the systematic scoping review returned two documents published by Volunteering England that highlight a number of issues relevant to service organisation and delivery which are not addressed within the published literature (Gaskin, 2006b; Gaskin, 2006a). The practice guide (Gaskin, 2006b) responds to findings of a study, undertaken by the Institute for Volunteering and Volunteering England (Gaskin, 2006a), in which organisations using volunteers indicated that there was a need for guidance concerning risks, liabilities and insurance. Services and activities are delivered in an increasingly litigious context and this is reported to have had a serious impact on volunteering. Organisations carry increased bureaucratic burdens, which are believed to limit their capacity to recruit and retain volunteers, while potential volunteers are concerned about risk and being sued and are put off by paperwork and levels of responsibility. Indeed, where volunteering might once have been undertaken on a casual basis, it is now laden with bureaucracy requiring Criminal Records Bureau (CRB) checks, adherence to risk management standards and formal commitments to volunteer at particular times. All of this, it is suggested, has led to the transformation of volunteering into something 'much more like a job' for many who continue to view it 'as a leisure activity or the expression of altruism' (Gaskin, 2006a:8). It is also noted that such developments have had an exclusionary impact, particularly on those whose first language is not English, have low literacy or who have visual or other impairments.

Gaskin (2006b) acknowledges that there are particular risks associated with volunteers and those listed include breaches in confidentiality, misleading or incorrect advice being given out and volunteers exceeding boundaries. The practice guide, however, clearly highlights how such risks can be minimised by providing adequate and regular supervision and support (Gaskin, 2006b:18). Adequate supervision and support therefore emerges as something which is of benefit both to lay people, and to the host organisation.

6.5 Lay worker experiences

There was limited primary data reflecting the experiences of lay workers in the formal literature. Discussion around this was often confined to commentary (particularly in the US literature) and was sometimes reported

via excerpts from interviews with professionals. One paper included ethnographic field-notes, in which the activities and experiences of peer health advocates were recorded (Dickson-Gomez *et al.*, 2006). Another, which drew directly upon lay workers' accounts, emphasised their commitment to distributing health promotion messages concerning HIV/AIDS in their community (Downing *et al.*, 1999). Those papers which contained evidence from lay people themselves tended to focus on either their motivations for getting involved in an intervention, or what they had gained from it. For example, a US study of community health advocates specifically focuses on changes in empowerment affected by participation in the programme (Booker *et al.*, 1997). Meanwhile, in the UK, community support workers reported in Attree (2004) stated that their work enabled them to feel part of and make a contribution to their community. The result, for some, was that it 'boosted my self-confidence [...] I've started talking to people and stuff like that.' (CSW, male, aged 35, quoted in Attree (2004:157).

For the prisoners at Wandsworth Prison, reported in Farrant and Levenson (2002), involvement in a drug misuse peer support initiative gave them 'responsibility' but was also 'helping yourself by helping others'. Another peer supporter said: 'I had previously never been in a position where I'm relied upon... it makes me want to do better things' (quoted in Farrant and Levenson, 2002:13).

Some of the most detailed accounts of lay experiences can be found in the UK breastfeeding literature. These women, reported in Curtis *et al.* (2007), saw their peer support work as a social resource, enabling them to 'get out of the house', to relieve the boredom and isolation of being at home and to provide an opportunity for 'the kids to interact with other people'. Another volunteer said: 'I wanted it to help with my (planned return to education)' (quoted in Curtis *et al.*, 2007:150). These women also reported increased self-esteem from making a contribution to others. One of Raine's (2003) interviewees spoke of the personal satisfaction and fulfilment linked with supporting other breastfeeding women, stating that 'I get lots out of it, I can help someone in a positive way' (quoted in Raine, 2003:467-468).

Breastfeeding supporters quoted by Ingram *et al.* (2005:114) are reported to have wanted to 'give something back' following their training. Additionally, one woman spoke about having acquired new knowledge about breastfeeding and that being involved in the group had increased her own confidence when it came to breastfeeding in public. Additional outcomes reported Curtis *et al.*'s (2007)' breastfeeding supporters included improved interpersonal skills and greater assertiveness in the way they relate to health professionals.

Elsewhere, Springett *et al.* (2007) present a range of reflections from the Lay Advisers employed at the 'Fag Ends' smoking cessation project regarding the support they provide to their clients. Among other things, it was suggested that lay health advisers might be attractive to clients because they were effective without formality: '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' (Springett *et al.*, 2007:251). Likewise, Faulkner (2005) also presents reflections from three volunteers regarding the work that they carry out. One volunteer pointed out that through the involvement with a voluntary advisory/referral service s/he had developed skills in unpicking the complexity of patients' needs, in order to signpost them to other services more appropriately.

Examples of qualitative research that focus exclusively on the experiences of lay workers include Hunter and Power's (2002) paper which reports Big Issue sellers' views on peer education to reduce drug-related harm among homeless people, and Hainsworth and Barlow's (2003) study reporting the reflections of older lay leaders attending tutor-training for arthritis self-management. In the grey literature, an evaluation of the Healthworks Linkworker scheme in Newcastle draws upon 43 interviews with lay people at different stages in the intervention with a chapter specifically focussing on their experiences (Green, 2005, Healthworks, 2004). This includes reflections on personal progression/ development, skills and learning, confidence and quality of life. Elsewhere, Brown *et al.* (2007) draw upon lay educators' reflective diaries to report on a range of matters, including experiences of training and the need for preparation for the realities of clinical practice and ongoing training and support. In a rare example of primary research from the US that includes lay workers' experiences, Schulz *et al.* (1997) demonstrate how engaging with and reflecting upon these experiences are important in the design, implementation, evaluation and support of LHA programmes. The authors provide data from focus groups that addressed a range of important questions, including why they got involved in the Detroit-based Village Health Worker Project, what they do within their role, and what they believe to be the most significant barriers or challenges in doing this kind of work. The data provide valuable insights into how lay work is perceived by its participants, including their criteria for what makes a good LHA, such as being 'people persons' or 'community-orientated' (quoted in Schulz *et al.* 1997:469). Participants also highlight the issue of incentives, which is absent from other papers, both in the US and the UK. Indeed, while they value their work being appreciated by their communities, they also acknowledge that 'if you don't have an income coming in […] you want more than a thank you', and one woman acknowledged feeling 'taken advantage of, but because I love what I do […] I would come even when I have no gas money' (quoted in Schulz *et al.* 1997:472).

In a qualitative study of Community Nutrition Workers (CNWs) in Canada, Leaman *et al.* (1997) asked their respondents about why they undertook CNW training, skills learned, activities, support received and barriers encountered. In spite of the benefits felt in terms of increased confidence and being rewarded by their successes with clients, some of these lay workers expressed disappointment that their sessional work (up to 10 hours per month) had not led to part or full time work which would enable them to 'make a living from it' (Leaman *et al.*, 1997:36). Indeed, financial need was seen as being barrier to continuing. Although CNWs were paid $10 an hour, they were not paid for preparation work which, one worker said, meant that:'I maybe made $1 to $2 an hour [...] I am frustrated by money issues', while another said: 'It's more like a volunteer thing' (quoted in Leaman *et al.*, 1997:37). As discussed above, these workers also spoke about their sense of isolation and lack of support from the host agency.

In a paper reporting on Latino involvement in community-based HIV/AIDS initiatives in Chicago, Ramirez-Valles and Uris Brown (2003) present both motivations and outcomes of involvement, as well as potential barriers. Alongside individual factors, these also include fear of stigma associated with homosexuality and HIV/AIDS, and organisational factors. Organisational factors were specified as perceived racism and cultural ignorance among community-based organisations which are staffed by predominantly White workers, resulting in reluctance among Latino men to volunteer. Additionally, unchallenging volunteer activities, such as office work and staffing telephones, was also reported as a barrier.

6.6 Service user experiences

In general there was a dearth of primary data representing service users' views on lay workers. More often they were consulted as part of an evaluation of an intervention and most of the data can, again, be found in the breastfeeding literature, but this also lacked depth. Interestingly, Curtis *et al.* (2007) point to a challenge for the conduct of research; volunteers were not required to keep records of their clients and were reluctant to distribute letters concerning the evaluation focus groups as they felt that this would undermine the confidentiality that they had offered clients.

Programme recipients in Scott and Mostyn's (2003:273) paper highlighted the importance of peer support as it enabled women to share their experiences, 'pass on tips' and provide the encouragement needed to keep going. One of Battersby and Sabin's (2002) respondents also points out that peers could explain things in language which was more accessible than that used by health professionals: 'They came out with words that you wouldn't expect a midwife to come out with. They described it in different ways' (Battersby and Sabin, 2002:S31). Reporting on social support provided by volunteers in healthcare settings, Faulkner (2005) provides a number of

quotes from patients who spoke positively of the support or input received from volunteers. For one person, this was as simple as a volunteer bringing his dog into the hospital setting, while another person reflected upon the value of having someone to talk to. Other studies where brief data on lay perspectives are presented include Allen's (2004) paper of a peer education project concerning fall prevention for older adults and Goodenough's (2007) report on an intervention aimed at reducing the social isolation of older people living in rural Devon.

Elsewhere in the literature, a US paper reports on counselled women's perspectives on their interactions with lay health advisors (Flax and Earp, 1999) based on interviews with 29 older black women conducted as part of the NCBSCP evaluation. These women reported having close relationships with the LHAs and saw them as credible sources of information both because of undergoing training and/or personal experience of breast cancer. Characteristics such as 'friendliness, understanding, open-mindedness and "plain talking"' made them feel comfortable talking with LHAs (Flax and Earp, 1999:20).

A process evaluation of 'Fag Ends' smoking cessation service provides a range of data from programme recipients (Springett *et al.*, 2007). This includes reflections upon the service provided by the lay advisors, what they had learned from various group activities, and the value of 'knowing that other people are going through the same things as you are.' (quoted in Springett *et al.*, 2007:252).

Conversely, shared knowledge or experience was not necessarily seen as an advantage by male escorts targeted by a pilot peer education intervention reported by Ziersch *et al.* (2000). While it was accepted that peers might be able to understand their circumstances better than professionals, professionals are bound by codes of ethics and rules of confidentiality, which was a particular concern within this target group. One man explained that it was precisely because of the sensitive nature of the topic that peers were an inappropriate source of information: 'If you've got an embarrassing question, then whatever way you look at it you want someone who is a bit more of an outsider.' (quoted in Ziersch *et al.*, 2000:451).

6.7 Summary

The literature review provided an overview of service delivery and organisational themes occurring in literature and also enabled gaps in research to be identified. The diversity of approaches, social contexts and health priorities reflected in the literature make it difficult to draw any firm conclusions about the efficacy of specific strategies, nonetheless there are some pertinent discussions within certain groups of interventions which

highlight both the potential variations that can occur within programme delivery and management, and the importance of supportive processes that take account of the social context of the intervention. There was some evidence that recruitment and training strategies can usefully build on the experiential knowledge of lay people, but there needs to be attention to aspects such as selection criteria, incentives, and personal development. Literature points to tensions between lay and professional roles and raises questions of costs, risk, governance and professional control. Whereas there was some evidence of lay workers reporting positive personal outcomes and satisfaction with their roles, there was overall a dearth of primary research on service user perspectives.

7 Expert hearings - methods

The study design included three deliberative workshops which aimed to:

- draw on evidence from current public health practice thereby providing a triangulation of evidence with other components of the research design
- explore some of the key questions emerging from the literature with individuals with relevant expertise within a UK context
- involve key stakeholders, including lay people, in the research process.

The workshops were designed as expert hearings, with the intention of providing a structured forum through which the research team could enter into a dialogue with invited 'experts' who were deemed to have theoretical and practical knowledge in the arena of lay involvement in public health, and thereby allowing valid conclusions to emerge on major themes for public health service delivery and organisation. The expert hearings were a core element of the study design, yet innovative in choice of methods, and a full account of the process is given here.

7.1 Deliberative methods

Expert hearings are designed to facilitate the process of deliberation on an issue or series of issues. The use of deliberative methods has been gaining prominence within the policy sphere through formats such as citizens juries and expert panels (Abelson *et al.*, 2003; Coote and Lenaghan, 1997; Davies *et al.*, 2006; Strategic Action Programme for Healthy Communities, 2000; Potts, 2004). There is, however, a sparse literature on deliberative methods within research. Expert hearings were held as part of the Strategic Action Programme for Healthy Communities study (Pickin *et al.*, 2002, Strategic Action Programme for Healthy Communities, 2000) and for the ESRC funded study investigating lay epidemiology of breast cancer (Potts *et al.*, 2007).

One of the principal objectives in engaging deliberative methods for this study was to explore contested areas through dialogue with those active in this field. A further objective was to facilitate shared learning between experts, participants and the research team. While the core element is the facilitation of a process of deliberation, there is no guidance available on the application of expert hearings as a research method in terms of optimum format and structure, sampling strategy, methods of data gathering, analysis and evaluation. In the context of this study, the expert hearings

were designed to fulfil the specific research objectives and choices made by the research team were documented and later evaluated. Although the approach taken inevitably drew on participatory methods, the steering group agreed that the purpose was more than a consultative exercise and needed to stimulate genuine debate. A working group was set up with representation from the research partners as well as the academic research team to plan the expert hearings and ensure that the events were relevant for public health practice.

7.2 Sampling strategy

It was planned that there would be three expert hearings with five experts giving evidence at each event, with the aim of capturing different perspectives but also allowing time for discussion and questioning. The sampling strategy was designed to ensure that a range of types of expertise was represented at each of the hearings in order to encourage the exchange of learning and reflect on contrasting views. The overall sample needed to have representation from different sectors and types of role. Selection of individual experts was done on the basis of relevant expertise or experience and willingness to present evidence in a public domain.

A sample of possible experts was drawn up through the contacts made through the literature review, the Register of Interest (see section 9) and personal contacts. Individuals were then contacted informally to find out more about their expertise and whether they were interested in participating. The final sample was drawn up in consultation with the full steering group. The invited experts represented NHS, local authority, voluntary and third sector stakeholders and also a range of roles including academics, national programme leads, practitioners supporting lay workers, commissioners and lay people. Each individual expert was sent a letter formally inviting them to present evidence and detailing the public nature of the events and how the evidence was to be used. Fourteen presentations of oral evidence were made at hearings and one expert submitted written evidence following the hearings.

7.3 Expert hearings process

The expert hearings were held in June 2008 in Leeds and invited experts gave evidence before an enquiry panel and public audience. Expert witnesses were asked to give a 10-minute presentation addressing two of the four questions provided, reflecting on their own experiences and insights:

- Why should we bother involving lay people in public health roles? Why should lay people bother getting involved?

- What has been found to work and in what contexts, and what has not? What are the best approaches to involving lay people in public health?
- What are the challenges in involving lay people in developing/delivering public health/health promotion activities and how do these impact upon sustainability and practice?
- What should the government/public sector be doing to support local people to be active in their communities?

Presentations were made before a public audience and an enquiry panel comprising members of the study steering group (including the research team and representatives of NHS partners involved in the study), a practitioner and, at the final event, a lay person. The function of the enquiry panel was to ensure that the research objectives were carried forward and that issues were debated fairly and reasonably. Members of the enquiry panel were able to question the experts following their presentations. Details of experts and panel members can be found in Appendix 10. Each event was chaired by the Associate Director of Public Health for the Regional Public Health Group in Yorkshire and the Humber.

The format of the hearings was designed to include the views of lay people as well as professionals. A prior public involvement event was held in partnership with NHS Bradford and Airedale to ensure that lay views informed the hearings. Volunteers, community activists and some front-line staff participated in a one-day workshop where they were able to discuss their experiences with members of the research team. The issues raised in the workshops were fed directly into the expert hearings in the form of a series of questions. Two lay people participating in the workshops later took part in the expert hearings; one as an expert and one as a member of the enquiry panel. Support to facilitate the lay involvement is discussed further in section 15.

The events were held in public and invitations were issued through the People in Public Health Register of Interest and wider networks of contacts. The public audience had an opportunity to listen to all the evidence and to express their views in the open and group discussions, via the comments board and via panel members. The morning session and post-lunch panel-led discussion at each event focused upon the presentations, while the afternoon sessions were dedicated to small group discussions of the issues arising from the presentations. These groups were facilitated by research staff. Each hearing ended in a plenary session where the key themes were summarised by panel members.

7.4 Data collection and analysis

The formal contributions made by the experts were digitally recorded with consent, along with any submitted written or electronic evidence, such as PowerPoint presentations or written reports, as detailed in the REC application. The panel-led questions and responses were also recorded but small group discussions were not recorded, instead notes were taken with participants' permission. These notes were not included in the data analysis as it was not possible to obtain full consent. All recordings were transcribed verbatim. Summaries of the presented evidence were placed on the study website: http://www.leedsmet.ac.uk/health/piph/hearings.htm

Framework analysis was used to analyse the data, as an appropriate method given the applied nature of the study and the emphasis on policy and practice (Pope *et al.*, 2000; Ritchie *et al.*, 2003). The framework of the key questions was used to create five charts and then two researchers independently indexed all the data, identifying all emerging themes. Themes were then charted and major categories identified and agreed. Due to the nature of the evidence and its production in a public space, care was taken to ensure that the narrative summary of themes reflected participants' interpretations. An initial write up was sent round all the expert witnesses and panel members for confirmation. The results are presented in the next section. Quotations are not attributed to the individual respondents to protect anonymity.

8 Expert hearings findings

8.1 Evidence from practice

The expert hearings gathered a large amount of evidence on different approaches to involving lay people in public health roles both through the formal presentations and the structured discussions. The selection of speakers and the role of the enquiry panel in directing questions resulted in each event having a slightly different focus as topics were explored in depth during the day. A number of lay people took part in the first event and the focus of the discussion was on motivations for, and routes into, public health among lay people. In the second event there was a longer discussion on the meaning of 'lay', the relationship between lay people and the communities they work in, and achieving sustainability. The third and final event focused on the barriers to lay involvement and how they can be removed.

As was expected from the selection of experts, divergent perspectives on aspects of lay involvement were offered. There was also variation in what the experts identified as issues of significance in their presentations. Some of the experts described specific programmes or projects involving lay people and based their comments on their experience of these programmes (see Table 11), while others made more general points about service organisation, delivery and support issues in relation to lay involvement. Evidence was heard in relation to parallel programmes that are outside the scope of the study, notably Health Trainers and the Expert Patient Programme (EPP). Four of the speakers presented research based evidence, including a summary of the National Institute for Health and Clinical Excellence (NICE) guidance on community engagement (National Institute for Health and Clinical Effectiveness, 2008).

The evidence demonstrated the diversity within UK practice, both within and outside the NHS. The presentations reflected different types of lay involvement, ways to define lay and professional roles, philosophical underpinnings and delivery methods. Differences in the conceptualisation of 'lay' were also evident, with some programmes involving lay people as volunteers through to others where lay was defined in the context of non-health roles within a public or voluntary sector workforce. Notwithstanding different understandings, common themes did emerge, particularly in relation to support processes and barriers to engagement. In presenting the findings it has been important to reflect the diversity of perspectives and also to identify where these common themes were present.

Table 11. **Evidence presented on specific programmes**

Programme	Description
Gateshead Healthy Communities Collaborative (HCC)	The HCC has 8 teams of local residents working together with NHS, local authority and voluntary sector staff. They use collaborative methodology to bring about health improvement in their own areas. The HCC commenced as a national pilot in 2002 and continued local funding has meant that the HCC has flourished. They have undertaken work around falls prevention in older people, improving access to a healthy and affordable diet and promoting the earlier detection of breast, bowel and lung cancer.
Little Angels Community Interest Company 'Making Breastfeeding Fashionable'	Little Angels is a community interest company working with Blackburn with Darwen PCT. It is commissioned to deliver breastfeeding support through paid peer support workers and volunteers. They run a 24-hour telephone helpline, community support groups and undertake home visits.
Thornhill Health & Wellbeing Project (THAWP)	THAWP is a neighbourhood based health project and is a partnership of New Deal for Communities, Southampton City Council, Southampton PCT and residents of Thornhill. THAWP run a range of activities from mental health drop-ins to health walks, tai-chi, smoking cessation, weight reduction classes, health eating. Volunteers from the local community run many of the groups.
Speakeasy Family Planning Association (FPA)	Speakeasy was developed by the FPA as an 8-week course for parents and carers to help them talk to children and young people about sex and relationships. The FPA run 3-day accredited training to train facilitators who include both parents and people working outside the health service, such as teachers and professionals working in the voluntary sector.
Healthy Living Network, Leeds Community Health Educators (CHEs)	CHEs programme is based on Paulo Freire's philosophy of education. Local people undergo a 14-week training course to deliver simple health promotion messages in their communities. The CHEs work in twos and threes in community settings and are paid as sessional workers. They work with a very diverse range of clients in the locality including faith groups, prison service, sex industry workers, and homeless people.
Health Trainers Programme	The Health Trainers Programme is a national public health initiative. Health Trainers offer tailored advice and support around the Choosing Health priorities. The intention was that Health Trainers would be recruited as lay people to work with disadvantaged communities.

	Health Trainers undergo training (Level 3) and while there are differences between local Health Trainer programmes, most Health Trainers are paid and work in the NHS.
Expert Patients Programme (EPP)	The EPP is a national programme focused on helping people with long term conditions self care. The programme uses lay volunteer tutors to deliver structured courses to people with long-term conditions. Most of the tutors have long term conditions or are carers. Originally rolled out through all primary care trusts, there are over 700 tutors and 12,000 people have been on the EPP course. Responsibility for the EPP now lies with a community interest company
IDeA Healthy Communities Programme	The IDeA Healthy Communities Programme is responsible for helping local authorities and their partners become more competent in dealing with health inequalities. IDeA has many examples of lay engagement in the delivery of public health including with public sector workforce.
North Carolina Breast Cancer Screening Programme, US	North Carolina Breast Cancer Screening Programme (Save our Sisters) is a project in the USA dealing with health disparities and uses Lay Health Advisors to improve access to services. LHAs are trained to provide information about breast cancer screening to women in their social networks, along with one-to-one support. They also organise events and give group presentations to women.

8.2 Reasons for lay involvement

The research team were keen to explore different rationales for involving lay people and to take the discussion beyond received ideas of community engagement being a 'good thing'. Experts were invited to address the question of 'why bother?' A range of arguments were advanced for supporting and encouraging lay involvement in public health and these are summarised in Table 12.

Table 12.   Summary of themes on rationales for lay involvement

Why professionals should bother to involve lay people	Why lay people should bother to get involved
Lay people want to get involved	Involvement can build confidence and self-esteem
Lay people have the potential to	It provides opportunities to learn

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reach communities that professionals cannot	new skills and access training
Lay people have knowledge of their communities that health professionals do not	Involvement can develop employability and market value
Health professionals can learn from working with lay people	It helps combat social isolation, particularly those who have become excluded through ill-health
Lay people can bridge the gap between communities and service delivery	Involvement can be empowering
Utilising lay networks and resources can be a cost-effective way of achieving health improvement and tackling inequalities	It can feel rewarding to be part of positive change
Involving lay people can lead to improved service delivery	It provides social contact and is fun
Involving lay people leads to long-term health gain	Involvement provides an opportunity to find out what is going on and how things happen
The government thinks it is important and has signalled a move to a *"fully engaged scenario"*	Altruism – lay people have a commitment to their communities and the principles of social justice

8.2.1 Commitment of lay people

Lay people were undoubtedly seen as having a commitment to their communities which could only come from their living among those people affected by the issues discussed, and lay people (and practitioners supporting them) also spoke of their wanting to 'give something back':

"Why should we bother involving lay people in public health roles? I feel local residents are committed to developing their communities. I have to say that because I am a resident and I've lived there for twenty years and I'm very happy doing what I do. The volunteers know the people involved and the needs of the area. It's all very well people coming in from outside and telling us what we need, but actually you don't live it." Expert Hearing 1

It was also recognised by health professionals that there is a growing commitment within communities to improve health and that lay people are well placed to find a suitable fit between promoting health and facilitating enjoyment.

8.2.2 What lay people have to offer (that professionals do not)

The value of local knowledge and shared experiences was a strong theme in the hearings. One practitioner acknowledged that some residents in her area were less fearful of approaching a face that they know than a professional worker, and it was suggested that volunteers could be less judgemental. A commissioner, at a later event, suggested that since lay people are role models, it is also important for communities to hear public health messages from 'people like us' precisely because 'they know how life is for people'. Because of this, it was argued that involving lay people in the delivery of public health is an effective way of engaging and informing people, thereby extending reach. Likewise, a practitioner responsible for delivering a peer education programme concerned with sexual health, highlighted that it is precisely because lay people are known and trusted in their communities, and have a better understanding of local cultures and how the programme would need to be presented to make it more acceptable within those cultures, that makes them appropriate peer educators.

The value of peer knowledge was seen as important in terms of tackling health inequalities. One speaker commented that it was not necessary to have a medical background to deliver a public health objective. Another speaker said:

"The calibre and the street intellect of the [lay workers] is amazing. You wouldn't believe how much street intellect is locked into these people. No surprises to anybody here I'm sure, the power of the person, but for postcode or parentage, have found themselves at a disadvantage." Expert Hearing 2

8.2.3 Professionals can learn from lay people

Working with lay people was perceived, by one practitioner, as having potential benefits for health professionals as it enabled them to see what prevents people from changing their behaviour and can, consequently, inform professional practice. Indeed, she gave an example of a course being delivered to third year medical students by teenage mothers in the area in which she works. Another speaker also highlighted that Health Trainers offer the opportunity for a multilateral flow of information to and from communities. Notwithstanding the benefits of lay involvement, one of the experts cautioned against seeing it simply in terms of better service delivery.

"I think it is actually about citizenship in a very broad way. It's about people being involved and taking a place in shaping what happens for themselves, for their families and their communities." Expert Hearing 2

8.2.4 Health improvement

There was some discussion about the potential benefits arising from lay involvement in terms of long-term health gain for individuals and for communities. Evidence from the US about the effectiveness of lay approaches in tackling health disparities was presented in the second hearing. Some speakers suggested that involving lay people in public health roles led to positive health and social outcomes, such as behaviour change, increased social capital, reduced social isolation, and increased employability. One commissioner pointed out that broader outcomes were not always considered in evaluation, but could be significant.

"I think breastfeeding is a really good example of where the developmental model can really take off because you have mums, through Children's Centres, who go to breastfeeding peer support groups, they breastfeed their children when maybe they wouldn't do, and then they get interested and become trained as peer supporters themselves, and do peer support training themselves. We have evidence then of mums then going on to train as midwives through further education and that's a developmental process. So actually you start off with somebody who maybe is not going to breastfeed who breastfeeds and ends up as a midwife." Expert Hearing 3

8.2.5 Financial considerations

The move toward a 'fully engaged scenario' was seen to make financial sense with speakers at the second and third hearings arguing that involving existing groups and volunteers was a cost-effective way to tackle inequalities. It was pointed out, however, in the panel-led discussion at the first event that volunteer time is 'freely given, but not cost free', and while services often see volunteers as a 'cheap option', this can ignore the fact that:

"…you need a volunteer co-ordinator who's going to provide support for the volunteers and if you don't put in training then you're not going to get anywhere anyway. So there are issues about costs that, again, statutory services don't always recognise." Expert Hearing 1

8.2.6 Lay perspectives

Reasons presented for why lay people should bother to get involved in public health/health promoting activities in their communities focused primarily on what lay people could gain from their involvement. Speakers highlighted a range of benefits, with lay people taking part in the hearings offering personal reflections. Identified benefits included increased self-confidence and self-esteem, and opportunities to learn new skills and access training which would, in turn, help develop employability and market value. One volunteer responded:

"Why should lay people bother getting involved? It has developed my confidence. I spoke earlier about men in suits. I've always been particularly wary of men in suits because, as I've said before, they're the professionals. They're hierarchy; they know exactly what they're talking about. I think, because of the courses I've been on and the training that I've done and through the drama, I'm just as good as what they are." Expert Hearing 1.

For people who were affected by ill-health, becoming involved in volunteering had helped to get them out of the house, increased their social networks and had a rehabilitative value in helping them to relearn simple skills adversely affected by, for example, stroke. Volunteering was regarded to be particularly beneficial by one participant who had experienced long-term mental health problems.

Altruism, along with a commitment to address community issues, was seen as a motivating factor by several speakers. Evidence from a survey of online tutors with the Expert Patient Programme (EPP) indicated that lay tutors were strong advocates for EPP and characterised themselves as highly

motivated, responsible citizens. One practitioner suggested that involvement in promoting the health of their communities had empowering potential for lay people and that it was rewarding to feel part of positive change. She also emphasised that for lay people, it was important to get involved because of the commitment they have, both to their communities and the principles of social justice, and that these interests would best be served by finding out about what is going on and the processes involved in making things happen. This was echoed in the first hearing by a member of the audience who made a comment that anger and frustration were also motivations.

8.3 Effective strategies

The presentations reflected a number of different approaches to involving lay people in public health roles and a range of solutions to barriers were identified (see Table 13). While common themes did emerge, the expert hearings served to demonstrate the diversity of UK public health practice in this field and therefore reported effective strategies and methods vary between programmes and different contexts. It was also noted that research evidence from evaluations was 'very patchy' and the majority of the evidence presented was based on experience from practice. In discussing what had been found to work, or otherwise, responses were categorised in terms of recruitment, training, incentives or rewards, support and management, delivery and implementation, and strategic partnerships.

Table 13.   Summary of themes on effective strategies

Summary of what works	Summary of what does not work
Adopting an inclusive approach to the recruitment of people into lay roles and recruiting from the local community	Recruiting lay people via poster campaigns
Designing training packages which are inclusive and flexible for people traditionally excluded from the education system	Regimented recruitment processes which emphasise contractual obligations for volunteers
Establishing a learning culture in which people are keen, committed and interested	Poor management and support of lay people once training has been completed
Making connections to adult education opportunities both for self development and as a route to employment	Delivering an intervention in a structured and prescriptive manner which might reassure primary care trusts, but which limits opportunities for lay people to engage with intended beneficiaries
Providing opportunities for people to have fun	Rushing the implementation of interventions with inadequate time to prepare lay people to deliver public health activities
Paying lay people out-of-pocket expenses and in line with benefits	Trying to deliver interventions on an inadequate budget
Providing an adequate infrastructure to support people beyond training	
Establishing clear demarcation lines in relation to roles and professional boundaries but valuing the equal worth of volunteers and paid workers	
Using bottom-up approaches in developing new ideas that incorporate the ideas of lay people	
Involving local people in planning, design and delivery	
Adequate funding, including awarding grants to very small community organisations	

Establishing effective partnerships between the NHS and other sectors	
Passionate leadership at the highest level	
Sharing learning and information effectively	
Service delivery being offered outside of the NHS	

8.3.1 Recruitment

Speakers from different stakeholder groups stressed the importance of recruiting people with local knowledge of their communities, what one speaker described as 'street intellect'. Shared experiences, commitment and 'down to earth' attitudes of lay people were seen as more important qualities than prior knowledge or formal qualifications. For example, one programme purposively sought people with empathy and passion.

"You can teach people breastfeeding techniques, I can teach you to position and attach a baby, but I can't teach you the passion for it or the skills that you need to support people. It's just a vocation but it comes across when you speak to people." Expert Hearing 1

The importance of engaging inclusive approaches to recruitment and employing people for what they can do, as opposed to what they can not do, were also stressed. In the case of one programme, selection criteria were not applied, and in some cases people were recruited with significant social problems. While there was an identified risk with this strategy, the focus was on the contribution that could be made.

"We had a community member whose children were on the at risk register, so all the health professionals we've ever worked with have been lovely to us but they said 'how can you have somebody going out teaching somebody about healthy living when they can't even look after their own kid?' …She never worked with kids and what she did do was a lot of first aid work for us and healthy cooking. So it's employing people for what they can do and not for an absence. Her kids are not off the at-risk register, but you can understand how controversial that it, it's a big challenge for us." Expert Hearing 2

In relation to recruitment strategies for Health Trainers, one speaker reported that trying to recruit lay people via poster campaigns had proven

ineffective but conversely going out to community groups and talking about health has stimulated interest. Speaking of a national programme, another reported that the recruitment process had itself been off-putting for volunteers as it had involved going.

"...through CRB checks, they had to go through quite a tough interview process, they had to sign a document saying they would do certain things during the year. And that was at odds with the limited responsibility a lot of people expect from a voluntary role." Expert Hearing 3

8.3.2 Training

Training was a theme in a number of the presentations and different types of training were reported in relation to the different initiatives, such as Speakeasy and EPP. Nonetheless some common themes were reflected in the discussions, and it was in the context of training that most successes were reported. For most, this had involved establishing 'a learning culture where people are keen, committed and interested'. Practitioners at each event stressed the importance of enabling lay people to identify their own training needs, with one organisation devising its own training programme to encourage volunteers to 'step onto the training ladder'. The notion that initial training might lead to other educational opportunities was raised and the significance of adult education was commented on. A lay person described how her involvement in local groups had led her to develop other skills and take up educational opportunities: 'I'm a firm believer in adult further education; it's a bit like a drug you can't get enough, that's how I am'. One practitioner spoke of the significance of training in any approach to lay involvement. She reflected on the value of having training courses at Levels 1, and 2 that will allow people to eventually undertake Level 3 (the level for Health Trainer competencies). This graduated approach was regarded as essential for people who might struggle without formal qualifications. On her courses, participants were actively supported to look at other routes to skills development.

"Like going out and getting more English, so doing English as a second language course or doing I.T., basic understanding [of] Word and being able to write on a computer and things like that. It was about signposting them onto other Learn Direct courses, so it was about confidence building, getting them onto some of the confidence building courses." Expert Hearings 3

All those who spoke of delivering training successfully highlighted the importance of using inclusive teaching and learning methods which would not exclude people whose first language is not English or those who had traditionally been excluded from the education system. Typically, these drew upon interactive or arts-based methods and enabled students to

reflect upon their experiential knowledge. Well facilitated courses were also highlighted as important, as was being flexible in terms of how and when training was delivered. The value of engaging people in practical activities in the training and getting them out into the communities early on was highlighted. Furthermore, one practitioner said that in his programme, it had proven successful to enable students to be delivering and training simultaneously.

8.3.3 Incentives and rewards

The issue of benefits and rewards was touched on in all the hearings and was a major point of discussion in the third hearing. Again different models of employment and rewards were reflected in the presentations At each event, however, it was unanimously agreed by speakers and participants that providing opportunities to have fun, often through social activities, was an extremely important reward.

Additionally, it was stressed that paying volunteers out-of-pocket expenses, and having mechanisms to do so quickly and efficiently, was important. Several of the projects had systems to ensure quick payment of expenses to volunteers that bypassed the bureaucratic barriers. During the third hearing, members of the audience also provided examples where systems were used to reimburse transport costs or child care immediately through petty cash because, as one audience member said: 'we're dealing with people who've got no dosh at all so they can't lay out any money'.

Most programmes involved lay people on a voluntary basis, the exception being the Health Trainers initiative where people from local communities usually become NHS employees. There were two further examples of where lay people were paid in their roles. One programme utilised both volunteers and paid lay peer support workers, and the other paid people on a sessional basis in line with their benefits as this was seen as an appropriate reward for the work undertaken. A speaker argued that employment created greater accountability:

"One of the reasons that [project name] works is because it's paid support and when you pay people they're accountable for what they do. So I could say to a volunteer 'I've got a mum that needs seeing on Monday are you free?' and she might say 'I might be but I'm not sure'. If it's a paid worker I know she's available because she's at work from 9 'til whatever." Expert Hearing 1

Another speaker however cautioned that payment altered the relationship between the lay person and the community:

"Once people are in a paid job you are changing that dynamic. We learned some difficult lessons as a result of employing someone from the Gypsy and Traveller community without giving enough thought to the tensions she would experience. It put her in a completely different situation with the people that she lived with. We must look at those implications." Expert Hearing 3

8.3.4 Support and management

Speakers acknowledged the importance of providing continued support to lay workers in their roles; this included providing an infrastructure to support students beyond their initial training in order to enhance their development and confidence. Elsewhere, more practical support was emphasised and in one programme, for example, it was reported that established volunteer mentors supported new volunteers. Other speakers spoke of ongoing professional involvement from community workers or community development teams to help people identify, plan, develop and evaluate health improvement activities. As reported above, one practitioner had also found it beneficial to support lay people in getting involved gradually, without having to assume trustee and management responsibilities before they were ready.

Conversely, recognition of the need for ongoing preparation and support was seen as a gap in two major national initiatives. In terms of what has not worked, it was reported that the Department of Health had underestimated the amount of time and financial investment required to adequately prepare people to deliver the Health Trainers programme as the Health Trainers themselves required some 'handholding' initially. Poor management style in relation to volunteers involved in one national programme, as discussed above, was also reported to have failed to have harnessed the potential of these volunteers. Indeed, this expert explained that:

"Volunteer[s] would be coming on with an awful lot of altruism and goodwill and they wanted to improve the health and to do things for their communities but PCTs were just focused on the management 'right you will run this course and this course'… The courses went on every 6 weeks and a certain number of people got really enthused and wanted to carry on this group and they got so much out of it but PCTs weren't very good at supporting that and making it happen, so they didn't build on what was there." Expert Hearing 3

This was contrasted to a more successful approach where a voluntary organisation managing the programme provided a permanent physical space for volunteer tutors to work from which enabled tutors to support each other and develop social networks.

8.3.5 Styles of working

A number of factors were reported as important to successful delivery. A strong theme across all the hearings was the importance of approaches that were able to harness the ideas and experience of lay people in developing activities. The Healthy Communities Collaborative was held up as an example where lay people were involved in teams with other stakeholders to plan, deliver and learn as a team.

"The other things that makes it work is that it's bottom-up, it's ideas from the team that make it work because they know what the issues are. As mentioned earlier, it gives people confidence, particularly when their work is recognised by others." Expert Hearing 1

Volunteers were told that 'it's ok to fail'. Here, they start off with small-scale ideas 'so if it doesn't work we've not actually invested a lot of time and effort in it'. Flexibility was highlighted as important, both in relation to accommodating lay workers' needs regarding their working arrangements, but also in terms of the programme itself: 'it learns as it does, as it adapts'.

Another factor in successful delivery was valuing the contribution of lay workers. Lay people and practitioners representing initiatives in different parts of the country spoke about creating a sense of equality between paid workers and volunteers. One practitioner described her volunteers as 'co-workers'. For volunteers involved in a programme based in the North East of England, this included staff at all levels in the NHS hierarchy. For example, one community member explained that:

"If your leader is willing to listen and take on board what the lay person or the volunteer is actually saying and go back to their, and really sell it to them as [NAME] does, I think you do get somewhere and you don't notice that there's a split between them." Expert Hearing 1

In terms of what has not worked, a practitioner reported that the pressure to get volunteers out and delivering health promotion messages in the community had meant that some had started work before they were ready to. In relation to the EPP, it was reported that while primary care trusts may have been reassured by the structured nature of the course being offered

by volunteer tutors, participants had been less than satisfied as it did not encourage much interaction.

8.3.6 Strategic partnerships

Establishing effective partnerships between the NHS, local authorities, voluntary and third sectors was identified as a key prerequisite for success, as was adopting a long term, strategic approach to problem solving with leadership prepared to make things happen. Additionally, speakers also stressed that it was important for local people to be involved in the partnerships, for example, through participation on panels, and to include community perspectives in public health planning. In one primary care trust, making funds available to allocate small grants of £500 to very small organisations had also proved an effective mechanism. Local authorities who were beacons for equality were described by one speaker as sharing a number of attributes, including strong functioning partnerships, passionate leadership, a good track record on community engagement and able to learn and then mainstream good ideas. There were estimated to be between 4,000-5,000 examples of lay people involved in health improvement, although many were not mainstreamed.

Among those speakers from outside the statutory sector, being independent from the NHS was highlighted as being important to success. Indeed, it was reported that since management and delivery of the Expert Patient Programme had been transferred to a community interest company, this allowed for more leeway and flexibility, free of Department of Health bureaucracy. An expert representing a community interest company valued her organisation's independence:

"We work hand in hand with the NHS and the local authority but we are also independent so it gives us a lot of freedom to do what we want and say what we want and it removes us away from the restrictions that the NHS can sometimes put upon people or what people want to do." Expert Hearing 1

8.4 Challenges

Views on the challenges facing those organisations and individuals wishing to involve lay people, and also the barriers experienced by lay people themselves, were prominent in the evidence presented. A range of challenges were identified at each event. Broadly, these could be categorised as relating to organisational culture in the public sector, the structures and processes surrounding lay involvement in public health, and

issues specifically concerned with working with communities, particularly those which are seldom heard.

8.4.1 Organisational culture

Perhaps the most dominant theme was the nature of organisational culture within the public sector, and the NHS in particular. The 'top down' nature of the NHS mindset, both at an organisational and an individual level, was reported as an issue by experts from different stakeholder backgrounds at each event, particularly in relation to the approach to community engagement in the NHS. At different events, primary care trusts were described variously as 'territorial', as reluctant to power-share with communities and as needing to develop more positive relationships with the community and voluntary sector, which would involve a move away from the labelling of community activists as 'the usual suspects'.

It was also suggested that there is a need for more joined-up working between primary care trusts and local authorities. One expert commented on the tendency of the public sector to 'dictate' in partnerships involving the third sector, and it was suggested that some public sector organisations approach third sector engagement as a 'tick-box' exercise. While it was recognised that the public sector has restrictions and guidelines, this expert suggested that it was a 'matter of compromising and working together'. Expert Hearing 1

Particular issues were raised from the commissioning perspective. These included the tendency for primary care trusts to be driven by a medical model with a focus on clinical outcomes, which may be at odds with the priorities and concerns of communities and lay people working in them. One commissioner also reported that within her geographical area there had been a concern regarding the limited sharing of good practice between primary care trusts and, within her own PCT, a history of ineffective commissioning within the third sector. Academics and practitioners highlighted the challenges of moving organisations away from the belief that involving lay people represents a cheap option.

Getting health professionals onboard was identified as another major challenge. One speaker described how some health professionals were able to work differently but this type of approach was not always supported in the NHS.

"The challenges then are getting health professionals involved. It's the same old story. What we find is that there is a small group of professionals that get it, they get that you can change things and make a difference. But

actually particularly in the current climate it almost seems like that's being beaten out of them and those people that do get it are being moved into jobs where actually that's not wanted anymore." Expert Hearing 1

In speaking of peer support, another expert suggested that health professionals are the greatest barrier to lay involvement as they perceive service change to be 'threatening'. She explained that:

"...it's almost like saying they're not doing their job properly and we're not saying that. What we're saying is we're offering an enhanced service, we're here to work with you, but 95 percent of people don't like change. They're quite comfortable in their own comfort zone and if you suggest that they change their practice they don't like it and the barriers go up." Expert Hearing 1

Concerns about roles and boundary issues were also reported by different speakers in relation to the implementation of a national programme in the North East of England. Lack of clarity about where the role of the lay person starts and ends was reported to have led to mistrust and suspicion among health visitors in particular, while some community development workers were reported to be quite unsupportive of the role. Additionally, the absence of professional qualifications and experience had led some lay workers to feel that 'they weren't really trusted'. This was reinforced by general practitioners having expressed concerns about quality.

At each event, it was suggested that achieving sustainability need not simply be about working within familiar frameworks, be they about working practices or who traditionally receives funding, and that change is both healthy and necessary. This view was summed up effectively by one audience member:

"We (in terms of the establishment) are frightened sometimes to allow people to do things very differently because we throw out the governance issues etc, and we throw out a whole range of barriers in the way about why we shouldn't do it, instead of saying 'how can we make it happen?' ...the difficulty with sustainability, really, is that people, I think, sometimes think well it can only be sustainable if it starts to fit in some of our pre-existing models, otherwise we don't want to know because it's too scary." Expert Hearing 2

8.4.2 Structures and processes

Supporting lay people

Speakers from different stakeholder backgrounds commented on the range of structural or process barriers to involving lay people in public health. The absence of infrastructures to support lay people was cited as problematic and primary care trusts, in particular, were criticised for cumbersome bureaucratic processes that are difficult for lay people to navigate, involve a lot of paperwork, with staff being slow to respond to people's queries. Indeed, bureaucracy was seen as a major barrier to involving lay people, whether as volunteers in public health services or in running small community projects. There was a perceived risk of 'over professionalising' lay workers through the restrictions and red tape.

"I've seen the whole sector, with a little bit of sadness, become professionalized and it's that thing you can't grasp, that you lose when things become professionalized and it almost scares away the most vulnerable groups you were always after in the first place." Expert Hearing 2

Findings from the evaluation of the EPP indicated that volunteer tutors had been 'deeply shocked' by the levels of responsibility they had been expected to assume. It was suggested that this was due to the inexperience of primary care trusts in working with and managing volunteers, particularly those with long-term conditions. PCT management style consequently resulted in tutors feeling undervalued and exploited. Where there were dedicated staff, or those who understand and are committed to the principles of community engagement, better experiences were reported by experts. Staff turnover, however, was also cited as a problem which could lead to such people being moved on into other roles.

At the final hearing, there was a lively discussion concerning the need to provide appropriate incentives and rewards for lay people and the need for clarity regarding any potential impact on benefits. One speaker described her frustrations:

"We have very successful lay representation on a community grant panel, just three people, and we try to make it fun, that's about the best reward we can give them. We get good feedback from them, they feel they are making a real contribution. They have lunch with us, but I got so frustrated with our internal systems that I pay for their lunch myself in the community centre, which is only about £5 each, because it is just not worth the hassle in the NHS to get the money back. It's just the bureaucracy." Expert Hearing 3

A lay person described the paradoxical situation where the benefits system was acting as a barrier to the very groups who were being encouraged to get involved:

"In the voluntary sector, normally it's mostly people who are unemployed or in between jobs or things like that and they have to have social security or benefits and when you have a form to fill you have to declare anything and then that comes off your benefits. So that has actually made it a little bit difficult for people in the voluntary sector to actually come forward and those are the people who are wanting to do the voluntary work, so just thinking what could be helped in that situation because you have to declare everything on the form, even expenses." Expert Hearing 3

Funding and sustainability

The short-term nature of funding available for community-based work was widely cited as a challenge, as was the absence of a co-ordinated approach to implementation. Indeed, one lay person highlighted the problem:

"People, especially in the community, they get an idea, yes it's a brilliant idea let's get it running, and it takes a good eighteen months to get a project up and running and what happens, eighteen months later the funding has gone. That is one of the things that affects community members, why should they bother if they're going to do all this hard work and three years later, wham, it's gone." Expert Hearing 1.

This expert also complained that bureaucratic processes requiring detailed accounting are cumbersome, involving costs that are difficult for small groups to absorb:

"We have to account for every last penny, a big organisation doesn't have that same, £30 for a report, you've got to practically price your staples up and that sort of stuff, that's how hard it is for people on the ground." Expert Hearing 1

At a later hearing, one commissioner spoke of the need to make it easier to fund new ideas and, regardless of pressures concerning evidence and performance management, to find 'little pockets of money' (up to £500) which will enable people to implement these ideas.

The challenges of achieving sustainability and the importance of mainstreaming were highlighted. In some cases the lack of long term

funding was pinpointed, in other cases over-reliance on committed individuals was seen as a major factor.

"It has traditionally been reliant on the drive and perseverance of committed individuals. If you look at the breastfeeding issue, breastfeeding peer support groups, it's a committed midwife or a committed health visitor who has driven that forward. It hasn't come strategically from the top tier of PCT." Expert Hearing 3

It was acknowledged by one commissioner that projects involving lay people tend to be short-term pilots, rather than commissioned, indicating that people are failing to consider sustainability. In order to achieve this, it is necessary for early indications of effectiveness to be highlighted which could be linked to potential targets. A national programme lead spoke of the level of activity being high in local authorities:

"However there are some big problems with it because very often it requires the individual initiative of some champions. Very often it's funny money that comes and goes, and very often these projects don't feel, even now, quite as mainstreamed as they ought to be." Expert Hearings 2

Evaluation and Commissioning

Evaluation was a common concern. It was widely acknowledged that this had become a priority within the commissioning process and one commissioner complained of a dearth of evidence regarding what works to inform commissioning decisions. At an earlier event, a practitioner pointed out that monitoring and evaluation requirements can be too onerous for lay people and not what they had signed up for. Nonetheless, she reported that local people were involved in carrying out their own research, engaging 'excellent methodology', but that these findings cannot compete with those produced by academics. Additionally, it was noted that evaluation tends to focus on clinical, rather than social outcomes, at the behest of funders, potentially ignoring increased social capital and social networking, and one academic raised the question of how researchers can begin to evaluate such outcomes.

Policy Issues

At a more strategic level, one commissioner highlighted the politics of health and shifting policy agendas as a barrier. At a local level, this was reflected in local politics impacting upon decision-making, for example, through the funding of projects which are being championed by local

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politicians. At a national level, it was acknowledged that government agendas, and personnel, shift during the lifetime of government and so:

"…what is an important initiative at the beginning of an administration, by the end of the administration the headlines have been hit and things are often put away and forgotten about." Expert Hearing 3

Thus, important findings regarding effectiveness can be lost if a priority has shifted or been subsumed elsewhere. Concern was also expressed by one audience member regarding the possibility that the government agenda around volunteering might become focused on developing employability which could play down altruism as a motivating factor.

8.4.3 Working with communities

Recruitment of volunteers was identified by different stakeholders as a key challenge at each event. Speakers reported that it was particularly difficult to recruit male volunteers and younger people. One expert recognised that volunteering has traditionally tended to be the preserve of older generations and consequently expressed concerns about the next generation of that volunteering, an area in need of development.

At one event, it was acknowledged that on one national programme, volunteers tended to be 'white, female, middleclass' and that these were unlikely to engage people from seldom heard or more 'disadvantaged' groups. Another speaker, who had experience of working in culturally heterogeneous communities, spoke about the challenges involved in engaging people in training whose first language is not English, or who have been excluded from education in some way. Examples were provided of how this had been achieved, including developing entry level training aimed at engaging people around health.

"Actually if the [name] programme is recruiting what I call semi-professionals in and recruiting them, then that's fine, we can run a Level 3 course but if you're going to really get people from those communities that are hard to reach, from BME communities, and actually work with them then we need to think about introducing them right through the levels." Expert hearing 3

Other speakers highlighted retention of volunteers as an issue. This was not regarded as a local concern or one which was specific to particular communities. Indeed, reporting work on a national peer education programme, one expert pointed out that time constraints and demands of

other roles had an impact on retention to the training programme. Elsewhere, it was noted that retention of young people was a concern as they would often complete training and then move into paid employment. Speaking about another national programme, one expert reported that an onerous recruitment and training process, along with poor management in some primary care trusts meant that 'there was a real risk of tutors becoming disaffected and disengaged from the [name] quite quickly', leading to high levels of attrition'.

Engaging communities, particularly the seldom heard, was reported to be a concern at each of the hearings, and one which was expressed by volunteers, practitioners and commissioners. This was presented at the very simplest of levels, such as getting people to attend consultation meetings in their own communities, through to participating in training, or getting involved in the running and management of a Healthy Living Centre. Encouraging a sense of ownership was reported to be a particular challenge. However, one expert gave examples of how her own organisation had attempted to overcome the challenges of getting 'local people involved in managing it [HLC] and decision-making, in learning about the running finances, the usual management committee type discussions'. This had involved avoiding setting people up to fail by getting them to participate in a small community group initially, rather than imposing management and trustee responsibility from the outset. Additionally, volunteers engaged the wider community by carrying out customer satisfaction surveys to establish why certain people were not using the Centre.

8.5 What should the government and public sector be doing to support lay people?

Table 14. Summary of experts' recommendations for policy and public sector management

Recommendations for policy and public sector management
Provide more local support to lay people who want to get involved
Provide an appropriate reward system
Ensure the availability of funding for small groups
Build community work into training for professionals
Listen to what lay people have to say
Develop local strategic partnerships involving the statutory, voluntary and third sectors, and local communities
Provide opportunities for meaningful engagement
Harness the opportunities presented by World Class Commissioning (WCC)

> Stimulate the market to avoid domination by big organisations
>
> Promote innovation
>
> Prioritise lay involvement by government
>
> Government should lead on sharing of good practice
>
> Make long-term funding available
>
> Government should provide clarity regarding benefits/incentives

Much of the discussion in the hearings focused on challenges and developing effective approaches, while the question of the responsibilities of the government and the public sector received less attention at each of the hearings and tended to be addressed by those speakers whose roles within their organisations were strategic. Responses were categorised in terms of practical input at the local level; ways of working with lay people/ communities; developing strategic partnerships; observations about the commissioning process, and what it required from government.

8.5.1 Local level investment

Speakers who were either community activists or practitioners suggested that there needed to be more local level support for lay people wanting to become active in improving the health of their communities. This meant a person they could speak with face-to-face, rather than a list of telephone numbers. As has been highlighted in the previous discussions, offering an appropriate reward system and dealing with conflicts between incentives/payments and benefits were also deemed to be priorities for local work. There was concern expressed by one speaker that the government drive around volunteering was too closely linked to employment issues.

The funding for small, lay-led community projects was deemed important by some experts as providing a mechanism for supporting lay involvement.

"We mentioned funding for small, community groups and what I've found really interesting from this is how people have come up through, because they've started doing one small thing and it's grown and grown and that, I think, is crucial and we mustn't lose that small group funding." Expert Hearing 1

8.5.2 Ways of working with communities

The specific focus of the hearings was on the involvement of lay people in public health roles, however, many of the speakers touched on the wider

issue of community engagement. The link between patient and public involvement and lay involvement in the delivery of services was made transparent in some of the presentations. One presentation noted that:

"Lay involvement is possible at all levels, planning, design, delivery and governance of public health activities (and PCT services) but requires people to think differently and be prepared to demonstrate trust." Expert Hearing 3

This comment was echoed by a speaker at the second hearing who suggested that opportunities for lay people to get involved need to be built into local planning and that the statutory sector needs to learn to actively listen to what people have to say in order to find out about good practice and what does/not work. Additionally, there were suggestions made that there is a need for work with communities to be built into training for professionals.

8.5.3   Developing strategic partnerships

One expert emphasised the need to develop effective strategic partnerships which, in compliance with World Class Commissioning (WCC) competencies 2 and 3 (Department of Health, 2007), involve collaboration with community partners and meaningful engagement with the public. The value of lay people in public health should be incorporated into other strategic mechanisms such as sustainable community strategies and Local Area Agreements. It was also suggested that local government needs to support Directors of Public Health and that elected members should be used as health champions since they are uniquely placed to contribute to 'building that bridge' between the communities they have been elected to represent, and public health agendas.

"Some of the things local government should do, the elected members are your allies in this, they are the people who naturally understand the importance of being lay people in a professional environment because they are lay people elected by their local communities to take a representative role. The people I meet, and we train 30 or 40 senior elected members in the course of the year around the health inequalities issues, are passionate for their local communities. They may be struggling to get their voice heard amongst their colleagues in a particular local authority but they're really important because they understand more than many of us who are professionals what the significance is of building that bridge." Expert Hearing 2

8.5.4 Commissioning

There was discussion about changes in the context for health improvement commissioning at both the second and third hearings. While some challenges were identified, there were also deemed to be new opportunities to focus upstream on health gain and work with communities. One commissioner began her presentation with the statement: 'If you do what you've always done, you'll get what you've always got'. She went on to explain that, in her primary care trust, restructuring had left in place the same individuals who had been responsible for commissioning in the old organisation and raised a question about whether a regime change would produce change. For her, WCC presented the opportunity to do things differently. This would involve stimulating the market (competency 7) and enabling voluntary sector organisations and lay people to become providers who could compete with those who had traditionally been funded. It was also suggested that lay people need to be involved in decisions about the prioritisation of investment, which would make services more cost-effective and lead to better outcomes. Additionally, WCC was seen to present an opportunity through which innovation could be promoted, for example, initiatives driven or delivered by lay people, such as health walks.

Another commissioner reinforced the need for collaborative working with third sector partners in the commissioning of services, but acknowledged that there is a danger that 'big players' could dominate precisely because they have established infrastructures to allow them to compete in the new procurement processes. Within her primary care trust, efforts were reportedly being made to identify skills deficits, training and support to establish a preferred local provider list, and to create partnerships to tender for larger programmes.

8.5.5   Government

The current policy context was seen as creating some opportunities for lay involvement. One speaker drew attention to the need for a cultural shift from a paternalistic NHS to more of an emphasis on engaging people in order to change health behaviours:

"You can inform people, and that might improve service outcomes, but actually if you really want to win across all of those in terms of service outcomes, improving social capital, social cohesion, enhanced community empowerment, improved health status and reduced inequalities, then there are some issues about, you need to get up to that level around community control." Expert Hearing 1

It was argued by others that the government need to make greater commitments to lay involvement in public health. One speaker forcefully stated that 'the government need to make lay involvement a "must do'". As long as it's just an "ought to do", it might not get done'. Linked to this was commitment to long-term funding and the importance of leading by example and sharing evidence of good practice. As has been pointed out in the discussions above, there was also a call for clarity regarding conflicts between benefits and payments/incentives for lay people.

"What needs to be in place is a system to support these people during that process, and not just people on incapacity benefit, but all people so they can start by volunteering as a way back into employment, and that they need to be supported in having an additional allowance rather than losing any of their benefits. Because there needs to be incentives to encourage people to volunteer and not barriers, which seems to be what's there at present." Expert Hearing 3

8.6 Summary

The expert hearings provided stimulating discussion on both the opportunities and the challenges facing members of the public involved in public health roles, and also those people who support them. The evidence from experts demonstrated that a range of different approaches can be used in various contexts. Alongside the discussion around some of the challenges faced by lay people and professionals supporting them, many positive examples of good practice were presented.

Experts argued strongly that lay people have a role to play in tackling inequalities within their communities and many lay people would like the opportunity to give something back. Nonetheless, there remain a range of barriers, including organisational culture, professional protectionism, onerous bureaucratic processes and strategic factors, which are obstacles to their getting involved. Providing appropriate training and support and ensuring that lay people are not out-of-pocket were cited as important facilitators to lay involvement. It was clearly indicated that the statutory sector needs to both develop improved mechanisms for working with and listening to communities and to improve strategic partnerships with other sectors.

9 Register of interest and site visits

A small but vital element of Phase 1 of the study involved gathering evidence from public health practice in England. This element of the scoping study was achieved in two ways. Firstly a study website was established with a Register of Interest, seeking information from projects involving lay people in public health roles. Secondly the research team undertook a number of site visits and held meetings with key informants in order to engage in dialogue with front-line practitioners and programme managers. Liaison with public health practice was informed by the research partnership with NHS Bradford and Airedale and linked to the public involvement work. All elements allowed the views of practitioners and community activists to inform the development of the study. Information from scoping of current public health practice was used in a number of ways; thereby strengthening different elements of the research (see Figure 5). Contact with practice helped in the identification of grey and published literature on lay roles, informed the selection of experts for the expert hearings, and enabled the identification of potential case study projects. At the same time the literature review and expert hearings led to the establishment of further contacts. The findings from the Register and site visits are reported here, while further information on public involvement activity is presented in Section 15.

9.1 Register of Interest

9.1.1 Methods

In January 2008, the 'People in Public Health' website was launched to provide a mechanism for practitioners, researchers and community activists to engage with the study (http://www.leedsmet.ac.uk/piph). Included in the website was a Register of Interest where individuals and organisations were invited to give brief details of projects and programmes that involved lay people in public health roles. There was also an option for individuals to register to receive information about the progress of the study. The purpose of the Register was twofold; to gather information on current public health practice and to facilitate shared learning through signposting interested individuals to actual projects. Those registering projects online were asked to provide a summary of the project and data on a number of fields, which broadly matched the fields for data extraction in the literature review. In November 2008, the Register of Projects became a searchable database giving public access to the information.

Figure 5.   Construction of evidence in scoping study
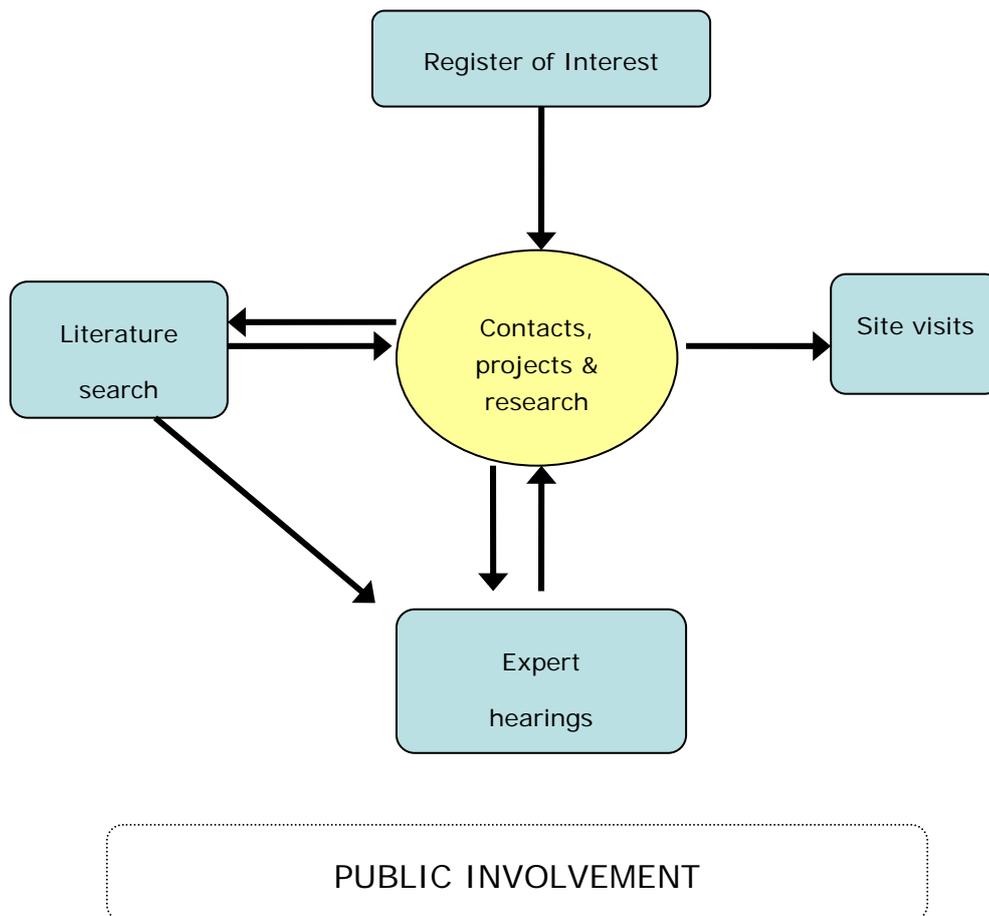
Following the launch of the website, electronic mailing lists were utilised to publicise the study and encourage individuals to register projects involving lay people in public health roles. An invitation to join the Register was sent out through a number of national, regional and local networks, including Teaching Public Health Networks, Health Trainer hubs, the Institute of Health Promotion and Education, and the Men's Health Forum. In addition, there was a 'People in Public Health' stand at the 2008 UKPHA conference where delegates were able join the Register of Interest.

9.1.2   Findings

In the first year of the study 41 projects and over 130 individuals joined the Register of Interest. Of the 41 projects that registered, 22 were deemed to be directly relevant to the scope of the study. Projects where the primary role of lay people was in research (5), service development and planning (3) and care roles (1) were not included in the scoping study. A further five

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registered projects were local Health Trainer programmes and fell outside the scope of this study. Insufficient information on lay roles was given in three projects. It is of interest that so many of the registered projects represented other types of public and community involvement and is indicative of the difficulty of defining boundaries for lay roles in public health programmes.

Twenty two projects with information on lay roles registered and all were current as opposed to completed projects. Eight projects were from the Yorkshire & Humber region which is likely to reflect the involvement of the research partnership and the links with local public health programmes. Notwithstanding the small size of the sample, the information from the Register provided a useful perspective on current practice. A summary of the results is reported here. Details of projects can be accessed through the study website:

https://piph.leedsmet.ac.uk/main/searchproject_cur.htm

Projects were broadly grouped based on summary information provided. The largest group was projects where lay people were involved in giving lifestyle advice and support (8), for example as Community Health Educators or lifestyle tutors. One project from this group was focused on nutrition with accredited training offered to local residents to become community food workers. Another was described as a community programme for obese children run by adult lay health workers. There were three walking for health projects registered including the Walking for Health national scheme (formerly Walking the Way to Health). Two projects were peer support projects, one focused on breastfeeding and one giving support to bereaved parents, and two projects were described as raising awareness of specific conditions. Some projects involved generic health promotion activities (3).

In terms of organisations involved, most projects involved health services (18) and/or voluntary sector or non-governmental organisations (15). Ten projects involved local authorities and six employers or workplaces.

Those completing the registration were asked to indicate the health focus of the project, ticking multiple categories as appropriate. The results showed a large spread of health topics and target groups, with most projects concerned with multiple aspects of public health. Figure 7 shows health focus of projects in relation to the Choosing Health priorities. Thirteen of the 22 projects were concerned with health inequalities as a health focus, 11 with access to services and seven with Black and Minority Ethnic health. In terms of target group, five projects worked with the general public, and seven either in areas of deprivation or with communities deemed to be

hard-to-reach. Two projects worked exclusively with older people and one with children.

Brief descriptive information was collected on lay worker titles and roles (Table 15). Description of primary roles included giving health information and advice, providing support, raising awareness, disseminating information, facilitating groups, supporting professionals and leading walks.

Figure 6.   Health focus of registered projects
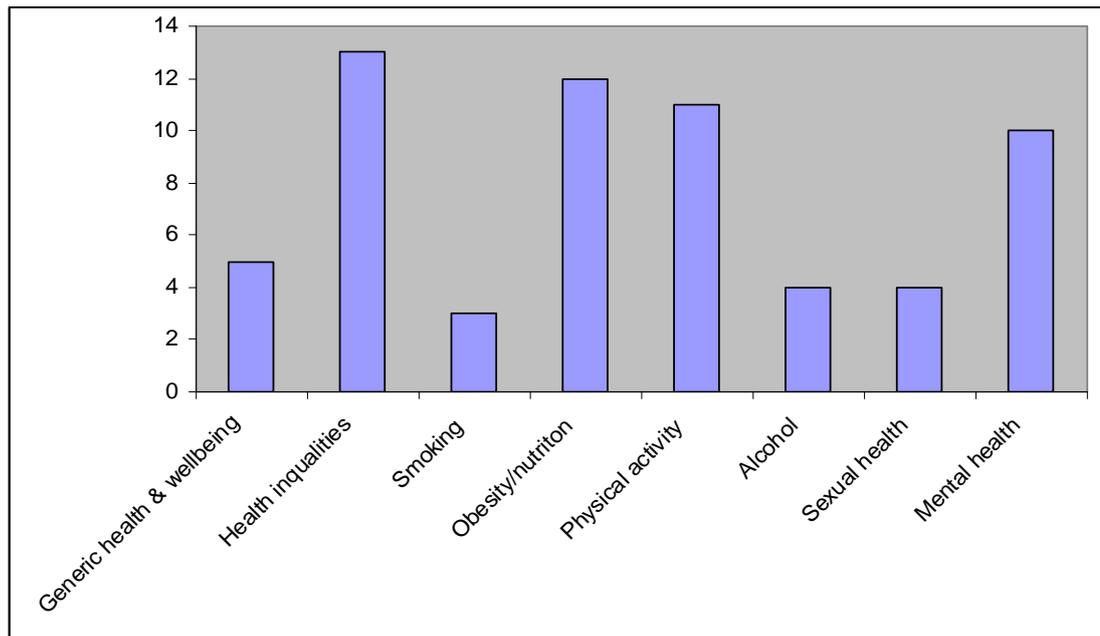
The majority of lay workers were recruited from the target group (16 projects) but three projects did not recruit lay workers from target groups including the obesity programme for children and young people. In terms of payment, the Register showed a split between payment and volunteer schemes with five projects indicating that unpaid volunteers were used and eight where lay workers were paid. Information was not known about nine projects, which could indicate that there was a mix of approaches to remuneration.

Table 15.   Lay worker titles used by registered projects

Titles of lay worker or volunteers
Ambassadors
Befrienders
Community Food worker
Community Health Activists
Community Health Champions
Community health development workers
Community Health Educators
Community team workers
Cookery tutors
Live for Life tutors
Mentors
Peer support worker
Peers
Self Care Support Volunteer Workers
Speakeasy Facilitator
Team members
Trainers
Volunteer Walk Leaders

9.2 Site visits and liaison with practice

The research team undertook a series of site visits and meetings with key informants in order to find out more about current practice (Table 16). Initiatives and projects were identified through the Register and through the expert hearings. During the visits, key individuals, who included programme managers, front-line practitioners, lay workers and community activists, took part in informal discussions with members of the research team about project activities and issues. A small number of leading academic researchers were contacted by phone. In addition, researchers attended consultation events in London and York as part of the Department of Health's review of volunteering strategy (Department of Health, 2008b).

Table 16.   Site visits

Organisation/project	Focus of work
Milan Project, Bradford	Community-led project for South Asian women
Equity Partnership, Bradford	Health needs of lesbian, gay and bisexual communities
Little Angels, Blackburn & Darwen	Social enterprise delivering breastfeeding peer support
CHILL project, Leeds	Community health project involving volunteers in a women's organisation.
Natural England	Co-ordination of Walking for Health schemes
Volunteering England	National organisation with a programme of activity around volunteers in health and social care
Sandwell Community Health Network	Community health workers working directly with black and minority ethnic communities.
Altogether Better Programme, Yorkshire & Humber	A Big Lottery funded programme of 16 projects, including Community Health Educators, mental first aiders and community health champions
Wye Wood Project, Hertfordshire	Project encourages participation in rural activities and walking to promote mental health, and reduce social isolation. Volunteers run various activities.

The site visits enabled the research team to understand some of the issues within practice and to start to select case studies. Some of the site visits illustrated the difficulties of categorising lay health worker roles. For example, the Sandwell Community Health Network was a well established scheme that involved community health workers recruited from local minority ethnic communities to undertake health promotion activity and community mobilisation. The community health workers were not health professionals but carried out a professional role and were PCT employees.

The Wye Wood project was an environmental woodland project that involved volunteers in delivery of environmental and physical activity sessions (Howie *et al.*, 2007). A number of different activities were run across several population groups including parents and children, older

people and young people. Of particular interest was the involvement of individuals that were experiencing social exclusion or had mental health needs. Referring organisations included a range of health and social services. Volunteers, some of whom had experienced ill health and/or social problems themselves, worked with individuals doing coppicing and other woodland activities. Although the project activities were environmental, the primary focus was on mental and social benefits and it was of interest that the project demonstrated a very inclusive approach to volunteer involvement and management of risk.

As part of the liaison with practice, there were strong links made with the Altogether Better programme (Altogether Better Regional Programme Team, 2009). This is a large Big Lottery funded programme in the Yorkshire and Humber Region with sixteen projects working on obesity, physical activity and mental health. All projects use a community health champion model based on empowerment of communities through capacity building, training and challenging services. The contact with Altogether Better gave the research team the opportunity to observe the development of large scale programme that was attempting to 'industrialise' the use of community health champions.

9.3 Summary

Information from the Register and engagement with those working in field indicated that current practice is diverse. Lay people were involved in delivering public health activity across a range of health issues, including nutrition, sexual health, mental health and physical activity. The team were unable to identify any projects with a primary focus on tobacco or alcohol through the Register, except within generic health and wellbeing programmes. In terms of service models, lay roles were supported through NHS and voluntary sector organisations. A notable difference was that some projects used volunteers, while others paid their lay workers. The evidence from practice again highlighted the challenges of categorisation and the difficulty in drawing clear boundaries around this type of engagement.

10 Discussion phase 1 – scoping study

Phase 1 of the study attempted to map available evidence across a diverse field of practice and involved a critical review of service delivery and organisational issues. Some of the themes identified in this scoping study were subsequently explored in more depth in Phase 2. In undertaking the scoping study, there were a number of challenges identified in relation to the boundaries of the review and the divergence between published evidence and patterns of UK practice. This section provides a discussion of the results, noting key themes and the existence of research gaps. It starts with a discussion of the limitations of the review, both methodological and practical.

10.1 Limitations of scoping study

Literature review

The literature review mapped and reviewed a large body of published evidence, greater than had been anticipated in the original proposal. Exclusion and inclusion criteria were successfully developed but categorisation of papers was difficult due to the complex nature of the study topic and the extensive range of terms used. This situation meant that an iterative process of selection was adopted with reference to the study objectives to produce the final group of studies included in the review. Unlike a systematic review process, the scoping review involved an inductive approach, building the analysis of roles as papers were reviewed. This enabled new evidence to be included in the review as relevant service delivery and organisational issues were uncovered but may have resulted in some researcher bias in terms of selection of publications. In order to minimise bias, details of the included studies were made available in an electronic searchable database through the study website.

A large number of borderline papers were excluded, many were in areas of work that are of fundamental importance to public health, such as parenting support. While it was assumed that lay worker models and organisational issues were likely to be similar in other areas of health and social care, this literature may have additional information of value to public health practice. Further research would be needed to provide an overview of service delivery and organisational issues across the full range of public health programmes. Moreover the scoping review was only able to include a fraction of the extensive literature on volunteering, as this literature appears to be largely separate from the public health evidence base.

A further limitation of the literature review is that community-led projects, which operate with a degree of autonomy from public services, are likely to be underrepresented in published literature because of limited research capacity in communities. It is interesting to note that many papers described intervention studies run by academic institutions. This may limit transferability of findings. Publication bias will result in an emphasis on papers dealing with successful projects and vital issues on long term support and sustainability may be underreported.

The literature review drew on an extensive North American literature on lay health workers. Notwithstanding the potential for learning from established programmes, this literature may have limited transferability to the UK health system. Many of the US lay health advisor programmes were working with underserved populations, in the context of a healthcare system markedly different from the UK welfare state. Additionally, the cultural and social context within African-American and Hispanic-Latino communities is likely to differ from new and established migrant communities in the UK. In the original protocol, we intended to include studies from developing countries where publications discussed relevant process issues. The scale of the eventual review meant that studies from developing countries were largely excluded, except where the subject of the paper was considered directly transferable to the UK context. Some studies may have been missed that present useful data, however, it is unlikely that these would have changed the overall results of the literature review. The narrative review of service delivery and organisational issues, presented in section 6, illustrates emerging themes from breastfeeding and sexual health programmes, prominent in UK literature. There is scope for further research reviewing the effectiveness of recruitment and training methods across the full range of public health programmes.

Evidence from public health practice

Evidence was drawn from public health practice, primarily through the expert hearings, but also through site visits and the Register of Interest. The expert hearings were based on innovative deliberative methodology in order to create dialogue on matters of relevance. The sample only involved a small number of experts but individuals were drawn from different sectors and types of programme. The expert views, however, cannot be seen as representative of current public health practice, indeed many individuals could be described as public health leaders and innovators.   This limits generalisability, but ultimately is balanced by the value of using deliberative methods, which allowed evidence to be tested and debated in a public forum, thereby strengthening the rigour of the results. The use of experts, drawn from across the country, enabled the main service delivery and organisational issues faced in public health practice to be scoped and therefore the findings have high policy relevance. It is unlikely that there

are major issues unidentified, although involving a wider range of experts may have produced additional perspectives.

The decision to base the hearings in Leeds was taken in order to facilitate genuine public involvement in the hearings and some lay representation was achieved. While this aspect was successful, there may have been a geographical bias in terms of dissemination of the invitation, and access to the hearings. There was a similar bias in the Register as local and regional networks were accessed. There is no indication that geography is an influencing factor, nonetheless there may be some limitations to the results.

Liaison with practice through the Register and website was in fact very useful but despite using multiple dissemination routes, only a small number of projects registered. The registered projects may be atypical of current public health practice. Liaison with practice through events such as the UKPHA indicates that this is not likely to be the case and many projects are based around generic health promotion, physical activity or obesity/nutrition as the Register indicated. A survey design would have provided a more comprehensive view of the programmes and activities within current practice but would not have been able to meet the additional objectives of the scoping study.

Triangulation of evidence

Overall as a scoping study, we are confident that the review uncovered major service delivery and organisational issues, and moreover some triangulation was achieved in relation to certain issues (Table 17). Other aspects did not triangulate well. The expert hearings, for example, were dominated by discussion of organisational issues, but these were not identified in the Register and were included in only a proportion of primary research reviewed for the literature review.

In an attempt to synthesise and critically analyse conceptually broad areas of practice, some published research and current projects were excluded that may have provided relevant data. Stringent criteria were applied to the literature review in order to systematically map the literature, but more inclusive methods were used to gather evidence from practice. The Register, in particular, was open for practitioners to define their projects and hence included a number that were not deemed directly relevant to the study aims. The original proposal was for the expert hearings to test emerging models identified through the literature review. As the study evolved, it was considered more important that experts were able to select the evidence that they deemed significant, rather than the research team imposing themes.

The lack of a common terminology presented difficulties for the scoping study and this remains a major challenge for any research attempting to synthesise, appraise or compare interventions and programmes using lay workers and volunteers. Overall the triangulation of methods and sources did meet research objectives and common themes emerged, but at the same time, there were aspects where results were not matched and therefore there are limitations in terms of synthesis of results. Some of these areas were the subject of investigation in Phase 2.

Table 17.   Triangulation of sources – scoping study

	Literature review	Expert hearings	Register & site visits
Terminology	Over 70 descriptors found. Very few definitions provided.	No evidence of a unifying terminology in practice.	Multiple terms used for roles.
Models	Five models identified with application to different health issues. Most UK research on peer education and peer support.	Models were not discussed although some programmes were based on specific approaches.	Evidence of a range of models in existence.
Roles	Broad range of activities and roles reported. Simple and complex dimensions of difference identified.	Expert evidence reflected diversity in current practice in terms of types of involvement, approaches and delivery methods.	Brief description of primary roles and health focus of projects.
Rationale for lay involvement	Main justifications advanced.	A strong rationale for use of lay workers was advanced from both lay and professional perspectives.	No data collected
Recruitment & retention	Some evidence on recruitment approaches but limited discussion on challenges and effectiveness of methods. Some limited evidence of poor retention in specific programmes but may be underreported.	Evidence on barriers to recruitment and effective approaches. Challenges for retention reported.	No data collected
Training	Evidence of diverse approaches to training and variations in intensity and content. Minimal data on education level and on impact of training.	Evidence on successful approaches to training.	All projects on Register involved some training.
Support & sustainability	Some discussion of support needs.	Extensive discussion of support requirements both at project and strategic level.	No data collected
Payment	Some evidence of different models of remuneration and impact.	Contrasting approaches discussed.	Evidence of volunteer-based projects and projects using paid lay workers.
Professional involvement	Limited research on professional roles or organisational support. Most from breastfeeding literature.	Some evidence on professional roles and organisational support.	Different organisations involved, from voluntary sector, local government and NHS.

Other organisational issues	No evidence on commissioning. Some discussion of evaluation and monitoring.	Some evidence on commissioning. Other policy and organisational issues raised. Discussion on evaluation and 'patchy evidence'.	No data collected
Lay worker views	Limited data, mostly commentary or from professional interviews.	A number of community activists gave evidence.	Some data from public involvement work and site visits.
Service user views	Very limited data from users on their experience of lay workers.	Not explored in depth.	No data collected

10.2   Critical analysis of models

The extent to which there were different descriptors for lay roles was surprising and the plethora of terms clearly presents challenges for the development of an evidence base. 'Lay', 'community' 'volunteer' and 'peer' are core concepts denoting some form of lay status but these are not interchangeable terms, as interpretations vary and meanings highlight different qualities and characteristics in different contexts. For example, peer status may be based on one or more matched characteristics, ranging from generic population categories such as age, through to more sophisticated concepts, such as experience of successful breastfeeding. In the expert hearings, some experts presented evidence on lay people defined as non-health professionals, further extending the definition. Some terms in practice, such as outreach worker, are ambiguous as they can apply to both employed staff and volunteer workers.

There are a small number of relatively well defined terms that were identified through the literature, examples being Lay Health Advisors (LHAs), Community Health Workers, Community Health Educators (CHEs) and Popular Opinion Leaders (POLs), but with the exception of CHEs, there was little evidence that these terms were used routinely in the UK practice. LHAs are a distinctive and well established model in North America, but even there the literature points to variation in role title, programme design and also in the fidelity of programmes to the ideal model (Bishop *et al.*, 2002; Eng and Young, 1992; Jackson and Parks, 1997).

Critical analysis of the literature resulted in five types or models of lay roles (Table 18). These models were grouped on the basis of the lay role in terms of the primary nature of activity undertaken with the target population. Even in the literature, it was evident that the distinctions between these models were blurred. Elements of peer education, peer support, bridging and community organising as *methods* were in evidence in many programmes and there were also hybrid models such as CHEs. We suggest

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therefore that these models are used to describe and categorise the dominant role of the lay worker within the public health intervention. The five models do not describe categories of workforce, or indeed skill levels, in contrast to other categorisations, such as the Public Health Skills and Career Framework (Public Health Resource Unit and Skills for Health, 2008)

Table 18. Types of lay worker roles in public health

Model	Description of primary role
Peer education	The primary role is the communication of health information between peers to effect behaviour change. Peer education roles form the basis of a range of interventions focused on health issues, including sexual health, health inequalities, drugs misuse, smoking, nutrition, physical activity, and also with a range of target groups. Peer education also seen as a method in other models.
Peer support	Where support is provided by peers to promote health and also protect against different stressors. Evidence of use in relation to promotion of breastfeeding, smoking cessation and prisoner health.
Popular Opinion Leaders	A theoretically- driven model based on Diffusion of Innovations theory. It involves the identification of popular individuals in social networks who act as role models endorsing certain health behaviours. Mostly used in the field of sexual health, but its transferability to UK context has been questioned.
Bridging roles	Involves lay workers acting as bridges between communities and health services, particularly where those communities experience health and social inequalities. Individuals are selected on their knowledge of social networks and their ability to translate health messages for community members. Strong evidence from US where lay health advisors are an established model. A range of activities may be undertaken including advocacy, communication, outreach, cultural mediation and interpretation, and in some cases provision of direct care, such as immunisations.
Community organising	The community organising model involves lay workers mobilising community resources and building community capacity to address health issues. This approach is linked to community development principles but not necessarily reliant on existing social networks.

The extent to which these models reflected the realities in UK public health practice was investigated further in Phase 2. Evidence from the expert hearings and other practice-based sources indicated there are a range of types of lay health worker programmes, with lay people carrying out diverse public health activities across different health issues. Some programmes outside of the scope of the study, such as Health Trainers and Expert Patient Programme, were also based on similar roles. Further research would be needed to provide an overview of service delivery and organisational issues across the full range of public health programmes. Most UK studies related to peer based approaches, focused predominately on breastfeeding peer support and peer interventions around sexual health. By and large the mapping results for the literature review were not well matched with current public health activity. One notable research gap was the lack of papers on lay workers with physical activity programmes, contrasted to the numbers of public health projects with a physical activity focus, including the national volunteer-led Walking for Health programme (Natural England, 2009). A further question arose over the evidence base for the community organising model. This model has evident links with community development approaches which are well established in UK health promotion (Adams and Cumming, 2002). The precise nature of community organising roles will be context specific and therefore the evidence base for these roles may be hidden within a broader literature or simply underreported because of publication bias to academic-led studies.

10.2.1 Defining roles

The five models offer a way of categorising the primary role of the lay person, however, there were a number of other ways in which variation in roles can be defined and categorised. Some of these dimensions, such as payment and health focus, were identified in the development of the data extraction protocol, while others emerged through the review process. The conclusion is that any understanding of lay worker roles needs to take account of the complexity and the potential variations that can occur between programmes and even over time within programmes. These dimensions of difference may be explicit features of particular models or programmes, such as the matched characteristics of peers or use of volunteers, or may be implicit and therefore more difficult to disentangle from the social context, such as the relative autonomy of lay workers vis-à-vis professional control.

From evidence gathered across the scoping study, it was clear that some dimensions were particularly significant in terms of defining roles. The literature review highlighted the significance of the relationship between lay workers and recipient communities in terms of aspects such as recognition within a community, extent of community ownership, and knowledge of existing social networks. Some of these themes were also reflected in the expert hearings. There were a number of examples given where community

mobilisation had occurred or where networks were reported to be strengthened, even where the primary purpose of the intervention was not community organising. Another significant dimension was the difference between a focus on personal development or delivery highlighted by (Shiner, 1999).

In contrast other dimensions allowed programmes to be adequately described but were not necessarily defining features of lay worker roles. For example, it was possible for bridging models to share a common approach but be adapted with a range of different target communities. One notable example was the question of remuneration. It was evident across all sources that both payment and non-payment (volunteer) models were used, as well as other approaches to remuneration. There was no evidence that the absence of payment was associated with any particular type of model. The expert hearings indeed aired some of the contrasting views on remuneration. This finding, that use of payment cannot be used to distinguish between different roles and approaches, is somewhat at odds with the very clear definition of volunteering within the UK (The Commission for the Compact, 2005).

The relationship between lay worker and professional appears to be a crucial dimension and is highlighted in some of the key discussion papers (Dennis, 2003; Eng *et al.*, 1997; Kennedy *et al.*, 2008b) as well as being a major topic of debate at the expert hearings. Eng *et al.*'s (1997) notion of a continuum from natural helpers through to para-professionals integrated into a health service is useful. Many of the studies reviewed and examples in public health practice can be placed on that continuum, with some lay workers trained and able to work independently and some working routinely alongside professionals.

Overall it is evident that defining the concept of lay and lay roles is complex and a number of dimensions are involved in distinguishing different approaches. This has implications for the development of an evidence base. The findings point to the importance of public health programmes and research studies being as clear as possible about the features of roles in order to aid learning across projects. It is unrealistic for projects to have complex descriptions of the relationships between both lay worker and target community and also lay worker and professional, although this was an important element of the enquiry in Phase 2. The diversity of terms is unhelpful and therefore it is proposed that a simple typology is used to broadly define lay status within a project (Table 19). Lay workers or volunteers may, of course, move from non-professional helpers to embedded community leaders, or even through to professional roles over the course of a programme.

Table 19. A typology of lay status

Type of lay status	Features of role
Non-professional	This is a lay role defined by absence of professional qualifications in the context of the intervention. Typically this might be a volunteer role or working alongside health professionals, with a focus on delivery of a service or intervention.
Peer	This is a lay role based on peer supporters or peer educators having matched attributes. The nature of peer status should be explicit as this is basis for the intervention. Peer status can be based on individual attributes (age, gender, ethnicity, neighbourhood) as well as types of experience and knowledge.
Embedded	This is where the lay role involves working embedded within a defined community, more often with a focus on development not delivery. The lay worker, either paid or unpaid, is recognised (and possibly selected) by a community, works within social networks and would be expected to have some degree of cultural competence. Individuals are likely to share peer attributes but may be also be community leaders. This is the basis of POL models as well as community organising. The term 'community health champion', recently appearing in UK public health practice, may be useful here[11] .

10.3 Rationale for a lay workforce

Justifications for a lay workforce identified through the expert hearings correlated well with the justifications advanced through discussion papers in the literature review (Table 20). There was a strong rationale based on lay workers/volunteers reaching disadvantaged populations. Furthermore, the potential for lay workers to act in a bridging role, whatever the main thrust of the intervention, is seen as valuable where inequalities exist and where groups experience barriers to access services or health information. It can be noted that where peer approaches were adopted, these were more often used with less advantaged groups.

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[11] see Altogether Better Regional Programme Team (2009)

Table 20. Justifications for a lay workforce

Main justifications - literature review	Main justifications – expert hearings
1. The ability of lay workers to reach and communicate with groups not in touch with traditional services. In particular where they work in their own communities and social networks.	1. Lay people are committed to their communities and want to get involved.
2. Mobilisation of community resources. Community capacity to address health needs is built but also service change is sought.	2. Local knowledge is invaluable and can enhance and complement professional knowledge.
3. Support mechanisms. Peer roles can provide emotional, information and appraisal support and lead to positive outcomes such as reduced social isolation.	3. Lay people have the potential to reach some communities that professionals cannot, including those groups deemed hard-to-reach.
4. Benefits to lay workers. Outcomes reported include: raised self esteem and self efficacy, improved confidence, personal development, employment.	4. Lay people are trusted in their communities and can deliver health messages and support in a culturally appropriate way. Therefore lay workers can bridge the gap between services and communities.
5. Economic benefits to organisations in terms of capacity.	5. Lay people can gain directly from involvement in terms of increased confidence and self–esteem, self fulfilment, better social contact, and improved or new skills.
	6. Involving lay people can lead to positive health outcomes including healthy lifestyles, increased social capital, and increased employability.
	7. It can make good financial sense to use the skills and resources in communities.

Notwithstanding strong evidence of the utility of these approaches within different contexts it would be inappropriate for the scoping study to draw conclusions about the effectiveness of such approaches. There is a research gap in UK literature around the bridging model, although there was some evidence that bridging could take place within peer based approaches. The rationales advanced in both the literature and the expert hearings have evident links with UK policy agenda around community engagement to address health inequalities (Department of Health, 2003).

10.4 Development and support issues

10.4.1 Recruitment and retention

A key theme in both literature review and expert hearings was the importance of inclusive recruitment processes that are based on an acceptance of the validity and value of lay and experiential knowledge. Recruitment criteria based on local knowledge, empathy and commitment were to be preferred to formal qualifications or school based knowledge. A range of recruitment methods were reported, including publicity materials, word-of-mouth and identification by professionals, however, expert evidence suggested that personal contact and use of community networks was likely to be the most effective approach. Lay perspectives reported in the literature indicated that motivations for getting involved were often altruistic but barriers to involvement included fear of stigma, lack of cultural competence of host organisations, and need for financial incentives.

The importance of recruiting within target communities was a theme reflected in the different sources of evidence. There were, however, some challenges identified in terms of managing the tension between the aspiration to involve lay workers from disadvantaged groups in addressing health inequalities, and the additional barriers that these groups faced in terms of engaging with bureaucratic procedures and accessing formal training. Recruiting individuals from groups that are seldom heard was seen as both critical yet challenging and it was reported that some programmes have faced difficulties in recruiting men and younger people. This finding is supported by other research on volunteering patterns (Low *et al.*, 2008; Niyazi and National Centre of Volunteering, 1996; The Commission on the Future of Volunteering, 2008). There was some useful discussion in both the literature and the expert hearings about the gap between aspiration and reality in relation to recruitment.

Retention of lay workers was identified as an issue. There was limited evidence about factors affecting retention, from published literature and expert evidence. Reasons for poor retention included lack of remuneration in the context of financial hardship, changing circumstances, including moves into employment, lack of time due to personal commitments, and inadequate support of volunteers. Overall the scoping study findings indicate that successful recruitment strategies need to be community orientated, but have to address pragmatic concerns in order to involve and retain target groups. Further research is indicated on effective recruitment methods as barriers and attrition is likely to be underreported.

10.4.2 Training and development

Predictably training was found to be a routine feature of public health programmes involving lay people, but there was a huge variation in terms of training philosophy, content, and duration. There is some evidence of the use of standardised training packages, such as Speakeasy (Coleman *et al.*, 2007), which are well established and have been evaluated in some cases. The literature review identified a distinction between training approaches that focused on providing information on the health issue and those focused on the development of personal, social and communication skills. This is an important dimension as it relates to the eventual outcomes from a given programme and can be seen to link with an emphasis on development or delivery. There was some triangulation between different sources highlighting the value of training focused on personal development rather than preparation for delivery. There were many examples reported of training using interactive discussions, practical exercises, and creative methods, and some courses were explicitly based on a pedagogy valuing experiential knowledge. In contrast there was a reported risk that formal training and accreditation can result in inappropriate professionalisation of lay workers.

While expert evidence reported many successes around training, there was, however, little published research on the effectiveness of training. A key theme in the hearings was the link between recruitment strategies and the use of training approaches that are inclusive and flexible enough for people traditionally excluded from the education system to access. There was potential for lay workers to move through to adult education, gradually developing a range of life and employment skills. This can be seen to link to current policy on broadening the public health workforce (Department of Health, 2008a, Department of Health, Undated).

10.4.3 Management, support and sustainability

The need for adequate support for lay workers/volunteers, and the challenges of achieving sustainability were dominant themes from the expert hearings. A good support infrastructure was required, as inadequate management and supervision had been a problem in some programmes. It was considered important that professional practitioners offered personal support in preparing lay workers for roles, and in sustaining that support over time. The limited literature on professional support indicated that support, supervision and management were likely to produce more positive outcomes within programmes. These findings are confirmed in other research around volunteering support (Gaskin, 2003). A further issue is that the economy of utilising volunteer support may need to be balanced by the costs of professional time in development and support; it was not always a cheap option. Table 21 provides some examples of the range of support that lay workers may find beneficial, identified through the literature review. The

first column focuses on aspects that might aid the delivery the intervention, the second on support to enable development of the worker.

Table 21.　　Support required by lay workers/volunteers

Support for delivery	Support for development
Help set up groups / make contacts	Access to a supportive contact/ mentor/ co-workers
Make referrals	Regular contact with supervisor
Promote intervention	Effective communication
Supply facilities	Encouragement
Transportation	Help with problem-solving
Resources	Opportunities for ongoing training

There was evidence from both published and expert evidence that boundary issues can arise between health professionals and lay workers. More research on professional attitudes is indicated as there were some suggestions that professional resistance and lack of support could be a barrier to the development of programmes. Conversely there were examples given in the expert hearings where volunteers were regarded as co-workers, of equal worth to paid community workers and health professionals, but with distinctive roles.

Payment and expenses are a specific form of support. As indicated above, there was evidence that different choices were made around remuneration including volunteer-only schemes, compensation and incentives, and sessional payments. Some limited evidence from the literature suggested that use of payments and incentives may support recruitment and retention. Expert evidence raised a specific issue of the importance of providing appropriate rewards but at same time highlighting a need for clarification about the impact of any remuneration on benefits. Overall the scoping review found that financial reward was a contested issue where different options could be justified dependent on the context. This aspect was investigated further in Phase 2.

The expert hearings raised a number of pertinent issues about the organisational and policy context for this field of practice, this may be due to the selection of experts and the orientation of some of the discussions. These wider issues were not generally reflected in the literature where there was a dearth of discussion on commissioning and organisational support. Expert evidence indicated an absence of infrastructure to support lay people in public sector, with the result that programmes were not mainstreamed and were often reliant on committed individuals. The frustrations of short

term funding were reported to impact on sustainability but at the same time small grants were regarded as an important mechanism to promote lay involvement. There were clear conflicts between the constraints on lay involvement and current public policy.

Organisational culture in the public sector, but particularly in the NHS, was reported to be generally antithetical to approaches involving lay workers. Evidence from practice, including the Register, indicate that public health programmes involving lay workers are based both in the statutory and non-statutory sectors, and can involve a range of organisations from charities, and social enterprises though to health services and local authorities. It was argued that there may be benefits in service delivery outside the NHS in terms of independence and support. In summary the expert hearings revealed a number of issues about support both within and outside the health system.

10.4.4 Other issues

The scoping study identified a small number of additional service delivery and organisational issues that were not included in the original proposal. The issue of the management of risk was highlighted both in the literature review and the expert hearings. As the theme of risk was identified through the scoping study, it was included later as an area for investigation in the case studies.

A number of additional themes emerged from the expert hearings around public involvement. There were seen to be strong links between lay involvement in delivery and patient and public involvement in planning and decision making (PPI). There were examples where lay people had been involved in developing as well as delivering programmes and additionally where lay workers moved on to involvement in planning and decision making structures. There was a consensus that the NHS needed to become better at sharing power with communities and effective leadership at all levels was recommended.

10.5 Summary

The scoping study brought together scientific evidence from published literature, expert evidence and evidence from current practice. This enabled a comprehensive picture to be built up regarding approaches to develop and support lay people in public health. There was a strong rationale advanced for involving lay people, one which fits with the UK policy imperative to address health inequalities and engage communities in health. Five models

denoting the primary role of the lay worker were identified and a number of dimensions that distinguish lay worker roles and programmes.

Major service development, delivery and organisational issues were reviewed, drawing on different sources of evidence. Findings indicate that recruitment, training and retention strategies are required to address barriers to involving lay workers, particularly when individuals are drawn from disadvantaged communities. Processes based on participatory methods and adopting an inclusive stance appeared to be the most effective way of addressing what are considered essential support and development needs. Many of the themes around organisation and support merit further investigation to examine the role of professionals and the effectiveness of training and recruitment methods. Issues and questions raised in the course of scoping study were fed into Phase 2 where further investigation of development and support processes was undertaken.

11 Case studies - methods

Phase 2 of the study involved qualitative research in order to investigate the development and support of lay people within public health practice. Findings from the scoping study (Phase 1) identified a number of salient issues that could potentially affect the establishment and sustainability of programmes and these were investigated in more depth in this phase of the study. Five case studies of local public health programmes were undertaken with the aim of understanding the perspectives of a range of stakeholder groups, both professional and lay. This section introduces the case study design and methods. The results are reported in sections 12-14.

11.1 Case study design and methods

A multiple case study design was used with different public health programmes as the cases. The design used qualitative methodology in order to gain in-depth understanding of roles and relationships within social contexts and to retain flexibility to pursue lines of investigation (Mason, 1996; Patton, 2002). Case studies examine phenomena, in this instance lay roles in public health, within real-life contexts. Yin (2009) argues that they are an appropriate design for an inquiry where the boundaries between the phenomenon and context are not clearly understood and where there are many variables of interest. Each case study attempted to gain a holistic view of how approaches worked in practice through exploring the perspectives of different stakeholders. The research team were able to investigate both the development of programmes and individual journeys using this design. The focus was on understanding how service delivery and organisational issues constrained or facilitated lay engagement and programme sustainability. Relationships between social actors were seen as core to understanding these types of roles and matters identified in Phase 1, such as role boundaries and payment, were investigated.

The research methods were interview-based to allow study participants to relate their experiences and views. Individual and paired semi structured interviews were conducted. Focus groups were also used for the service user interviews where established groups were in existence. The aim was to collect rich data from different stakeholders, across the spectrum of roles from commissioner through to service user. It was important to explore the social dynamics of support mechanisms, and to gather views on the value, acceptability and appropriateness of lay roles. The scope of the interviews was informed by the results of Phase 1 and covered topics such as project development, lay and professional roles, recruitment, training, support issues, perceived value of lay engagement and boundaries of practice.

Interview schedules were developed for each of the major stakeholder groups based on a series of core questions (Appendices 11-14). The interview schedules were used across all the case studies, although the schedules were sufficiently flexible to allow for adaptation. The interviews with service users covered a smaller range of topics and focused primarily on perceptions of roles and views on the acceptability of lay workers (Appendix 14).

11.2 Case study sites

The sampling strategy had two elements; the selection of case study sites and the construction of a sample within the cases. Phase 1 led to the identification of common models and role variations. The selection of cases was therefore designed to illuminate the different models found in practice and to cover diverse target populations, in line with the study objectives. It was anticipated that around six small scale public health programmes or projects would be chosen across England.

The primary selection criteria were public health programmes that demonstrated the types of lay role found in the literature review: peer education, peer support, bridging and community organising. The Popular Opinion Leader model was excluded as this is a very specific, theoretically-driven intervention which was not found to be effective in the UK context (Elford *et al.*, 2004; Hart *et al.*, 2004) and therefore there were unlikely to be examples in current practice. Given the significance of professional support (Britten *et al.*, 2006; Eng *et al.*, 1997; Jackson and Parks, 1997), two case studies were selected on the basis of the extent of professional involvement; one to illustrate a relatively independent approach and the other to reflect greater service involvement. A secondary consideration was to ensure that where possible case studies reflected a spread across public health priorities and target groups, bearing in mind that breastfeeding and sexual health interventions predominated published literature from the UK.

Potential case studies were then identified primarily from the Register of Interest, but also through the expert hearings and liaison with practice (section 9). Members of the research team visited a number of potential programmes/projects to find out if their structure and activities matched the selection criteria. Five public health programmes were eventually selected as case studies and all agreed to participate in principle (Table 22). The term '**public health programme**' is used here to describe the development, delivery and organisation of public health activity. It is used in preference to 'project' as some of the programmes included separate projects or were linked to services. Three of the case studies were based in Yorkshire and Humber region, one in North West England and one in South East England.

Table 22. **Case study sites**

Case study	Model	Target group	Public health focus	Lead agency (delivery)[12]
Sexual health outreach	Peer education	Men who have sex with men	Sexual health (uptake of screening)	Voluntary sector
Walking for Health (local scheme)	Peer support (independent)	All population groups Involves BME groups	Physical activity	NHS
Breastfeeding peer support	Peer support (service-linked)	Parents Involves BME groups	Nutrition (breastfeeding)	Third sector
Community Health Educators	Bridging	All population groups	Nutrition Physical activity	Voluntary sector
Neighbourhood health project	Community organising	All population groups Urban setting	Health and wellbeing	Local authority

11.3 Sampling strategy

Following the selection of cases, a sample was constructed within each case to encompass different roles and responsibilities. The basis for selection was individuals' current or past involvement in the case study programme and this included public health commissioners, managers, practitioners, health professionals, lay workers, representatives from partner organisations, and service users receiving support through the programmes. The priority for sampling was to gather sufficient data to produce explanations about processes within each case study and to ensure lay perspectives were included. The number and composition of the sample varied between case studies because of the differences in programme activities. Across the study there was an overall target to interview a minimum of 30 lay people with public health roles (lay workers and volunteers) and 40 service users.

Initial meetings were held with local managers or lead practitioners in each of the case study sites and a list of potential participants was drawn up. The research team then selected a sample across the different stakeholder groups. Following the initial sampling, further participants were identified through snowball sampling as individuals were suggested by other study participants. Often these

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[12] All programmes had some or all activities commissioned through the NHS

individuals were regarded as critical cases, illuminating specific perspectives (Patton, 2002).

11.4 Recruitment and access

Recruitment took place through the case study sites, with the assistance of local managers (see Appendix 15 for the recruitment flow chart). In all of the sites, the research team were given an opportunity to explain the research and the decision to participate as a case study was made through the normal governance mechanisms. After the initial sample was drawn up, local managers then distributed an information leaflet and a letter of invitation to potential participants. Contact details were withheld from the research team at this stage. While there was potential for these key informants to act as gatekeepers, choosing participants who would perhaps present more positive views, the research team were careful to explain the non-evaluative nature of the study and the importance of gaining different perspectives. Potential participants were able to contact the local project if they did not want any further contact with the University. The research team then followed up the letter by phone, by email or through visits, to ascertain if individuals were willing to take part and to arrange an interview. At the point of the interview, participants were given a further opportunity to ask questions about the study and written consent was obtained. Participants were made aware that they could decide to pass over any questions or withdraw from the study at any time. Participants who were unwaged or volunteers were offered a shopping voucher following the completion of the interview to acknowledge their contribution of time.

11.5 Data collection

A small team of researchers conducted the interviews and focus groups from March to July 2009. Almost all interviews were conducted face-to-face in programme settings or in other local organisations. Three interviews were conducted by telephone; these were all with individuals with strategic roles. Interviews with service users were conducted in three of the case studies: breastfeeding peer support, Walking for Health and the neighbourhood health project. In most cases recruitment took place through the group activities taking place in the programmes. It was not possible to recruit service users for interview in the other case studies primarily because of the nature of the activities undertaken, where only brief interactions were taking place. In total, 136 people participated in the primary research. Tables 23 and 24 give the breakdown of interviews and participants within case study sites. All interviews were audio recorded on digital recorders, with permission, and transcribed verbatim.

Table 23.   Case study interviews – number of respondents

Case study (number of interviews)	Lay workers/ volunteers	Practitioners	Commissioners/ strategic leads	Other stakeholders	TOTAL Respondents
Sexual health outreach (12)	3	6	1	2	12
Walking for health (19)	10	10	1	2	23
Breastfeeding peer support (20)	9	5	2	4	20
Community Health Educators (15)	9	10	2	0	21
Neighbourhood health (14)	6	4	4	0	14
TOTAL	37	35	10	8	90

Table 24.   Service user interviews – number of respondents

Case study	Number of interviews	Total number interviewed
Neighbourhood health project	Paired Interview (1) Focus groups (2)	15
Breastfeeding peer support	Individual interview (1) Focus groups (1)	11
Walking for health	Paired Interview (3) Focus groups (4)	20
TOTAL	12	46

The research team spent time in each of the case study sites. They were able to observe first hand the delivery of public health activities, and how lay people worked and interacted with service users. For example, researchers attended breastfeeding groups, took part in health walks and accompanied the outreach service to bars. Many informal conversations were held with professionals and lay people. While these conversations were

not treated as part of the formal data collection, researchers took reflexive notes and their observations were helpful in understanding the social context of each case study. The informal meetings also helped with recruitment and allowed more naturalistic data collection to take place in the different settings, as is appropriate with qualitative research, for example, conducting interviews after group activities.

11.6 Data analysis

Thematic content analysis was used to code, organise and summarise the data (Mason, 1996). Case study analysis presents particular challenges, as there is a need both to describe and understand the individual cases and to build explanations across multiple case studies (Bergen and While, 2000; Yin, 2009). An inductive approach was taken to data analysis and the process was in four stages (Table 25). The NVIVO software package was used to assist in the management of that process due to the volume of data.

In the first stage, themes were identified through the data, and then mapped onto a loose framework developed from the study objectives (Huberman and Miles, 1998). This framework was then expanded and refined as analysis continued, until there was a good fit with the whole data set. Explanations were built within case through the production of individual case study reports for each of the case studies (Yin, 2009). These reports organised and displayed the data as a conceptually ordered display (Miles and Huberman, 1994) across the major thematic categories but also used narrative summaries of project history and networks. The main topics for the case study reports were:

1. Project background (some information also drawn from secondary sources).
2. Project development and current context
3. Project activities and organisation
4. Lay worker roles (including rationale, types of role, boundary issues, progression)
5. Support and organisational issues (such as recruitment, training supervision, commissioning)
6. Other emerging issues
7. Research notes

The final stage of data analysis involved cross case analysis, comparing findings and using an iterative process to build explanations (Yin, 2009). Service user interviews were analysed separately as the emerging themes provided different perspectives.

Table 25.   Data analysis

Stage	Methods
Stage 1- Data organising and indexing	Uploading to NVIVO; transcripts labelled with attributes. Initial coding framework drawn from interview questions, emerging themes and fieldwork notes. All interview transcripts coded; new codes added and framework finalised. Coding of service user interviews.
Stage 2 – Case study reports	Descriptive accounts of each case study using different thematic categories drawn from coding framework. Summary displayed with quotations in a standardised format to allow for later cross case analysis. Also includes a narrative and visual mapping of context, history and project networks.
Stage 3 – Cross case analysis	Using case study reports to identify patterns, differences, similarities with regard to service delivery and organisational issues. Themes mapped onto a matrix. Emerging explanatory accounts with more abstract categorisations.
Stage 4 – Write up	Synthesis of the key points from the case study narratives and cross case thematic analysis. All researchers involved in analysis checking final report.

A major challenge was ensuring the validity and reliability of the thematic analysis as five researchers were involved in data collection. Members of the research team undertook initial analysis of interview transcripts and were involved in construction of the first coding framework and agreed subsequent revisions. In the second stage, the lead researcher for each case study prepared the report, but one researcher worked across all five case study reports to improve reliability. In the final stage, two senior researchers synthesised the findings of the case study reports using an iterative process, returning to the data as necessary to build explanations.

11.7 Ethical issues

This was a qualitative study that was relatively low risk as it did not research sensitive issues nor involve vulnerable groups. Ethical approval was received from Leeds West NHS Research Ethics Committee and Research Governance approval was gained at each of the case study sites. The overall ethical approval process was challenging and led to delays in study implementation. It was difficult to reconcile community practice, mostly taking place outside formal services, with formal ethical requirements. This was a factor in the withdrawal of a proposed sixth case study involving mental health service users participating in environmental activities.

In reporting results, there has been a need to ensure confidentiality and to protect anonymity. Although case study sites were not identified, anonymity could potentially be compromised within the case setting. Confidentiality was also a concern as many study participants were well known in communities and there was an additional risk where negative experiences were reported. In reporting findings and displaying quotations we have removed all identifying details, titles, attributes and references to actual locations and organisations.

12 Case study findings – development and support

Five case studies of public health programmes were conducted. This and the following section present the findings from the interviews with stakeholders involved in programme implementation: lay workers and volunteers, practitioners, managers, strategic leads, commissioners, and representatives from partner organisations. The perspectives of service users accessing three of the case study programmes are reported in section 14. Each case study represented a different aspect of public health activity and reflected different ways to involve lay people, nonetheless cross cutting themes were identified through analysis. This section reports on the results in relation to the development and support of lay people in public health roles and related organisational matters. It starts with a brief descriptive summary of each case to allow themes to be set in context.

12.1 Case study programmes

12.1.1 Sexual health outreach

The sexual health outreach programme was run by a voluntary sector organisation working to address the sexual health of gay and bisexual men. The organisation also offered support and information through a wide variety of groups, counselling services and telephone helplines. Sexual health outreach formed part of a broader programme involving rapid HIV testing, screening for Chlamydia and Gonorrhoea, and Hepatitis A and B vaccinations, all provided in non-clinical settings and targeted at men who have sex with men. Community testing took place in commercial gay scene venues in the city centre, including licensed premises and other events where LGBT (lesbian, gay, bisexual and transsexual) communities socialised. The testing and vaccination service was provided by healthcare workers, who were employed by the organisation, and sessional nursing staff. Volunteers were introduced in order to support the role of the paid workers and sessional nurses. This service had been running for four years and was commissioned through the local primary care trust.

The sexual health outreach programme was selected to provide an example of a peer education model but it was evident that the bridging role was significant, with volunteers providing the 'eyes and ears of the organisation'. Volunteers supported the work carried out by paid staff and took part in the outreach on the gay scene. Their roles included:

- Promoting the screening service on the gay scene
- Recruiting individuals to the screening service and administering urine samples
- Providing service users and potential service users with information about community testing
- Giving out information and answering questions about sexual health, including STI transmission, treatment and prevention
- Helping with condom packing and assisting with administration, such as filling in forms with service users
- Serving drinks and talking to service users before and after testing
- Signposting individuals to other services within the organisation or to other services and groups.

A volunteer co-ordinator was in post and all volunteers received an induction and training for the role. Strict protocols were in place delineating the volunteer role in the programme.

12.1.2 Walking for Health

Walking for Health is a national initiative, co-ordinated through Natural England that promotes volunteer led health walks (Natural England, 2009). The case study examined a local Walking for Health scheme within one primary care trust. The overall programme aimed to encourage people to take up walking, either as part of a group walk or independently. Some of the walks were led by professionals or paid employees, but an important element of the programme was the training of volunteer walk leaders who then went on to lead community walks. This was a relatively large scale programme and a range of walks were available across the district, in both urban and rural areas, and varying in distance and group ability. Walk leaders' responsibilities were to organise walks, sort out routes and carry out a risk assessment, take registers and support walkers. Most walks were open to all, but there were some closed groups, for example, women-only walks. The case study programme had originally received some funding to pilot a scheme. The original remit was increasing physical activity and general health improvement, but recently the emphasis within the primary care trust had shifted to obesity prevention and weight management.

Walk leader training was provided by the primary care trust who initially employed a Walking for Health co-ordinator. Volunteers received a short one-day training giving practical advice on leading walks and running a group, basic first aid and risk assessment. Following organisational changes in 2008, the primary care trust continued to have a commissioning role as part of the obesity prevention work but no longer employed a central co-ordinator. The case study was chosen as an example of the peer support model with minimal professional involvement. There were also some elements of community organising as self sustaining networks were formed.

Three groups were involved in the case study, one involving women from South Asian communities. There was also the opportunity to explore views on rewards as in the past some volunteer walk leaders had received a sessional payment to cover expenses.

12.1.3 Breastfeeding peer support

The breastfeeding peer support programme provided peer support to parents with the aim of promoting breastfeeding, and offering evidence-based information and support in a friendly and approachable manner. The programme originated as a breastfeeding peer support group set up through a local Sure Start Children's Centre in 2002. This community-led group was superseded by the establishment of a social enterprise which sought to employ members of the local community. The programme provided a range of support activities for parents in community and service settings and was jointly commissioned through the primary care trust and local authority. It was chosen as a case study to reflect a peer support model and as an example of a programme linked closely to health services. It also had elements of peer education, bridging, and given its origins, community organising. At the time of the interviews there was a core staff of part-time paid peer supporters who worked between 16 and 25 hours a week, arranged flexibly to fit in with childcare and family commitments. Paid peer support workers roles involved:

- providing information about the benefits of breastfeeding in the antenatal period, on a one-to-one basis, in the home, or at various groups
- visiting the postnatal wards at the local maternity unit to support new mothers
- one-to-one home visits in the days following birth and as required in the postnatal period
- working closely with local Children's Centres and voluntary breastfeeding support groups and referring parents to local support groups.

The main emphasis was on paid peer support workers but volunteers were involved in supporting and facilitating local parentcraft sessions. In addition, the programme provided a 24 hour telephone line that had some volunteer involvement. All peer supporters were required to complete a two day multidisciplinary breastfeeding management course run by the NHS and paid peer support workers also completed a 12 week La Leche League course. Peer support workers were supervised by two team leaders, who were former peer supporters, and an area team leader. There was a training coordinator and a volunteer co-ordinator had been recently appointed.

12.1.4 Community Health Educators

The Community Health Educator programme was established in 2004 and was one of a number of initiatives co-ordinated by a healthy living network, based in the voluntary sector. The programme primarily involved health promotion work for a range of community-based clients and health services. Community Health Educators delivered across different geographic communities, mostly those defined by economic and social disadvantage, and also worked with marginalised communities such as gypsies and travellers, drug users, people with physical or learning disabilities, and newly arrived migrants. Community Health Educators worked in a variety of settings including schools, prisons, residential homes, mosques and community centres. The Community Health Educator role was to deliver or assist in the delivery of sessions, using a non-medical approach to present simple, preventive health messages. The programme was selected because the use of lay health advisors in addressing health inequalities matched the bridging model, however, a peer education approach was also evident. The programme was underpinned by a community development ethos and also reflected some of the community organising model. Many of the activities involved lay workers working with professionals to support and facilitate service users' participation. Examples of activities included:

- delivery of healthy eating messages and training to a wide range of groups
- promoting healthy eating at community events through providing free tasters of fruit
- supporting people in residential homes and sheltered housing to do physical activity, such as chair-based exercises
- facilitating participation in exercise classes
- supporting people receiving immunisations at a community event.

Training and support were provided through the healthy living network. Community Health Educators completed a 14 week training course, accredited by the Open College Network, and were paid for work on a sessional basis. The programme was originally funded through the New Opportunities Fund (NOF) and later commissioned through the primary care trust and the local authority. Since 2007, a regional health programme had used Community Health Educators in two projects focused on healthy eating, increasing physical activity and improving mental health.

12.1.5 Neighbourhood health project

The neighbourhood health project was set up to help improve the health of residents and reduce health inequalities in a large housing estate. It was located in the heart of the estate where it offered residents a friendly and confidential place to talk about their problems, to seek advice, to join one of the organised groups or to access information about other services available

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in the area. The project was set up in 2002 through a New Deal for Communities programme and received funding from that programme. The local authority was also involved in supporting and managing the neighbourhood health project and there were strong links to the primary care trust. The project was a small organisation with a two paid staff and was heavily reliant on volunteers, mainly local residents, to help run and develop health promotion activities. These activities included walking groups, Tai Chi, drop-in sessions and weight management groups, as well as community events and stalls. There was also a community-based smoking cessation group and volunteers acted as peer advisors to provide support to quitters.

The neighbourhood health project was selected to provide an example of a community organising programme as the aim was to build capacity within the community and to empower the community to take control of their own health. The project was closely linked to an independent community committee consisting of a small group of residents who were actively involved with the development of the project. This committee aimed to help local residents to obtain a healthier lifestyle by active promotion of healthy eating and exercise, and the committee had successfully bid for money from the primary care trust to run a social group for isolated people with mobility problems. There was a reciprocal relationship between the neighbourhood health project and the community committee as volunteers from the committee were actively involved in project activities but also received some support from the project. The volunteers' role involved a level of responsibility as they were involved in making democratic decisions and writing bids.

12.2   Motivations

The case studies examined the transition of lay people into public health roles and their subsequent journeys within the programmes. A number of motivations were identified and these were consistent across the case studies. These were: altruism; career pathway; being at the right stage of life; gaining health and social benefits; and experience as a service user. These are discussed in turn.

12.2.1 Altruism

Altruism is the deliberate undertaking of an activity for the benefit of others, a specific group of people or society, and this emerged as the strongest motivating factor. Public health roles were seen as appealing because they offered the opportunity to give back to society without the expectation of material reward. Communities were formed around a number of identities,

particularly geography and sexuality. Community pride and protectiveness were aligned with the public health role.

"*I think it has been one of the successes in [neighbourhood health project] because I think it's a feature of [city] there are actually a collection of little villages and people are quite wedded to their area and often quite fiercely proud of their area. Certainly there's been a real strength for what's gone on in [area] with local people doing it for their area.*" T18

"*I was looking for volunteer work in general and this was something that actually interests me and I wanted to do something useful for the community, even though it sounds a bit cheesy.*" L22

While lay people's altruism was selfless materially, their public health role did provide softer benefits, such as engagement in social activities and improved sense of self-worth. The following quotation not only illustrates an individual who gets enjoyment from a particular activity but also shows a desire to give back to others by getting involved.

"*I wanted to do it because I love (the exercise class). I absolutely – well, you know, I do. I absolutely love it. And because it's helped me so much and I feel that if it's helped me as much as it has, I'd like to pass that on to somebody else. And the only way you can do that is to get involved in a big way. And that's what I decided I wanted to do.*" L25

Additionally, some lay people saw mutual benefit because they were able to develop their skills, which left them better placed to create and respond to opportunities for their own community.

"*Because we've gone back into our community, the community know who we are and they've seen some of the work that we've done, they do come back to us all… 'could you put this on for us?', or 'how do you go about?', or 'can you support us?' … and we're signposting them as well, as we know our area quite well now …*" L2

12.2.2 Career pathway

Public health roles were described by some respondents as part of a trajectory towards part and full-time employment. Taking on a public health role was seen as helping to build confidence and skills, providing training and practice based opportunities that would look good on a CV. The opportunity to volunteer offered college or university students practical

experience to build upon their academic skills but could result in people participating merely for the training without offering anything to the service. Training courses provided networking opportunities through which people could learn about job opportunities in a comfortable environment. As well as developing new skills, participation also validated prior knowledge and experiences.

"It's changed people's lives in terms of health training services … they've gone from thinking they are 'worthless' to being maybe healthier … and then going onto do a degree or into another job (such as) becoming a paramedic." T2

Lay people described themselves as previously lacking the confidence to apply for jobs, including health promotion positions.

"Honestly if I'd seen the advert in the paper and I hadn't been volunteering and I hadn't got involved with health promotion, there's no way I would have applied for the job, it wouldn't even have entered my head." L26

Consequently, the public health role served as a stepping stone into employment for some, albeit that others never considered nor wanted to leap into a career. Retired lay people were much more interested in the altruistic aspects of their involvement. There were also those who still benefited from increased confidence, which enabled them to better engage with their community, as this quotation illustrates.

"It's not just about the community, it's also about that lay person and again the skills that they could learn for career progression whether back into education or back into work or into work if they've never worked before. It gives them that confidence 'well if I can do it as a volunteer, I can do it'." P21

12.2.3 Time is right

Stage of life emerged as a motivating factor. Some lay people, particularly older people or those unable to commit to full-time employment, saw themselves as benefiting from society over the years and were therefore duty bound to give something back. For older people and young people, such as students, the time was right to get involved because of the amount of free time afforded them.

"*Well I'm a student and I have quite a bit of free time and I figured it would be better to do something useful than just sit at home and watch TV and I quite like doing volunteer work. I used to do it in school as well.*" L22

"*...some of them come because they want to be involved in something, they're probably a bit lonely and isolated, other people want to carry on, you know, this is where you get these, particularly women, as you mentioned, who don't work any more, people in retirement, some people want to carry on and they recognise that they've got a contribution to make and that it's probably going to be good for them.*" P32

12.2.4 Health and social benefits

Public health roles were seen as providing health benefits. Many lay people had their own health concerns; there were some with physical disabilities or serious illnesses that meant they were unable to work. Others had specific conditions, such as asthma, and they hoped that improving their health would alleviate associated symptoms. There were examples of lay people who had no explicit health concerns but wanted to start living a healthy life.

"*For me it was a bit of a joke because anywhere where I go my husband drops me off and my husband picks me up...When I got to do it I enjoyed the walking, getting out, fresh air, it was something to do. It was something different and it wasn't so difficult because I used to think if I had to walk from A to B it would be so time consuming and difficult but it wasn't.*" L14

Public health roles were seen as helping to aid recovery, stimulating the mind and giving a focus. Also, the roles gave lay people an opportunity to learn how to live healthier lives and provided opportunities to engage in healthy activities, such as walking. While the health benefits were primarily concerned with the individual, they were also passed onto their families.

"*Then the impact it's had on my family is that my children are now also walking and they enjoy walking whereas you find with a lot of children they don't or they won't. They really struggle to walk anywhere so it's been really positive on them as well.*" P21

In addition to the health benefits, there were social aspects. Some had felt lonely or isolated and found that they made good friendships through their role. Others, such as students and the retired, were just keen to meet new people. A sense of enjoyment and achievement was a motivating factor.

"If you can make one person smile in a day it's worth everything … and we have had a lot of people smiling." L3

Some emphasised, however, that any health and social benefits were secondary. For example, one individual's priority remained meeting the needs of the older people in her community, saying that *"it's not just to do with healthy living … it's to do with voluntary working with older people."* L2

12.2.5 Previous experience as a service user

Practitioners reported that some lay people became involved because of their experience of using a service. For example, in some smoking cessation and weight loss projects, lay people were recruited because they could provide the added legitimacy of having been through the service.

"More often than not our volunteers come from our communities and therefore have that first hand knowledge of what kind of services are needed and that is very much fed into the whole ethos [of the] organisation that we provide and a lot of volunteers at some stage or another have in some shape or form been a service user or certainly the target group." P28

In most of the case studies, the lay people interviewed did not raise this issue and this may be because the programmes selected did not rely on previous experience. For some, a public health role was a means of extending their involvement in delivering services to particular groups of people with whom they worked previously in a voluntary capacity. Those committed to their community talked about specific activities, such as with care networks and other local groups. One lay person, for example, had been running a social group in her locality for over seven years and had become a Community Health Educator because she thought it would provide a new avenue for working with older adults. In contrast to the other case studies, some breastfeeding peer supporters were motivated by their negative experiences and voiced their passion about promoting breastfeeding in the context of having witnessed or experienced inadequate support.

"And it's something breastfeeding that I do feel quite passionate about and I do feel it's a real shame when you do speak to mums and, you know, I've got very good friends who, you know, gave up. Gave up's a bit of a harsh word but, you know, didn't manage to breastfeed as long as they wanted to because they didn't feel they got the support." L7

12.3   Recruitment and selection of lay people

12.3.1 Recruitment methods

Recruitment of lay people to public health roles was largely initiated through informal 'word-of-mouth' networks. Community groups, such as the local church, and community-based activities, like an annual fete, were particularly important. The breastfeeding peer support programme, for example, recruited many peer supporters through breastfeeding support groups in the community. Service users also helped with recruitment by passing on information to, and recommending, family and friends. In most case studies there are examples of service users making the transition from service user to being volunteers or lay workers.

"*Generally our volunteer recruitment comes from other volunteers who have told friends or sometimes it can be service users that have come through and used the service. If it's been beneficial to them and then they decide that they are really appreciative to what we do as an organisation and they want to give something back or just lay people who call and say 'I have seen your organisation, I have seen your website, are you looking for volunteers, I would like to be one.*" P26

The programmes all used more formal advertising methods of recruitment, such as project websites, posters in community health centres and leafleting households. The sexual health outreach programme had their volunteers wear t-shirts with 'I am a (organisation) volunteer speak to me about volunteering' written on them. Community and local publications, particularly newspapers, were important. Indeed, newspapers were routinely used to advertise paid vacancies although they were often filled with people found through word-of-mouth. The use of community networks was seen as a valuable strategy, but may leave gaps in recruitment. Despite the high visibility in the community, the neighbourhood health project was struggling to gain new volunteers.

Barriers to recruitment were not explored in depth in the interviews. It was interesting to note that literacy was raised as a barrier but at the same time there was an example of how it could be overcome through inclusive recruitment processes.

 "*Literacy. Well I think the things that put people off are the forms and stuff and it puts them off …Yes because a lot of people have got the skills to do the activity but they might not have the literacy and they're not going to say I'm not doing it because I can't fill the form out because I can't spell and I can't write. And there's languages as well. There's paper work,*

registers for putting people's names down and it's surprising how many people can't do it particularly round here." P18

"I couldn't read anything. And then I went for the interview …and then I told them, I said you know this is my application form, my husband wrote it and I can't write anything and she said to me, … she said to me, there's nothing to write." L8

The process of recruitment was usually initiated once someone was interested in a vacancy or joining or a programme. This initial interest was followed up in a number of ways. In some programmes, an appointment was made for an informal chat with a key member of staff. The sexual health outreach programme ran induction sessions throughout the year where candidates were told about the service and the roles available.

12.3.2 Selection criteria and skills required

There were a variety of characteristics and skills that programmes selected for and communication skills were a primary consideration. Programmes wanted people with 'good communication' and 'listening skills', people who were 'good listeners' that had the 'confidence to talk to people' and the 'ability to give impartial information'. Additionally, 'people skills' and empathy were highlighted. Lay people needed to be approachable and caring and have the ability to relate to people. The importance of being non-judgemental was also emphasised.

"They need to be able to communicate for a start off. And they need to be friendly and they need to listen, and not condemn. Because we do see a lot of people who get in trouble. I've always said if I'm down in the town and I see drunk man lying on a bench, I don't say to myself, well that's so-and-so, look at him drunk again. I don't know what put him there." L23

The following quotations illustrate the requirement for high level social skills. In the first quotation, a volunteer talks about the combination of communication and social skills that were needed when doing outreach in the gay scene. In the second quotation, a Community Health Educator talks about the ability to engage people.

"The ability to talk to someone and almost read them, so if they are nervous try and reassure them, if they are angry or frightened do things that won't antagonise them. Especially when you are in bars you need to be able to read whether the people are drunk or on drugs or just slightly aggressive and you have to really, really pitch your spiel on the right level otherwise you could potentially be out into some dangerous positions." L21

"I can go into a group of women that are stood nattering away and I can sort of squeeze myself in and say 'excuse me', and just get myself involved". L2

'Enthusiasm', 'open mindedness' and a 'thick skin' were also brought up as useful criteria. Other criteria were brought up less often and were more specific to the lay role. So being 'organised' was useful for people having to complete paperwork or plan activities, such as walks. Those helping when HIV tests were being conducted required 'sensitivity and decorum' and those working at public events, particularly on the street, needed an ability to grab the attention of appropriate passers by.

One interesting aspect of selection was the issue of whether lay workers needed to share the same attributes or be drawn from the same community. There were a mix of views advanced, but in fact no programme excluded people from outside the target community. Whereas local knowledge and peer status were helpful, they were not always seen as essential as these quotations demonstrate.

"Yeah, local knowledge and also an understanding, you know, I think if they are delivering their walks in the local community then they often have a knowledge of the people as well as just publicising it." P25

"I know there are a few straight people working here as well so it really doesn't matter as long as you don't mind talking to gay people basically." L22

"It's difficult to describe really I think it's the passion more than anything else and you don't have to have breastfed." P11

"But I think you need to have done it, because I've had midwives tried to help me who've never breastfed anything in their lives and they're just hopeless and I think you need to be able to listen to people, and have confidence in the facts that you're giving, but other than that that's really all you need." L9

The question remains about how selection criteria were implemented in the process of recruitment, as this was rarely discussed in depth in the interviews. In the breastfeeding peer support programme there was a formal process of recruitment with interviews, and this was seen as

necessary and useful in terms of screening. Other programmes had a more open recruitment policy, taking anyone that was interested. The implications are that the emphasis was on ensuring lay people had the support to fulfil their role once they completed any initial training. Having an open recruitment strategy was seen as helpful, as it got people engaged in the activities, but there could be drawbacks.

"*I mean initially it was the approach, right from the start whenever we do anything we always involve anybody that we can really that might be interested… obviously it's got to be people that are helpful but you can't always choose that. You know everybody comes along and you do get unhelpful people too who you know.*" P32

Open recruitment and selection processes could also lead to inequities, particularly when lay people were paid as in the Community Health Educator programme, because it resulted in lay people with different competencies and responsibilities. Those lacking in certain skills inevitably required more staff time for support.

12.3.3 CRB checks

Established by legislation, the Criminal Records Bureau is an executive agency of the UK Home Office that provides CRB checks for organisations putting employees or volunteers in contact with children or vulnerable adults. A standard disclosure shows information from police records of current and spent convictions, reprimands and cautions. Where relevant, the standard CRB check will also search legislative instruments listing those who are a risk to children, vulnerable adults and those banned from working with children. There were differences between the programmes in terms of whether CRB checks were required.   In the breastfeeding peer support programme, CRB checks were in place as part of the selection process. In other programmes there were different views expressed about the need for checks. This was complicated by issues about whether the work was one-on-one or group and if it was located in the home or elsewhere.

"*And part of the rationale we use is that they're never on their own with an individual, they're always in a group, they're not going into people's houses.*" T9

"*Well this is the process everybody else is going through, and if you don't have anything to hide then it is the right thing to do because there are a lot of people who are vulnerable so it's only right… they can work with people who are vulnerable, so you really don't know.*" L14

In general, lay workers and volunteers were not concerned about requirements for CRB checks. It was highlighted, however, that it is those who self-select out of roles that may be most concerning.

"*To some people, yes particularly the clients that I work with because due to their illness or whatever they have had a brush with the law shall we say at some point, some people. They're quite ashamed of it because it's like 'it were when I was ill I didn't know what I were doing' but it stops them volunteering. I have had three brilliant volunteers, they would have made and they were helping but as soon as you mention CRB they're gone. They just won't do it because of the stigma to mental health and stuff like that.*" P18

12.4   Training

12.4.1 Training methods

Training was seen as important not only for inducting people into a public health programme but because lay workers and volunteers were being given considerable responsibility in their roles.

"*Lay people have got a huge role to play and do play a huge role in delivering, you know, an awful lot of work. I guess for me it would come down again to consistent training and development of individuals. Not putting people in situations where they weren't equipped to deal with them.*" T10

"*If you give people a label, expect an awful lot of them and don't give them the right tools and the training as it were then they can't have the credibility in their community. But if it's done well the community will recognise a skilled member of their community who is still a part of their community but actually has something to offer.*" T18

Training varied considerably between programmes. Courses could be delivered in-house in one hour talks or half and full day sessions. External bodies were also delivering training, some of which gave formal accreditation. Training topics usually included issues specific to the programme but could be much broader in focus. Topics included:

  • working with groups, communities, young people, vulnerable people

- health and health improvement, smoking cessation, stress management, nutrition, food hygiene
- equal opportunities and awareness about alcohol, disability and mental health, disclosure of heterosexuality
- risk assessments on site, how to take people across a road
- induction into service delivery, particularly explaining the relevance of risk assessment and paperwork.

Within training programmes, there were different pedagogical styles. Play and games were used to add an element of fun while demonstrating important topics. There were plenty of discussions of scenarios and how to deal with them. Additionally, there could be site visits or demonstration activities where something specific was acted out with the group. For example, those training to lead a walk could go out as a group with their trainers playing the role of walk leaders.

"*They play a few games about health and health risks, and the benefits of physical activity … it takes it away from 'I'm a mountain leader' to 'I'm a health walk leader'. There is a demonstration health walk, so they'll go off on a health walk. Just discussions about the responsibilities of a walk leader, you're not a carer, and you're there to lead the walk.*" T9

Feedback from lay people was regarded as important and was used to make decisions about the development of training. Interestingly, there was a example where new roles were suggested through such feedback, which led to the initiation of new training courses.

12.4.2 Training opportunities and challenges

Once the introductory training was completed, some of the case studies provided regular training that volunteers were encouraged to attend. Programmes also encouraged and supported their volunteers or lay workers to take part in other training. In the Walking for Health programme, the regular updates aimed at developing new skills had stopped with the change in service structure, but one respondent commented on the benefits of training for keeping people engaged.

Lay workers and volunteers gained from, and supported each other, during training. There were examples of a strong sense of mutual support and camaraderie. This was particularly so when there were set training periods and therefore cohorts completed at the same time.

"*Even though people have gone off to do different things, we're still in touch with each other.*" L1

"*Because you're empowered, you're able to identify other workers / students alongside that are not quite as far on the journey as you are … you're able to support them and help them.*" L2

Training and development were seen as effective tools to develop the lay workforce and manage some of the more difficult issues around risk by preparing people for their roles (see Box 6). Training led to lay people having confidence to take on new responsibilities.

"*Some of them [lay people] have gained the confidence to actually run the sessions and actually be very skilled at actually doing things that 12 months, 24 months ago they wouldn't have believed themselves capable of. I think the development training, support they've had, the encouragement they've had, the mentoring they've had has enabled them to take a step up and take on roles that it's really encouraging to see them in.*" T18

A weakness of training identified by one volunteer was that it provided too little preparation for working in the role. This would seem to emphasise the appropriateness of shadowing and supervision as a link between training and working in role.

"*I don't know if it prepared me that much I think what did really prepare me was actually going out for the first time with a guy who had done it lots and lots of times and was really good at it so he showed me the ropes he was like this is how you do it and these are the things that you say to people.*" L21

The amount of time that training took up for both the programme and the individual involved could seem disproportionate. An additional barrier was that training could appear to be too formal, adding a 'professional' element that made people question their suitability for such roles. Importantly, the time taken could clash with other commitments and be time consuming. One volunteer commented 'sometimes it seems you're doing something every day', while a practitioner described some of the barriers to volunteering:

"*What I have done is that I received recently a CV from a person who is interested in the walks and she was thinking to do some volunteering work with the [name] project. I think it would be a good idea but she needs to go*

through the process of becoming a volunteer in the primary care mental health team NHS which means she needs a CRB check, training, health and safety training, the walk leader training so it's not as easy as I would have hoped it to be. It's a very difficult process and it takes a really long time..."
P16

Box 6: Sexual health outreach – induction and training

Volunteers for the sexual health outreach programme were initially invited to a volunteer induction day where they were told about the core aims and values of the organisation and the service it provided. They then learnt about equal opportunities, confidentiality and boundaries. While there was no formal selection process, the induction day was seen to act as a bit of a 'filter' so people could select which activities they wanted to sign up for but also could select out.

"*So I think the fact that you bother to give up half of your weekend, a whole Saturday to come and do this was, is a bit of a filter, to make sure only the more committed people are volunteers.*" L20

Volunteers were then invited to attend role specific training. For the sexual health outreach programme, volunteers were required to attend sexually transmitted infection specific training but they were also expected to attend at least two additional training sessions within the first year of volunteering, such as listening skills, safer sex, working with vulnerable people and disclosure of sexuality. Training was seen as a way of giving people the right skills and ensuring that they understood the boundaries of the role. In terms of ongoing training, the organisation offered twelve training sessions a year and asked their volunteers to attend a minimum of two. This kept volunteers up-to-date with their knowledge. Volunteers were able to attend the same training that was offered to staff. This provided them with an opportunity to update their knowledge and add the training to their CVs. One volunteer explained:

"*They usually do stuff that is actually related to what you do. But it can be anything and I noticed a mental health training session this week as well. It can be quite specific stuff that might be useful for your job...*" L22

Training was very much seen as an essential part of the risk management strategy as volunteers worked in autonomous way.

"*We try to reduce the risks involved through screening and training, training and training and also refresher training. Issues with volunteers could potentially be that they become complacent and they don't have*

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updated knowledge. Say for example, if they say 'oh I know about HIV transmission' but something new comes up with HIV transmission and they don't learn about that then they might be giving out the wrong information still." P27

In addition to training, systems of shadowing and supervision were in place to enable volunteers to be supported as they developed skills. Training was seen as a necessary investment but one that took up significant resources in the organisation. This was problematic when there was an inevitable turnover of volunteers.

12.5   Support and supervision

Support was seen as something that came into place after introductory training, when the lay person took up their role. There was in-depth discussion about support in the interviews which suggests that it is a more complex issue than recruitment or training. Broadly speaking, the more autonomous the public health role, the greater the need for support. The sexual health outreach work was one example of an autonomous role, as was the breastfeeding peer supporters' role in home visits. In contrast, many of the activities undertaken by Community Health Educators involved working alongside professionals or with their fellow workers.

Support was managed by programmes in a number of ways. Part of dealing with support needs was to ensure that each person was assigned roles appropriate to their skills and competency.

"I would never have a volunteer or a lay person working with me that I wasn't a 100% trustful of or I knew their ability. If I had any sort of questions about that I wouldn't have them doing what they do..." P26

There was some acknowledgement that lay workers had different skills and competencies and this needed to be actively managed. In one example, a walk leader was exhibiting inappropriate behaviour that had to be dealt with.

"One of the volunteers was quite abrupt and was upsetting some of the ladies by just saying things to them...I had to have a chat with her and say 'please don't tell her that she's fat and that's why she's walking so slow'...She said but it's true. I said I know but don't do it please. And she sort of said 'well I'm leaving' and that was fine, thank you very much for your help." P21

The provision of what could be termed 'light touch' support was valued by both lay people and practitioners. In this way problems could be dealt with and organisational issues addressed. Having telephone contact before or after a particular activity was seen as particularly important.

"*I think while we're out on the scene we need to be able to reach people in the office should anything come up. Like last week, we couldn't get into the place we wanted to be in. So I think it's important to have a contact person when you're actually working out. It's probably good to have somebody you can talk to afterwards if anything particularly disturbing came up or something you feel you should get some advice on.*" L22

Regular meetings were another way programmes provided support to their lay workers and volunteers. Meetings were either one-to-one, usually with a team leader or volunteer co-ordinator, or with a group when all lay workers would attend. Regular meetings with walk leaders had stopped at the time of interviews and these meetings and the contact with the co-ordinator were very much missed.

How lay workers support each other was not explored explicitly but it did emerge as a feature of these programmes. Group development and support was not limited to training cohorts but also came about as lay people got to know each other.

 "*I feel like we're equals if you will and in that way you become really close friends. There's three, four of the girls who I'll see you know during the school holidays, weekends, we go out together, we have lunch together and I think you always kind of lean on each other and discuss things with them… you just become part of like a little family and that helps you know to again put your mind at rest.*" L12

12.5.1 Support needs

Lay workers often commented that they were aware of the availability of support and recognised their own support needs.

"*Yeah, offloading and also we get a lot of support, we do get a lot of support because…We do need it…I know that if I've got any problems either with staff who've done something I don't agree with or, you know, I've seen a mum whose housing conditions I don't think are suitable, anything like that I know I can come back to [name] and we can discuss it.*" L12

It was notable that lay workers and volunteers talked about support in connection with how their contribution was valued. Support and being valued were seen as intertwined, and this was a motivating factor, whereas a lack of support left people devalued. These two quotations illustrate contrasting experiences.

"Yeah very much so, right from, '[name] we really need you… you're such a star, thank you!' and that was the biggest thing for me I really felt like I was helping them out because they respected my efforts, right from the friendly attitude I got from all the staff… but that was the main thing, the pat on the back when I agreed to do something, the thank you." L20

"All this thing is like the PCT and the NHS but we don't feel we get support from the PCT, besides the fact that we were signposted and we had the training and the original first aid things that we did, after that the only thing that we have with them is those forms that we send …We don't have support that's incentives for the ladies, more encouragement…" L14

Failing to see people face-to-face emerged as a thorny issue. One lay worker described feeling devalued because a senior member of the service failed to meet with them*: "we don't see that much of the higher up ones … I wish they would appreciate us a little bit more, I don't think they appreciate us enough".*

The significance of adequate support was also recognised by professionals. Lay workers could have personal needs and require support.

"They can be quite needy. A lot of volunteers volunteering within this type of agency will have been service users and may well have been service users with quite a number of issues." P29

"My major criticism of most peer support is that people deliver the peer support [training] and then let people loose and they haven't thought about what they're doing next…You can train them, but you can't suddenly expect them to know what they're doing. They need support." T6

There was a fine line between a programme failing to provide the support and a lay worker/volunteer being seen as particularly needy. Practitioners often had competing priorities, although lay workers were aware of this.

One respondent in the breastfeeding peer support programme explained how she felt unable to meet expectations for assistance.

"*Yeah you do end up worrying about them or you get the other extreme like we had someone on the helpline who would take a call and ring me at half eight and say 'this mother needs a visit' 'you know I don't do visits after 7 o'clock' 'yes but she is absolutely desperate' '…and I sit there thinking should I go, but I can't or maybe I could, but you can't because of lone working and whatever, and it's difficult especially when you get really involved with some mums.*" P11

12.6   Progression

Progression is the movement between roles in the same service or onto new roles, with the emphasis on an upward trajectory, such as increasing responsibility or pay. Those programmes that ran multiple activities provided much more opportunity for progression. As a consequence, an individual could move between lay roles undertaking relevant training and broadening their experience. Indeed, some of the programmes encouraged this movement and attempted to give lay people increasing responsibility as they became more experienced with, and established within, their project. In one organisation, there was flexibility for volunteers to develop their own roles by building on their experience, expertise and interests and lay people had gone on to design project websites and take up mentoring and trustee positions. In all of the programmes there were examples given of progression, both within the programme and to paid roles. In the Community Health Educator programme a number of examples of progression were reported. These included:

- taking up a post as a health trainer
- taking up paid positions as support workers in the healthy living network
- establishing a holistic health training consultancy
- volunteering in a local women's group
- developing new services and groups within programme.

Many talked about progression from lay roles onto paid health promotion or community development positions. The following quotations illustrate how people can gain in confidence as they gather experience and knowledge.

"*That's where my involvement became, originally I started leading walks as a volunteer and I think that was for about a year or 18 months. I then went to work in a school part time, my children's school and I was also doing work with parents, so again it then started that I started working with the*

parents and I carried on with the walking project. I then moved on and got a full time job but still in community development working with people from a wide range of things." P21

"It seems to give them the confidence. It empowers them to actually move on. You know, they think they can do nothing when they come through and the first thing they're excited about is when at the end of the course they sit a little exam and they're successful and they get a certificate because they've passed." T7

12.7 Retention

Some of the case study programmes appeared to have few problems with retention, and it was suggested that this was because there was investment in a small core of volunteers. Even then lay people still left their roles, and it was not possible to interview those who had left. Reasons for leaving roles were largely outside the control of the programme. Personal and work lives could take up more time and be given greater priority than the public health role. For example, a family member could become ill and require care or a colleague could be absent temporarily leaving greater workloads. Students were seen as transitory and therefore difficult to retain once they finished their studies because they were most likely to move for work. What is notable about these external causes is that they can be temporary.

"It's personal circumstances why people drop out mostly. There's not many people who drop out because they don't enjoy doing it anymore. I've dropped out recently…because my mother's come to live with me and I seem to suddenly have loads of appointments and various other things to do and I just can't spare the time and energy at the moment. I'm hoping to come back to it at some stage when things settle down." L19

Lay people could lose interest and this was further compounded by a lack of recognition for the responsibilities they fulfilled, particularly when they were unpaid. One volunteer spoke of the balance that had to be struck between commitment and enjoyment.

"I think sometimes people perhaps get fed up with doing something for nothing, you know. And perhaps they feel pressured, I don't really know…I think perhaps sometimes if you're doing too much, you lose that enjoyment from it, you know." L27

Across all the case studies, there were many examples of where volunteers and lay workers were committing large amounts of time and energy to the

programme activities. A key challenge was that lay people sometimes saw services as expecting too much while providing insufficient support. In a minority of cases, lay workers expressed dissatisfaction with the support they received from their programme, as one individual reported 'they just are not keeping in touch' and this had led them to set up a similar, more informal, project. This is a particularly interesting example because it highlights that failure to retain lay people may not mean the end of engagement with public health activities.

Retention did not necessarily equate with sustainability. In the neighbourhood health project, a small band of volunteers committed many hours of their time and this encroached on their lives. So while they were retained in the project, this was not considered sustainable, as quotations from these volunteers indicate.

"It's asking volunteers to do too much because they invariably have got other responsibilities, they have got families, and with the older people around now, there are a lot of people with elderly relatives. And it changes all the time…So the result is that if anything needs to be done, or somebody needs to stay at home for some reason or another – it's the volunteering [that suffers]." L24

"I think at the moment we're about stagnant. I think there are so few of us, and we've got to be very careful what we're taking on. Because we're stretched quite thinly at the moment anyway, you know. I feel that if there were a few people, we could move on, yeah we could definitely sort of move on." L27

12.8 Payment and rewards

The five case studies represented different payment methods and this allowed the research team to explore views on those options. The neighbourhood health and sexual health outreach were volunteer-only programmes, as was Walking for Health, although there had been a history of sessional payment for some walk leaders. The breastfeeding programme had both paid and unpaid roles and the Community Health Educators were paid on a sessional basis.

12.8.1 Volunteer models

In the programmes where lay people were unpaid, expenses could be claimed back. Few raised any concerns about the lack of payment. For some, this was because they felt that they gained in other ways, such as

going on a trip or the pleasure of being altruistic. The lack of remuneration did not mean that people felt unrewarded, as social rewards were viewed positively.

"*I've got a core of them who will turn up to anything and do anything and we'll all go out for a drink afterwards and tonight we're packing condoms, so that's quite a sociable bunch, so they will come and we'll get some wine or whatever and we'll all go out for a pint afterwards. So there are a core that, a lot of them are my mates, but there is that and some people do, you know, volunteer just to meet people, which is fair enough. Volunteering has many different functions for people whether or it's to gain skills, give back time, you've got some spare time and you want to use it in a way that fulfils it in a way of whatever you want to get out of it.*" P28

"*We only get expenses. There is no financial reward what so ever, I just do it because I enjoy it.*" L21

Two of the programmes organised social events as a way of thanking volunteers. There was a suggestion that programmes should be able show their appreciation by giving small rewards, and a sense from some volunteers that it would demonstrate the value of their contribution.

"*But maybe they should say, thank you for all the time you volunteer for us and say, you know, take them out, give them a Christmas lunch. Yeah. It's not so much a reward, more like a thank you, you know what I mean? Yeah, all the good work that they've done over the year and that sort of thing. No, we go out for a Christmas lunch, and you'll pay for yourself. But it would be nice, especially the amount of hours that some of them put in for (the neighbourhood health project), if they turned round and say, you know, thank you, you've done really well.*" L26

"*That it's important, that there should be a reward system for those people. I'm not sure what that reward system should be at the moment and that there is a way that you can eventually go from that volunteering into some paid job, because we all need to earn money at the end of the day…. And it values those women. And also it spells out the message that we value the work they're doing, we value breastfeeding, so that there's some, you know, payback for that.*" T7

Some respondents argued that volunteers should be paid because of the responsibilities they were given or because they were pivotal to the programme, while others argued payment would be contrary to national or service guidelines. The following quotation from the Walking for Health case

study again illustrates the perceived discrepancy between responsibilities and rewards.

"*Good grief, they provide a lot as it is, you know. They produce a timetable, keep their website up to date, make sure they're insured, make sure they're recce-ing the route, they make sure they're trained, they're taking all their health questionnaires, and keeping it all locked away. To say 'Oh, we're not going to pay you but you have to do this as well'.*" T9

The lack of payment was reported to raise difficulties when faced with service users who were unaware of the distinction in lay and professional roles. One walk leader explained.

"*It's very difficult to explain that to the ladies. Some of the ladies just don't believe it; they think it's not the case that nobody would do something for nothing. It's very difficult when people don't understand. For that reason you feel like saying 'well I should be getting something because this is what people are thinking anyway, so I should be getting something.*" L14

12.8.2 Using payment

Different types of payment were used by the case study programmes. There was a fixed-fee for undertaking an activity, such as leading a walk, sessional pay, or in the case of the breastfeeding programme, peer support workers received a wage of around £14,000 pro rata. The Community Health Educator programme provided some interesting data on the pros and cons of payment. Pay was seen as giving credibility to the role, providing a sense of worth to the lay person and demonstrating appreciation for their contribution. Importantly, pay was seen as making it possible for people in difficult circumstances to contribute and could help with employability.

"*The rate I got paid was fantastic … it made you feel even more wanted and worthy.*" L2

"*I think it definitely helps, because sometimes you don't realise just how much work that you're going to put into it.*" L1

The following quotation from a Community Health Educator illustrates how remuneration did not change the fact that motivation was primarily altruistic.

"I find that I have other things to do that mean really I don't want to see it as a wage, I don't want to see it as doing so many sessions a week so that I get paid so much money. So I'm not looking at it as a sort of a paid job it's just something extra to do besides the voluntary work." L2

There are difficulties with pay nonetheless. For some, pay undermined the volunteer ethos, which would help explain why some lay workers in different programmes would refuse expense refunds (discussed in the next sub-section). There could be tensions where volunteer and paid lay roles co-existed; one programme was described as having a 'hierarchy'. There was also a fear that pay would leave programmes unsuitable for mainstream practice because of the expense. A further issue was that when lay workers were paid the same amount, there was still a perception of inequality because the amount of responsibility for each task and the capability of the lay person varied. There were examples where programmes chose to pay specific volunteers because financial support was considered necessary to secure their involvement.

"We paid some volunteers, but it was very specific ones, it was people who were unemployed who had to go out of their way to come. It wasn't a case of paying volunteer expenses, it was more if people were employed in whatever capacity then they got nothing but if you are unemployed and you really need this money to get to it, you know that sort of thing." P24

12.8.3 Expenses

While practitioners and those with strategic responsibilities wanted to avoid any financial burden on lay people, this was complicated to achieve. Some roles were seen as rarely requiring expenses because they were, for example, part of a project that was run in a venue with all materials provided. Hidden expenses still occurred and remained difficult to claim, for example, obtaining receipts with the use of pre-paid mobile phones. In roles that did require expenses, some lay people were reluctant to claim them back. The following quotation illustrates some of the difficulties with expenses, where volunteers, some of whom were putting in many hours, felt unable to claim back.

"No they don't get not an awful lot actually in specific rewards. I mean...I hope no one's out of pocket, I think they don't get expenses in terms of personal expenses but if we were to go anywhere and there were any cost implications I would offer to cover them. It's funny they're quite reluctant about that because [the community committee] itself has its own organisation ...and I said well surely [the community committee] can buy diaries and give it's, you know, committee the diaries. Ooh no, we can't do

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that, people won't take them. You know, they're very sort of reluctant to, it's bizarre." P32

Importantly, there were costs that were additional to the work of a programme, which lay people had to cover. Childcare was the most prominent of these 'personal expenses' and highlights a difficulty of relating rules of employment, where it would be inappropriate to claim for childcare, to lay roles in public health. Personal expenses will be particularly important where many experienced difficulties with finances because of, for example, chronic illness. One breastfeeding peer support worker explained the difficulties of balancing demands.

"Or, earlier on, before my mum was having her, my husband would come home from work early but he gets paid by the hour and we kind of sat there one day and just thought well I've given up work, this is actually costing us a quite significant amount of money for him to come home from work … and miss an afternoon's work when he, he's self-employed and those hours make a big difference." L13

12.8.4 Benefits

In the UK, the term 'benefits' refers to a raft of payments to individuals from the state in the provision of welfare or social security. While 'benefits' are seen as payments for the unemployed (and hence 'benefits' is sometimes short for 'unemployment benefits'), criteria for inclusion and the purpose for the payment vary. There are, for example, payments for those under 65 with mobility needs (Disability Living Allowance) and for those under pensionable age who cannot work because of disability or illness. Benefit payments can be means tested, such as with Housing Benefit or Pension Credits, and key criteria are income, savings and time spent in paid employment. For example, Income-Based Jobseeker's Allowance is reduced for claimants with savings between £6,000 and £16,000, can be further reduced if they earn a small amount, and will be withdrawn if the claimant works for more than sixteen hours per week (this excludes voluntary work).

There was a split in the case studies about benefits. In those programmes where public health roles were filled by retired people, the issue of benefits was rarely mentioned. In contrast, the conflict between pay, including expenses, and benefits was a recurring theme in those programmes where lay people were of working age. Pay was seen as advantageous as long as it did not affect benefits.

"The money was really good, because I was self-employed at the time … I wasn't on benefit, so it was a good income … if you're on benefits, then you've got to watch what you can earn and what you can't earn." L3

"If we do get payment if affects the benefits, but it shouldn't be so. For some people £10 isn't a lot of money and for some people it is." L14

Indeed, pay was seen as particularly important for those on benefits because they were likely to have little income. Consequently, the risk of losing benefits was magnified because that income was precious. Additionally, there were familial and social risks, particularly when others relied on the income from benefits.

"It's not a vast amount of money and it shouldn't affect the benefits. If it affects the benefits then their husbands will get a bit wary, if it's going to affect our benefits then what will happen when you stop doing it and that kind of thing, so leave it, it's not worth it." L14

12.9 Commissioning

Commissioning is the process for assigning funds across the NHS and Primary care trusts are moving towards what is termed a commissioner-provider split, and health services may be provided through a third sector or voluntary organisation. In relation to commissioning, some respondents considered that primary care trusts were knowledgeable about health but lacked the skills to deliver health services effectively to marginalised or poorly served communities. An alternative perspective was that official health funding was needed to legitimise programme activities.

"Just because they [the programme] are the experts really, when you are trying to reach some marginalised communities that are vulnerable because of a certain issue, there are projects that can reach them better than what you can coming from the NHS…These are front line projects who are commissioned because they have the skill and expertise to actually reach the most vulnerable." T12

"Because it's health I think they do need almost the kudos of working with the primary care trust to give it that health stamp. And then they can say…'This is a health [project], it's funded by the primary care trust'." T9

In relation to the commissioning process, there were significant themes about the tensions between professional and community control. One aspect was the use of targets and monitoring systems. Programmes had to report

to their funders on the use of funds. In some cases, reports were formal and required periodically, such as quarterly. In other cases, the reporting process was much less formal because it relied on a subsequent round of commissioning when programmes would have to make the case for further funds. Commissioners and practitioners repeatedly mentioned targets as part of reporting, particularly for justifying use of resources, but these were not specified in interviews. For example, one practitioner said that a service would have to meet its targets but when pressed admitted none had been set when the service was commissioned because the 'whole provider-commissioner split was going through a process of evolving'. The only examples where programme targets were given in detail was in relation to performance outputs, such as having to screen a minimum number of people over a specified time period.

Additionally, the use of targets raised questions about the relevance of performance measures and whether the commissioning process was able to capture the impact of lay engagement as targets were often about volume of activity not quality. There were further issues about whether volunteers should be asked to collect data without administrative support. The tensions between NHS targets based on public health priorities and the wider social benefits delivered by lay workers over a longer time were evident in two of the programmes. In the Walking for Health programme, for example, the change of focus with commissioning had implications.

"*Nationally and locally it is the agenda obesity so I can understand why the focus has to be very target driven. Obesity is now in provider services, so it's very much a matter of proving that the target that was given has been achieved so anything else can't be catered to, so walks for mental health and social wellbeing can't really be catered to.*" P17

A further theme was around how far commissioning should remain 'hands off' and be limited to funding rather than supporting delivery. For example, one commissioner regarded the delivery organisation as the experts and commissioning was a matter of setting the direction, as 'how they actually deliver services is up to them'. This left the delivery organisation with freedom, but no funding for infrastructure. In contrast, another commissioner explained how the delivery organisation had been supported to develop an infrastructure including policies and business plans.

The issue of gaining funding for community-led activity was particularly pertinent in the neighbourhood health project where the approach was based on the premise that a high level of community involvement would lead to sustainability. Volunteers were engaged with the process of bidding and trying to draw down funds to support activities, however, one respondent highlighted the burden of expectations on volunteers.

"So why should it be a surprise that volunteers who you then try and turn into administrators and managers actually don't want to do that, they want to do the other stuff. You give them both roles, they get very tired." T16

12.10 Sustainability

There were a number of challenges to sustainability identified through the case studies; some of these were specific to individual programmes and their social contexts. Nonetheless the overarching theme was the importance of achieving a balance between community involvement and professional support. Some programmes provided examples of where high levels of community participation were a factor in building sustainability. In the sexual health outreach programme, the volunteers added a dimension that enabled the organisation to keep in touch with its community. This in turn led to the development of new activities and new volunteers.

"If you are using a lay person doing the outreach or doing the admin or in any sort of role, they have, it's weird it's like yes we are involved in the community, but it's like they are the next step they know exactly what's going on, what's happening and where it's happening and what they can do so they are like the eyes and ears of the organisation, they can tell me that's happening there, or this is happening here… which is great. It's a real benefit to have the lay person working in the roles that they do, not only are they doing a great job but they are also promoting the service possibly unintentionally, they might go back and talk to friends and family and then they might say 'I might be interested in that' and that's how quite a few volunteers do come through." P26

There were also examples from the Walking for Health programme where high levels of volunteer engagement had led to sustainable walking groups existing with minimal professional support.

"They're not worried about us. We are a successful group and we are self financing so we don't actually need a great deal of support and we are quite capable of asking as and when we do need it." L19

The neighbourhood health project was based on the belief that community involvement would achieve sustainability, particularly after the regeneration funding came to an end. The level of community participation in the project was very high, which made project activities sustainable, but at the same time there was a strong theme of over-reliance on volunteers.

"*I think if you didn't have volunteers lots of things wouldn't get done. For one thing if we didn't – if [name] didn't have her volunteers she would have to do everything on her own, and it wouldn't exist. She wouldn't be able to cope with it. It's not possible because of the workload. So without the volunteers it would come to a grinding halt, she just couldn't do her work.*" L25

Lay people talked about their need to be available all the time to volunteer for the neighbourhood health project and feeling over stretched. They also commented on 'feeling pressured and tired' and volunteering even when they felt there were not up to it because they 'don't want to let anybody down'. Nearly all of the lay people commented on the lack of volunteers and said the project needed to recruit new volunteers in order to ensure sustainability. One questioned the level of responsibility that volunteers should carry.

"*Basically, health and wellbeing and all sorts of health projects are very, very important, and they need to be done, but they can't rely on volunteers running them completely, they can help and they can support and they can do all sorts of things, but not to put too much responsibility, on people's shoulders.*" L24

This theme of the balance between community participation and professionalisation was also played out in other programmes. In the breastfeeding peer support programme, some respondents saw a clear difference between the community-led model of the early years and the more business-oriented model that had superseded it. Volunteers were no longer the focus of organisational activity and some gaps in support were identified by respondents. For some programmes, attracting NHS funds came with a need for greater professional control, which could be in conflict with empowerment approaches.

"*…it brings with it its own problems, which means that they don't fit into a nice professionalized world. They won't be deferential to any hierarchical system here.*" P1

"*There are all kinds of other issues with volunteers, like them keeping their own identity and doing what they want and the PCT recognising that they need to all be standardised well for everyone's safety really, so you have the conflict of the PCT saying 'you need to be working to these rules' and they are going 'why we are volunteers, we never have before, who are you to tell us what to do'.*" P11

12.11 Summary

The case studies illustrated a variety of approaches to the recruitment, development and support of lay workers and volunteers. Many of the issues raised by stakeholders indicated that support was essential to enabling lay workers and volunteers to undertake their roles. More critically findings indicated that a balance needed to be achieved between management of support needs and exerting inappropriate levels of professional control. There were also important themes about motivations of those who volunteer for community work and how commitment can be nurtured by appropriate training, development, support and payment systems.

13 Case study findings – roles and boundaries

13.1 Roles and responsibilities

Lay people were undertaking a range of activities in each of the programmes. Respondents were asked to discuss the benefits and value of involving lay people in public health roles, what the role entailed and whether there were any issues around appropriate boundaries. In some of the case studies, roles were clearly defined, particularly in relation to professional roles. One example was a community-based smoking cessation service, where lay workers assessed clients and recommended services, while practitioners gave out nicotine patches, lozenges and gum.

Health promotion activities were central to roles including promoting and recruiting for the programme and signposting service users onto other health services. In some roles signposting was very specific, such as to Hepatitis B vaccinations or to different steps of treatment in a smoking cessation service. Signposting requires lay people to listen to service users, assess their needs and the potential for a service to benefit them, and the provision of information and advice about using such services. Additionally, lay people signposted to practitioners in their own programme when the task was seen as being beyond their remit.

"*I usually do outreach, so we go on the gay scenes, we go to the bars and we actually talk to people and tell them like if they want an STI test now because we've got a nurse upstairs or across the road or wherever we are at the moment. And just tell them what we do and if they ever need anything then they should just find us on the internet or come over to the office if they know where it is.*" L22

"*But I would always, always share that with the midwifery team, with the health visiting team, so that they could pick up, you know, and share that information and visit and support, as well as my information, you know, this is what I've done today, this is what I've said.*" T8

There were some differences between programmes in relation to the intensity of health promotion encounters. So at one end of the spectrum, walk leaders related to a small group (or groups) of walkers, whereas Community Health Educators were utilised to cover many population groups

and this was described as a means of securing 'fast and rapid engagement', with a view to bringing about 'rapid behaviour change'.

There was a large amount of what was referred to as 'helping out' in most of the programmes. Examples of helping out include the collection of money, buying and serving refreshments, preparing and cleaning up rooms and completing paperwork, such as registers. Lay people were seen as essential to deliver programme activities and in some cases the activities were led and organised by them. While 'helping out' was necessary for delivery, it was not necessarily a health promotion role. One respondent from the sexual health outreach programme explained:

"I think it's quite a big ask for people because the outreach work is kind of hard and the work in the waiting room it's quite, it's a reasonable amount of responsibility for a job that's boring, it's like motorway driving you have to concentrate really hard on something that is quite boring. So I think the biggest thing is…I think it can work quite well and be beneficial for volunteers and the organisation but I think finding the right people and giving them the right incentive." L20

In some cases, lay people offered experiences that added legitimacy to the programme. For example, involving people who had successfully quit smoking was seen as beneficial, due to them having been through the difficulties of change and, in some cases, having experience of using the service. There was evidence of peer support from lay workers who were seen as being able to empathise with service users.

"I used to smoke and … they tend to like support from ex smokers… from a normal person that can understand what they're going through day to day. And in fact they say, oh it's been so many weeks and I say 'I've been seven years and I still get sometimes, I still fancy a cigarette'. But it goes… we give an awful lot of emotional support more than anything else. […] And, you know, and lots of praise and things like that. I don't think you get that from a doctor." L26

"Well yeah, people like me, just a normal mum who's breastfed, I'm not a midwife, I'm not a doctor, I'm just a normal mum who's breastfed and I can come to your house and I can show you how I did it, I can give you information about how other mums do it, which is what your sister-in-law and your auntie and everyone would be doing if you lived in Sweden or somewhere like that." L10

Roles were seen to increase capacity for programme delivery. Responsibilities could be extensive, as illustrated by Box 7. Interestingly even in programmes that involved volunteers rather than paid lay workers, their 'work' was acknowledged. These two quotations, the first from the neighbourhood health project and the second from the sexual health outreach programme, demonstrate how the contribution of volunteers was recognised and valued.

"*They do see it as work and, actually, it is work. Let's be truthful. They are working. They're just unpaid workers.*" P35

"*They [staff] do see volunteers within the organisation as colleagues and they do see them as added value to the projects, the staff team also realise that a lot of the projects what we are doing, …we wouldn't be able to do without volunteers.*" P29

Box 7: Walk leaders' responsibilities

Walk leaders take overall responsibility for leading a health walk. Prior to walks they organise routes and carry out a risk assessment. On the actual walk, they take a register and lead the group and ensure everyone is returned safely. There is usually a volunteer who acts as back up by walking at the rear of the group. Leaders carry a first aid kit and water, and get new walkers to fill in a health questionnaire. They also promote the health benefits of walking and often publicise the group or actively recruit new members.

"*I don't think there's one main role. I think it's first about being that first point of contact with their own community because it tends to be that you will work within your own community. But it's also then about giving out positive health messages that walking is good for you and it will help you. Also that sort of role of encouragement, if we can do it then you can come and join us. It's about the safety aspect of it as well, they feel safe with you. In particularly the Asian community if it's younger girls that are coming along, we did get some teenage girls that came and we felt that the parents, particularly the fathers, felt comfortable that there was somebody that they knew. I think the main role is that you're being a role model and showing people that yes it's something they can do for free and you can do it at any time of the day.*" P21

Volunteers spoke about the responsibilities that come along with the role of walk leader, such as making sure all the walkers are safe and that they stay within the group, providing support to walkers and being friendly and talking to people in the group.

"*See one of my roles is in the group is to encourage people to try and spend time with one another, actually I think they do it naturally, you don't have to do it an awful lot, so all that normal stuff in terms of organising a walk, this is where we are going, planning it.*" L15

Some volunteers talked about the constant need to change the walk route to ensure their walkers did not become bored of walking the same routes.

Two further aspects of the role emerged. Practitioners saw lay people as having a key role in contributing to a programme's agenda and shaping its direction. Inclusion of lay people meant that a programme could aspire to become sustainable. This was particularly pertinent in the neighbourhood health project.

"*They provide many roles don't they. I think …they're one of the keys to sustaining the project because we sort of rely on them to actually keep it going when the [regeneration] funding has ended, … they've set up the health and wellbeing network, you know that's, that was always how the project was going to continue, its activities, or some of the activities. We don't expect it to deliver everything but that was how the project was going to continue.*" T15

13.2 Boundary issues

As lay people take up a role in helping to access communities of which they are a part, boundary issues emerge. When working on the scene in the gay community, for example, volunteers had the difficult job of approaching potential service users and talking to them about their sexual health. Not only was this role inherently challenging but also raised the possibility that volunteers would have to confront people who they knew personally.

"*Yeah very much so, you don't go up to them in the gay bar and say how was your HIV test last night. It's a little bit odd respecting people's confidentiality. As a [organisation] worker, you are paid to do it so you do… if you are sat having a drink with your mates and someone who came for a HIV test the other week comes into the bar, it's quite a big ask to say to them don't turn around to your mate and say 'oh I saw him the other week, he came for a HIV test'… it's not just two hours a week [but] it's constantly being aware of not saying anything you shouldn't.*" L20

These boundary issues were not just confined to the sexual health outreach programme, as lay workers and volunteers were likely to encounter people when they were going about their daily activities in their communities. The result was that lay people could feel like they were constantly 'on duty', suggesting that their role extends into their personal and social lives.

"*Yeah and I think it's a real key issue and that's why the girls choose not to work where they live, because I was constantly being invited to children's birthday parties and for my son to come along and it's having that boundary, but you make really good friends so it's nice, but the other side of it is I could be at the school gates and I see a mum and she's 'could I just ask you…' and I have got my son tugging me because he wants to get home to watch TV and I finished an hour ago…*" P12

Practitioners within programmes were aware of the potential for boundary issues, particularly when they were drawing upon people because of their place within specific communities. Confidentiality issues required management, as did provision of support for volunteers.

"*It could also be that somebody comes in that you have slept with maybe quite recently and is coming in maybe for a HIV rapid test and where does that leave you and how do you handle that. So there is a whole million of issues that could come up and kick you or it could be something from your past that comes back, you could be discussing something with someone on the scene and they will say something that triggers a memory in you, and it happens to me, it happens to all of us and you are taken aback for a minute and you say 'I need a break here'. And it's allowing the volunteers, allowing them to actually do that and say 'hang on a minute I am taking 10 minutes', so they can go away from that shift and find a nice quiet place and chill out.*" P29

Related to this was an awareness of the need to be sensitive to lay people's evolving consciousness as they develop within their role. This was particularly pertinent where participation in the programme raised levels of understanding about health inequalities and social injustices faced by communities.

"*I realised some of the factors that would contribute to my health … and felt quite uncomfortable at certain parts because I was just sort of seeing how things had affected my health.*" P9

These sensitivities have the potential to be heightened when lay workers or volunteers came into contact with health professionals, who may inadvertently undermine their confidence by referring to the relatively low level qualifications or refer to their home community in disparaging terms.

"*Sometimes people have been to groups and said that they've come back and felt like they were a bit stupid just because they hadn't got the qualifications that other people assumed …because I think people sometimes assume, if you're working in health, you must be trained formally as some kind of health practitioner.*" P9

There were also boundary issues between the role of lay workers and professional activity, although in most cases these boundary issues were actively managed through developing understanding of roles and systems of signposting. Box 8 contains an extended quotation where a respondent talks about how role boundaries were managed by training in the breastfeeding peer support programme.

Box 8: Managing boundaries in breastfeeding peer support

"A bit like a traffic light system and it's all in the induction training. So green is a normal breastfeeding support, a healthy baby, a normal mother, everything is fine peer support not a problem."

"Where it starts becoming amber is with things like thrush and mastitis and things that could potentially turn medical, these are the bits that the girls need to think 'ok we are now moving slightly away from normal breastfeeding, can I manage this…'. And I'd say normally 75% of the time they can, this is when they'd start communicating with the health professionals, 'I saw a mum today she looks like she has mastitis I'm referring it on'."

"And of course you get your red bits which are just not our remit at all, so you go in and 'baby's got a temperature he's been up al night crying', you know what I mean, he could have a cold or he could have meningitis. As soon as it becomes apparent the mother or the baby is, is nothing to do with normal breastfeeding, it must be referred on either by yourself or you get the mother to do it. And you do find because it's peer support the mothers will ask permission, so they'll ring the helpline 'I don't think he's well what should I do?'. 'Ring the doctor'…"

"So it's that type of thing, so it's very clear and the thing that happens is the longer that you are a peer supporter, they are surrounded by midwives, health professionals, terminology you know, they begin to

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recognise a jaundiced baby, they begin to recognise a hypoglycaemic baby and they begin to know what to do. They need to be able to think 'I need to pull back this is out of my remit', so there is a lot of training around that as to what the barriers, boundaries are." P11

13.3 Managing risk

There were two separate but overlapping risks identified. First, there were risks associated with lay people as individuals. These were risks to their personal safety as well as those risks they potentially pose to service users. The risks to service users were seen as a result of doing their work badly, particularly in comparison to professionals. Risks to personal safety were about entering risky geographic areas, being associated with a community that is subject to abuse or carrying items, such as drugs and syringes that people may want to obtain illegally. Few lay people mentioned being at risk of personal violence and when they did they tried to underplay it.

"I have never felt threatened, well I have, well I have felt slightly threatened but I have never thought because of that experience I'll never do this again." L21

The second kind of risk was associated with the service more broadly, although also involving risks to employees, volunteers and lay people. One notable example of this was in the neighbourhood health project where the volunteers had planned to run a social group where people with leg ulcers would have treatment at the same time as meeting socially, thereby providing an integrated service. This plan was not allowed to go ahead because "infection control was the thing that really was the problem –it wasn't a sterile environment." L24

In contrast to the example of infection control as a service level risk, there was the potential that over-professionalisation and bureaucratisation would make health promotion impossible. Several respondents talked about making the distinction between the support and advice provided by lay people as part of 'normal' life and professional expertise, which was not always appropriate in every situation.

"There's a big distinction between ordinary, you know, choices you make in a shop with your shopping basket and the expertise you need from a dietician because you've got some complicated, you know, medical issue. And it seems to me …if you're going to say anything about food it has to be

run past some dietician and I'm thinking well, you know, come on, we have to make choices and decisions daily." P32

Risk management was primarily talked about as utilising appropriate recruitment, training and support practices. Additional to the risk management processes was recognition of the need to build up an emotional and trusting relationship between services and lay workers.

"*There's an element of trust in any volunteer, that you are trusting them and hopefully you have got to that stage through the training and through the initial selection and all the various bits and pieces that are in place to protect both sides."* P28

Practitioners and managers were able to discuss appropriate boundaries for the work and also the level of professional control. The following quotation about walk leaders illustrates decision making processes and the need to adopt a common sense approach.

"*I mean you could go all the way to doing group assessments like they do in schools when they take groups of children out, that totally negates exactly where they are going to be. But they are actually in the role of the supportive friend in terms of doing this and would you expect a supportive friend to take you somewhere totally inappropriate, you'd expect them to use their common sense."* P19

In the Community Health Educator programme, a balance needed to be struck between managing the risks of an empowerment approach, where lay workers could potentially go 'off message', and the danger of diluting the potential impact of the approach by controlling messages and constraining the creativity of the lay workers. One respondent explained:

"*As soon as we have to sort of regimentalise it, it gets a bit dead … the better qualified they [Community Health Educators] are, the more likely it is that what comes out is a bit sanitised … the key thing that's happening is that somebody is engaging … then we can trust them to say the right things … we want people who are enthusiastic, and who understand the local picture … it may not need to be 100% accurate, as long as it's fairly accurate."* T1

There were different mechanisms for insuring the work of a programme, and lay people within that programme Some services had their own insurance policies and others used those of their primary funder or of the

provider services. One service reported that it had Public Liability insurance, which covered third party claims for accidental damage but would not cover claims by employees.

13.4 Value of lay roles

13.4.1 Perceived benefits

Respondents discussed the value of involving lay people. Some of the discussion was centred on the organisational and individual motivations for engagement and it was difficult to separate these from perceived benefits. Inevitably there is some overlap in terms of the themes, for example, increased capacity was both an organisational rationale and a perceived benefit. The main groups of benefits are listed in Table 26 with illustrative quotations. The bridging role of lay people, who brought their non-professional status and life experience to roles, was a prominent theme. Providing an alternative to health professionals meant that communities not in touch with traditional services were reached and barriers were reduced.

Table 26.   Reported benefits of involving lay people in public health roles

Benefits	Examples
Increased capacity. This increases programme reach and leaves professionals free to do other tasks.	"*Plus we don't have the money, it's the NHS and there's only a certain number of people that we can employ and it's public money we've got to use it effectively and it was found through all the different kind of things that have gone on in the past that using volunteers is one of the best ways forward.*" P17 "*I'd say it definitely has value, it provides a service that I don't think the professionals can provide, not with the time restrictions they're on now.*" L9
Bridging role. Non-professional status reduces barriers between professionals and community.	"*…people are much more at ease and it's not that sort of authority figure that's part of this establishment coming over telling me how to live my life sort of thing, you know it's informal, it's done on the scene sort of thing, your asking when you have finished your pint let's go over and wee into that bottle or whatever.*" P28 "*It allows you to interact with community members who would never in a million years go near the NHS or any other professional service, and in extreme cases have an absolute pathological hatred of authority.*" P1 "*And also they can put themselves in the position of the people who are joining the [walking] group. They often have very similar experiences and needs and therefore they have the understanding that perhaps a professional person*"

Benefits	Examples
	wouldn't have." L19
Better communication as they are trusted and accepted therefore can get messages across.	*"The people are from the heart of communities, so they'll experience all the problems that that community experience so that they've got an inner knowledge and they've often got a trust within a community that a professional won't have."* P9 *"[…] we can talk to them in their own language that they can understand, because we're just normal people. And I think they trust us because we are normal people. And they take on board what we say, whether sometimes we stumble and try and cover it up because we've made a big mistake somewhere, you know, but we're only human at the end of the day. And I think we get through to quite a few people, don't we? Because they trust us. I think it's trust."* L25
Cascade health messages through own family and social networks	*"I can be in my house and the next street along I can see people and I know my own community really well, I know of all the groups I went to when I had kids, all the good ones and what they are like, you know 'this one is good for that age group, or you'll probably enjoy this one because…' and that's because they are near to me and they might not even know about it, but it's at a school down the end of the road and they don't even realise there is a group there…"* L6 *"They tend to get to know your face, you can talk to them in the paper shop, in the queue at the post office. They know who you are. They're not frightened to approach you at a fete or anything like that, they come across, they have a natter with you. And they say, what are you doing? We'll say, we're doing this today, so and so, do you know about this."* L26
Community knowledge can feed in and keeps organisation grounded	*"To make sure that we maintain links with the community. There might be a danger in ourselves being educated … maybe becoming a bit removed from the community so we use volunteers to maintain links with the community and also to give us news because there's such a thing as being in a work bubble and not realising that something else is going on outside in the community."* P27 *"You get people in the community who have knowledge of community issues and they are able to then use that to influence how a project works so it's more relevant for a community, rather than something that a professional's dreamed up that they think people need, but without consultation with the community itself."* T15

13.4.2 Perceived drawbacks

Some drawbacks were identified but these were often specific to an individual case study and generally these drawbacks were not given as much emphasis as the benefits. It is important to note that the case studies focused on the role of lay people and therefore did not examine if similar difficulties were found with the professionals employed in the programme.

One issue raised was that lay people were seen as lacking the knowledge of professionals. This could result in time delays for service users when they were signposted for help.

"*I think the only drawback that I have found, can find, this is very rarely but a lay person's knowledge base within this sector isn't, I would never expect it to be the same as my own, so they might not know something and that can sometimes be a slight barrier because by the time they have got the information they need from me, the person that needed the information has gone or has moved on and gone somewhere else, that can be the only barrier.*" P26

Lay people were seen as potentially lacking an element of 'professionalism' in how they conducted themselves. Professionalism was talked about in terms of consistency and quality of delivery and about communications to others outside the service. Those acting in a 'professional capacity' were more likely to stay 'on message'.

"*When you involve people that aren't part of an organisation you, you are reliant upon them as individuals to stay on message and to have the right information and to portray a professional image of the organisation that they're representing, which is something that you can't control as much as if they're directly employed, of course but er, it's a pretty small risk because the people that tend to volunteer tend to be committed and passionate about what they do anyway.*" T10

Decision making was seen as particularly difficult when lay people were involved as there was a need to keep volunteers 'happy'. Resources were required to train and subsequently support a lay workforce. Support could include continual training but also the time of professionals to monitor and help where required. Some saw lay people leaving as a loss of investment for the programme. In other instances, moving onto paid employment was a natural progression that was difficult to accept in terms of the programme, but at the same time the wider benefits of progression were recognised.

"*Volunteers are there until they get a job. If they get a job tomorrow they say goodbye, I'm leaving. They might stay for a year but they will stay until they get a qualification and then they might leave after that. So it's not stability, it's better if the PCT stays with their own staff because they know they are there and they are committed and they are responsible.*" P16

Reliability emerged as an issue as volunteers could not be expected to be reliable and may fail to turn up on particular occasions or put personal commitments before their responsibilities to the service.

"*Volunteers are more likely to turn around at short notice and say they can't make it because I have got a dentist appointment or whatever.*" L20

13.5 Acceptability to health professionals

As public health programmes, each case study worked with health professionals across their geographic area and in some cases employed them within the programme. Consequently, acceptance from health professionals came up as a particular concern. One problem was a general unjustified dismissal, that health professionals saw lay workers as lacking relevant knowledge and skills.

"*I think some of the professionals boo hoo us.*" L25

"*I think they [lay workers] need credibility, I think they need that, I think a lot of … a lot of healthcare professionals see themselves as the professionals and they know best.*" P23

Failing to gain acceptance from professionals could be problematic. For example, the Walking for Health programme initially hoped to get GP referrals but this proved to be difficult. GPs were sceptical about the scheme saying that it lacked credibility and there were fears about risk and insurance.

"*The GPs were scared because again people making a claim and how can they refer people onto something that they weren't directly in control of, you know, and yeah I think their biggest issue was someone would trip over and fall and make a claim. I found the healthcare professionals quite hard to get around, the community sector, the voluntary sector, you know, most people were open to the idea and said yeah that's logical lets work on it.*" P23

Such difficulties with acceptance were not universal as other examples were given of GPs who were allowing lay people to put up leaflets in the reception areas and to arrange walks that met outside the surgery. In many instances, the scepticism of health professionals had moved to acceptance and support and these findings suggest that acceptability is fluid and something that can be built up over time.

"*I think in the beginning they would rather we hadn't been involved in medical issues or things like that. But gradually – I mean, [name of a member of the PCT]… I mean, he appreciates what we do… we're being accepted.*" L25

Despite the difficulties, lay people saw health professionals as important stakeholders, particularly when they had to work with them. In the following example, a volunteer draws upon ideas of professionalism to defend the credibility of their programme.

"*Every once in a while we get somebody asking why on earth are you doing STI testing in a bar but we can always tell them we've got a fully certified nurse there and it's completely professional, it's anonymous, we're not publishing your names or chatting to our mates about it, stuff like that.*" L22

In another example, a practitioner highlights that acceptability works both ways:

"*I hate to hear the professionals saying 'oh they are only lay people' and I'd hate to hear the lay people saying 'they are always blocking.*" P19

13.6 Community acceptance

The 'community' in which a programme worked was frequently talked about in the interviews. Often the community was perceived as a place where lay workers were accepted. Many reasons were given for community acceptance including because lay people had local knowledge, were of a similar age so experienced same health concerns, or that they talked in a similar language. The neighbourhood health project was seen to have strong links into the community, as this quotation illustrates.

"*Generally the people come from their own community, work in their own community, relate well with the people that they're working, that they you know the clients they're seeing there, then that's what I really think has worked for [neighbourhood health project].*" P33

The difficulties of working with communities that face disadvantage, particularly deprivation, was also highlighted.

"*And I think a lot of it is trust as well. Because a lot of people in [area] don't trust each other. And winning their trust over is a major issue, you've really got to work hard at getting the trust over to them, and that's what we try to battle against all the time, is getting people to trust us.*" L25

Notwithstanding the cross cutting themes about the bridging role, there were suggestions that professionals sometimes had greater credibility with certain groups.

"*[...] sometimes you get that distinct feeling that … [the community is] not really bothered because you're not a professional…*" L25

"*An awful lot of the South Asian community do look towards certain people and give them the respect and stuff if they're trained medical professionals and a) as a volunteer you're not a paid professional but b) it's not medical training. So if the podiatrist did take them on the walk, they would then go on the walk…so half and half of the training used to be volunteers and half paid professionals because to some sections of the community they'd go on walks with those professionals and some would be ok with a volunteer.*" P17

As lay people were often members of the community in which they worked, difficulties with gaining acceptance could impact them individually.

"*And it can be anything down to the neighbours mocking you, look at that, 'she's a do-gooder getting out there and walking all the time' and you can become isolated, there are all sorts of factors.*" P19

As one practitioner noted these were concerns for all those who had a visible role in service delivery regardless of whether they were professional or lay.

"*Quite a number of the full time staff team don't regularly go out on the scene because you are not allowed to switch off, for a volunteer it can be the same.*" P29

As with professionals, there were methods for supporting lay people to deal with what are called 'role boundaries'. The focus was on ensuring that lay people were able to relax when out of role. Alongside the difficulties that lay people could experience, they could also have benefits when they are out of their role: 'If you name drop…, "I volunteer for [organisation]" … I've generally found you get a bit of kudos, a bit of respect, a bit of "oh really"?'.

13.7 Summary

The findings indicate that the primary role of lay people was to provide a bridging mechanism through offering low level advice and assistance in an approachable way. The non-professional status of lay workers was seen as an advantage as it helped reduce barriers to health promotion and therefore programme reach could potentially be enhanced. The contribution of lay workers and volunteers in the case studies was critical to the delivery of the programmes and was seen to increase capacity. Boundary issues were present between the lay person and their community and risks needed to be managed in a sensitive way. With regard to professional-lay relationships, clarity over roles was important and relationships sometimes needed to be built over time.

14 Service user perspectives

One of the study objectives was to examine the perspectives of community members with experience of public health programmes delivered or led by lay people. Interviews with service users were conducted in three of the case studies: neighbourhood health, breastfeeding peer support and Walking for Health. Most of these interviews were conducted in pairs or in small focus groups, and in total 46 service users participated (Table 24). Four of the interviews were with groups of service users from minority ethnic communities. This section presents the findings on public perspectives, looking first how service users viewed the role of the lay workers/volunteers (referred to here as lay workers) within the individual programmes. Further themes emerging include the relationships between the lay worker and service user, the experience of participation in group activities and views on volunteering.

14.1 Role and activities of lay worker

Service users were encouraged to describe the role and activities of the lay workers/volunteers and discuss skills and qualities required for that role. A number of distinct roles were identified which broadly correspond to themes in other interviews. These roles included:

- Supporting and encouraging participation in group activities
- Organising and planning activities
- Facilitating and leading group activities
- Signposting to services and information
- Listening and support
- Cultural mediation (including interpreting).

There were recurrent themes around support roles and providing access to health information or services, although the emphasis was different in each case study. In the breastfeeding peer support programme, service users talked about the provision of personal support but also saw the peer supporters as being able to signpost to other services or sources of information. The access to the 24 hour help line and the provision of 'proactive support' was discussed.

"…they put you through to a support worker and they come and visit you at home if you've got a problem. You don't necessarily need to come down here (to the group)." S2

In the neighbourhood health project, service users saw the role of volunteers as vital to the running of the project and identified a number of roles including helping to arrange for speakers to attend groups, making drinks and serving snacks, making service users feel welcome, helping with the running of activities and giving up their time to listen to service users' problems. This welcoming and caring ethos was seen as important.

"*The volunteers they make the tea and make you welcome. We have a little raffle; we have a laugh and joke.*" S10

A similar picture emerged in Walking for Health, where the role of the walk leader was described as encompassing many different responsibilities. As well as promotion, recruitment and organising walks, some service users also highlighted responsibilities for safety on the walk, such as being prepared to take control if an accident occurred or making decisions about weather. These two quotations illustrate how the fairly extensive responsibilities of the role were viewed.

"*To be a walk leader they should know their pupils, they should know about their health, they should know if anybody falls or injures themselves, they should know about their health. They should be able to help them out if they have any problems or anything. If they need help or professional help that as well.*" S4

"*The walk leaders have the responsibility of getting the people together, writing the names down, how many people are going with her, taking us there obviously like a walk leader getting us to the actual place. Then making sure that we all meet together back at the end again. Getting us all back together and bringing us to the centre and then we leave from there wherever we need to go.*" S3

The role of lay workers in connecting people to either health information or services was regarded as important. Lay workers organised professionals to give talks or other health promotion activities and this appeared to be a natural extension of the role. In one Walking for Health group, for example, the walk leader organised swimming sessions and took service users to health talks at other community centres. Facilitating access to health resources was also achieved through signposting individuals when they had problems or sought information. For example, one peer support worker suggested visits to the doctor or put mothers in touch with other mothers who had similar problems.

14.2 Boundaries of role

One of the key areas for investigation concerned the distinctiveness of the role, and public perceptions of appropriate boundaries for lay activity given that professional-lay boundaries were a potential issue. In fact there was no evidence that service users had anything other than clear understandings of the distinctions between professional and lay roles, with some articulating their own decision making processes when seeking health advice.

"*I've been very clear in my mind what I would talk to the health visitors about and what I would talk to the (peer support) people about.*" S1

"*I think if it's something that's worrying us about health or something like that we'd talk to a professional. Any local advice or something that's easier we would refer to our group leaders because we're used to them.*" S3

Service users also described how lay workers signposted to health professionals as needs arose. It was particularly important to explore this aspect in the breastfeeding case study where peer support workers, both paid and volunteer, worked alongside health professionals. Although only a small number of service users were interviewed, role boundaries between professional and lay support were understood across the interviews.

"*Yes because she tells us like if we have like a medical query she'll actually tell us I can't answer that and she'll advise us to go to a doctor if we're worried about our baby or something. She wouldn't give us medical advice […].*" S2:3

"*She points you in the right direction. She directs you.*" S2:4.

Interestingly, the matter of payment for volunteers was raised by a number of service users. While volunteer status could signal commitment to the community, the mismatch between the extent of responsibilities and the lack of remuneration was highlighted in both the Walking for Health programme and the neighbourhood health project.

"*Well it wouldn't be running if it wasn't for them would it. They've organised it. Well they work a lot in all the sort of voluntary things. And they don't get paid do they, they put lots of hours in and it seems a shame that they don't get anything for what they do. Sometimes they work quite late in the evening by the time they've finished.*" S11

"He does a tremendous amount as it is, we need to value these people and use them." S6

"Because really it is all down to [name] letting people know, making sure the GPs are aware, getting publicity, that costs money, [name] has spent quite a lot of money on various things and he doesn't get anything back for that so it seems slightly unfair if there is obviously a need and if it does help people's wellbeing which it does." S6

14.3 Skills and qualities

Service users were asked what they considered were the qualities required for lay workers. A range of attributes were identified that were related to the social contexts of the different programmes and their local communities. These attributes included types of knowledge, social skills and experiences. One common theme was the need for lay workers to have good communication skills and to be approachable, what was sometimes described as 'people skills', as these quotations illustrate.

"They need to be non-judgmental. They need to be, um, good listeners." S1

"They are the glue aren't they, they keep us all together. [name] is a great communicator, even though I haven't been for a few weeks he gave me a call to see how I am, he makes you feel as though you are part of the group." S7

"She's approachable and she understands our culture as well and that's a big issue." S2

Service users were emphatic that the absence of professional qualifications was not an issue but there were different views on the extent and type of knowledge required by lay workers. For example, one service user believed that individuals should have previous experience of breastfeeding if they were to become peer supporters, but in contrast others emphasised the need for the peer support worker to be approachable, and be able to interpret community languages. In Walking for Health, there were again differences, with some service users talking about the need for some basic level of health knowledge to cope with possible events on walks, while others chose to emphasise the need for local (geographical and historical) knowledge. The need for social and cultural knowledge of a community was considered important in some contexts, particularly where language and cultural skills were considered necessary in order to access health information.

"First of all she's bilingual and I know it's a breastfeeding group but we pick up so many different things as well whilst we're here. So just like health and different contraception and breastfeeding and you pick up on other things like cooking." S2

The idea that lay workers needed to be drawn from within the community was discussed. A range of views were advanced, from those who saw it as helpful but not necessary, through to those who perceived that shared identity was a critical factor.

"I think they need to know the community. That makes the ladies feel more comfortable if they know the person and they get on with them." S4

"Well they want to be here for a start, professional people might only come for the money...I think that's the main thing because they want to be here rather than get a wage cheque at the end of the week." S12

There was some discussion in one of the walking groups of the value of having someone paid who had a base and access to resources such as a minibus, compared to a volunteer who might know a local area well. One person concluded that the ideal would be 'a health promotion person who also lived in the community and was paid but in the absence of that then a volunteer who knows the area very well and who lives locally'.

14.4 Relationship with lay worker

A number of themes emerged relating to the relationship between the lay worker and service user, with many describing their relationship with a named lay worker in very positive terms. Mutual respect was in evidence:

"We don't feel like they're big or in charge. It's the same rule for everyone. Everybody is the same." S5

Some described a very close relationship developed over time, and this was linked to the constant nature of the support.

"Yes because we know them a long time, it's like a family friend now." S3

"*She's like a mum and she gives you support and sometimes you need that.*" S2

The warmth of some relationships was highlighted and many interviewees described sharing a joke or having fun.

"*Well they are really friendly and they are confident with us and we can talk to them and joke with them and everything so it's like that. You can't be with outside people like that.*" S5

The issue of trust was explored in the interviews. Those responding were emphasised trust and often described the boundaries of confidentiality.

"*No they keep it like professional. There's a trust. That's really important.*" S5

"*You can talk to them if you want to. If you want to talk quietly you can go to one side and talk to them. They're patient with you.*" S12

A further theme was the ethic of care demonstrated by the actions of the lay worker in providing assistance or anticipating problems. The caring nature of the relationship was linked to the provision of personalised support to meet individual needs, as this example illustrates.

"*They look after us very well, not that we need looking after but they do. We come here and they, how can I put it, feed us loads of tea and gingernut biscuits. I've not been walking terribly well and one of them would always come over to the shop with me and they still come now even though I've got a walker now.*" S12

14.5 Benefits

The study sought to explore the perceived benefits of involving lay workers within public health programmes and if there were any drawbacks from the perspective of service users. In all three of the case studies, similar views about the benefits of using lay workers were expressed and three main themes emerged relating to being the lynchpin of activities, offering an alternative to professional support, and improved access to support. In the neighbourhood health project, the volunteers were seen as essential to provision as without the volunteers activities would not run.

Contrasts were made between the inevitable limitations on professional time with the time that lay workers were able to give in supporting individuals. It was not simply a matter of capacity, lay workers were seen as offering something additional to professional support, as illustrated by this discussion.

[*I: So what can [name] offer that a professional, maybe a midwife, couldn't offer*?]

"The language, the cultural side of breastfeeding really." S2:10

"Well [name] is always there." S2:4

"Yes you can just call her." S2:3

"I think a midwife would only come for the first few weeks and then after that they're gone." S2:4

14.6 Participation in group activities

Although the primary purpose of the interviews was to explore views on the role of the lay worker, service users talked freely about their experiences within the different programmes. A strong theme to emerge was the benefits from participation in group activities. This was linked to the role of the lay worker in terms of facilitating access to the group or delivering activities. Social benefits were identified in relation to all three case studies. Typically service users described the value of getting out of the house, meeting people and making friends. In some cases this had led to a reduction in social isolation and connecting to wider social networks within their community.

"I did yes find it helpful. I made new friends, it got me out of the house or else I would have gone mad at home, it stopped me from going crazy and walking round like a zombie." S2

"Yes and it makes a difference because you know a lot of people so if you see people on the street you can say hello because otherwise I'd just be stuck in not speaking to anybody." S12

The social aspects were motivating in walking groups; walking with other people made the experience much more pleasant, with all the ingredients of 'an enjoyable morning out rather than a trip to the dentist'. Service users were more at ease and they were likely to cover longer distances. The issue

of personal safety was also raised as walking groups were seen as offering a safe way of taking exercise compared to walking alone.

Other identified benefits across the three case studies included access to health information, such as having health professionals giving talks, gaining local knowledge and the physical benefits of exercise. Peer support gained from the groups, as well as the lay worker, was seen as valuable. For example, one mother spoke of the benefits of sharing problems with other mothers.

"*I got a lot from people just saying 'oh yeah, I went through that. I remember when that happened, and you know, it doesn't last forever and just keep going another couple of weeks and see how it goes'.*" S1

One interesting theme to emerge was the participation of service users in the planning and delivery of activities. In many cases individuals described taking an active role in the groups through having a voice in planning, offering peer support to other service users, or in helping with organisation. In the neighbourhood health project, most of the service users interviewed were also on the community committee and were actively involved in the planning of activities and in assisting with delivery, for example, collecting money at the beginning of an exercise class. They also helped to recruit service users for their health walks, talking to members of the community and by putting up posters. Their inclusion in planning activities was discussed.

"*You can go to them with an idea of something and they'll say well that's a good idea, what does everybody feel. And then if everybody else feels the same way then you know [name of volunteers] will arrange it.*" S12

While this high level of service user involvement might be expected of a community organising model, it was also a reported feature of some of the walking groups, where participants were routinely consulted on additional activities or where individuals helped recruit people, organise aspects of the walks or offer peer support.

14.7 Transition to volunteering

The picture that emerged was of one where a number of service users were currently engaged in some volunteering activity or had experience of volunteering in the past, including taking on roles within the programme, often to assist the lay worker. Interviewees discussed the transition to volunteering, or alternatively why they felt unable or unwilling to volunteer

at the present time. In some cases, project leads or the lay workers had asked for assistance with running of activities or additional capacity was needed. One individual who helped with walks described her motivations.

"*He knew that there was a walk leaders course coming up and he said 'why don't you do it', and I thought well I'm not working at the moment and if he has a health issue he doesn't know what is round the corner, so the group wouldn't have to stop because there is no one here to take it, so I am doing it primarily to be a backup for [name] and if we need another walk in the week.*" S6

Some service users described not wanting the responsibility that comes with being a volunteer while others were 'willing to support but not to lead.'

"*I'm happy to help, taking the back post of the walk and stuff and making sure everybody is alright, I'd quite like to help and I'll quite happily communicate things but I wouldn't particularly want to be a leader.*" S9

Altruism, expressed as a desire to give something back to the community, was identified as a motivation. This was a prominent theme in the neighbourhood health project, with many service users engaged in other community activities.

"*I do a lot of it (volunteering) in [area] because I think I've had a good life there and I'm putting something back, simple as that really and I've got time to do it now so I do whereas when I was working I didn't have time.*" S11

Several people described a transition to volunteering where their personal need to have more social contact had motivated them to seek volunteering opportunities. Those who were volunteering described the enjoyment and the sense of achievement for doing something for the community. One mother in the breastfeeding peer support programme highlighted the reciprocal nature of volunteering.

"*It's just helping other mums to be honest. Obviously advising them and just being there for somebody because I know how it felt when I came.*" S2

A number of barriers to becoming a volunteer were identified, some of these were quite specific to individual circumstances, such as physical limitations

or health concerns. A recurrent theme was the pressures of family commitments.

"*Well that's the only thing a lot of people have got commitment and they can't be bothered to do voluntary work cause they've got families, they've got children, grandchildren, they're running shopping and they're doing work for other people. It's a shame we just couldn't get more people to come out on the walks.*" S11

The 'paper work', CRB checks and being asked to be on a committee were seen as barriers. Formal processes of training and registration had a profound impact on the engagement of those who were not able to read or write English. One Asian service user described how she wanted to become a walk leader but felt she could not take the opportunity up because of the literacy levels required for the training course. Another stated:

"*So to be a walk leader you need to write names and to take names and things like that. We both have difficulty with writing so it would be hard for us, so I don't think we'd be able to.*" S4

14.8 Summary

The interviews with service users provided some illuminating insights into how lay workers support people within public health programmes. What emerges is a picture of lay workers and volunteers carrying out extensive duties, covering a range of responsibilities to support the activities and people's engagement in those activities, but at the same time able to offer highly personalised support if required. Lay workers were seen as essential for delivery as well as well as offering benefits in terms of access to health information and cultural support. While service users articulated clear distinctions around the boundaries between professional and lay roles, a more complex picture emerged regarding lay engagement in community activities. Many, but not all, service users valued participation in planning and supporting activities and in other volunteering roles.

15 Public involvement

The study was undertaken as a partnership between Leeds Metropolitan University, NHS Bradford and Airedale and the Regional Public Health Group, Yorkshire & Humber. The research partnership enabled the research team to form strong links with public health practice and ensured that the implementation of the study reflected the real life concerns faced by practitioners and members of the public. The study was also underpinned by recognition of the distinctiveness of lay knowledge and the intrinsic value of incorporating lay perspectives (Williams and Popay, 1994; Entwistle *et al.*, 1998). There was a commitment to the core values of community practice in terms of respecting diversity, collaborative working and mutual learning (Banks, 2003). The research team actively sought dialogue with practitioners and members of the public and this section briefly describes the main public involvement activities, which took place in two distinct phases.

15.1 Shaping the research

NHS Bradford and Airedale has a long history of supporting schemes involving lay people in the delivery of public health activities and was one of the early adopter sites for the Health Trainers initiative. To ensure that lay views were genuinely reflected in the study, practitioners from the PCT, who were then based in Bradford District Health Development Partnerships, led the initial public involvement work in the first year of the study. This involved a series of inclusive and interactive workshops with front-line practitioners and volunteers where the research team were able to engage interest in the study and harness ideas. The first workshop was held in December 2007 with staff from both public and voluntary sectors who were working directly with lay workers and volunteers.

A further event was held in May 2008, which brought together people who were volunteering in community health activities or were active through patient and public involvement structures, along with some front-line practitioners. A number of geographical and communities of interest were represented, including the South Asian community and people living with long term conditions, all of whom were active in health promotion. Care was taken to organise the workshop in a way which put participants at their ease and enabled them to share their experiences and views in a relaxed setting. As part of the workshop there was a live radio broadcast by Bradford Community Radio which highlighted the many and varied ways in which lay people were contributing to public health in the district, as well as the study itself. One of the objectives of the workshop was to enable lay people to

take part in the expert hearings and following participation some of lay people volunteered to take part; this resulted in one individual presenting evidence as an expert witness and one sitting on the enquiry panel.

A number of areas for investigation emerged from the initial public involvement work, which were incorporated into the expert hearings, via the enquiry panel:

- Why do people get involved? Why do they stay involved?

- Obstacles to involvement, including issues of payment, expenses and impact on benefits.

- What are the pathways for individuals gradually getting involved? Why do some people move through to formal roles?

- Why people choose not to take on roles and the ways that people are socially excluded.

- Some groups are community-led. Do they need 'interference' by public health or are they more effective if left alone?

- Differences between large community organisations and small, local level activities.

- The need for greater dialogue and partnership between sectors and community members, particularly to avoid replication of activities and undermining of those being organised and delivered by community members.

- The need for joined-up thinking in relation to commissioning.

15.2 Views on dissemination

The second phase of public involvement took place towards the end of the study in collaboration with NHS Bradford and Airedale. An informal consultation with stakeholders was conducted to explore their views on 'how the findings from the study should be presented and disseminated so that they are most likely to be accessed and used to inform practice'.   This involved informal one-to-one interviews with commissioners and managers from the NHS and other organisations. In addition, a meeting was held with three of the volunteers together with three of the practitioners who had been involved in the lay workshop in May 2008. Respondents were keen to be able to use the evidence from this study in their practice and were able to make a number of recommendations for dissemination. The key points coming out of the consultation included the need to present findings that relate to the realities of the target audience, whether they are commissioners, practitioners or volunteers. It was also seen as important

that the study findings were placed within a broader framework of values such as prevention, equity and empowerment.

15.3 Themes from public involvement

Throughout the study, the research team listened to many people with relevant first hand experience. It was evident that people feel passionate about the role of lay people in health improvement and there is a real sense of commitment to the work going on within different communities. The People in Public Health study was recognised as raising the profile of this type of work and everywhere we went the response to the study was positive. In terms of public involvement in the research process, there was a consensus that this would be best achieved by 'getting out there' and talking to people on the ground about their experiences and organising one-off workshops, rather than by representation at formal meetings. While the public involvement activities were very successful, it is salutary to reflect that many individuals reported feeling very remote from academic research.

The study investigated a specific type of lay engagement, that of people engaged in the delivery of public health activities as lay workers or volunteers. In practice, the people who were consulted as part of the study reported that it is difficult to separate out different types of community engagement and one activity frequently connects to another. Labels can be artificial, for example, many individuals contributing to community health would not recognise that contribution as a 'health' role, and many people who are formally involved through patient and public involvement structures started out supporting a community health initiative. The term 'lay' is used within research and policy, sometimes in preference to 'community' because it is less ambiguous and does not indicate collective action, but it is not recognised by the general public as having much meaning. One individual noted that it should be avoided as it can have religious overtones. INVOLVE (Buckland *et al.*, 2007) recommend 'members of the public or public' but again there is potential for misunderstanding within the field of *public* health. This absence of a shared terminology in current public health practice is a major challenge, particularly because the term 'volunteer' excludes the work of people who receive some form of payment.

15.4 Summary

The public involvement work added an important dimension to the study. It gave the research team ideas and topics for further investigation, provided suggestions for ways of framing issues and raised considerations regarding the implications for public health practice. The research partnership was a genuine academic-practice collaboration that provided a firm foundation for the study, leading to findings of relevance to policy and practice. We believe

that this partnership model, and some of the methods used for public engagement, have enriched the study and provide a transferable model for other research.

16 Discussion phase 2 – case studies

Phase 2 investigated lay engagement in public health delivery and related organisational issues. This section discusses the case study findings and considers their significance for public health practice. It starts by outlining the strengths and limitations of the research.

16.1 Limitations of case studies

The case study design offered a way of constructing a rounded picture of a series of public health programmes where members of the public were involved in delivery, either as lay workers or volunteers. These programmes were selected because they reflected certain features found in the literature review. The case studies explored how lay roles developed within those specific social contexts. The five cases cannot, therefore, be seen as representative of current public health practice. Indeed given the complexity of the study topic and the different dimensions of lay roles uncovered in the scoping study, it would be difficult to select projects that provided 'typical' approaches. Evidence was presented on three of the cases at the expert hearings. This can be seen as a strength in terms of building explanations based on triangulation, but there is a risk that these are atypical or extreme cases. Liaison with practice and the site visits confirmed that this was not the case and the final sample did reflect organisational patterns and priorities within current public health practice.

The extent to which the five case study programmes matched the models identified in the literature review was the subject of investigation. Community organising, bridging and peer support models were represented but the case selected for peer education involved awareness raising and signposting rather than delivery of a traditional educational component. There would be scope for further research to conduct a case study of a more formal peer education programme based on changing knowledge, skills or behaviour.

One of the strengths of the study was that a range of different perspectives were sought. There were relatively few problems in terms of access and recruitment due to the high level of support from the case study programmes. In fact data collection exceeded the original targets. The sampling strategy was very dependent on key informants within the different sites and there may have been a motivation to present a positive picture through selection of respondents. However, different perspectives were sought and negative voices were heard in the interviews. There are significant challenges in getting the views of those people, both lay and

professional, who were only marginally involved or dropped out of activities, although these individuals may have interesting experiences to relate. It would also have been useful to have interviewed more health professionals to ascertain their views.

Obtaining the views of service users was difficult because of the nature of the contact between lay workers and the target population. It was not possible to obtain any service user views in two of the case studies because of the brief nature of contacts and the context of the work. In the case of the sexual health outreach programme, some bar owners were approached but declined to participate. The largest number of interviews were conducted with Walking for Health because these were established groups with a regular membership. Despite working closely with the breastfeeding peer support programme and attending a number of parent groups, only a small number of service users were interviewed. This was due partly to attendance patterns at groups and partly because the group setting, with many mothers and small children present, was not ideally suited for interviews. There is scope for further research to gain a more comprehensive picture of service user views, especially from programmes not based on group activities.

Notwithstanding methodological debates about the extent to which case studies can be generalised (Flyvberg, 2004), the study was able to illuminate key processes and understand roles in real life situations. This enabled some conclusions to be drawn about how and why lay roles work and the factors influencing programme delivery and sustainability. While there were differences between the case studies, as would be expected, there were also common themes emerging about supportive and constraining processes. A rigorous process of cross case analysis made it possible to identify overarching themes and therefore some of the results will be transferable to other contexts of practice.

16.2 Lay workers in practice

One of the objectives of Phase 2 was to examine whether the models and role dimensions identified through the scoping study were reflected in the organisation and activities of actual public health programmes. The sample of cases was designed to illustrate the four main models (peer support, peer education, bridging and community organising) and have maximum variation across explicit features (Patton, 2002), such as setting and target population. The case study results confirmed earlier findings from the scoping study that there are inherent difficulties of categorisation because of the variation between and within programmes, and because of the complexity of relationships between social actors. The main models provided adequate descriptors of core roles but as was expected lay

workers/volunteers were carrying out subsidiary roles within the specific programmes.

A further theme was that bridging roles were prominent in all of the case studies. Practitioners and commissioners were utilising lay experience and social networks to reach communities. Lay workers were cascading information in their communities and being the 'friendly face' of the programme and service users reported being signposted to services and support. Moreover, some of the bridging was two-way, in that lay workers provided a mechanism to draw in community knowledge into organisations. These themes directly relate to arguments advanced in international literature on lay health advisors and community health workers (American Association of Diabetes, 2003, Baker *et al.*, 1997, Rhodes *et al.*, 2007). Despite the differences in context, it appears that broadly similar mechanisms are being utilised to promote greater equity in health. It highlights the need for more evaluation, given the gap in research around bridging approaches in the UK.

Core roles found in practice reflect roles identified in Phase 1 and included:

- providing health information

- providing direct services or activities

- social and peer support

- promoting access to services or signposting

- cultural mediation and interpretation.

One aspect not reflected in the literature review was the diversity of activities within case study programmes. Even single activities, such as leading a walking group, could encompass a number of roles and involve fairly extensive responsibilities. Where multiple activities were undertaken, the composition and boundaries of the intervention were not always clear, and this will have implications for evaluation. Some of the activities undertaken by lay workers might be seen as merely 'helping out', but there were many instances reported where this type of support was both essential to delivery of activities and valued by service users who reflected on the social and health benefits of attending groups. This again supports the notion that the bridging role is the key mechanism within these programmes.

The role dimensions that were identified in Phase 1 help explain variation in programmes. As well as the more explicit features such as target population, sector or payment model, the case studies illustrated how relationships were constructed between professional, lay worker and

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community within the context of programme organisation and structure. In comparing the dimensions identified through the literature review with the features of the case studies, some dimensions appear to be useful in distinguishing programmes:

- The relative autonomy of the lay worker and the extent to which the programme was linked to services. For example, lay workers/ volunteers were largely autonomous in the neighbourhood health project and Walking for Health, but the breastfeeding peer support programme was part of an integrated service.

- The relative focus on peer development or peer delivery (Shiner, 1999), which was linked to the variation in training. For example, the Community Health Educators programme was based on an empowerment approach where personal development was sought, whereas Walking for Health involved a short one-day training course to equip walk leaders to organise walks.

- Whether the programme was based on natural (embedded) or created social networks (Dennis, 2003). Some programmes were based on the premise that lay workers/volunteers would access their natural networks, for example, the gay scene. Other programmes were helping create new networks, such as parent support groups. While these differences have implications for recruitment, it was largely a matter of emphasis as, even within natural communities, groups could be created and networks strengthened.

- The type of knowledge and expertise sought. Again this was a matter of emphasis about the extent to which lay workers were matched to the target population in terms of attributes (peer status) or common experiences (Andrews *et al.*, 2004).

Other dimensions identified in the literature review did not provide a strong basis for categorisation in the case studies. For example, the extent to which lay workers delivered an intervention or were the intervention by acting as role models did not help distinguish the case studies, as these elements were present in all to a greater or lesser extent in the programmes.

16.3   *Factors affecting service support and sustainability*

The case studies investigated the ways that public health programmes dealt with the development and support of lay people. Organisations and practitioners evidently had a role in recruiting lay people, facilitating their transition to a public health role and supporting them in the delivery of programme activities. This took place in a wider organisational context where programmes were funded, service specifications developed, and

structures for delivery were established and maintained. Through the cross case analysis, it was possible to see patterns and identify factors that were shaping both individual journeys and programme capability and sustainability. Indeed, in many ways, the individual journeys of lay people were at the heart of issues around sustainability. This was not evaluation research able to test the links between mechanisms and outcomes, so conclusions cannot be drawn about the effectiveness of methods of professional support. Notwithstanding that limitation, the case studies were able to identify key processes and trace how those affected the participation of lay people.

16.4 Taking on a public health role

All five programmes were considered successful as they had developed, evolved and reached a maintenance phase. At a most basic level, this required the ability to recruit and retain volunteers or lay workers. Motivations for members of the public taking on health roles reflected the reasons advanced in the scoping study. Altruism was the strongest theme, expressed as a desire either to help people or to put something back into their community. This was taken to an even deeper level in the neighbourhood health project where a model of citizenship was being implemented, with the volunteers forming a health network and participating in democratic structures to develop new work. Other motivations included employability, social benefits from meeting people and being at the right time in life, such as becoming a mother or entering retirement. These findings are supported by wider literature on volunteering (Brooks, 2002, Low *et al.*, 2008, Wilson, 2000).

Not all models in this study were volunteer models but payment did not seem to be an influencing factor and was not found to interfere with the personal contribution made by lay workers. Instead, what emerged strongly from all the case study was evidence of a high level of commitment and sometimes passion for the work. Some lay workers and volunteers took on responsibilities far beyond their role in terms of putting in hours, providing extra activities or supporting individuals. Although it was likely that the research team heard the more committed voices, this theme was echoed by practitioners and by service users. What drives and sustains lay workers is, therefore, not just what professionals and services do but also their own agency in making a contribution to public health. This is a key finding from the study and one which has implications for understanding the role of public services in nurturing that gift of time and assistance freely given. Moreover, positive or negative experiences as a service user can be a motivating factor. The case studies show that people are able to move from participant to volunteer to community leader given the right opportunities and support. Service users frequently helped out in groups and while this activity cannot be viewed as a formal role, it indicates that participation in

public health programmes can occur at many levels (Taylor, 2003, The Commission on the Future of Volunteering, 2008).

Recruitment methods varied between the programmes, but like the results of the scoping study, the most effective methods were reported to be personal contact and use of community networks. Some of the programmes exhibited very successful recruitment strategies, with new recruits coming through to replace the inevitable turnover, but others struggled to gain new volunteers. There were no examples of community-led recruitment, as described elsewhere (Jackson and Parks, 1997; Watkins *et al.*, 1994), although social networks were used.

Service users threw light on some of the reasons people chose not to volunteer, such as disability and family commitments, again reflecting other literature (Niyazi and National Centre of Volunteering, 1996; The Commission on the Future of Volunteering, 2008). Whereas some service users did not feel able to volunteer due to language barriers, there was also an example of where a programme had supported someone who was unable to write to successfully apply for the role. There are evidently still barriers that need to be addressed to support the participation of people whose first language is not English and this links to themes raised in the expert hearings. A further issue was the perceived problem of CRB checks for some potential volunteers with mental health problems, again resonating with earlier findings. More research is needed to look at reasons why people choose not to be involved in public health and whether barriers to recruitment can be removed, particularly with groups who experience social exclusion.

Selection processes were generally relatively informal and this was seen as helpful, supporting findings from the expert hearings. It was interesting to note that in some instances activities ran with quite small numbers of lay workers. There remain questions about whether it is better to have high recruitment and accept turnover as inevitable, or to focus efforts on smaller numbers who receive intensive support. This has implications for scaling up programmes and understanding the costs and benefits of different approaches to recruitment and selection. Achieving the right balance may be critical for retention of lay workers and ultimately programme sustainability. There is the potential in a large scale programme, such as Walking for Heath, to evaluate different models and compare the intensive approach with one based on wider recruitment but allowing for more attrition.

16.5 Skills and qualities

We were keen to explore skills and qualities of lay workers because this has implications for selection processes and training. Despite being a key process, the literature review had revealed that very few papers reported educational level, and there was a dearth of literature evaluating training. Some strong themes emerged in the case studies about skills, with an emphasis on valuing the skills people bring to their role in terms of life experiences and ability to relate to people. Views on required knowledge and skills for the role were similar across the case studies and in the interviews with service users. These skills could be grouped into:

- Social skills, being approachable or having confidence to talk to people
- Communication skills, like listening skills
- Language skills and cultural insight
- Non-judgemental attitude
- Enthusiasm and commitment
- Caring approach
- Local knowledge

Clearly these social skills and qualities are based on a recognition that lay perspectives and experiences have value and meaning within the context of health (see Entwistle *et al.*, 1998; Popay *et al.*, 1998). That is not to suggest that all these attributes are somehow commonplace, as some of the skills required, for example, to talk to men about sexual health screening in social venues and be able to anticipate concerns, require a high level of social competence. As a set of skills required for public health roles they bear very little resemblance to the competencies set out in the current Public Health Skills Career Framework for Levels 1 & 2 (Public Health Resource Unit and Skills for Health, 2008), which is based on the accumulation of skills through the different levels of professional public health practice. The case study findings indicate that personal and social skills are integral to lay roles and complement any 'professional' development. There are clear implications for selection, training and ongoing development as programmes need to recognise, foster and enhance these social skills and personal qualities. Indeed, much of the training in the case studies was focused on personal development and building confidence and communication skills, in addition to training on specific health topics. Additionally, the value of experiential knowledge should be recognised as complementary to professional expertise. Inappropriate professional training could potentially lead to bridging roles being less effective (Love *et al.*, 2004).

The requirement for local knowledge and the question of whether people need to be drawn from the target community was explored but it was

difficult to draw firm conclusions. In most of the programmes, the majority of lay workers were drawn from immediate communities and in many cases were true peers, in terms of matched characteristics such as age, ethnicity or sexual orientation. However, as an attribute for carrying out a public health role, being from the same community was more often considered helpful rather than essential. This finding contrasts with other literature, for example, the definition of community health workers used by the World Health Organization (2007:1) which states that they: 'should be members of the communities where they work, should be selected by the communities, should be answerable to the communities for their activities'. Local knowledge and shared experiences can be a basis for performing a bridging role so it is somewhat surprising that this was not seen as the most critical factor, rather it was lay workers' ability to relate to people and their non-professional status that was valued above other qualities. The distinction between communities of place and identity is pertinent here (Campbell *et al.*, 2008) and the findings suggest that a more sophisticated analysis of how 'community' is interpreted in relation to lay roles is required.

16.6 Support and development

In examining the mechanisms that case study programmes used to develop and support lay workers, a number of factors can be identified. Training was a key mechanism not only to equip people to undertake the role but also in terms of supporting their progression either to higher levels of activity or through to other roles within or outside the organisation. These training opportunities were appreciated by lay workers who felt valued. The patterns of training varied from short courses to extensive training and this again reflects findings in the scoping study about the variation in content, duration and approach. While some literacy barriers were reported, there was evidence that people from a variety of backgrounds had been able to access training and some of the problems highlighted in the expert hearings around appropriate levels did not emerge. Overall training is a key process within any intervention involving lay workers, both at induction and through ongoing training opportunities. There is value in considering training as part of broader strategies for recruitment and workforce development.

It was not surprising that support systems, in particular support from practitioners involved in the programmes, were regarded as a critical mechanism to support delivery. This confirms findings from the scoping study on support and links to some of the wider literature on volunteer management (Gaskin, 2003; Hawkins and Restall, 2006). Receiving support helped lay workers feel valued and peer support from other lay workers was also in evidence. In all the case studies, examples were reported of how support and development after initial training enabled people to progress both within the organisation to higher level roles and as a way back to other

paid employment. This confirms earlier findings about wider benefits and the potential for people to move into the workforce.

One interesting finding was the use of training and support mechanisms in relation to the management of risk and role boundaries. Some of the activities undertaken by lay people appear low level, but there is a degree of responsibility and, moreover, personal issues can be raised for lay workers as they try to assist service users. Practitioners spoke of a need for trust and articulated anxieties about people being 'off message', so that handing over to volunteers could, as one respondent explained, be 'scary'. The findings suggest that risks and boundary issues are inherent but these can be successfully managed through training and through support mechanisms. The sexual health outreach programme offers a useful example in that there was an acknowledgement that risks would occur because of the autonomous way volunteers worked. Training, both the induction and the requirement to attend further sessions, was seen as a mechanism for managing risk by keeping people up to date and clear about role boundaries. This was complemented by a light touch support system where lay workers could contact practitioners 'back at the office' when there were concerns or they wanted to talk.

The effectiveness of specific training and support systems were not evaluated and there are questions, not only about what levels of support are needed, but how a balance can be achieved between support and professional control. Gaskin (2003) notes that volunteer support is different from workforce management as choice, flexibility and informality need to be retained. Findings demonstrate that it is possible for these risks to be actively and successfully managed, leaving people with clear understanding of their roles and well supported to do the tasks in hand. These findings suggest that training, development and support needs to be considered as part of the commissioning process, not only because there are direct benefits for lay workers, but also because some of the more thorny issues around role boundaries, risks and quality assurance can be managed through support processes.

16.7 Rewards and remuneration

In the scoping study, the issue of remuneration was found to be a contested issue. One of the considerations in selecting the case studies was to be able to study different approaches to payment and rewards. What is clear from the findings is that there are very different approaches to remuneration and there are valid reasons for adopting different approaches that are linked to the specific contexts and the needs of volunteers. It was suggested that some form of payment may have some advantages in terms of helping with employability, supporting people on low incomes, indicating value, and assisting with retention and therefore sustainability (see also Leaman *et al.*,

1997; Schulz *et al.*, 1997). On the other hand, sessional payment has costs, there may be equity issues as lay workers take on different levels of responsibility, it needs management with people on benefits, and in addition, payment can potentially undermine the ethos of volunteering.

A further issue about fair rewards for the work undertaken was raised both by volunteers and by service users. This theme concerned being valued for their contribution and suggestions were made that some small rewards would be appreciated. The implications are that a flexible system of rewards should be considered in programmes involving volunteers, perhaps using rewards in kind rather than financial payments. The overall conclusion is that programmes need to consider all the options around remuneration and rewards and be prepared to consult with service users about options.

16.8 Commissioning and link with health services

The case studies were undertaken at a stage when new commissioning arrangements for public health (Department of Health, 2007) meant that robust systems were still in the process of being developed, and in one specific case processes were so undeveloped that the commissioner felt unable to take part in an interview. All the case studies received some NHS funding, but it was a complex picture in relation to how the delivery organisation was funded and which activities were commissioned through the health service. The NHS commissioning process was in most cases at arms length from delivery and management of the programmes; the local Walking for Health programme was the only case study co-ordinated by NHS provider services.

The distance between commissioning and delivery can be seen as giving provider organisations the necessary freedom to develop lay activity to meet community need. Third sector organisations also offer a wealth of experience in working with volunteers and lay workers. Indeed, one commissioner described a delivery organisation as the 'experts'. There were, however, gaps in terms of funding and organisational infrastructure to support and sustain lay activity. With one exception, primary care trusts appeared to have little involvement in either commissioning or supporting wider training and development opportunities, yet paradoxically it was these support mechanisms that were identified as being critical for managing risks, for example, delivering inaccurate health messages. The implications are that commissioning processes need to have a broader focus and consider the sustainability of programmes. These themes linked to issues highlighted in the expert hearings on the importance of securing long term funding to develop and support community participation.

There were found to be tensions between business models that satisfy NHS demands for professional control and the passion of lay–led models where empowered lay workers/volunteers are out in the community delivering activities with enthusiasm and commitment. The tension between community mobilisation for empowerment and community mobilisation to reduce service costs has been noted elsewhere (World Health Organization, 2002). Location of services outside the NHS can allow a more community centred approach to develop, yet the question of sustainability was raised. In the neighbourhood health project, despite an aspiration to get high levels of community involvement to achieve sustainability, overstretched volunteers were described as having to consider becoming more like managers and administrators to draw down funding. This echoes some of the themes in the expert hearings about the need for small grants to support community engagement.

In terms of relationships with the operational end of health services, these varied depending on the context, as some projects operated very autonomously. The scoping study had found that boundary issues could arise and professional resistance might be encountered (Neuberger, 2008). In the case studies, there was little evidence to support this, although this finding has to be viewed with caution as there were relatively few interviews with health professionals. A common story was initial scepticism then the development of functioning relationships with health professionals. Moreover service users were very clear about distinctions between roles and the value of non-professionals. There was little evidence that clinical services were actively promoting these programmes, with the exception of breastfeeding peer support, although this aspect was not explored in depth. There is scope for further research about how effective links can be formed between healthcare services and community-led public health programmes.

16.9 Value and acceptability

The scoping study found good evidence from different sources of a strong rationale for lay people taking up public health roles. In the case studies, stakeholders' views on value and acceptability were further explored. The conclusions are that there are both pragmatic and value-based reasons for involving lay people in delivery. Service users not only valued the contribution of the lay worker but reported benefits from participating in group activities. These findings indicate that there is some level of public acceptance from those directly involved in the projects, but it would be useful to undertake more research about acceptability, especially with people choosing not to participate. There is also scope for further research on acceptability and barriers to volunteering for minority ethnic communities. Boundary issues and confidentiality were raised as issues facing the lay workers in their own communities but service users reported that they trusted their worker. There was evidence that acceptance by the

community could bring its own pressures but again support systems helped lay workers manage this.

One of the strongest themes related to the bridging role was the non-professional status of lay workers, coupled with local knowledge of community culture and networks, as it allowed programmes (and ultimately health services) to connect into a community. The social skills brought by lay workers and the lack of professional status meant that service users felt comfortable and this facilitated their participation. There was a reported ripple effect out to the community, particularly those communities described as hard-to-reach, but also lay workers were a conduit for community views to be fed in to organisations. Lay workers were considered the lynchpin of activities and without their contribution many activities would not run. This frees professional time, but more critically, some respondents connected capacity with reach in that more people could be reached and drawn into health promoting activity.

A further issue was the gap between the goals set by primary care trusts in terms of targets and the type of benefits resulting from these approaches. All stakeholders identified a range of health and social benefits both to the lay workers and to service users including health literacy, knowledge of communities, changes in health behaviour, reduction of social isolation, enjoyment, employability and empowerment. This confirms findings from a recent systematic review on volunteering (Casiday *et al.*, 2008). Benefits could also cascade out to families and friends through various means, such as providing role models. The perspective that lay approaches work primarily as a bridging mechanism, and that there are significant social benefits, appears somewhat at odds with commissioning focused solely on health behaviour targets such as obesity. Several commissioners, while supporting the need for more robust evaluation, suggested that more sophisticated ways of capturing outcomes should be developed to capture long term change and the wider impact of these approaches.

16.10 Summary

The case studies illuminated a number of issues pertaining to roles and organisational processes. While these public health programmes cannot be seen as exemplars, they do illustrate the main challenges and the mechanisms that support lay people on their journey. The findings support many of the themes uncovered through the scoping study around role dimensions, value of lay involvement and variations in public health practice. Factors affecting the sustainability of public health programmes included the commitment of lay people, the provision of training for delivery and for development, systems to provide personal support to lay workers, offering rewards, and strategic level support. Bringing lay activity into public health delivery raises issues for commissioning and for practice. The

findings have highlighted the need for common sense solutions that remove barriers but do not increase professional control whilst maintaining or enhancing the quality of public health services.

17 Conclusions and recommendations

The 'People in Public Health' study sought both to synthesise evidence in a complex area of public health practice and to improve understanding about how services can best develop and support members of the public involved in delivering public health programmes. The broad aims of the study were to:

- improve understanding of valid approaches to identifying, developing and supporting lay people who take on public health roles in community public health activities
- undertake research on public perspectives regarding the acceptability and value of lay people in public health roles
- aid public health commissioning and planning by identifying elements of good practice and how these might be applied to different contexts.

This final section of the report assesses whether the original aims and research objectives have been met, discusses the limitations of the study and draws conclusions. Recommendations are made for policy and practice and for future research.

17.1 Approaches to involving lay people in programme delivery

The starting point for the investigation was the growth in the number of public health programmes that were involving members of the public in programme delivery and the need to understand the different patterns of development, organisation and support. A key research objective was to undertake a scoping study on approaches to involving lay people in public health roles. This was achieved through a systematic scoping review of the literature, a series of expert hearings and contacts with current public health projects.   What emerges from that scoping study is a picture of diversity in practice. Approaches involving lay people are being applied across a range of settings, target populations and health priorities. The study findings demonstrate the adaptability of these approaches to different contexts and communities.

The plethora of terminology describing roles and the inherent ambiguity of concepts, such as 'lay', is challenging. On an individual programme level, the title of a role is not an issue as long as stakeholders, including service users, understand the nature of that role. Within the public health system, however, multiple terms can be a barrier to exchanging learning across

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practice and to building an evidence base, especially where there is a need to compare the effectiveness of interventions or modes of service delivery. Furthermore, our public involvement activity highlighted that the academic term 'lay' has little meaning for the public, yet the terms 'service user', 'volunteer', 'members of the public' do not really encapsulate the full range of independent community-based activity seen in this study. Until the community of practice develops sufficiently to share a common language then programmes need to be clear about the dimensions of specific roles and make explicit where there are similarities or differences to recognised models.

17.2 Rationale for involving lay people in delivery

In order to improve understanding of valid approaches, evidence was collected on justifications advanced for lay involvement in programme delivery. Here there was triangulation of evidence from the scoping study and the case studies around the various rationales for involving lay people. Some drawbacks were also identified including reliability of volunteers, challenges in recruitment, the impact of turnover, and boundary issues with communities. Overall the findings indicate that there are sound reasons for public health programmes and health services to engage members of the public in delivery, either as lay workers or volunteers. In summary, the main justifications are to:

- provide an essential bridging function reducing barriers between services and communities, particularly where groups are at risk of social exclusion
- reduce communication barriers as lay workers have the potential to reach some communities that professionals cannot
- increase service capacity by having a 'community workforce' as well as a professional workforce
- offer an opportunity for people to gain directly in terms of increased confidence, health literacy, self-fulfilment, social contact, skills and employability
- provide peer support to help other community members participate in activities that might improve their health
- open up a conduit so that information can be cascaded through social networks and community knowledge can be fed into back up to inform strategic planning and service delivery.

The study revealed that while the potential to increase service capacity is important, this is as much about programme reach to people not in touch with services as it is about economics. The bridging role of lay people in connecting into communities and improving access to health resources is

the most significant mechanism here. Such approaches allow people who are accepted and trusted in communities to deliver health messages and offer support in appropriate ways to people who might otherwise be disengaged or who face barriers to participation. Findings suggest that lay workers and volunteers add an important dimension and therefore such approaches need to be considered as a way of addressing persistent health inequalities.

17.3 Dimensions of roles

A further objective for the scoping study was to present a critical analysis of models of involving lay people in public health roles and provide clarity over the core elements of different models. The primary research allowed further exploration of these roles. The study was able to provide a comprehensive overview of theoretical and practical approaches. A number of dimensions were identified that explain variation in programmes (Table 27). Programmes involve complex processes and relationships. These dimensions are, therefore, not exclusive categories, rather ways of describing programme organisation and processes and, in many cases, are better considered as a continuum. It is important that role dimensions are used in research and evaluation to allow comparisons, as this will assist later synthesis of evidence. Awareness of dimensions of roles can aid those planning programmes and drawing up service specifications. It will also help in building an evidence base, as lessons can be shared across programmes using similar approaches, for example, around the utility of sessional payments.

Table 27. Dimensions of programmes involving lay people

Dimensions	Variations
Intervention	Health focus Targeted or Generic Target population Intervention method Setting Delivery organisation (sector)
Role dimensions	Primary role • Peer education • Peer support • Bridging • Community organising Mode of working • Individuals (one-to-one) • Groups • Community
Service dimensions -	Training & development • Emphasis on preparation for delivery • Emphasis on personal development and empowerment Payment • Volunteer model • Sessional payment • Employment model • Mixed Extent of autonomy • Linked to health services – working alongside or directed by health professionals • Working autonomously
Community dimensions	Lay (community) status • Non-professional - not matched to target population, bringing general life experience • Peer - matched to target population • Embedded - known and working in own community; can include peers and community leaders. Social networks • Role primarily uses existing social networks • Role primarily creates new social networks

17.4 Support and sustainability

Organisations have a role in recruiting, developing and supporting lay people taking on public health roles. It is the existence of professional/

practitioner involvement, coupled with the delivery of specific interventions that distinguish lay workers from natural helpers working unaided in existing social networks (Dennis, 2003; Eng *et al.*, 1997). In line with the research aims and objectives, the study investigated recruitment, training, management and support processes and attempted to identify factors that affect the development, effectiveness and sustainability of programmes which seek to involve lay people in public health roles. The study was able to collect a volume of data on these issues through the case studies and the expert hearings. Strong themes emerged that threaded across the different projects and stakeholder groups. At the same time, the variety and the complexity observed in practice meant that it was not appropriate to match conclusions about organisational issues to specific models.

The findings revealed that relationships should not be seen as simple functional chains from professional input to lay delivery in a community. Instead there are a set of relationships and flow of information can be two way. The expert hearings also illuminated the role of public services in creating a wider infrastructure to support these types of approaches. A number of key processes were identified through the case studies that appear to impact on programme effectiveness and sustainability (see section 16). These included:

- the commitment of lay workers/volunteers to the communities that they work within

- recruitment strategies and training that recognises experience and builds on lay knowledge and skills

- options for offering rewards and remuneration

- accessible support and development opportunities

- expertise in delivery organisations

- tensions between empowerment approaches and NHS demands for professional control

- lack of a wider infrastructure to support lay engagement.

Evaluation is needed to examine how these critical factors affect programme outcomes at an individual and community level. The implications of these findings for the different parts of the public health system - lay people, practitioners, commissioners and the wider health service are discussed in section 17.8

17.5 Community perspectives

A small but important part of the study involved examining the perspectives of community members with experience of public health programmes delivered or led by lay people. As discussed in section 16.1, recruitment

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was challenging and therefore it was not possible to build up a comprehensive picture of community perspectives. Nonetheless the data illuminated some critical issues. In general there was recognition and acceptance of the lay contribution and good understanding of the roles performed. One interesting finding was that the social connections with and outside public health programmes meant that the boundaries between the service user role and the volunteer role were blurred, with many of those interviewed taking on smaller helping roles. Additionally, the service user interviews shed further light on some of the motivations and barriers to volunteering.

17.6 Study limitations

The study examined a large and diverse field of public health practice. The design was based on primary qualitative research combined with synthesis of scientific and practice based evidence within the scoping study. The use of evidence from different sources meant that the study was able to provide a comprehensive map of factors shaping the development and implementation of programmes involving lay workers. The scale of the overall study and the number of case studies selected inevitably limited the depth to which issues could be investigated through empirical research and further recommendations for future research are therefore identified in 17.7.

The study design enabled issues identified in the scoping review to be further investigated through case studies. Some triangulation of evidence was possible, particularly in relation to the scoping study as discussed in Section 10.1. On the other hand, triangulation was limited because each element of the study in effect explored service models and organisational issues from different perspectives and therefore generated different data. The mismatch between a body of international literature focused primarily on intervention studies and an investigation of the realities of community-based public health practice in England was particularly stark. Nonetheless it was possible to draw some conclusions about programme dimensions and justifications for lay involvement.

The focus of the study was on the Choosing Health priorities (Department of Health, 2004). Programmes dealing with the wider determinants of health and those related to the management and care of long term health conditions were not included. These restrictions in the scope of the study will limit transferability, however, we consider that results have relevance to other areas of public health practice, including national initiatives such as Health Trainers. A further challenge has been distinguishing this type of lay engagement from the broader field of community participation in health. The wider context for lay engagement is discussed in section 2. While the attempt to maintain study boundaries enabled clear findings for public

health practice to emerge, it was not possible to explore the connections between these approaches and patient and public involvement or community development approaches in any depth.

The strong focus on the practice of lay engagement meant that study conclusions have relevance to public health policy and practice in England. The original study protocol had proposed the development of a planning matrix to make recommendations on the effectiveness of different ways of developing and supporting lay people in programme delivery. There was insufficient data to draw these type of conclusions and, moreover, the study findings indicate that simplistic solutions are inappropriate, given the variation seen in practice and the complex nature of these roles. An alternative approach has been to develop a research briefing for practice which identifies the options that are available.

17.7 Recommendations for future research

The People in Public Health study has developed an understanding of how lay people can be supported in public health activity and identified some areas that merit further research. These can be considered in relation to three main areas (Table 28) which are discussed in turn:

- evaluation research to determine the effectiveness of lay health worker programmes in a UK context

- research on service delivery and organisational issues, including effective recruitment strategies

- further studies to examine stakeholder perspectives.

The scoping review confirmed the predominance of North American literature in this field and highlighted the need for more evaluation research on UK programmes. There were notable gaps in evidence around areas that feature in current UK policy and practice, such as physical activity or healthy eating interventions. Furthermore, despite the bridging role being a dominant feature of many of the programmes studied, the scoping review found little UK literature on bridging approaches. Furthermore, there were gaps in evidence around areas that feature in current policy and practice, such as physical activity or healthy eating interventions. We therefore recommend that a large scale evaluation study or series of studies are undertaken, across a range of communities and public health priorities within a UK context, in order to examine the rationales advanced in literature and practice. Evaluation research should focus primarily on checking the effectiveness of lay workers in bridging and increasing access to health resources and activities. This is in line with the continuing quest to find effective ways to address persistent health inequalities and social exclusion (Piachaud *et al.*, 2009).

This study has thrown light on the range of social and health benefits that can result from lay people becoming involved in delivery. In designing evaluation studies, researchers should be prepared to take account of the wider societal benefits, such as increased social capital and social inclusion. Based on the findings, we recommend that evaluation studies should where possible attempt to capture the full range of individual and community outcomes over time, rather than focus exclusively on short term behavioural outcomes. Future research also needs to account for the range of activities that lay people can be engaged in within a single programme. Trying to 'shoehorn' practice into a standard intervention study would be counterproductive. There is scope for development of an evaluation framework and set of indicators that are appropriate for the nature of practice. We recommend that evaluation studies use the programme dimensions identified in Table 27 to aid categorisation of interventions.

In relation to service delivery and organisational issues, there is scope for further research on recruitment and training strategies. A priority area is examining reasons why people choose not to take up public health roles and whether barriers to recruitment can be removed, particularly with groups who face stigma. Questions were raised about whether approaches based on high levels of recruitment and minimal training work better than intense, tailored support for a smaller cohort of people. There is also a need for research around the level and type of strategic support that is required to develop and sustain citizen engagement in health. This is an area that is evidently under-researched, but the study findings suggest that this was a critical factor in sustainability.

More research is needed on public and professional perspectives on the acceptability of these types of programmes. While some interesting perspectives emerged in this study, we were only able to involve service users who were regularly engaged in group activities. It is important to gather the views of those service users and members of the public who do not become engaged in programme activities or who receive only brief interventions. We recommend that the experience of service users within these types of programmes is investigated in more depth.

Finally, throughout the study, the research partnership has pioneered different ways of lay engagement in research, through the expert hearings, websites and registers, workshops and other participatory methods. This involvement has enriched the study and will hopefully influence dissemination of findings into practice. The partnership model, combined with some of the methods used for public engagement, provides a transferable model for other public health research.

Table 28. Future research topics and potential questions

Research area	Sample questions
Evaluation of effectiveness	What is the long term impact of programmes that utilise lay workers and volunteers? How can this best be measured? Do programmes involving lay workers result in wider societal benefits, such as increased social capital? Are lay health worker programmes an effective mechanism to increase access to health resources for socially excluded groups?
Service delivery and organisational issues	Which recruitment strategies work best and with which groups? Can barriers to recruitment can be removed, particularly for seldom heard groups? What intensity of training and support is most effective? How can programmes be mainstreamed and achieve sustainability? What sort of strategic support is required?
Stakeholder perspectives	How are programmes delivered by lay people received by service users and the wider public? How do health professionals view lay workers? Is there scope for further integration of lay-led approaches within mainstream services?

17.8 Recommendations for policy and practice

This final section discusses the implications of the study findings for the public health system and makes recommendations (Table 29). It starts with the contribution of lay people who become involved and moves on to identify how organisations can directly nurture and support this contribution and ultimately develop sustainable programmes. The significance of system level change is also highlighted. A research briefing for practice will be

produced based on the study findings. This will provide practical guidance on how members of the public can become involved, what the choices are for those commissioning and implementing public health programmes and how elements of good practice might be applied.

Health citizenship

This study has highlighted the commitment of lay workers and volunteers in making a contribution to public health and this must be considered a key factor in programme sustainability. Reasons for participation were mainly altruistic, but others included enhancing employability and social benefits. This suggests that public services and delivery organisations should aim to nurture, not stifle, the altruism and commitment within different communities. Moreover, if public services want to stimulate recruitment and increase participation, they need to ensure that people get enjoyment and can benefit personally, as well as providing good support to enable them to undertake the role. Findings suggest that maximising the contribution of lay people is in essence about 'hearts and minds' as opposed to a narrow focus on delivery of health outcomes and service targets, although lay workers undoubtedly contribute to these. It should also be noted that service users participating in programmes can and do take on lesser roles such as peer support to other group members. While there is little to be gained from formalising such roles, and indeed much to be lost, there needs to be greater recognition of the contribution of members of the public to public health across all the different levels of engagement, from helping out through to community leadership. Fundamentally, this 'health citizenship' is not about developing another layer of workforce but concerns more profound changes in the way citizens are involved in all aspects of public life (Department of Health, 2009; Secretary of State for Communities and Local Government, 2008).

Reducing barriers to recruitment

The study identified a number of barriers to recruitment and participation, including lack of formal education, language barriers, extensive bureaucracy, fear of stigma, CRB checks, financial concerns and worry about impact on benefits. It is likely these barriers impact most on those who are from groups that are seldom heard or are from disadvantaged neighbourhoods. With appropriate support, taking on a public health role can offer the individual a gateway to opportunities for wider participation, new life skills, and employment, aside from the benefits to public health. It is important that services try to reduce the barriers to participation and that recruitment strategies are developed and evaluated, particularly where there is an aspiration to scale up programmes. There is scope for a policy framework to facilitate involvement, such as guidelines on entry level training. In addition, joint commissioning may offer a strategic approach to address barriers, as many local authorities have considerable experience of engaging disadvantaged communities in shaping and delivering local services.

Recognising skills and qualities

The skills brought to, and developed within, public health roles are around life experience, combined with social, communication and language skills. Lay people were valued for their caring and non-judgemental attitudes and their non-professional status was important for the bridging role. There is poor match between these valued skills and attributes and the competencies of levels 1 and 2 of the Public Health Skills and Career Framework (Public Health Resource Unit and Skills for Health, 2008), which suggest that only limited/low-level skills are needed. The study has shown that lay workers bring a range of complementary skills and qualities and offer a distinctive alternative to professional support. Enhancing the confidence and natural helping skills of lay workers does not conflict with the need to ensure governance and quality of services. There is potential to develop competencies that provide a better fit with the roles seen in practice, however, inappropriate professionalisation should be avoided. Individuals bring diverse experiences and qualities to public health roles and it is the way that lay workers improve connections with communities that is significant here.

Payment options

The study has shown that there are many options around remuneration and rewards, and programmes need to consider all the pros and cons of different choices. Use of sessional payment can support engagement, particularly where communities are facing financial hardship. Service users and volunteers suggested that small rewards, financial or in kind, would be welcomed as an indication of a service valuing its volunteers. While this may deviate from the definition of volunteering set out by The Commission for the Compact (2005), there is scope for a wider debate on remuneration and rewards within public health. Overall, the findings suggest that common sense protocols are needed at a local level to facilitate involvement. There is potential for NHS organisations to link with welfare benefits and advice services in order to help their lay workers and volunteers 'navigate' the benefits system. A wider issue flagged up by the study is the need for a review on how volunteering, sessional employment and welfare benefits fit together.

Investment in development and support

Practitioners within delivery organisations have important roles in supporting lay workers. Sustainability may mean different things in different contexts, but investment in people is one of the mechanisms for achieving it. There are inherent risks in handing over delivery to lay people and a need to negotiate appropriate role boundaries. Despite some professional scepticism, the findings indicate that risks can be successfully managed through training, continuing development, and through having good support mechanisms, both involving both peers and practitioners. The NHS supports

greater lay engagement, but also has to mitigate risks to the public and ensure that the right health messages are communicated. Consequently, there needs to be investment in development and support systems within delivery organisations. This would involve partnerships with third sector organisations as they offer expertise and a wealth of experience in working with volunteers and lay workers.

Findings from both the expert hearings and case studies support the recommendation that commissioning should be for development, with investment in a wider infrastructure to support lay workers and volunteers, rather than being limited to funding delivery of an intervention. In the long run, investment for development may bring greater social returns and links to a new public benefit model based on the assets that people can bring (Ryan-Collins *et al.*, 2007).

Building trust

The study has shown that engaging lay people in public health roles is acceptable to various stakeholder groups. Ultimately, relationships between lay workers, communities and professionals need to be built on trust. Those service users who participated in the study were clear about distinctions between roles and the value of non-professional support. The expert hearings highlighted a need for wider cultural change in the health service. Many programmes involving lay workers are not mainstreamed and are dependent on committed practitioners. There is scope for exploring whether there could be better integration between healthcare services and lay-led public health programmes.

There was a tension between NHS demands and the empowerment of lay people that was articulated throughout different elements of the study. At the same time, there was evidence that partnership approaches based on mutual trust are achievable. Public health services need to achieve an appropriate balance between professional support and community control when commissioning, planning and managing programmes involving lay people.

Social returns

Overall findings revealed the limitations of what can be seen as an instrumental approach to lay engagement, focused on achieving specified (health) targets, often within time limited policy cycles, and the strengths of a more holistic approach that is about the development of people who can broker connections between communities and services, allowing for a two-way flow of information. The mismatch in aims and expectations can present dilemmas for organisations that are trying to support community

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activity. These approaches are about changing relationships between public services and the public and there are evident links to the patient and public involvement and citizen empowerment agendas (Secretary of State for Communities and Local Government, 2008). Wider health benefits and social returns need to be recognised in planning and commissioning processes. Overall the findings fit with approaches that aim to build on community assets, rather than focusing on social problems (Morgan and Ziglio, 2007).

Table 29. Synopsis of recommendations for policy and practices

Enabling people to contribute to public health	Lay workers and volunteers add an important dimension to public health programmes and such approaches should be considered as a means to address persistent health inequalities. Services should foster the altruism and commitment of people to communities and ensure that people can benefit from involvement. Barriers to recruitment need to be minimised, particularly when working with groups that may experience social exclusion. Services should recognise and enhance the skills and inherent qualities that people bring to public health roles.
Support systems for delivery	Training and development opportunities should be offered to lay workers and volunteers. This is a way to manage risks as well as developing skills. Delivery organisations should consider the pros and cons of remuneration and decide on the best options to fit with the local context. Payment and expenses need active management in programmes as these aspects generate concern, especially where there is financial hardship. Delivery organisations should develop adequate support systems as access to 'light touch' support helps people feel valued and any issues can be managed effectively.
Adopting a strategic approach	Commissioning should be focused on investing in a wider infrastructure to support the development of lay workers and volunteers, rather than being limited to funding a discrete intervention. Commissioning, target setting and evaluation should be

	informed by a broad understanding of the wider health and social benefits of involving members of the public. High level local leadership is needed to mainstream programmes instead of relying on the commitment of champions. There needs to be an appropriate balance between professional support and community control as relationships between communities and services have to be built on mutual respect and trust.
Policy issues	There needs to be greater recognition of the contribution of active citizens to public health across all the different levels of engagement, from helping out through to community leadership. There is scope for developing a framework that adequately reflects the social skills, knowledge and qualities that lay workers bring to their roles. Simple protocols are needed that provide guidance on how volunteering, sessional payment and welfare benefits fit together.

17.9 Concluding remarks

The People in Public Health study has developed understanding of the value of involving lay people in public health delivery and how individuals can be supported to make a contribution. The Commission on the Future of Volunteering (2008) sets out a vision for a more integrated approach to volunteering.

'Volunteering can make a huge difference, at all levels, to individuals, organisations and society, so we wish to see a cultural change about how we think of volunteering. It should not be seen as an add-on, but as part of how we live and how services are provided'. (p.25)

Notwithstanding the variation in roles, remuneration and support systems found in public health practice, this quotation illustrates the need for a shift towards approaches that recognise the broader context of lay engagement. In framing lay people as part of the solution and not the problem, public services have a role to play in nurturing and supporting them. This signals a move from a consumer model of health, to a citizenship model where services are better connected into communities. The key challenge is how policy makers, commissioning and provider services, academic institutions along with communities, can develop practice and build a strong evidence base.

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Addendum:

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Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.