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Population and Community Programmes addressing Multiple Risk Factors to Prevent Cardiovascular Disease:

A qualitative study into how and why some programmes are more successful than others

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Declaration of authors' competing interests

No authors have competing interests.

List of abbreviations

CVD	Cardiovascular disease
DPH	Director of Public Health
GMT	Greenwich Mean Time
NGO	Non governmental organisations
NICE	National Institute for Health & Clinical Excellence
PCT	Primary Care Trust
PDG	Programme Development Group (Prevention of Cardiovascular Disease)
PenTAG	Peninsula Technology Assessment Group
PD	Programme deliverers
PDG	Programme Development Group
PE	Planners and evaluators
PM	Programme managers
UK	United Kingdom
USA	United States of America
WMHTAC	West Midlands Health Technology Assessment Centre (University of Birmingham)

Definition of terms

Asynchronous	The sending of electronic data in just one direction at a time – in an online forum, this allows for messages to be read and sent at a time to suit the user whilst still allowing them to participate fully in a discussion.
Open Source	Software distributed under a free licence that allows the modification and redistribution of the original program code.

Table of Contents

Acknowledgements	2
Declaration of authors' competing interests.....	2
List of abbreviations	3
Definition of terms	4
TABLE OF CONTENTS.....	5
1. SUMMARY	7
1.1. Background.....	7
1.2. Aims and objectives	7
1.3. Methods 8	
1.3.1. Sampling & Recruitment.....	8
1.3.2. Conduct of the online focus group.....	8
1.3.3. Analysis	9
1.4. Findings9	
1.5. Research recommendations.....	13
2. AIMS AND BACKGROUND.....	14
2.1. Objectives and Rationale	14
2.2. Review Questions	16
3. METHODS	17
3.1. Study design	17
3.2. Sampling & Recruitment.....	17
3.3. Conduct of the online focus group	25
3.4. Methods of data analysis	29
4. FINDINGS.....	30
4.1. Programme development and fidelity: "The intervention may not be completely pure"	30
4.2. Community engagement strategies: "starting the spark"	32
4.3. Staffing: "No magic solutions"	40
4.3.1. Leadership: "You need people to stand up"	41
4.3.2. Staff engagement: "Keeping them involved"	46
4.3.3. GPs: "The proper role for general practice is to support efforts in their community to promote healthier lifestyles"	47
4.3.4. Volunteers: "Put your arms around them and support them"	49
4.3.5. Working with multi-agency, multi-disciplinary teams: "It's all about highlighting the benefits of each service if they work hand-in-hand"	51
4.4. Legacy: "Putting something back into the community that's going to be there even if the project disappears"	54
4.5. Impact of short time frames.....	57
4.6. Structural barriers to success: "political landscape changed"	59
4.6.1. The place of public health in health policy	59
4.7. Monitoring and Evaluation.....	61
4.7.1. Piloting and monitoring feedback "It's about trying to make everyone happy, isn't it?"	63
4.7.2. Evaluation challenges	65
4.8. Successful population based programmes: a conceptual framework.....	67
5. DISCUSSION.....	70
5.1. Statement of principal findings	70
5.2. Methodological limitations and considerations	70
5.3. Further research	74
APPENDICES	75
Appendix 1 Email sent to potential participants suggested by other participants	75
Appendix 2 Research protocol.....	76

Appendix 3	Participant email following initial telephone contact.....	85
Appendix 4	Participant information sheet.....	86
Appendix 5	Participant consent form	91
Appendix 6	Participant email sent if unable to make contact by telephone	93
Appendix 7	Registration email sent to online forum participants	94
Appendix 8	Topic Guides.....	95
Appendix 9	Reminder email sent to participants.....	97
Appendix 10	Email invitation to comment on focus group discussion.....	98
Appendix 11	Email invitation to hold a telephone interview.....	99
Appendix 12	Bibliography.....	100

List of figures

Figure 1	Home page of the online focus group discussion	26
Figure 2	Sub-group page to access the online focus group discussion.....	26
Figure 3	Screenshot showing the introductory discussion within a sub-group.....	27
Figure 4:	Arnstein's ladder of participation	34
Figure 5:	Conventional evaluation process	62
Figure 6:	Cyclical evaluation process	62
Figure 7:	Conceptual framework for successful programmes	69

List of Tables

Table 1	Study recruitment	20
Table 2	Study Participants.....	21
Table 3	Location and role of participants in online focus group.....	21
Table 4	Summary of effectiveness findings for programmes in which online focus group participants were involved	22

1. Summary

1.1. Background

This report is the fifth in a series of six linked research projects commissioned by the NICE Centre for Public Health Excellence examining programmes addressing multiple risk factors to prevent cardiovascular disease (CVD). This is one of two reports produced by PenTAG looking at qualitative evidence to try and understand the barriers to, and facilitators of, successful community and population based programmes. Review four was a systematic review of the qualitative research about programmes aimed at reducing multiple-risk factors for CVD.

1.2. Aims and objectives

We aimed to explore several questions related to community and population programmes aimed at reducing multiple-risk factors for CVD:

- What are the factors associated with the successful (or unsuccessful) implementation of population level programmes addressing multiple risk factors for the primary prevention of cardiovascular disease (CVD) in a given population?
- What are the important factors influencing the achievement of health outcomes associated with the primary prevention of CVD?
- How do these factors interact, both with each other, or with other aspects of programme design, implementation and evaluation processes or context to influence increased or reduced programme effectiveness?

In order to address these questions and try to identify elements that contribute to programmes' success or failure, we conducted a series of online, focus group discussions and telephone interviews into the processes of planning, implementing and evaluating of population level programmes (or key components of them) aimed at reducing the first occurrence of CVD in a given population.

1.3. Methods

1.3.1. Sampling & Recruitment

We contacted people who had been involved in 21 multiple risk factor CVD projects in Britain, the rest of Europe, and the USA. Involvement was as frontline project workers, project and programme managers and coordinators and programme evaluators. People involved in other UK based projects were also contacted, having been identified through snowball sampling. Initial contact to assess interest in principle was made by telephone, and formal invitation was by email.

The primary method of data collection was asynchronous, online focus groups, moderated by PenTAG researchers. Thirty three people out of the 88 contacted agreed to participate in the online discussion groups, however, only 16 took an active part in the discussion despite a number of reminder messages being sent. Those who were not active were offered a telephone interview instead and three people agreed to this (one had contributed to an online group too but not as much as they had hoped), giving a total of 18 active participants.

1.3.2. Conduct of the online focus group

The online focus group was run using Open Source forum software which was adapted to simplify its appearance and use. Participants were assigned to one of three groups, depending on their role in the CVD prevention programme – programme managers, deliverers or evaluators. They were given unique user names and passwords to log in. Although the user names were anonymous, some participants chose to reveal their identity to the group. The groups were online for three weeks during November 2008 during which time the participants were free to log in and write to the group at any time they chose. An automatically generated email was sent to participants each time a new contribution was made to the online group. The moderators used a topic guide to broadly inform the on-line conversations but also responded to topics raised by participants within topic areas.

After the online discussion group was closed, all participants were sent a transcript of the group in which they had participated and asked if they wanted to add to or clarify anything they had written. All those who had registered to take part but who did not

participate were invited to take part through a telephone interview. Three such interviews took place in January 2009.

1.3.3. Analysis

Transcripts were read and re-read by two researchers and a coding scheme was developed based on themes identified in the participants contributions together with understandings gleaned from the systematic review of qualitative research about CBVD prevention programmes and discussions with the PDG. The coding scheme was piloted and refined through discussion and then used to produce a thematic analysis of the findings.

1.4. Findings

We analysed the findings under seven broad themes:

- Programme development and fidelity
- Community engagement strategies
- Staffing (sub-themes around leadership, staff engagement, GPs, volunteers, and multi-agency teams)
- Legacy
- Impact of short time frames
- Structural barriers to success
- Evaluation challenges

In addition, a conceptual framework was developed showing the links between these themes and mechanisms of enhancing successful community based programmes for reducing CVD.

Summary finding for each of the thematic areas were also produced and are reproduced here.

Summary statements
Programme development and fidelity
To be successful, the design of programmes aimed at multiple risk factors to prevent CVD may need to be responsive to environmental changes and community needs. Flexibility may be

required on the part of commissioners and funders to recognise this and not require fixed plans for precise design and evaluation schemes to be in place prior to entry to the field. Changes and reasons for any such changes could be documented.

Community engagement

Positive community engagement requires trusting, respectful relationships to be built which motivate and support change. Community engagement should be an ongoing and dynamic partnership which responds to community needs.

As CVD may not be seen as an immediate concern within targeted communities, staff may first need to listen and respond to the existing concerns of the community. This may be done through participating in existing networks and forums, or creating forums that have more open agendas, at least to start with.

Sufficient time is needed to ensure that this is done appropriately, and also to ensure that changes become adopted by the community so that they are empowered to continue, even if the project itself comes to an end.

Information and education is likely to be more effective if it relates to the experiences of the community, and if those that deliver it are seen as part of that community. Appropriately skilled staff are needed for effective community engagement.

Greater levels of participation, that involve community members as partners or devolve power to them, may have additional benefits – ensuring that programmes are truly responsive to community needs, involving local people in the complexities of planning and delivering such programmes and so facilitating understanding within the community.

Done well, community engagement may create a positive feedback loop which motivates change, improving health and which produces greater motivation. However, care needs to be taken to ensure that those adopting behaviour change are not just those already motivated to change, thereby increasing, rather than lessening, health inequalities.

Staffing - Leadership

Strong, inspirational leadership may be important to initiate, coordinate and drive complex programmes and motivate and encourage cooperation among multiple staff across a number of agencies with a range of responsibilities.

To fulfil this, staff are needed whose role is dedicated to the programme and those with multiple

roles need to have appropriate time freed up.

Leaders may be needed for the project over all, but also for specific elements of the project, for example, to encourage primary care participation or ensure local political or funding support. Leaders from within the community are also needed to champion the project and facilitate engagement.

Expectations of leadership roles should be matched by appropriate control and responsibility, and given the necessary training and support.

Staffing – Staff engagement

To ensure that staff are engaged with the aims of a CVD prevention programme, they require appropriate training and resources, a good understanding of how their role fits into the programme overall and a clear understanding of the extent of their roles and responsibilities.

Staffing - GPs

The role of primary care was complicated and sometimes contradictory. Some GPs may be more comfortable with a secondary, rather than primary, prevention role, which may explain why some participants found it difficult to engage them in CVD prevention programmes. Conversely, other participants viewed primary care as crucial partners in CVD prevention. Advocacy among other local organisations may be a key role.

Where primary care is involved in CVD prevention programmes they need to receive appropriate resources to free up staff time.

Engaging primary care and keeping them appropriately informed may require tailored approaches.

Staffing - Volunteers

Volunteers from within the community may be particularly effective at informing, motivating and engaging their peers in the community and enhance community empowerment.

Volunteer workers need to be properly trained and supported to ensure that they continue to be involved and don't get burnt out.

The issue of paying those involved should be considered carefully.

Staffing – Multi-agency, multi-disciplinary teams

Public health work to reduce CVD is likely to require the involvement multiple agencies and

disciplines.

Coordination and cooperation is required to build trust and a sense of shared purpose through aligning the goals and activities of different agencies involved, and assigning clear roles and responsibilities to participating organisations and staff within them. Joint appointments may facilitate this. Ongoing feedback and communication is vital.

Sufficient time is needed to successfully negotiate and accommodate different expectations and bureaucracies.

Legacy

CVD reduction programmes may enhance their longer term impact through ensuring that programme activities are embedded within organisations and the community.

Appropriate training and support for key staff, and community members, from project inception may help to ensure activities become “institutionalised”. Ongoing sources of funding should also be identified.

Programme impacts should be regularly assessed and results fed back to staff and organisations so that successful activities are recognised and adopted. This will require the identification of appropriate resources.

Early and ongoing community engagement may ensure ongoing changes in healthy behaviours, empowering the community to maintain positive changes. Short term projects often fail to leave lasting benefits to a community as their short term goal setting may preclude the necessary engagement required.

Short time frames

Short time frames for CVD prevention programmes may threaten success at a number of levels: implementation, staff engagement and training, community engagement, evaluation and legacy. It is difficult for such programmes to meet community needs, staff needs or to permit changes to become embedded in the community. This may lead communities and local agencies to lose faith in such interventions, further hampering the ability of future work to be successful in those areas.

Structural barriers

At a macro-level, changes in the broader political environment can have dramatic effects on the adoption and continuation of prevention activities.

Support for CVD prevention programmes may be affected by changing political priorities around prevention and treatment of illness.

Piloting and monitoring

Cyclical approaches to monitoring and evaluation, such as piloting, process evaluation and action research, allow projects to be responsive to local needs, adapting or removing inappropriate projects and allowing successful projects to be rolled out.

Information from this process fed back to staff in a timely way can help develop a sense of ownership and cooperation and motivate good practice.

Organisations and individuals should also learn from the experiences of previous projects.

Challenges of evaluation

Commissioners and funders may need to allow flexibility in programme and evaluation designs to allow them to adapt to local needs., rather than requiring fixed plans prior to finding. In addition, programmes and evaluations should allow sufficient time for outcomes to be achieved.

Multiple methods may be needed to evaluate important aspects of CVD prevention programmes, such as community empowerment, that are not all easily captured through numerical outcome data.

Programmes that measure only population level changes may not capture large impacts for some individuals, and this may be important, especially where health inequalities are addressed.

1.5. Research recommendations

Future research should explore the impact of increased time for recruitment and increased time during which the online focus group is active, on the ability of people to participate and, in particular, to develop interactions between themselves as well as the moderator.

Future work with online focus groups could explore the impact of different types of participant groupings and numbers of participants on the interaction of the group.

People who were involved in CVD reduction programmes outside the UK were not well represented in this project and their views should be sought in future research.

2. Aims and Background

2.1. Objectives and Rationale

This project forms part of a series of linked research projects commissioned by NICE to assess effectiveness of programmes that aim to prevent CVD. The programme is concerned with population level interventions and programmes which address multiple risk factors for CVD (diet, smoking, physical activity etc). For simplicity, in the rest of this protocol, we will use the term programme to encompass both programmes and interventions.

PenTAG is in collaboration with WMHTAC, although they have not directly contributed to this research. WMHTAC have undertaken systematic reviews of the evidence for the effectiveness of such CVD prevention programmes which have been drawn upon in order to inform the design of the study reported in this document. WMHTAC have also undertaken a systematic review of related economic evaluations and will develop a computer model to estimate the cost-effectiveness of such programmes.

PenTAG has undertaken a systematic review and synthesis of qualitative research about factors which militate against or enhance the success of these programmes (see separate report presented at PDG meeting 4). In addition, in this primary research, we solicited the views and experiences of those involved at a number of levels with planning, implementing and evaluating CVD prevention programmes.

The objective of this project was therefore to conduct a series of online, focus group discussions and telephone interviews with participants who had been involved with the CVD programmes identified in the first four reviews conducted for the NICE CVD PDG. The study was commissioned in order to address the expectation that the review into the barriers to, and facilitators for, the effectiveness of CVD programmes (Review 4) would not identify substantial quantities of qualitative research on the topic. Furthermore, the study allowed an unusual opportunity to hear anecdotes from participants regarding the delivery of CVD programmes that would normally be limited by journal paper space restrictions. In summary, the study aimed to gain insight into the processes of planning, implementation and evaluation of population level CVD

programmes (or key components of them) and to identify elements or factors that contribute to their success or failure.

A protocol for the research was developed in consultation with the CVD project team at NICE. The main method of data collection was through online, written focus group discussions. The groups operate in similar ways to traditional offline focus groups; a topic guide is used to structure the discussion (which was intensively monitored and guided by researchers at PenTAG) which produces data not simply through the participants' responses to the moderator, but also through the interaction between participants. An online (as opposed to in-person) focus group was particularly appropriate in this study for a number of reasons:

- Participants were geographically dispersed (both within the UK and internationally) and the majority were still employed in time consuming posts. An online focus group allows participants to engage in the discussion at a time and place to suit them, and is therefore not limited by geographical location or (to a lesser extent) by other work commitments.
- Given the nature of their professional roles, participants would be likely to be familiar with expressing themselves in written form, as well as having competent keyboard skills and being sufficiently computer literate to participate.
- The nature of the knowledge that we intended to research required reflection on experiences on the part of participants rather than immediate responses. The asynchronous nature (see glossary) of an online focus group allows for considered responses to be made in response to questions both from the moderator and from group members, as well as allowing those for whom English is not their first language to have a longer timeframe in which to compose responses.
- It has previously been noted that, while online focus groups may produce shorter transcripts, the quality of information gained using this method is the same or greater than that obtained using traditional techniques (Reid & Reid 2005). This is because people communicate more fully and accurately when using written rather than verbal language.

We considered that this approach would be most likely to maximise participation in the online focus groups (i.e. with sufficient participants to create rich online debate) whilst also giving the opportunity to all potential participants within the sampling frame to provide their accounts of barriers and facilitators in their programmes. However, we recognised that, even with close moderation of the online discussion and the provision of assistance to those participants who required it, it would be possible that the discussions would not produce as much or as rich data as expected. For this reason, we also included provision in the study design for telephone interviews to take place; the process of recruitment and conduct of these interviews is detailed below.

2.2. Review Questions

The aim of this research was to gain a better understanding of how and why population programmes to prevent primary CVD are successfully (or unsuccessfully) implemented, and achieve (or fail to achieve) their intended outcomes. To achieve this aim, a particular focus on identifying the factors which militate against or enhance programme effectiveness (“barriers” and “facilitators”) was adopted. This included identifying elements associated with key areas of programme success such as evolution, acceptability, and sustainability.

The specific research questions were:

What are the factors associated with the successful (or unsuccessful) implementation of population level programmes addressing multiple risk factors for the primary prevention of CVD in a given population?

What are the important factors influencing the achievement of health outcomes associated with the primary prevention of CVD?

How do these factors interact, both with each other, or with other aspects of programme design, implementation and evaluation processes or context to influence increased or reduced programme effectiveness?

3. Methods

3.1. Study design

3.2. Sampling & Recruitment

Potential participants were identified from the lists of authors of studies included in the preceding reviews,¹ or suggested by those we contacted as appropriate for involvement in the study because of their first-hand experience of population level CVD programmes. Members of the PDG also made a number of suggestions regarding potential participants in UK programmes whom we could contact, in particular with regard to programme delivery staff that were problematic to identify through the lists of authors of identified studies. We wanted to involve people who were involved at a number of different levels (planning and funding, programme design, management and delivery and programme evaluation) in each of the identified programmes. We used purposive sampling to recruit people who were involved in those CVD programmes identified by WMHTAC and PenTAG in their systematic reviews of effectiveness and of qualitative research literature. Potential participants were initially identified through publications related to such programmes. These were supplemented by web searches, contact with experts in the field, and information provided by NICE, including that supplied by the PDG. We also used snowball sampling - initial contacts were asked if they knew of other people that we should talk to who had been involved in the programmes (see 0 for details of the email sent to these potential participants).

We contacted people who had been involved in the following projects:

- Action Heart (UK)
- Bootheel Heart Health Project (USA)
- British Family Heart Study (UK)
- Coeur en Santé St-Henri (Canada)
- Danish Municipality study (Denmark)
- Di.S.Co (Italy)

¹ Reviews 1, 2 and 4; the programmes included in review 3 were not known at the time of participant recruitment.

- Finnmark Intervention Study (Norway)
- German Cardiovascular Prevention Study (Germany)
- Good Hearted Glasgow (UK)
- Hartslag Limburg (Netherlands)
- Heartbeat Wales (Welsh Heart Programme) (UK)
- Kilkenny Health Project (Ireland)
- Look After Your Heart (UK)
- Minnesota Heart Health Programme (USA)
- National Research Programme (NRP 1A) (Switzerland)
- Norsjö study (Västerbotten Intervention Programme) (Sweden)
- North Karelia Project (Finland)
- OXCHECK (UK)
- Pawtucket Heart Health Programme (USA)
- South Carolina Cardiovascular Prevention Project (Heart to Heart) (USA)
- Stanford 3/ Stanford 5 projects (USA)

In addition, information provided by these initial contacts or by members of the PDG also identified people who were involved in current UK programmes in Barnsley PCT and Knowsley PCT.

Recruitment to the study was made by contacting potential participants by telephone or email. Initial contact was by telephone where possible, and followed guidance shown in Supplement 1 of the protocol reproduced in Appendix 2. Contact was made by one of the three research team members (RA, RG, MP). This initial contact was used to outline the project and to establish initial interest in taking part. If interest was expressed, we then assessed whether potential participants had appropriate computer access and skills to participate in an online focus group. This allowed us to provide additional information for those wishing to take part but uncertain of their technical ability to do so and to note those who required additional support during the period of data collection. In addition, we were able to ask if people would only be able to participate through telephone interview. In the event, all those who said they would take part initially said they would participate through the online focus groups.

Formal invitation to take part in either online focus group or interview was then made by email (see Appendix 3), outlining the nature of the linked programme of research and details of this particular project, the timing and research methods. The email included the relevant participant information sheets and study consent form (see

Appendix 4 and Appendix 5) as attachments. Confirmation of interest to be involved in the study could be made by post, phone or email. Participants were asked to read the study consent form, clarify any issues of concern with the research team, and return a signed copy (either by fax or post, with the relevant boxes ticked indicating whether or not anonymity was required) to the research team.

A summary of the numbers contacted and outcomes is provided in Table 1. In total, we contacted 88 potential participants; if no reply had been obtained after two or more attempts by telephone, or if messages left on an answering machine or with a person had not been responded to, then an email inviting potential participants to take part in the study was sent² (see Appendix 6).

Eighteen of the people contacted declined to participate in the study;³ 9 stated that they were unavailable (or lacked the time to participate) on the dates that the online focus group was scheduled to run, 2 stated that they had nothing to add to what they had already published regarding the programme concerned, and 7 were of the view that (although they had been involved in the CVD programme concerned in some capacity) they were not an appropriate person to take part in the study.

A total of 33 participants agreed to take part in the study, of whom 16 took an active part in the online focus group (see Table 2) and three took part in a telephone interview that was recorded and transcribed. Two of those who went on to take part in a telephone interview had not actively participated in the online focus group, while one had made some contribution, but asked for the opportunity to say more. We therefore had 18 participants overall.

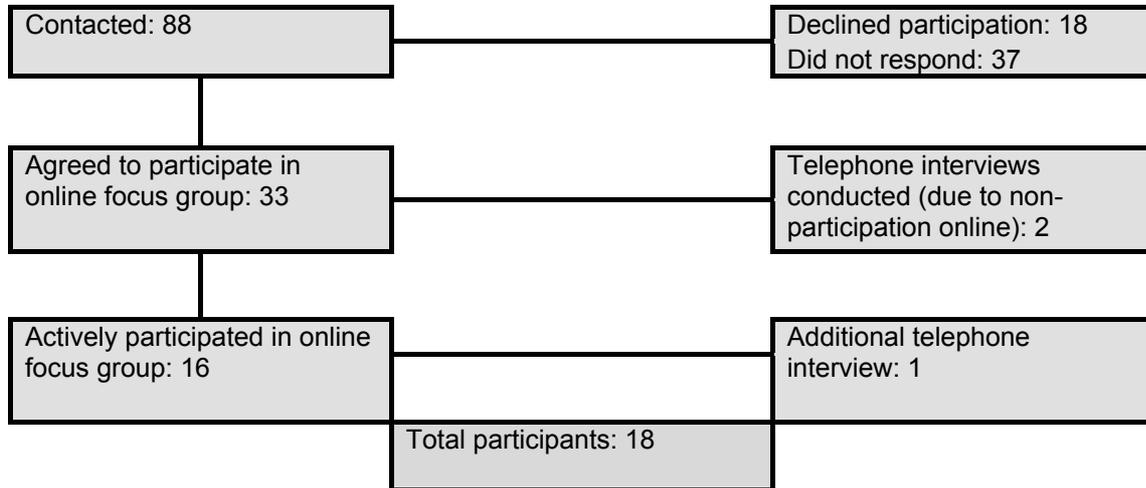
The location and role of participants in the online focus group is shown in Table 3; the three participants interviewed by telephone were all based in the UK and were all programme managers. The participants who requested an interview all did so due to their unavailability during the time that the online focus group was scheduled to run.

² 15 were contacted solely by email as we were unable to obtain a telephone contact number; a further 40 potential participants were contacted by both phone and email in an effort to recruit them to the study. The remaining 33 potential participants were contacted by telephone alone.

³ These potential participants had worked on the following programmes: Action Heart (2), Bootheel Heart Health (3), Coeur en Sante St-Henri (1), Danish Municipality Study (1), Good Hearted Glasgow (2), Heartbeat Wales (2), Minnesota Heart Health (2), Norsjo/Vasterbotten Intervention (1),

Table 4 summarises the findings from the effectiveness reviews related to those programmes in which participants in this study had been involved.

Table 1 Study recruitment



OXCHECK (1), Pawtucket Heart Health (1), South Carolina CVD Prevention (1), and WISEWOMAN (1).

Table 2 Study Participants

CVD programme	Number of participants
Action Heart (UK)	4
Barnsley PCT (UK)	2
Good Hearted Glasgow (UK)	1
Hartslag Limburg (Netherlands)	1
Have a Heart Paisley (UK)	1
Kilkenny Health Project (Ireland)	1
Knowsley PCT ⁴ (UK)	4
Norsjö/ Västerbotten Intervention Project (Sweden)	1
OXCHECK (UK)	1
Pawtucket Heart Health (USA)	1
Salud Para Su Corazón (USA)	1

Table 3 Location and role of participants in online focus group

Country	Programme delivery	Managers	Planners & evaluators
UK	3	7	3
Ireland	-	1	-
Netherlands	-	1	-
Sweden	-	-	1
USA	-	-	2

⁴ Interviews with two participants involved with the Knowsley PCT programme also drew on their experience with working on a number of other CVD prevention programmes.

Table 4 Summary of effectiveness findings for programmes in which online focus group participants were involved

Project	Desirable outcomes	Mixed outcomes	Undesirable outcomes	Summary from WMHTAC
Action Heart (UK)	Statistically significant decreases in smoking and increases in consumption of low-fat milk (adults) and wholemeal (children)	Physical activity ≥ 3 times/week increased in 11 year olds, but decreases in 14 year olds	None	"... appears ineffective in producing behavioural change in schools or the wider community... low-intensity, small-scale nature of the intervention may have been responsible for lack of effect." (Review 2)
Barnsley PCT (UK)				Not included in WMHTAC reviews – no published evaluation to date
Good Hearted Glasgow (UK)				Not included in WMHTAC reviews
Hartslag Limburg (Netherlands)	Statistically significant decrease in fat intake	Cholesterol and smoking – no significant difference between intervention and control (smoking decreased in both groups) Blood pressure and body-mass index increased, although magnitude of increase smaller in intervention group Plasma glucose – unchanged in males, significantly decreased in females Physical activity – no overall treatment effect	None	"... significant net changes in physiological and behavioural risk factors suggest positive intervention effect." (Review 2)

CVD: Focus group research project

Methods

Project	Desirable outcomes	Mixed outcomes	Undesirable outcomes	Summary from WMHTAC
Have a Heart Paisley (UK)	None	No significant differences for behavioural (e.g. physical activity) or knowledge (e.g. regarding diet) outcomes (except for knowing advised number of portions of fruit and vegetables to eat each day).	None	“... may have been insufficient time for implementation or environmental changes” “... contamination of control area may have contributed to lack of programme effectiveness” (Review 3)
Kilkenny Health Project (Ireland)	None	Blood pressure and smoking decreased in both intervention and control, and cholesterol remained similar in both groups (no significant differences between any of these groups)	None	“... little intervention effect... [prevailing attitudes and] strong secular trends may have prevented lifestyle changes and the detection of any intervention effect.” (Review 2)
Knowsley PCT (UK)				Not included in WMHTAC reviews – no published evaluation to date
Norsjö/ Västerbotten Intervention Project (Sweden)	Cholesterol – Decreased Note from WMHTAC review - No net difference presented for the following, therefore difficult to assess treatment effect over time: Blood pressure – Decreased	Smoking – Varied, no trend established	BMI - Increased	“...a community CVD intervention that actively involves the health care sector may have a positive impact” “... individual counseling appeared to bring about an earlier decrease in some risk factors, but did not reduce risk factors

CVD: Focus group research project

Methods

Project	Desirable outcomes	Mixed outcomes	Undesirable outcomes	Summary from WMHTAC
	CVD risk factors – Decreased			overall” (Review 1)
OXCHECK (UK)	At year 3 after initial health checks; statistically significant reduction in cholesterol, blood pressure, and body-mass index between intervention and control groups	Smoking – no significant difference between intervention and control groups	None	“... shows modest, positive effects following patient health checks for all outcomes except smoking.” (Review 1)
Pawtucket Heart Health (USA)	Body-mass index initially increased, but post-intervention it decreased (significantly more so in intervention group) (Results from cross-sectional surveys)	Cholesterol and smoking decreased, but no significant difference between intervention and control Blood pressure increased in some groups, but decreased in others, with no significant difference between intervention and control (Results from cross-sectional surveys)		“... failed to achieve positive behavioural or physiological outcomes in spite of ample funding... apparent failure of the 9 year intervention may be due to poor initial programme implementation and ineffective community involvement (Review 1)
Salud Para Su Corazón (USA)				Not included in WMHTAC reviews

3.3. Conduct of the online focus group

The online focus group was run using Open Source forum software (phpBB 3.0) that was accessed over the internet by each participant using a unique user name and password to access the web pages. The presentation of the online focus group was adapted in order to simplify its appearance and functions and thereby make it as straightforward to use as possible; for example, the home page provided a number of links that would take the user straight to the sub-group to which they were assigned, and also included links enabling the user to contact the research team and access the participant information sheet (see Figure 1). The various sub-group discussions could then be accessed by the participant (see Figure 2). The aim was to give a similar feel to a Microsoft Word document or an email rather than having the traditional discussion board format which might be confusing for those less familiar with such e-communication. Unnecessary tools (such as 'emoticons' and the traditional web-forum 'frequently asked questions') were removed so as to make the appearance of the online focus group as clear and easy to use as possible. The presentation of contributions made by participants to the online focus group was also streamlined so as to allow other participants to scroll through sequential posts rather than having to 'click' through to separate pages (see Figure 3).

Figure 1 Home page of the online focus group discussion

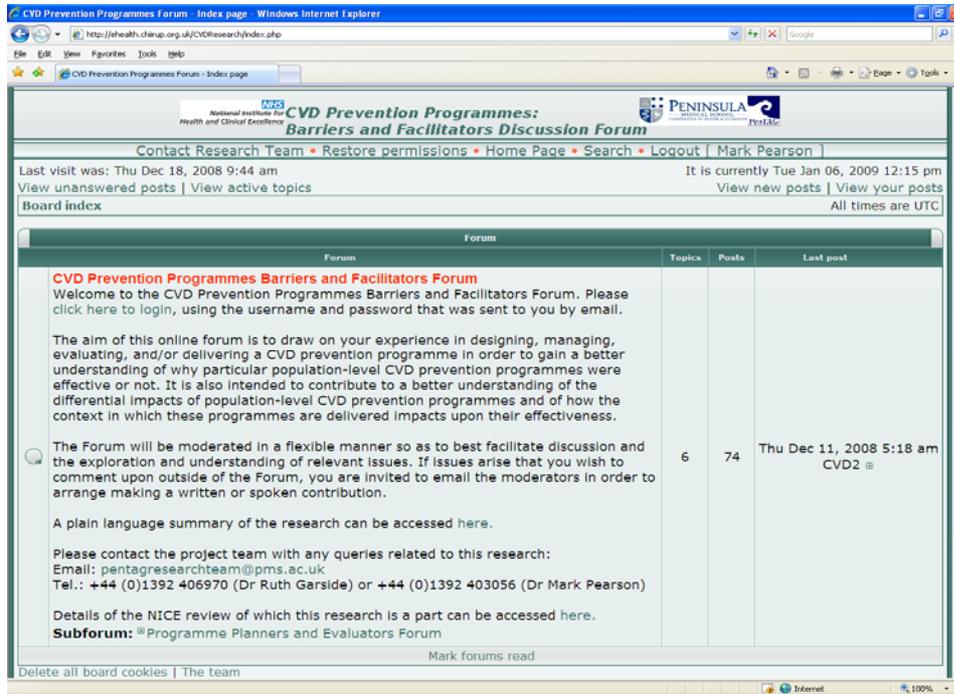


Figure 2 Sub-group page to access the online focus group discussion

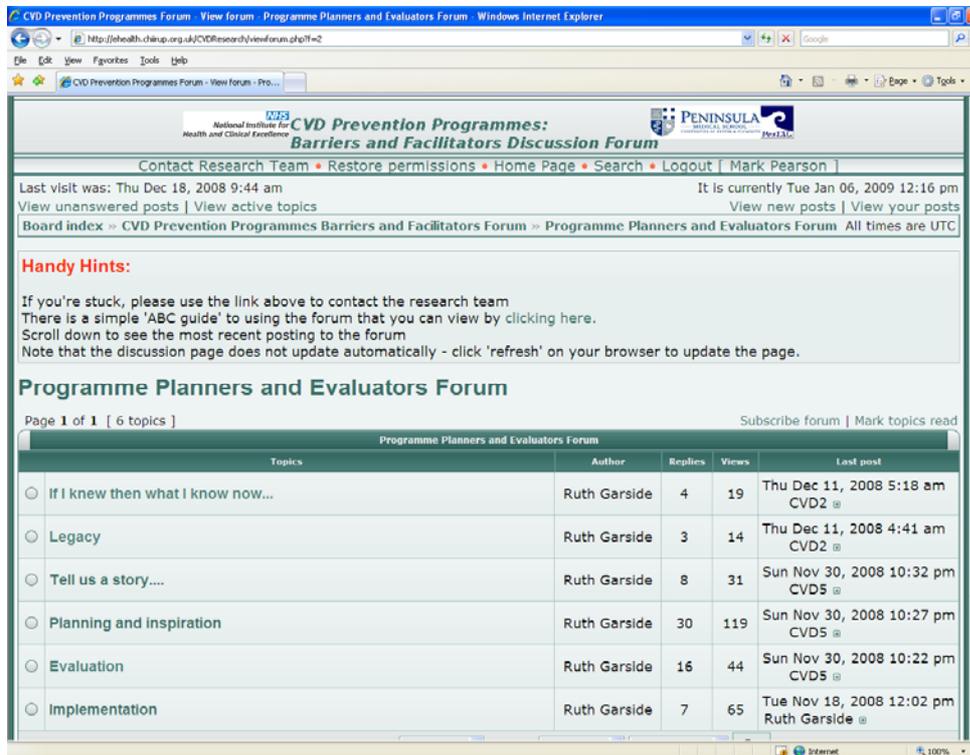
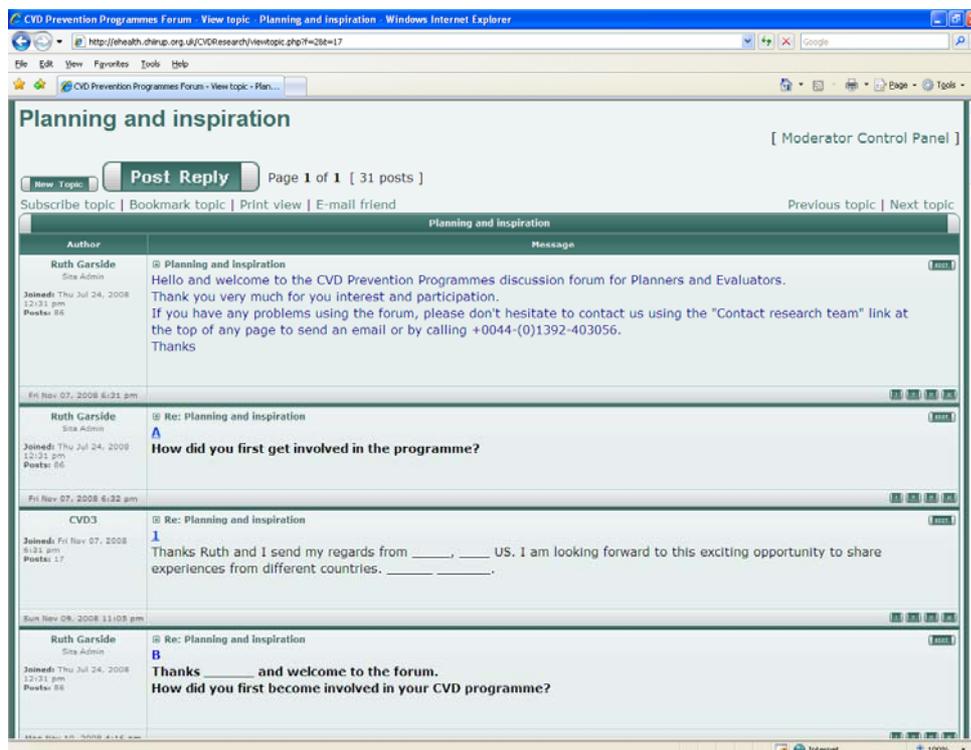


Figure 3 Screenshot showing the introductory discussion within a sub-group



Participants were assigned to one of three sub-groups within the online focus group - programme managers, deliverers, or planners and evaluators. Discussion with participants (by telephone or email) about their responsibilities within a programme provided the basis for assigning them to a particular sub-group⁵. Two days before the start of the online focus group, participants were sent a registration email (see Appendix 7) with a hypertext link to the online focus group, a reminder of the start date, and notification that they should shortly expect an email containing their user name and password to gain access to the focus group. In the middle of the first week of the online focus group another email was sent (see Appendix 9) to all participants who had not yet contributed as a reminder that the discussion was in progress and to encourage participation. In particular, this email endeavoured to allay any anxieties that participants might have had about starting to contribute to the discussion by

⁵ Two participants were subsequently assigned (during the second week of the focus group) to an additional sub-group following email correspondence with PenTAG researchers which indicated that their programme involvement had extended beyond the boundaries of the sub-group to which they had been assigned.

assuring them that, just as in a face-to-face meeting, it was normal for substantive discussion to be preceded by 'small talk'.

The three online discussion groups were active from November 10th-28th (2008) inclusive and were checked at least 3 times each day during weekday office hours (GMT) by researchers at PenTAG. Moderation of the online discussion group was informed by the topic guide appropriate to each group (Appendix 8) and was also responsive to topics and debates raised by the participants.

Moderation followed previously described principles for running in-person focus groups (Morgan & Krueger 1998); a conversational style was adopted in the framing of questions so as to encourage participation, and participants were prompted to consider others' contributions in their own responses so as to both foster discussion between participants and draw out similarities or differences between programmes. Participants received an email (automatically generated by the online focus group software) notifying them each time a new contribution had been made to the sub-group of which they were a member. Towards the end of the second week, the period for which the online focus group was active was extended from two to three weeks so as to not unduly constrain the discussions that were developing.

After completion of the active online focus group period, participants who had contributed were emailed transcripts of each of the discussions held (within the sub-group of which they were a member) and invited to clarify or make additional comments (see Appendix 10). No participants wished to do so, although a participant who *had* contributed to the online focus group expressed a desire to contribute more by means of an interview (which was subsequently arranged). Those who had registered to take part in the study but who had not contributed to the online focus group discussion (n=17) were sent an email invitation (see Appendix 11) to take part in a telephone interview; two further interviews were arranged in this way.

Through the National Research Ethics Service, we obtained ethical approval for this project from the Essex 1 Research Ethics Committee. All relevant documentation was submitted, and a meeting of the full committee was attended on the 18th September 2008. At this meeting, several clarifications to the protocol were requested which were subsequently addressed in writing and submitted to the chair of the committee. Full approval was given on the 16th October 2008.

3.4. Methods of data analysis

The transcripts from the online focus groups consisted of the online discussion pages while the telephone interviews were tape-recorded and transcribed. Both types of transcripts were analysed together. Initially they were read and re-read by the two researchers (MP and RG) who developed coding frame based on participants' contributions which identified the thematic areas discussed. The coding frame was also informed by the previous systematic review of qualitative research undertaken by the same research team (Review 4 in this sequence) and subsequent discussions about this review in the PDG meeting that considered it on 14 January 2009. This coding frame was piloted with the first few pages of scripts, after which the same researchers met to discuss and refine the scheme before independently coding the transcripts. We used disagreements to discuss key findings, refine themes and sub-themes and consider relationships between the themes.

The coding frame initially identified six topic-based themes – programme development, community engagement, staffing, structural barriers to success (including local and national policy), legacy and evaluation challenges. Associated sub-themes for each of these broad themes were also used. Through reading and coding the transcripts, the impact of time-frames was also seen as a cross-cutting theme which we reported on in the write up. Through writing up the findings and considering the relationships between the themes in discussion with the research team, we also developed a conceptual framework which united the key findings around key conceptual aspects across these themes.

4. Findings

Quotations below are provided with details of whether they came from an online group or interview, in which group they participated (PM = programme managers, PD = project deliverers, PE = planners and evaluators), and the location of the programme in which they were involved. Any clarification added by the authors is given in square brackets, and where quotes have been edited this is marked with a row of dots.

The findings are reported under the following thematic headings:

- Programme development and fidelity: “The intervention may not be completely pure”
- Community engagement strategies: “starting the spark”
- Staffing: “no magic solutions” (leadership, staff engagement, GPs, volunteers and multi-agency teams)
- Legacy: “Putting something back into the community that’s going to be there even if the project disappears.”
- Impact of short time frames
- Structural barriers to success; “political landscape changed”
- Evaluation challenges

Finally, we present and describe the conceptual framework which unites the findings. In addition, at the end of each thematic section we have produced a summary statement. As this report is about a single piece of primary qualitative research, rather than a systematic review of the evidence, it was not felt appropriate to try and formulate evidence statements for this piece of work. The findings are likely to be used to support, supplement or extend findings in the reviews.

4.1. Programme development and fidelity: “The intervention may not be completely pure”

We are using “fidelity” to refer to how well the programme as delivered, corresponded to the programme as planned. It is clear that changes may be made for positive or negative reasons – for example, approaches or particular activities were reportedly dropped or adapted if they are seen not to work. Other activities or approaches may be introduced that were not planned for, because they were requested or a new piece

of information or policy emerged, such as the introduction of nicotine replacement therapy. However, changes may also be the result of overambitious plans, the inability of a programme to deliver anticipated activities, loss of funding or other potentially negative reasons. All of which raises the question, when do things change, and how should projects decide what to keep and what to change? In some cases, there were clear pilot or process evaluation mechanisms in place that informed change. These are discussed below in Section 4.7.1. In other cases, possible reasons for change were frustratingly elusive in the online groups and interviews. There are potential tensions. On the one hand, CVD programmes, particularly those with a community base, need to respond to the needs of that community. On the other hand, where programmes have a strong evaluation component, designed to demonstrate a particular effect, it is already very difficult to establish causal pathways between activities and outcomes, without continually changing models.

[T]he programme evolved over its life, so that the emphasis shifted from a broad based community programme that sought to work across a wide range of CHD risk factors and in a range of settings, towards a more targeted programme that worked on achieving measurable outcomes in specific areas. eg. reduction in smoking, changes to diet. (PM group. CVD24. UK.)

The participant did not elaborate on reasons for such a change, although the achievement of targets may have been driven by the need for the evaluated programme to demonstrate an effect. In other words, the programme may have shifted focus in order to change the demonstrable, rather than responding to preferences in the community, or to activities with a long term goal. This is also seen below, showing the tension between deliverable outcomes and other considerations.

Commissioners ideally want to know detailed designs and methods prior to selecting an evaluation team, yet the theory-driven approaches we tried to apply required the developing programme theory to drive the selection of methods and design. We, to some extent, still ended up with a traditional design with too short a follow-up and too limited sample sizes and low response rates given the levels of programme development. (PE group. CVD32. UK.)

Being responsive to local community needs may mean “the intervention may not be completely pure!” (PE group. CVD11. UK) to the original design, adding further difficulties in evaluating the impact.

Summary statement: programme development and fidelity

To be successful, the design of programmes aimed at multiple risk factors to prevent CVD may need to be responsive to environmental changes and community needs. Flexibility may be required on the part of commissioners and funders to recognise this and not require fixed plans for precise design and evaluation schemes to be in place prior to entry to the field. Changes and reasons for any such changes could be documented.

4.2. Community engagement strategies: “starting the spark”

So, for me, community engagement in health and health improvements – if we don’t do that bit right, then you’re just wasting your energy really, because the information you can pass to people, and the support, needs to start at the beginning. (Interview. CVD27. UK.)

We asked participants about community engagement, which was felt to be of key importance in Review 4 and among the PDG. We tried to ascertain its constituent parts, how it might enhance both projects and communities and how it was important. Participants confirmed the importance of community engagement.

There are a number of different ways that community engagement was discussed in the groups and interviews. “Community engagement” can mean many things; “community” was interpreted in a number of ways by the participants – the population in a targeted location, personnel working in other statutory organisations in a given location (such as social services, education or recreation and leisure) and other people working in NGOs in that location, (such as charities or local residential committees.) Different types of community engagement have been previously noted, for example Figure 4 shows Arnstein’s classification of different types of citizen participation, from top down mechanisms with no community participation to

community control. In our research, we found different understandings of “engagement”, including providing health promotion information to a population, inviting people to programme activities or supplying information about them (all stage three – “tokenism” - on Arnstein’s ladder), to enlisting community leaders to promote CVD prevention messages (level seven – “delegated power”). In addition, some participants described ensuring that CVD was included on other organisations’ agendas as a kind of community engagement. Finally, the type of activities in which local people might be engaged ranged from taking part in a fun run to organising it, being engaged as health questionnaire administrators to acting as lay health advisors, to being a lay member of a commissioning board.

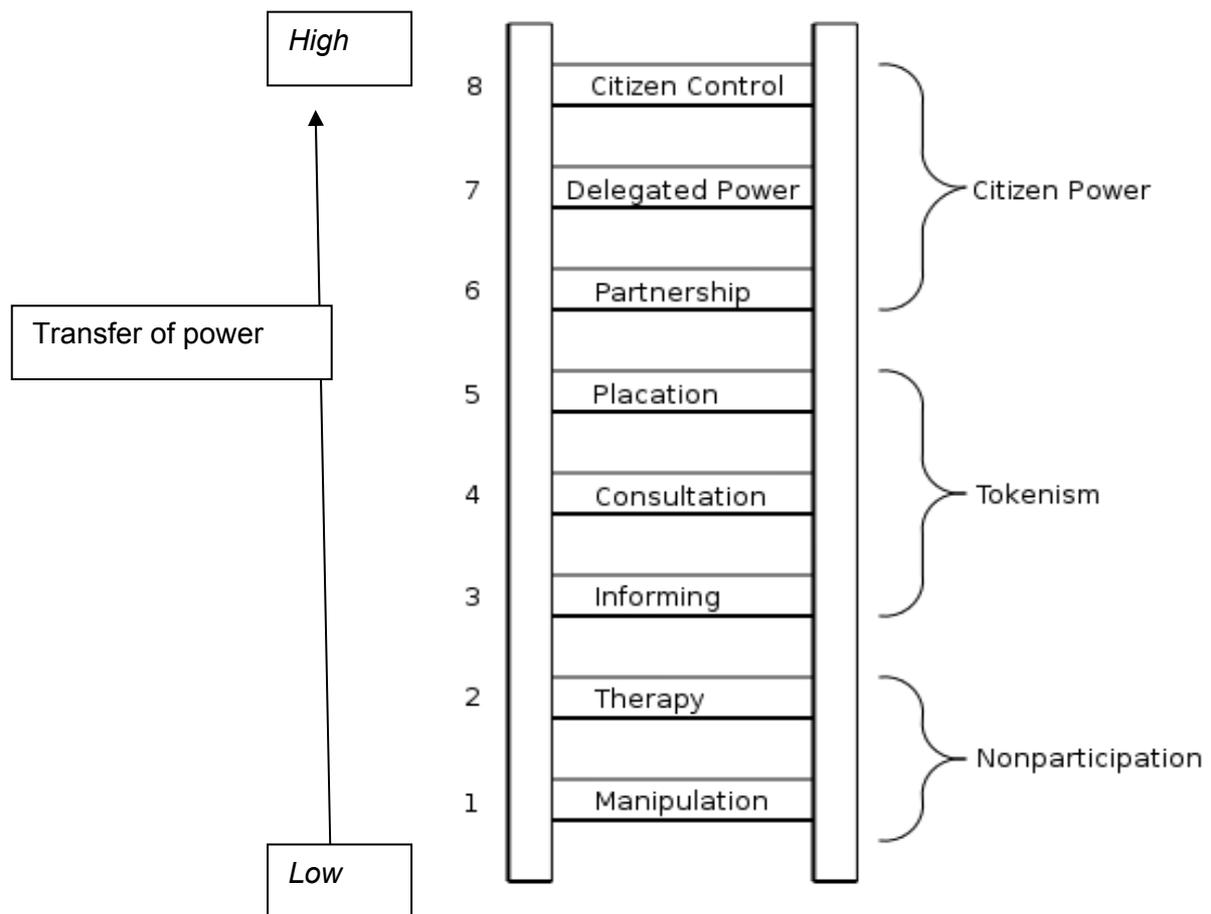


Figure 4: Arnstein's ladder of participation

(source: <http://www.partnerships.org.uk/>)

However, several common themes about how to engage people emerge across this range of meanings: building trust and respect in partnerships, ensuring that communities are motivated to tackle their own health problems, and cooperation and collaboration across different areas and bodies.

To change behaviors as we all know is very challenging. What we have learned is that the community needs to be engaged on a permanent basis. We need to enter communities with dignity and stay there as much as we can to begin to learn how to incorporate programs, policies that work (and to learn from the community). We have learned that communities are complex, as people are. A conceptual framework that brings community involvement, and community engagement through different mechanisms is a promising strategy to reach families and to work

with them in their own context, and at their own pace. We need to be relevant. Community health workers are not sufficient per se, they need to be integrated into a public health model that embraces community mobilization strategies, community engagement, and that brings many interdisciplinary groups into play. We have spent more than 15 years trying to learn how best to infuse a community engagement component to the [name] program. We are still learning! We have learned that working with communities is an art, and that this art needs to be discovered and even more importantly, that it has methods and principles of science. This new paradigm has been difficult to embrace by many in the public health field (prevention field). That is, the need to "discover" that artistic imprint (cultural, social, contextual milieu) that takes into account the complexity of people, and communities and that brings relevance, harmony and makes sense to people. Thus, we have to bring methods, programs and a new philosophy of prevention that works in our multicultural and very heterogeneous communities like the Hispanic/Latino community in the US. (PE group. CVD 11. USA.)

Key elements of this statement focus on the complex nature of building respectful and trusting partnerships between the community and those who wish to work within them. Health professionals need to listen to, and learn from, communities, if they expect to be listened to and learnt from in turn. A commitment may be needed over a long time-period, and engagement is a dynamic evolving process, that cannot be formulaic, but must involve the judicious, and usually iterative application of general principles of "best practice".

One programme reported that community members were helping to devise questions about the patient experience that would be part of the tender documentation going out to potential service providers. This is the highest level of engagement seen among the programmes discussed, "delegated power" on the ladder of participation shown in Figure 4. At least three benefits of this kind of involvement were seen. Firstly, local people helped to define what was important to them and would judge how well applicants addressed their concerns, leading, it is hoped, to services that better meet their needs. Secondly, they were able to appreciate complexities related to organising health services about which they were previously unaware. Finally, they could carry information about their experiences back to community:

If you engage people, bring them through the process and, actually, it's really good, 'cos people go "Flippin' heck – I didn't know there was this much involved, it's an awful lot isn't it?"..... And that message goes out. So when we get people who may be critical, and they are. You know you have those champions going "Now hang on a minute, I was there. I didn't realize this was going on, this was going on." (Interview. CVD27.UK)

Such involvement is about developing partnership, trust and understanding on both sides.

Another way of building trust in a targeted community is to listen to, and engage with their interests before trying to engage them on the CVD agenda. In addition, this participant emphasises the type of skilled delivery needed, aimed at immediacy and tapping into people's real life experiences.

Even if you go to residents' meetings, most of the time people will be talking about antisocial behaviour, environmental kinds of clean-ups – the bins aren't done, dog poo, those kind of things. But it's about health workers getting in on that and bringing it all to the table...People will come because they're passionate about something but then you've got to engage people. And you can make it interesting and engaging. It's not about those bloody dry boring power point presentations either. You know, how many meetings are there you've been to where you say "Bloody Hell! When's this thing finished?" Why should I have a local resident give up their time to go watch some plod giving a power point? No, you want to go in and say "Look, how many people in this room, as an example, have been touched by somebody who's had a heart attack or heart disease?" –"I have." "I have." "I have." "What was their experience when that happened?" "Bloody awful! and you never got any information and..." da di da di da di da. That's how you get it. 'Cos people will have an opinion. But it's just how you start the spark. (Interview. CVD27. UK)

"Starting the spark" here involves accessing the right environment and, once there, speaking to people in a way that is immediately engaging through contextualising the health problem experientially. This participant also described using actors to debate "in role" with audiences about health concerns. Done well, community engagement creates a positive feedback loop through which motivation to make health

improvements is increased, leading to changes in health behaviour, which boost motivation, and so on:

It requires, but also fosters, a "can do" frame of mind in the community. (PD group. CVD13. UK)

Once people have been engaged, it is important that they are not let down, or abandoned by raised, but unmet, expectations.

It just undoes everything you've done. If you empower someone to say 'I want this. I want a health check, da di da di da' and then they have a really bad experience, that resonates.... it's how you look after people to be honest. (Interview. CVD27. UK)

There is also a danger that short term projects (most of those discussed lasted no longer than three to five years) may "hit and run", leaving communities and voluntary organisations frustrated and abandoned, leading to broken trust between communities and those designing and delivering CVD or other prevention programmes.

We cannot [any] longer "enter" communities, "raise expectations" and then see projects fade.....We are in a challenging journey to build a new model of community outreach that agencies and organizations can embrace. (PE group. CVD3. USA.)

There was a recognition that community engagement had not always been well done. Asked why, one participant responded:

I just think a number of things really. One is lack of skill and a lack of understanding. I think that is getting better, although I still think that some people pay a lip service to it. And I think the other reason is I just suppose the historical context of the NHS which is kind of hierarchical and I suppose professionally driven, so that the professional knows best. (Interview. CVD33. UK)

As well as building trust in the community served, trust between professional organisations, and recognition of their skills, is also vital for programmes that operate across a number of agencies. This allows appropriate outsourcing of specific tasks

and activities. The lack of skill and understanding among some traditional workers was also recognised by another participant who suggested a solution:

You can engage, I don't think anyone's hard to reach but some people are challenging when you engage them. You've got to be confident enough to manage the situation. So with things like that, I do think you bring that expertise in to support you. Don't assume you have to do it all yourself – that would be my tip. (Interview. CVD27. UK)

This comment is perhaps unsurprising from someone whose role is community engagement but it is clearly vital to identify staff with the correct skills for the correct task, especially with community engagement, where trust is crucial and, once lost, may be difficult to regain.

Another challenge to successful community engagement relates to the way in which funding is allocated to particular disease areas. This is unlikely to map onto the concerns of the community.

And again that's another problem, in the fact that much of, kind of development monies, is badged up under different disease headings and consequently we're doing projects that have got a disease heading when, actually, that means absolutely nothing to the community you see. The community will buy into health and wellbeing. (Interview. CVD33. UK)

However, another participant, involved in community engagement, put it rather differently. Rather than expecting the community to “buy into” areas of interest defined by health authorities, they engaged initially with the community through listening to their existing concerns through attending existing forums like residents meetings. These concerns may be more to do with residents' immediate, physical environment. Once communities had forums in which they were active, and attention was being paid to the topics that they had identified, other topics could be introduced. Other participants also described tapping into existing community work:

I was lucky to be involved with a multidisciplinary team who were experienced in similar work in the same community. In other words, we were encouraged to carry

on as we had been with our engagement, only this time it would be more focused on individuals over a longer period of time. (PD group. CVD15. UK.)

Part of the purpose of community engagement may well be to reach those traditionally poorly served by existing services. Addressing health inequalities may well be an aim of community engagement, but this may not be easily achieved. Activities may attract only those already motivated to change to healthier lifestyles.

[A]ll self referred....I think they then came onto the [weight management] course with a positive attitude and were open minded in relation to making lifestyle changes. (PM group. CVD31. UK.)

Activities based in the community may be innovative, but motivating people to use them can be difficult. If only those already motivated to change participate, existing health inequalities may be exaggerated. Community engagement therefore needs mechanisms to ensure that the wider community is reached and not just those already motivated to change and engage. One way of capturing a broad interest base is to ensure that people are engaged on the topic areas that matter to them:

In terms of engagement – big, big awareness – get out into the arena really, in the public there's different reasons why people came. Some people came because they were fed up with antisocial behaviour going on and the businesses were getting robbed, broken into. So some people came about employment – lack of training education and employment opportunities. Some people came about education because the employment rates were dismal and they wanted better schools for their kids. And some people came about health. But what started to happen is, once people came, we had joint tasks so everyone came together and then we would present across the streams. (Interview. CVD27. UK.)

It was noted that “women are much more likely to respond to invitations to become involved in health related activities in the community” (PM group, CVD19. Europe). Inequalities may be addressed by ensuring that that all people have access to healthier choices, one example described introducing food co-ops through school and vegetable delivery vans in the targeted localities (Interview. CVD27. UK.)

Summary statement: community engagement

Positive community engagement requires trusting, respectful relationships to be built which motivate and support change. Community engagement should be an ongoing and dynamic partnership which responds to community needs.

As CVD may not be seen as an immediate concern within targeted communities, staff may first need to listen and respond to the existing concerns of the community. This may be done through participating in existing networks and forums, or creating forums that have more open agendas, at least to start with.

Sufficient time is needed to ensure that this is done appropriately, and also to ensure that changes become adopted by the community so that they are empowered to continue, even if the project itself comes to an end.

Information and education is likely to be more effective if it relates to the experiences of the community, and if those that deliver it are seen as part of that community. Appropriately skilled staff are needed for effective community engagement.

Greater levels of participation, that involve community members as partners or devolve power to them, may have additional benefits – ensuring that programmes are truly responsive to community needs, involving local people in the complexities of planning and delivering such programmes and so facilitating understanding within the community.

Done well, community engagement may create a positive feedback loop which motivates change, improving health and which produces greater motivation. However, care needs to be taken to ensure that those adopting behaviour change are not just those already motivated to change, thereby increasing, rather than lessening, health inequalities.

4.3. Staffing: “No magic solutions”

No magic solutions - just follow good human relations practice and have effective team leaders. (PD group. CVD 14. UK)

In this section, we consider issues to do with staffing around leadership, staff engagement, GPs, volunteers and multi agency teams.

4.3.1. Leadership: “You need people to stand up”

Most of the CVD prevention programmes described by participants required multiple staff, from a range of agencies, to engage local communities and deliver a variety of activities to provide services, raise awareness, and promote behaviour change. In some cases, existing activities were incorporated and re-branded with an umbrella programme badge, whilst in others, multiple projects might be developed from scratch. There was usually some mixture of the two. In both cases, leadership was required to inspire, drive and coordinate the range of people and activities involved. In some cases, programmes were initiated by strong leadership and CVD champions:

I guess the initiation of this came down to a group of enthusiasts being at the right place and right time with the right setting. (PD group. CVD14. UK.)

You need strong leadership, you need people to stand up. It did seem at that time a big investment. (Interview. CVD33. UK.)

Leadership may be provided by a range of people. Other types of leadership or programme champions included an elderman in the municipality board that ensured a programme was on the political agenda. Losing this champion a few years later was linked to the loss of project funding, and its subsequent collapse (PM group. CVD22. Europe). One participant described a champion in primary care whose role was to engage other GPs to the programme or particular elements of it, through discussions which can outline the justification and evidence base informing activities such as community-based vascular checks (Interview. CVD25. UK.). Senior staff, such as PCT chief executives may be important leaders (Interview. CVD33. UK). In addition, it was suggested that successful community engagement requires an initial identification and engagement of existing community leaders, who also recommended other opinion leaders and potential volunteers (PE group. CVD5. USA.)

Effective leadership is critical, in a number of ways. Problems arose where the expectations of leadership roles were not matched by final responsibilities for allowing aspects to proceed:

Whilst initially it [the various commercial and statutory bodies involved in the CVD programme] seemed a good mix of approaches, these had evolved in a piece meal fashion from different people and different groups having different experiences and thinking their perspective should be accommodated. My role was to try and bring

all these elements into a coherent whole, whilst having little influence on the decisions to include them or not..... It feels that 6 months work has just been thrown away. This is not a moan, but I think it does provide some lessons in respect of having agreed responsibilities and leadership from people who are actually "working on the ground" and know what is required and working closely with decision makers, rather than the decision makers coming in at the end and though not knowing the ins and outs of the project making decisions that throw the whole thing into the melting pot. A "champion" with ability and decision making authority (at a high level in the organisation) is vital. (PM group. CVD18. UK).

Other challenges to the successful champion role might be relevant experience:

There were people involved in the project at various stages of their professional careers and whilst I was fairly experienced in health promotion, I hadn't been involved in anything of that nature before and I daresay it was new for everybody involved. There's only so much you can learn from the literature and what have you. (Interview. CVD33. UK.)

There was confirmation for some of the findings in Review 4 (Section 5.7.1) such as the challenges, particularly for senior staff, of allocating time to CVD work when their role was diverse and demanding:

One of the main challenges for me personally was being the public champion of the project, which meant the team of implementers expected me there at every celebratory event - which with schools, shops, pubs, local groups, charities, NHS agencies, and programmed events was a challenge for me as DPH [Director of Public Health] with regard to the mainstream job. (PD group. CVD14. UK.)

In addition, as also noted in Review 4, it was important to ensure that a full time coordinator was primarily responsible for the CVD work.

it became very evident that we needed a coordinator who needed to work on it full time, on their full time, and not it being just part of your job – very evident. (Interview CVD33. UK.)

The champion role may be about visibility and identification with CVD, which may be more difficult for senior staff with non-disease specific, and very busy, roles. While

leaders are clearly important, reliance on individuals is not without risk, and it may be unrealistic to expect all those co-opted to work with a project to be enthusiastic about involvement.

Well again, I can't say that everybody was kind of buzzing with it. I think it would be wrong to do that. Clearly there were some people who could see their role and were keen to develop it but some people just couldn't see the point in it. A lot of it is around personalities, a lot of it's around leadership. You could apply social marketing principles to the staff. There will be some groups of staff who are the early adopters. There will be some people who are the laggards who need a bit more time, a bit more investment, a bit more coercion. And there'll be some people who are just not interested at all. I just don't think we got to a point where we had the point of the pendulum swing where everyone was on board with it. But we were getting there, more and more people could see it. (Interview. CVD33. UK)

This also implies that projects need to disseminate responsibility within professional communities. There are potential tensions between the need for strong and visible leadership, particularly among the professional agencies involved in the programme, and the needs for community engagement:

No one wanted someone from an ivory academic tower coming in telling them what their community needed. They wanted to tell us what was needed. (PE group. CVD5. USA)

It may be that there are different needs at different levels of the programme and champions may be needed at a number of different levels. The participant below clearly focussed on organisational and management concerns in order to plan how different levels of influence could be focussed on CVD across and beyond the health authority:

we need to know at a project level and a programme level what potential risks could affect this project and the programme effectively you know?.... Corporately, they're saying we need to do something about this, but actually for example, if I go and work with the Assistant Director in Commissioning, the Assistant Director in Commissioning has got a whole spectrum of these areas to look at and a whole load of pressures and then me knocking on the door saying these are the

timescales I've got that want delivering as a Project Director, they see it's extra work, so it's trying to get the cultural changes around project management, stuff like that. (Interview. CVD25. UK.)

Within organisations such as the NHS, a CVD programme champion may be required to coordinate collaboration across multiple work streams. In addition, champions may be needed to focus on engaging the community – in both directions, that is, finding the right ways to work with communities, but also selling the value of this work to professional organisations.

And it is a challenge. And some people are really hard. They're hard and they're really rude. Well, you've got to embrace that, and you've got to take it on the chin and go "Right, OK. I hear what you're saying, what can we do about it?" There's no point in hiding. 'Cos if it's important to people, it keeps coming back all the time. (Interview. CVD27. UK)

This speaker recognises that difficulty, and that it may not be easy to persuade others of the value of community engagement.

Finally, champions are needed within and from the community. One participant from the USA wrote movingly about recruiting an office cleaner as a lay health educator (*promotora de salud*):

She became one of the most valuable promotoras we had. She worked really hard and got her training on the manual for promotoras from the [name] program. She taught many Hispanic families in our program. People loved her. She was a true "health educator". Her life has changed even though she continues to clean offices at [workplace]. She is a true inspiration to all. (PE group. CVD3. USA.)

This participant saw the contribution of this lay health educator as key in championing the aims of the project, engaging with her community, building her own confidence and also inspiring other people involved professionally or voluntarily in the project.

We have been using the word "champion" to describe individuals who, through their enthusiasm and commitment to a project, provide impetus for getting things done, and encouraging others to be actively involved. In the above quote, the meaning is slightly different, with a senior member of staff seeming to have a kind of "official"

expected role to champion the programme, with expectations of promotional activity that are difficult to accommodate within a varied role. This was different to some others who, without ever using that term, seemed likely to be operating as champions for the programme in which they were involved, through their evident sheer enthusiasm and charisma:

I didn't intend my career to be in cardiovascular disease and stroke. Now I've got a passion for it..... I am sometimes like a dog with a bone.... I think you need that – that sort of passion and that drive in order to deliver. I'm not saying I'm perfect, I'm a world beater, but I will deliver something before I leave the organization (Interview. CVD25. UK.)

For me the inspiration for the group was the common purpose - doing something differently and innovatively to promote health and reduce inequalities. (PD group. CVD14. UK.)

These quotes exhibit a kind of “pioneer zeal” to achieve the programme goals. However, while the right staff are critical in a project and may be seen as the most important element, there may a risk with this, in that individuals may be irreplaceable, and, from an evaluation perspective, their impact may not be transferable. It is not clear how the programmes can ensure these critical people are in place, and what will happen if they leave:

[A]ny successes we were able to achieve were very much reliant on the individuals who were part of the project..... It's not very helpful in some respects because, if the success of the project is largely dependent on individuals or individual qualities, then how do you replicate that? (Interview. CVD33. UK.)

Creating successful leadership opportunities will require identification, training and support of talented staff with drive, and commitment to CVD.

Summary statement: Staffing - Leadership
Strong, inspirational leadership may be important to initiate, coordinate and drive complex programmes and motivate and encourage cooperation among multiple staff across a number of agencies with a range of responsibilities.

To fulfil this, staff are needed whose role is dedicated to the programme and those with multiple roles need to have appropriate time freed up.

Leaders may be needed for the project over all, but also for specific elements of the project, for example, to encourage primary care participation or ensure local political or funding support. Leaders from within the community are also needed to champion the project and facilitate engagement.

Expectations of leadership roles should be matched by appropriate control and responsibility, and given the necessary training and support.

4.3.2. Staff engagement: “Keeping them involved”

Key aspects that ensure staff are engaged in the process of delivering CVD programmes and the projects with them include, training, resources, understanding how their role fits onto the programme overall, and understanding the extent of those roles and responsibilities.

And it’s really important, I feel, that those who are delivering the projects have an understanding of the wider implications of the programme, ‘cos they do tend to work in silos. You know, head down, “this is the project that I’m delivering on.” So in terms of keeping them involved, it’s like, “look, this is how it impacts on the programme.” (Interview. CVD25. UK)

This suggests that motivating staff is very important and that people need to feel that they are part of a large collaborative effort when addressing big issues like CVD.

As well as ensuring the workforce has the appropriate skills for their role, training for locally based staff is also a way of enhancing sustainability.

...sustainable things, like providing training for local people. So that, irrespective of what happens, they still have that skill, still able to use those skills, still able to generate income from those skills.... We trained a lot of health visitors, a lot of people were involved in kind of local centres, et cetera. Now that training will have carried on, people with those skills will have carried on. (Interview. CVD33. UK)

Whilst being close to the community in which they work is clearly important for staff, so that trusting relationships can be developed, there was also a note of caution. The following quote relates to initiatives aimed at weight loss that involve free gym membership and free fruit and vegetables.

One downside of a having a team of individuals such as ours is that a trust is built up between community members and staff, therefore it must be strived that it does not reach a stage were 'familiarity breeds contempt', and liberties start to be taken..... Problems are often made worse if friends or even family of workers are participating on the programme. (PD group. CVD15. UK.)

Staff clearly need appropriate training and support to manage difficult situations constructively.

Summary statement: Staffing – Staff engagement

To ensure that staff are engaged with the aims of a CVD prevention programme, they require appropriate training and resources, a good understanding of how their role fits into the programme overall and a clear understanding of the extent of their roles and responsibilities.

4.3.3. GPs: “The proper role for general practice is to support efforts in their community to promote healthier lifestyles”

A complex and sometimes contradictory picture of primary care involvement, particularly with GPs, was reported. A number of projects were keen to involve GPs and other members of the primary care team in CVD prevention work. The findings of Review 4 suggested that GPs might be more comfortable in a secondary prevention role. This was strongly supported by a GP involved in a prior UK project, in relation to health checks, who believed that this had not been shown to be either clinically- or cost-effective.

I find it very disappointing that the idea of health checks in primary care seems to be re-emerging despite the lack of evidence that they would be effective and would divert resources, particularly practice nurses, from chronic disease management. I also feel there is a danger that lifestyle issues become medicalised, particularly by

inappropriate prescribing, and victims become blamed. This is also true for the current concern about obesity. The proper role for general practice is to support efforts in their community to promote healthier lifestyles, and only to treat those at higher risk as patients. (PD group. CVD13. UK)

There is a key understanding here of public health issues being related to issues beyond the traditional arena of health services. This may help to explain why it was reported “very difficult to maintain the interest or involvement of the local GPs in the project” (PM group. CVD24. UK.) Another UK study tried to encourage GP participation through offering free PCs (this was in the mid 1980s), but not all signed up. Alternative ways of reaching the target population, such as through workplaces, were used instead (PD group, CVD12. UK.).

Where primary care staff were involved, some activities and roles were regarded as crucial, and very supportive, including the development of GPs as clinical champions and acting as links to other relevant community based organisations:

it is important that messages about lifestyle are consistent and supported in consultations with doctors and nurses in primary care. However I also believe that "Community Orientated" primary care can have a much wider role. This includes setting good examples eg about exercise, and advocacy about health promoting facilities and policies. The team can also identify health problems and needs in their community, and most importantly identify other agencies and assets in the community with whom to work. (PD group. CVD13. UK).

This quote situates primary care as a community health organisation that provides clinical services, but which best addresses primary health promotion through acting as advocates through links with other organisations, rather than directly.

A number of considerations for successful primary care involvement emerged. Staff with such multiple roles need to be resourced properly to take on roles that extend beyond their usual activities.

Money for GPs - not personal gain but to fund the additional resources the practice has to put into doing extra work - staff time in particular. (PM group. CVD18. UK)

In addition, communication about the project might need to be tailored to GPs' manner of working and communicating:

As you know like you know GPs, for example, will access their information differently, won't read their emails, so that's useless; won't read letters, 'cos someone else will read them for them, but actually how? Are they in certain forums we can go to? Can we do it through other groups? How can we get that information to them to keep them updated and engaged in this programme to show look, this is the progress that we're making? And all of a sudden, they want to be involved then. They want to do something. (Interview. CVD25. UK.)

The use of the phrase "as you know..." at the beginning of this piece suggests that it is considered to be common knowledge that particular strategies are required to engage GPs. The implication is that, information needs to be taken to GP focussed forums, and especially with positive reports about the programme, in order to encourage GP participation.

Summary statement: Staffing - GPs

The role of primary care was complicated and sometimes contradictory. Some GPs may be more comfortable with a secondary, rather than primary, prevention role, which may explain why some participants found it difficult to engage them in CVD prevention programmes. Conversely, other participants viewed primary care as crucial partners in CVD prevention. Advocacy among other local organisations may be a key role.

Where primary care is involved in CVD prevention programmes they need to receive appropriate resources to free up staff time.

Engaging primary care and keeping them appropriately informed may require tailored approaches.

4.3.4. Volunteers: "Put your arms around them and support them"

As mentioned in Section 4.2 about Community Engagement, using lay health advisors and volunteers in CVD programmes has clear appeal in reaching into communities and tapping into existing networks of trust within peer groups:

[T]hey aren't gonna listen to people like me telling people at forums in a real, sort of, ummm, formal way, they're gonna listen to like little Billy from [location] down the road who's gonna say 'You know what? You know..' and really take all that on board. It's really about peers isn't it? (Interview. CVD25. UK)

Such involvement enhances community empowerment, through types of engagement that are towards the top of Ainstein's ladder of participation shown in Figure 4. There are ethical implications of using such volunteer forces, however, and they require appropriate support and training just as much as the staff described in Section 4.3.2.

And then, once you do hook people in, put your arms around them and support them. Don't use volunteers. And I think that's where everyone goes wrong. They either burn them out, or they just pick them up and drop them when it suits, and that's why things like that don't work. (Interview. CVD27. UK.)

Well supported and truly participatory engagement with community volunteers needs support financially and politically, and was not always felt to be recognised as critical:

Integrating a more ecological model of prevention into public health using community based participatory research and true community engagement has been difficult to sell. (PE group. CVD3. USA)

In addition, the question of financial compensation for such work also came up and was clearly a tricky issues for this participant, whose programme relied on a the work of a network of community health workers (*promotores de salud*) providing information and training within Hispanic communities in the USA:

The topic of paying community health workers should not be so complicated in that people should be compensated for their work they do, that is only fair and just. However, many community health workers begin their work as volunteers and some like that role, although based on my experience, if they have a choice they would like to be paid for their work. Some people are concerned that some promotores would lose their qualities if they move away from their role as volunteers. ends for their work in the different grants. (PE group. CVD3. USA.)

In other cases, community workers were paid, although this is discussed more in terms of the benefit to the research programme, rather than to than to the community:

[W]e did, however, have much success with training lay community members to be paid health surveyers or medical record abstractionists. This kept the cost of the program down, and also helped us get into local homes for the door to door health survey (which we were able to conduct in English, Portuguese, and Spanish). (PE group. CVD5. USA)

This use of local people in order to gain access to the community seems very different to that described by others, where the language used: “put your arms around them and support them” (CVD27) as shown above and “link arms with them” (CVD 25) - which provides nurturing and supportive imagery about the involvement of volunteers and the community from which they come.

Summary statement: Staffing - Volunteers

Volunteers from within the community may be particularly effective at informing, motivating and engaging their peers in the community and enhance community empowerment.

Volunteer workers need to be properly trained and supported to ensure that they continue to be involved and don't get burnt out.

The issue of paying those involved should be considered carefully.

4.3.5. Working with multi-agency, multi-disciplinary teams: “It's all about highlighting the benefits of each service if they work hand-in-hand”

You can't improve health through the NHS, it's got to be working in partnership with others and for others to recognize what role they've got in promoting health. (Interview. CVD33. UK)

Working in large teams which are both multi-agency (across different organisations) multidisciplinary (across different professional groups) is ubiquitous for successful public health work such as preventing CVD, but may be challenging. Different organisational cultures, and unfamiliar bureaucracies, may add to the challenge (see

Review 4, Section 5.4.1). People in different organisations may have different specific goals within their service:

That was bloody difficult trying to get them two to work because they've both got different key performance indicators but, actually, it's all about highlighting the benefits of each service if they work hand-in-hand. (Interview. CVD25. UK.)

In order for such teams to work, there needs to be a shared sense of purpose through raised awareness across many different people and their organisations, engagement with those people, making sure that there are mechanisms for sorting out problems, continual feedback, communication, building of trusting partnerships, clear roles with understandings of individual and collective remits and accountability, and coordination and cooperation across the streams. These elements require the leadership described in Section 4.3.1.

The secret is, how many agendas can you get it on, and how many people can you motivate to do something about it? (Interview. CVD33. UK.)

Having a structure, an accountability structure, so that you know who's being held to account for what. (Interview. CVD33. UK.)

You need now to understand your role, where you fit into this project and where you fit into the wider programme, do you know what I mean? When I highlighted all the projects and where the projects, how they report, when they report and how that has an impact on the organization, because every programme delivered within an organization has to work towards a corporate goal or else what's the point in doing it, do you know what I mean? And the corporate goal and the corporate vision is to make obviously [location] a much healthier place obviously.... to reduce cardiovascular disease,.... so I've now sort of built this sort of governance infrastructure that there's a reporting structure, all that sort of stuff and people can see that diagrammatically. They'll say 'oh I know where I fit in now' whereas actually it was all sort of a blur to them and they were just running around in circles. (Interview. CVD25. UK)

Expectations about how funding can be transferred to other organisations, clashes of timetables and requirement for programmes, which may run over a number of years,

to account for spending within a particular financial year, can all cause problems between agencies.

But more importantly when you you're working with external sort of bodies if you like, like the university, there's loads of barriers put in the way and them barriers are not the same barriers that are in our organisation, I think, to overcome them. For example, can we shift money out from our organization? – no we can't.....you have to go through a tender process. Then, getting the money into that organisation, we don't want to pay it in one, it's a nightmare, you know what I mean? So working with – that's not gone so well so far – and that's taking much longer than we'd anticipated cause we wanted to start this back in around about April/May. So things like delays in projects like this can have a real big impact on the programme and it's about the lack of understanding on how other organizations work and financially and all that sort of stuff, the barriers in place. But that's learnt with experience isn't it? (Interview. CVD25. UK)

Trying to work across organisations may lead to unanticipated barriers and delays, collaborating may be time consuming and this is difficult in time limited programmes.

Across different levels of an organisation, across organisations and among various people who may have a focus on other areas, coordination and cooperation about CVD is vital. Staff engagement at all levels is needed, from the corporate recognition of the problem, to ensuring that frontline staff are aware of how their work might fit into that health priority. One UK participant, described how working across teams was facilitated by a number of joint senior, health and social care appointments:

We are all one, which makes it so much easier. One – because of the finances. But two – because of the political side of it. We're all working on the same end. And we're all part of this kind of big organisation of health and wellbeing so we have got a massive forerunner that I know that other areas don't. (Interview, CVD27 UK.)

Such appointments aid coordination and cooperation across departments in a locality, and may bridge cultural differences between organisations. In addition, this allows for roles and responsibilities to be delineated and agreed.

Summary statement: Staffing – Multi-agency, multi-disciplinary teams

Public health work to reduce CVD is likely to require the involvement multiple agencies and disciplines.

Coordination and cooperation is required to build trust and a sense of shared purpose through aligning the goals and activities of different agencies involved, and assigning clear roles and responsibilities to participating organisations and staff within them. Joint appointments may facilitate this. Ongoing feedback and communication is vital.

Sufficient time is needed to successfully negotiate and accommodate different expectations and bureaucracies.

4.4. Legacy: “Putting something back into the community that’s going to be there even if the project disappears”

The PDG expressed a particular interest in understanding about the legacy of any historical CVD prevention programmes and specific questions were asked about this.

As described above, many programme are, at least initially, short term projects with limited time horizons, often no longer than three to five years. In order for there to be a positive programme legacy, project need to become embedded in the community. A number of potentially appropriate mechanisms for this are suggested by the comments of the participants – through projects and interventions being embedded within a major organisation (PM Group, CVD19. Europe); ensuring that local healthcare workers and other relevant local staff (Interview. CVD33. UK) and/or community members (Interview. CVD25. UK.) have received relevant training to continue activities beyond the life of the programme; through securing ongoing funding for activities and projects (PE group. CVD3. USA), ensuring timely delivery of positive results (PE group. CVD11. UK) engaging the community from the beginning (Interview. CVD27. UK.); through ensuring that local partners, including commercial partners, “institutionalize” activities (PE group. CVD5. USA);

Several of the participants noted that there was little or nothing left of the programme in which they were involved due to the time limited nature of a project or a change in political environment leading to withdrawal of funds.

[A]fter 5 years of intervention the administration of the municipality changed from left winged to right winged and they closed the money tap for the project. All the collaboration that was built in the last years fell apart. (PM group. CVD22. Europe.)

...but if you looked at the whole community most people probably wouldn't have heard of it. Despite our successes, it's not something that, whilst it's probably ingrained in my memory, my heart, for the rest of my life, it's long time forgotten in most of [location]. (Interview. CVD33. UK.)

For many of the programmes, legacy is hampered by the short term nature of the projects themselves. Many run for short periods of time (often three to five years) with associated funding streams, outcome targets and evaluation projects running over that time slot. There is likely to be tension between the goals of truly embedding lasting changes within targeted communities, and the need for short term outcomes to be recorded for the funders and/or the evaluation stream. Behaviours and activities need to be embedded in the community, if they are to have a positive impact beyond the life of a particular programme or project.

I'm also not sure to what extent the interventions that were successful were embedded and mainstreamed after the project ceased....the big challenge is to see prevention and promotion as legitimate calls on mainstream resources so that interventions can be sustained as long as needed. (PE group. CVD11. UK.)

Activities or mechanisms of a programme that have been shown to be successful will require on-going financial support. One participant described lay *promotores de salud* (health promoters) recruited from, and operating within, Hispanic communities in the USA. These voluntary workers were felt to be successful and the model worth rolling out, but was yet to attract sufficient funding:

Our projects have left a number of experiences with promotores de salud that can be replicated and maintained if further investment is given. However, in many instances, the successes are short-lived because funding ends. We have created

demand for promotores de salud in our communities. We have provided a supply of well-trained work force of promotores de salud, however we have not seen yet the buy-in from stakeholders. (PE group. CVD3. USA)

Handover from project to community may also involve other participatory bodies if the activities seem to be working. Separate projects, based in the UK and the USA, reported that food retailers became, and remained, involved with promoting healthier options. In the former, a local dairy promoted lower fat milk products and sponsored various community events while, in the latter, local restaurants agreed to label healthy options on their menus:

First, the labels were [programme name] labels, but as the program became more institutionalized, the [programme name] markings on the logo started to disappear until the intervention was "owned" by the restaurants and successfully institutionalized. (PE group. CVD5. USA.)

In other cases, training was seen as key, equipping the local staff to perpetuate good practice.

...any kinds of bids for new money, there's always a clause about sustainability. You know you have to put that case forward, but I think, in my experience, it is a kind of lip service..... providing training for local people so that, irrespective of what happens, they still have that skill, still able to use those skills, still able to generate income from those skills. (Interview. CVD33. UK)

There is a danger that “sustainability”, like “community engagement”, becomes a buzz word to which only “lip service” is paid because it is needed in the game of funding acquisition, but which may into translate into real activities or impact on the ground.

Summary statement: Legacy
CVD reduction programmes may enhance their longer term impact through ensuring that programme activities are embedded within organisations and the community.
Appropriate training and support for key staff, and community members, from project inception may help to ensure activities become “institutionalised”. Ongoing sources of

funding should also be identified.

Programme impacts should be regularly assessed and results fed back to staff and organisations so that successful activities are recognised and adopted. This will require the identification of appropriate resources.

Early and ongoing community engagement may ensure ongoing changes in healthy behaviours, empowering the community to maintain positive changes. Short term projects often fail to leave lasting benefits to a community as their short term goal setting may preclude the necessary engagement required.

4.5. Impact of short time frames

The impact of short time frames was identified as a key concern in the review of qualitative research about CVD prevention programmes (Review 4 Section 5.7.1, p. 50), and was reiterated by participants in this research. A number of crucial outcomes were mentioned, including the loss of trust among local voluntary groups and the wider communities:

There is a cynicism, a scepticism from the voluntary sector, on an annual basis, about "are we really concerned about doing something that's going to impact our communities". 'Cause all we're doing is, we're doing kind of yearly projects, or 3 yearly projects, and at the end of that the funding is pulled and the voluntary sector is, the project is left with no money and it just folds..... I think if you look at the projects that have been highly successful, they are long term projects. They transcend any kind of political change in a community or a country or a region. It's something that if there is commitment to than it sort of becomes part of the fabric of the community. (Interview. CVD33. UK)

In addition, communities cannot be engaged successfully, quickly, and projects may need time to adapt and respond to the needs of communities in which they work

We have seen in many instances, that communities work on their own pace and we have to be flexible. (PE groups. CVD3. USA)

It is also noted that, in the UK, public health programmes may be required to “demonstrate an impact” (PE group. CVD11, UK) which is challenging where long term health gains are anticipated, but the funding for programmes is short term programme funding is provided.

Other possible impacts of short times frames include the inability of projects to recruit and train the right staff properly, or to engage in ongoing monitoring and evaluation feedback to refine projects (see section 4.7.1). Projects may not therefore, be responsive to local needs. Further down the line, this may lead to target outcomes not being met, either because projects continue without refinement, or simply because such changes are over ambitious within the time frames. Finally, the failure to engage staff and communities fully may mean that projects don’t become embedded in the locality and so activities fold with the end of the project (see Section 4.4).

One European study noted that rolling out a successful, regional level programme nationally took six years, however, this was possible because a long terms plan, for at least ten years, had been conceived from the start (PE group. CVD2. Europe.)

Within programmes, however, the short-term nature of particular projects or activities may be helpful. The below quote, about communication between staff and participants, relates to a weight loss project involving exercise and nutrition input over 12 weeks:

I think the short time frame helped, as the staff were able to maintain frequent contact with the participants i.e. weekly at sessions and phone calls in between sessions to monitor progress if necessary. This allowed participants to discuss issues outside of the group environment if they felt more comfortable doing so (PM group. CVD31. UK).

Summary statement: Short time frames

Short time frames for CVD prevention programmes may threatened success at a number of levels: implementation, staff engagement and training, community engagement, evaluation and legacy. It is difficult for such programmes to meet community needs, staff needs or to permit changes to become embedded in the community. This may lead communities and local agencies to lose faith in such

interventions, further hampering the ability of future work to be successful in those areas.

4.6. Structural barriers to success: “political landscape changed”

In public health, even if all of the appropriate activities have been undertaken, changing political priorities may be a kind of “wild card” that can negatively affect even apparently successful programmes.

after 4 years of successful intervention, [location] got a more right-winged administration and they withdrew the money that was supposed to be spent on the follow up of [CVD programme]. The whole project collapsed. That was really very disappointing for those who have worked very hard to make it a success. (PM Group. CVD22. Europe)

Current UK focus on evidence-based decision making may alleviate this to some extent, but the potential impact of changing political environments can be dramatic. Further, the NHS has been subject to repeat reorganisation

In 1997, the national political landscape changed in England. I suspect (but don't know for certain) that the organisational focus in [location] would have been on how to respond to the changing national policy environment rather than lessons learnt from a local project. (PE Group. CVD11. UK.)

4.6.1. The place of public health in health policy

The challenge of enhancing public health generally was discussed by several participants. On the one hand, this was linked to the need and challenges of multi-disciplinary responses to CVD. But it was also a result of structural or cultural norms within medicine and government, that may not have traditionally valued, or resourced, prevention of ill health rather than its cure. Some differences were evident between the UK and the USA in terms of how much priority was given to the promotion of public health, with the UK showing increased commitment to prevention over a series of government reports and white papers:

'Health of the Nation' which introduced targets for CHD reduction for health authorities, and incentivised family doctors to offer approved health promotion clinics. This indicated a shift in national political thinking at the time about the utility of health promoting interventions.....To paraphrase (in my words!) the conclusions of [the Wanless] report, if the nation carried on investing mostly in treatment services rather than balancing this with investment in prevention and health improvement then the economy would rapidly become bankrupt. (PE group. CVD11. UK)

This is in contrast to the US model:

The public health model has not been embraced within a national policy of prevention and for reducing health disparities here in the U.S. In this fragmented healthcare system the medical model still prevails and is not enough to bring about the broader changes that we need to make a holistic approach to prevention... Prevention has not been a priority in a national discourse. (PE group. CVD3. USA)

This participant is particularly committed to community engagement and empowerment to promote public health. They also note that public health models require a more holistic and multidisciplinary approach, embracing other public bodies involved in housing, education, parks and recreation. This is also noted by another UK based participant who also notes a shift in policy since the project in which he had been involved, some ten years previously, had taken place.

I think, at that time, I don't think there was the political climate for it or the policy climate for it [multi-agency working]. And therefore, any successes we were able to achieve were very much reliant on the individuals who were part of the project. And to some extent, that is the case now although I think things have moved on a lot more because of the political will and the political drive really for interagency working and health and wellbeing (Interview. CVD33. UK.)

Summary statement: Structural barriers
At a macro-level, changes in the broader political environment can have dramatic effects on the adoption and continuation of prevention activities.
Support for CVD prevention programmes may be affected by changing political priorities

around prevention and treatment of illness.

4.7. Monitoring and Evaluation

Monitoring and evaluating of CVD prevention programmes is crucial for a number of reasons; formative and process evaluation, and monitoring can help to shape the programme to ensure that it is adapted to the local needs and preferences, and may motivate staff to continue good work or adjust unsuccessful activities. Final and outcome evaluation may be required by commissioners, funders and research teams to explore programme effectiveness. The difference in these approaches is shown in Figure 5 and Figure 6 where the former shows a linear evaluation and the latter a cyclical process of learning and adjusting. The advantage of the conventional evaluation process may be to have a better grasp of what actually made up the intervention that is being evaluated while the cyclical process allows better match to what is possible and the needs of the community and staff, but attributing changes to particular activities may be more difficult, particularly in the long term.

You get sidetracked into focussing on the very... robust evaluation of methodology without kind of learning about the things that are going on, on a kind of day-to-day basis. (Interview. CVD33. UK.)

Cycles of piloting and monitoring, or process evaluation are described in Section 4.7.1 and those related to evaluation generally, are described in Section 4.7.2.

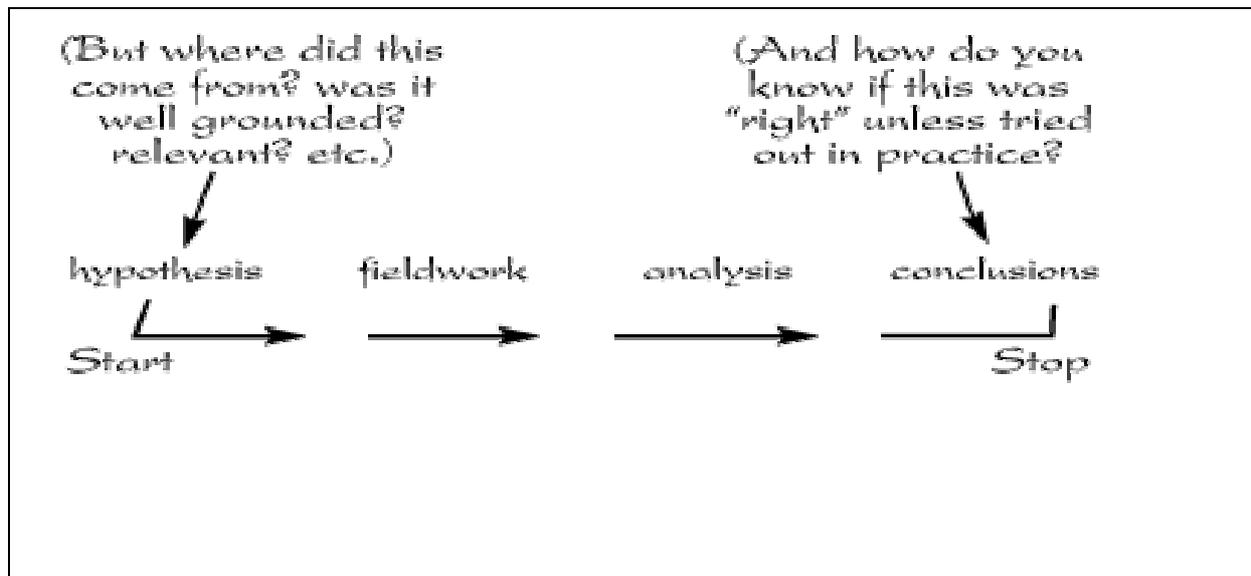


Figure 5: Conventional evaluation process

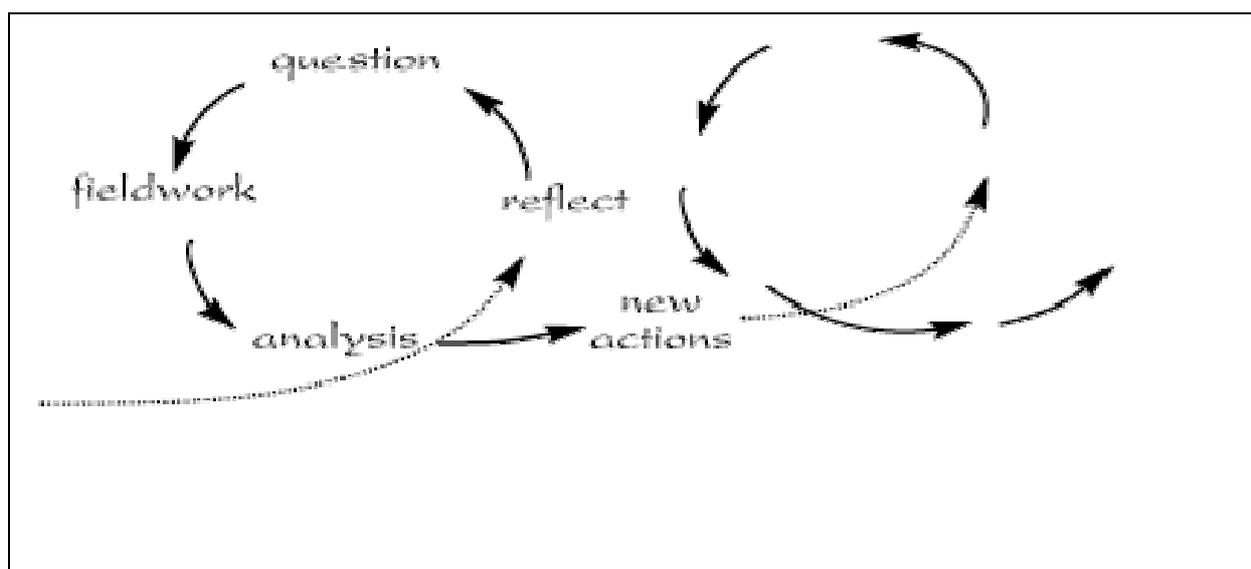


Figure 6: Cyclical evaluation process

Adapted from: <http://www.scu.edu.au/schools/gcm/ar/ari/p-ywadsworth98.html>

4.7.1. Piloting and monitoring feedback “It’s about trying to make everyone happy, isn’t it?”

The importance of piloting information and activities was evident from several comments made by participants. This might be the case for specific promotional materials, activities or potential working partnerships.

There was an outdoor poster health education campaign based on a logo of a knotted cigarette with text such as - Knot here, Know now, Knot in front of the children etc. We got posters with 'Knot in [county]' which we thought looked great. Our Education Officer brought them to a community meeting in a local town. The next morning she reported that they would prefer 'Knot in [town]!' With modern technology it should be possible to localise and personalise material to a greater extent than in the past. (PM group. CVD19. Europe.)

Despite a lot of discussion and many meetings, nothing got off the ground. (Relevant to 'if I were doing again' - I would work with groups which delivered, and postpone those where there was lots of talk but not much action.) (PM group. CVD19. UK)

Without mechanisms to recognise less than optimal activities, and the ability to be responsive and flexible to these findings, programmes are not able to maximise their potential in any location and time.

Regular feedback to staff teams about programme success is key for a number of reasons: it allows activities that are not functioning as hoped to be identified and altered or stopped, motivates staff, and, crucially, it may also provide the impetus to continue activities that are having an impact.

It’s about trying to make everyone happy, isn’t it? I think it’s always, to me I think it’s always about communication. If you don’t communicate back to them about how their role’s had a positive impact on the programme, they’ll never know that and you’re dependent upon their line managers telling them ‘well done’, that sort of thing. But actually, as a programme manager it should be us to say ‘look we’re in this together, all of us, regardless of what direction we work in and this is how it’s going – this is how the programme’s developing and you’re a part of it, a key part’. (Interview. CVD25. UK.)

Such activities aim to engender a greater sense of ownership and cooperation among staff by situating their efforts within a broader collaborative programme with a common focus. It is possible, however, that there is a disconnect between programme assessment and the programme itself which can prevent responsive programme development:

We were just asked to do the evaluation of the programme. In fact we were not allowed to interfere with the program. (PM group. CVD22. Europe)

If staff feedback about a project is not communicated in a timely way, key personnel may move, leaving no-one to push through further activities of adoption:

Seven years elapsed from the conception of the project to the time that the evaluation was complete and published..... many of the project evaluators and lead officers left [location] for pastures new. The organisations responsible for the commissioning of the project had also changed significantly. As a result, although I know that the findings were shared with decision makers locally, I'm not sure how the results of the evaluation were acted on or more widely disseminated and received (PE group. CVD22. UK)

This may be especially problematic where programme champions have been relied upon to play a key role.

From an external perspective, a failure to fully report successes and failures widely was reported, which inhibited shared-learning between projects:

Rather than try to reinvent things all the time, and something that's always puzzled me really is that, why don't we replicate things that happen and are deemed to be successful in other parts of the country? And I know there's a lot of emphasis being put on sharing learning and all that but, for me, it seems that it doesn't matter how much learning is shared, people always want to do something new. We reinvent those poor techniques, those poor projects, or whatever. (Interview. CVD33. UK.)

Funders and professionals may, perhaps unhelpfully, be drawn to apparently innovative approaches, rather than learning from others' experiences.

Summary statement: Piloting and monitoring

Cyclical approaches to monitoring and evaluation, such as piloting, process evaluation and action research, allow projects to be responsive to local needs, adapting or removing inappropriate projects and allowing successful projects to be rolled out.

Information from this process fed back to staff in a timely way can help develop a sense of ownership and cooperation and motivate good practice.

Organisations and individuals should also learn from the experiences of previous projects.

4.7.2. Evaluation challenges

In addition to the problems of *running* CVD prevention programmes are the challenges of evaluating their impact. A number of related topics were highlighted by the participants including the tensions between a pre-specified design for a planned evaluation and the need to adapt to community needs, the difficulty of measuring important but “nebulous” programme benefits”, time limited evaluations, the relative value of large changes for small numbers of individuals and population level programmes and evaluations, and different kinds of “success”.

In order to secure funding for research and development, a more fixed approach to the programme design and its evaluation may be required:

A key [challenge] for us was the mode of commissioning for the evaluation. Commissioners ideally want to know detailed designs and methods prior to selecting an evaluation team, yet the theory driven approaches we tried to apply required the developing programme theory to drive the selection of methods and design. (PE group. CVD32. UK)

This may limit the type of design used and the potential responsiveness of that design, particularly to community requirements:

[T]here is always the challenge to strike the right balance between applying scientific methods and keeping communities engaged. (PE group, CVD3. USA)

While there may be well developed mechanisms for establishing changes in knowledge, behaviour or clinical outcomes, other potentially valuable aspects of a CVD prevention programme may be less easy to measure.

Evaluating community engagement and sustainability of programs within communities is a major challenge. (PE group. CVD3. USA)

Even where changes are measurable, most programmes comprise many different elements and projects and attributing causation to any particular activity may be impossible.

If your intervention is multifaceted, it is difficult to attribute success to a particular component of the intervention. It is important to have several types of evaluation, including formative and process evaluation, which can better help you pinpoint how individual components of the intervention program fared. (PE group. CVD32. UK.)

In addition, projects may make a large difference to a small number of individuals, while the evaluation is likely to look at population level changes. It is possible that this will therefore underestimate the some impacts and specific efforts will be needed to establish is the programme has managed to address health inequalities.

We didn't focus to any great extent on the changes in the smaller numbers of the [location] population that were actually in receipt of intense services. (PE group. CVD32. UK.)

Where programmes or their evaluation are short term, there may be insufficient time for the programmes to have an impact on measurable outcomes:

The outcomes were also very ambitious for what was initially a three year programme. (PE group. CVD32. UK)

Any long term impact of CVD reduction programmes will be subject to even greater problems of attributing impact to particular interventions, and it may not be known whether changes in attitude or behaviour are sustained, or lead to better health outcomes.

Summary statement: Challenges of evaluation

Commissioners and funders may need to allow flexibility in programme and evaluation designs to allow them to adapt to local needs., rather than requiring fixed plans prior to finding. In addition, programmes and evaluations should allow sufficient time for outcomes to be achieved.

Multiple methods may be needed to evaluate important aspects of CVD prevention programmes, such as community empowerment, that are not all easily captured through numerical outcome data.

Programmes that measure only population level changes may not capture large impacts for some individuals, and this may be important, especially where health inequalities are addressed.

4.8. Successful population based programmes: a conceptual framework

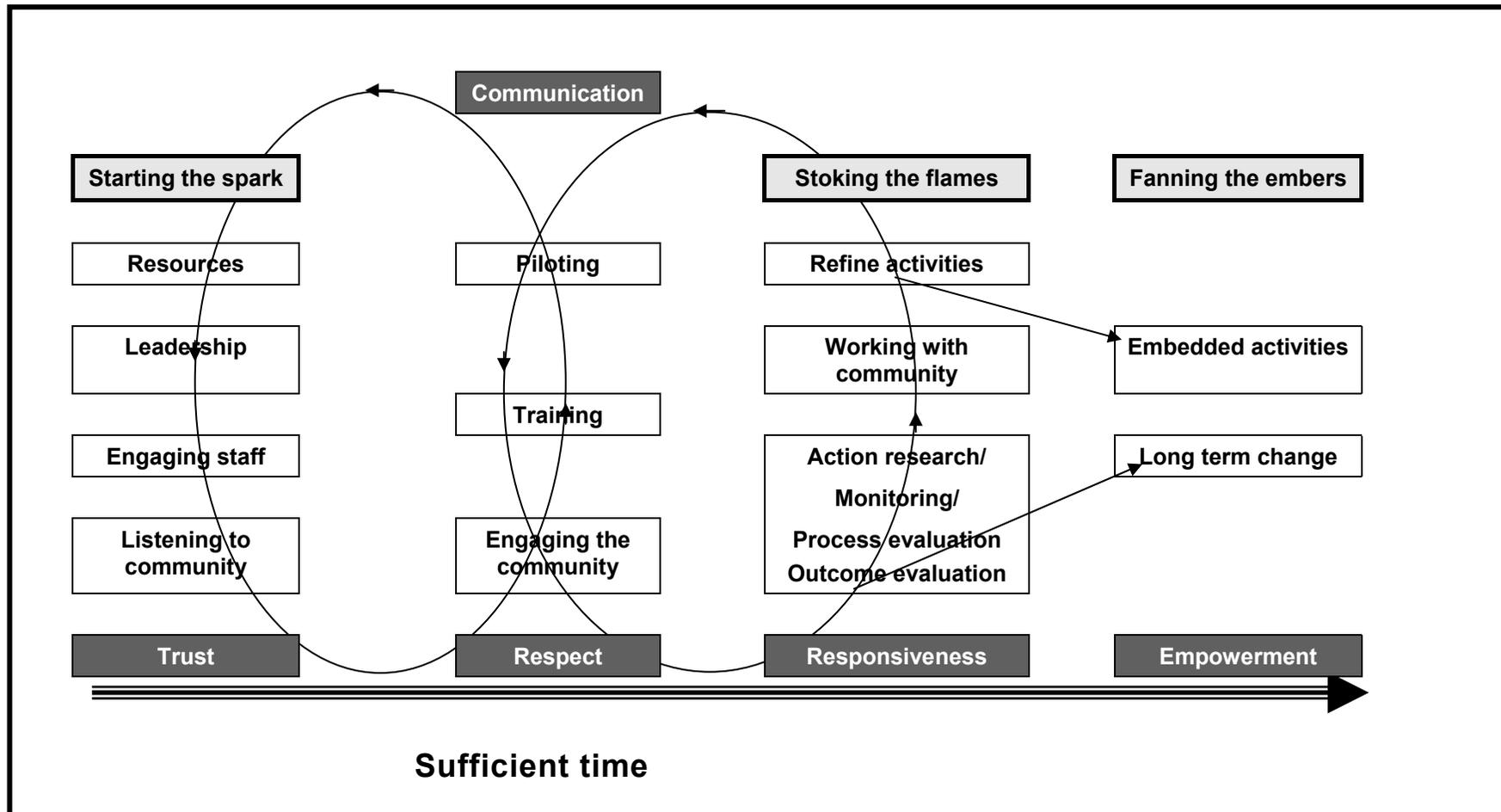
Based on the findings from the online focus groups and the interviews, we developed a conceptual framework through which to think about the key aspects of a successful community health promotion programme (Figure 7).

Building on the metaphor about “starting the spark”, used by one participant to described the initial engagement of community members, we also considered what is needed to “stoke the flames” (efforts to continue and build on activities, and keep them, and enthusiasm for them, “burning”) and ultimately to “fan the embers” of programmes (once the “fire” of the project is in the community, it continues to glow because activities are embedded, requiring only a little fanning to keep things going). These metaphoric stages are shown in Figure 7 in grey boxes with black lettering.

We also considered key aspects of the relationship building between members of staff, agencies and the community trust, respect, communication, responsiveness and empowerment (shown in dark grey boxes with white text in Figure 7). These in turn, link with the activities that enhance the possibility of success (shown in white boxes in Figure 7) such as adequate resourcing, training, listening to and engaging with communities and so

on. Underlying all of these elements is a need for sufficient time to undertake these activities properly.

Figure 7: Conceptual framework for successful programmes



5. Discussion

5.1. Statement of principal findings

Eighteen people who had been, or still were, engaged in population or community based programmes to reduce multiple risk factors for CVD as frontline deliverers of services, managers or evaluators took part in either online focus groups or telephone interviews.

Thematic analysis was undertaken considering the following in relation to successful and less successful programme implementation:

- Programme development and fidelity
- Community engagement strategies
- Staffing: (leadership, staff engagement, GPs, volunteers and multi-agency teams)
- Legacy
- Impact of short time frames
- Structural barriers to success
- Evaluation challenges

We were also able to construct a conceptual framework to illustrate the interrelation between these elements and the way in which positive feedback between them can enhance success.

5.2. Methodological limitations and considerations

Although we made every effort to encourage people to use the online discussion group, eventually only 16 of the 33 people who agreed to take part actively participated (49%). Three people initially had trouble accessing the board, and we had to send additional email instructions or talk them through signing in on the phone. It is possible that other people also found it difficult to log in at the first attempt and didn't return, despite our encouraging email contact. All those who had agreed to take part were also sent a copy of the relevant online focus group transcript after the data collection period had finished, and asked if they had any comments or if they

wanted to participate in a telephone interview instead. Only three people chose to take part in a telephone interview and no one sent additional comment on the focus group transcript.

Three UK based projects provided the majority of participants for this project (n=10 see Table 3 on page 21). A further three participants were from other UK based projects and of the rest, two were from the USA and three from European programmes. In the context of this project, information from UK based projects may be most pertinent as their information relates to the right political and structural environment. However, it is possible that we have missed obtaining information from other countries that could be usefully transferred. A couple of people from the USA have contacted us since the end of the data collection point and expressed an interest in the project, but saying that they did not have the time to take part while the project was live. Perhaps with a longer time to both recruit people, and run the online focus groups, we would have had greater numbers. One of the main reasons for the restricted time was the time it took to get ethics committee approval: we only received the final go-ahead on 16th October 2008. In our original timetable, we had hoped to receive ethics approval by the end of September, which would have given us six weeks to recruit people to the project. In the event, we had half that time. Contacting people in different time zones was more challenging than contacting those closer to home. In addition, there was less opportunity for maximising the use of snowball sampling techniques if our original contact declined to participate. The shorter recruitment period also meant that people had less notice about the dates when the online discussion groups were active.

There is a noticeable difference between the transcribed telephone interviews and the written, online focus group transcripts. The telephone transcripts, while perhaps containing no more detail than the online focus group transcripts that was directly relevant when it came to analysis, were both longer and more vivid. The written contributions seemed more measured compared to the spontaneous, rich verbal expressions of the interviews. It may also be that, to some extent, those people who are confident and articulate self-selected to take part in the interviews. In the write-up of the findings, nearly as many quotes from the interviews are used as quotes from the online focus groups, despite there being 16 online participants and only three

interviews. This was because, when using illustrative quotes, the interviews often provided the most engaging, immediate or insightful comments.

A key potential advantage of using group methods to collect data, rather than individual interviews, is the ability to capture social interactions between participants, and particularly to identify areas of contention and consensus. This was not very successful during the online discussion groups which proceeded more like a series of parallel email dialogues than as a group. Although some participants did refer to things written by other participants, nearly all of the comments were directed through the PenTAG moderator. We tried to encourage interaction through asking prompting questions such as “does this experience resonate with others?” or “what do others think?” when responding to postings. We also spent one nerve-wracking day without adding anything to the discussion groups in the hope that this would encourage direct interaction between participants. However, without our input, none of the participants contributed to the discussion that day. Given the short time frame of two weeks for the data collection (which we extended to three weeks), we did not feel able to experiment with this strategy any longer and resumed contributing to the board after one day’s silence. The short time frame may have negatively impacted on the ability of people to become familiar with using the discussion board, and to socialise with each other prior to dealing with the business of the group. We did ask people initially to describe their involvement with their project as a way of introducing themselves, and some people chose to give their name and full details at the beginning. It is possible that data collection over a longer time would have led to relationships to be built up in the discussion group, allowing the interactions to be more functional.

We chose to put people in different online focus groups depending on the sort of involvement that they had with the CVD project in which they were involved. Our rationale was two-fold: firstly, we thought that such groups would have more in common and so share experiences about similar kinds of progress and pitfalls (we thought that, for example, the concerns of the evaluators might be quite different from those of the frontline staff). Secondly, since we hoped to recruit people engaged in different roles but from the same project, we thought people might be more candid if they were not sharing a group with colleagues, particularly if senior and junior staff from the same project were recruited. In fact, many of the people who agreed to participate had multiple roles in projects, this was especially evident with crossover

between the manager and deliverer groups and the manager and evaluator groups. Several members of the one programme requested, and were granted, to join each other's groups to share experiences. These people had worked on the same project historically, and were now based in different locations. It is possible that it may have been productive to have a single online focus group for all the participants – more people could have created more “buzz” and so more potential for interaction. Different threads could have created space for “specialist” questions that might only be relevant for some participants. However, the potential for people to feel they needed to self-censor would have remained, especially as some people chose to reveal their identity on the board, although the online discussion group containing people involved in frontline delivery was the least active anyway. Future research should explore the impact of different size online groups and different types of people.

We found it challenging to tease out the stories behind the programmes. It felt at times that we were only accessing the surface “official” account of the projects. Chinks through this front were found, but were not common. This again may be partly due to the nature of the online focus group, written language is more formal than spoken language, and is the medium through which most official accounts are constructed. In the online focus groups, people have time to consider and construct what they choose to write about, and so contributions lack the immediacy and candour of speech. Again, time may be a factor and more information may have been obtained if we had more time to run the board, build relationships with those involved and for them to interact with each other. Other project and personal characteristics may also affect the people's willingness to describe barriers to success, errors or failures as well as successes, triumphs and their facilitators. We speculate that distance from, or time since, the project, current seniority and generally positive outcomes for a programme may permit speculation on the challenges and difficulties of a programme negatives more easily than still being involved or closely associated with a project or place.

There were some gaps in the areas that were discussed as barriers to successful implementation of programmes and interventions. Notably, although some remarks were made about the impact of local and national political environment, there was little mention of “upstream” factors such as availability and price of junk food or availability of cigarettes. Most comments related to the nitty-gritty of planning and

implementing CVD programmes. This was the focus of the topic guide which we used to moderate the group, and other topics may have emerged if we had specifically probed for them.

5.3. Further research

Future research should explore the impact of increased time for recruitment and increased time during which the online focus group is active, on the ability of people to participate and, in particular, to develop interactions between themselves as well as the moderator.

Future work with online focus groups could explore the impact of different types of participant groupings and numbers of participants on the interaction of the group.

People who were involved in CVD reduction programmes outside the UK were not well represented in this project and their views should be sought in future research.

Appendices

Appendix 1 Email sent to potential participants suggested by other participants

Dear **XXXXX**

Re: Population and Community Programmes to Prevent Cardiovascular Disease: A qualitative study into how and why some programmes are more successful than others

PenTAG is involved in a series of linked research projects commissioned by the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom to assess the effectiveness of programmes that are aimed at primary prevention of cardiovascular disease (CVD) at a population level through the reduction of multiple risk factors. The research will be used by an independent Programme Development Group (PDG) to develop guidance to improve such CVD prevention programmes. The PDG will consider systematic reviews of quantitative and qualitative evidence, economic modelling, as well as the views and experiences of people involved in such programmes.

More information about the project can be found here:

<http://www.nice.org.uk/guidance/index.jsp?action=byID&o=11881>

As part of this research, we shall be holding an **online discussion forum** through which people involved in the design, management, and delivery of CVD prevention programmes can share their experiences and contribute to the development of guidance related to implementation. **[INSERT NAME HERE]** has suggested that you might be able to contribute to this research. **We would like to invite you to take part** in this online discussion forum, which will take place over a 2-week period starting on November 10th.

Full details of the research are provided on the information sheet (attached). If you would like to participate in this research, please complete and sign the attached consent form and return to me at the address below. If your areas of experience mean that you would not be suitable to take part in this research, please disregard this email.

As we hope to involve people who were involved in all levels of design, management and delivery, it would also be helpful if you could **provide names of other people involved in [NAME OF PROGRAMME]** who you think it would be useful for us to include in our research.

Please do not hesitate to contact me or another member of the research team (pentagresearchteam@pms.ac.uk) if you have any further questions.

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Appendix 2 Research protocol

Population and Community Programmes to Prevent Cardiovascular Disease: A qualitative study into how and why some programmes are more successful than others

PROJECT TITLE

What are the barriers and facilitators influencing the effectiveness of multiple risk factor programmes aimed at reducing cardiovascular disease (CVD) (or the risk factors associated with CVD) among a given population?

1. Background

This project forms part of a series of linked research projects commissioned by the National Institute for Health and Clinical Excellence (NICE) to assess effectiveness of programmes that aim to prevent cardiovascular disease (CVD). The programme is concerned with population level interventions and programmes which address multiple risk factors for CVD (diet, smoking, physical activity etc). For simplicity, in the rest of this protocol, we will use the term programme to encompass both programmes and interventions.

PenTAG is in collaboration with the West Midlands Health Technology Assessment Centre (WMHTAC) at the University of Birmingham. WMHTAC will be undertaking a systematic review of the evidence for the effectiveness of such CVD prevention programmes, together with a systematic review of economic evaluations and developing a computer model to estimate the cost-effectiveness of such programmes. PenTAG will undertake a systematic review and synthesis of qualitative research about factors which militate against or enhance the success of these programmes. In addition, in this study, we plan to solicit the views and experiences of those involved at a number of levels with planning, implementing and evaluating CVD prevention programmes using online focus group discussions and telephone interviews. It is this latter project that is described in detail here.

We hope to gain a better understanding of how and why population programmes to prevent primary CVD are successfully (or unsuccessfully) implemented, and achieve (or fail to achieve) their intended outcomes, with a particular focus on identifying the factors which militate against or enhance programme effectiveness ("barriers" and "facilitators"). This will include identifying elements associated with key areas of programme success such as evolution, acceptability, sustainability or cost-effectiveness.

In the sequence of evidence reviews to be undertaken, this primary research will take place after the reviews of both quantitative and qualitative research have been undertaken. We hope to be able to investigate issues raised by the findings of these linked systematic reviews as well as obtain information based on the inputs of participants. The focus groups and interviews will supplement the review of qualitative research, especially where no qualitative element of programme evaluation has been published. In addition, we will be able to design questions aimed at understanding anomalous or striking findings from the earlier reviews. We will be particularly interesting in identifying contexts and mechanisms that are linked with particular processes and related outcomes.

2. Research questions

We anticipate that these will be refined in response to the findings of the linked systematic reviews. In addition, discussion guides will be developed separately for the different groups to allow areas of expertise specific to programme managers, funders and researchers to be investigated. However, we expect that questions will broadly focus on:

What are the factors associated with the successful (or unsuccessful) implementation of population level programmes addressing multiple risk factors for the primary prevention of cardiovascular disease (CVD) in a given population?

What are the important factors influencing the achievement of health outcomes associated with the primary prevention of CVD?

How do these factors interact, both with each other, or with other aspects of programme design, implementation and evaluation processes or context to influence increased or reduced programme effectiveness?

3. Objectives

To conduct a series of online, focus group discussions and telephone interviews into the processes of planning, implementation and evaluation of population level programmes (or key components of them) aimed at reducing the first occurrence of CVD in a given population and identify elements or factors that contribute to their success or failure.

4. Methods

4.1 Recruitment and sampling

Participants will be those with first hand experience of population level CVD programmes. We will use purposive sampling to identify people who were involved in those CVD programmes identified by WMHTAC in their systematic review of effectiveness and cost-effectiveness. We will also identify people involved in projects where qualitative research has not been published as part of any existing quantitative evaluation. These projects will be identified through PenTAG's systematic review of qualitative research literature. This will be supplemented by web searches, contact with experts in the field, contact with the authors of research papers related to these projects, contact with the commissioners of the projects and information provided by NICE, including that supplied by the PDG.

We will aim to recruit those involved in the CVD programmes at the level of either:

- i) planning and funding,
- ii) programme design,
- iii) management and delivery
- iv) programme evaluation.

Where participants take part in focus groups, these groups will comprise those involved in similar types and levels of involvement in CVD programmes. We aim to recruit 8-15 people from each of these four categories to form a focus group discussion. It is hoped that a group of this size will be large enough to generate debate, but also small enough to minimise

simultaneous responses and sideline conversations developing, which would be harder to moderate and analyse, and may be confusing for participants (Stewart & Williams 2005). We will therefore approach at least 20 people in each of the four categories with the aim of getting at least 50% agreement to respond.

The strategy for recruitment is shown in Supplement 1. Potential participants will be identified through information identified in published research reports concerning effectiveness, cost-effectiveness and qualitative studies identified through the linked reviews being undertaken by PenTAG and WMHTAC, experts in the field and from web searches. Potential participants will be contacted by phone and a script utilised (see Supplement 2) in order to outline the project's aims and to establish whether or not they are interested in taking part. This phone call will also be used to assess whether participants who have expressed an interest in taking part have appropriate computer access and skills to participate in an online focus group. This will allow PenTAG to provide additional information for those willing but inexperienced and to note those who may require additional support during the period of data collection. In addition, we will be able to identify people who can only participate through telephone interview. We anticipate that the most senior people or those who participated in historical programmes which may have run decades ago, are those least likely to be equipped with the access, skills or time to take part in the online focus groups.

Compared with alternative processes, we believe this approach is most likely both to maximise participation in the online focus groups (i.e. with sufficient participants to create rich online debate), while also giving the opportunity to all potential participants within the sampling frame to provide their accounts of barriers and facilitators in their programmes. Because those who choose to participate via telephone interviews will, to an extent, be self-selected, we will keep track of differences in the characteristics of participants in both type of data collection.

Formal invitation to take part in either part in the study through either online focus group or interview will then be made by post. Letters will outline the nature of the linked programme of research and details of this particular project, the timing and methods to be used. It will include patient information sheets, consent forms and a broad topic guide for the focus group to which they are invited. A follow-up phone call will allow for any questions to be addressed and gain feedback on the suggested topic areas. Confirmation of interest to be involved can be made by post, phone or email, and at this stage we will also determine participants preferred method of communication for the project. Participants will then be directed to online study information. In order to simplify access to the online focus groups, we will ask participants to provide us with a username and password that they are happy to use and we will register participants to the appropriate group. In this way participants will just need to log in to use the focus group.

A reminder will be sent to log on three days before the beginning of the fortnight-long online discussion period, with additional follow-up the day before and on the day for those who are not registered.

4.2 Data collection

In conducting this research, we will be particularly interested in stimulating discussion relating to key areas of programme design, and delivery/implementation and programme evolution/adaptation that are associated with programme success or failure. For example,

we will be interested in the context within which the programme was delivered, ways in which it was implemented and the extent to which staffing and collaborative practice impacted on the programme. This may include aspects that relate to feasibility, fidelity (to programme design), integrity (to programme theory, where it is explicit) acceptability, sustainability, as well as more specific issues such as collaboration between partner organisations, staff structure etc.

4.2.1 Online focus group

Given the likelihood that participants will be widely dispersed geographically, in some cases internationally, we plan to undertake online, written focus group discussions. This has the advantage of being able to proceed asynchronously to accommodate different time zones. In addition, participants may choose to be anonymous within the discussion groups (though known to PenTAG researchers) as members will choose their own username and password. In other ways, the group will operate in similar ways to offline focus groups, in that the discussion will be organised around a topic guide and intensively monitored and guided by researcher(s) at PenTAG and in which interaction between group members produces the data (Stewart & Williams 2005). It has previously been noted that, while online focus groups may produce shorter transcripts, the quality of information gained using this method is the same or greater than that obtained using traditional techniques (Reid & Reid 2005). This is because people communicate more fully and accurately when using written rather than verbal language.

As the group members will have been involved in the management and research of public health programmes we anticipate that they will already have competent key-board skills and be computer literate enough to participate. As the groups are asynchronous, fast typing will not be required. We also expect that, given the nature of their professional roles, participants will be used to expressing themselves in written form. PenTAG researchers will monitor the discussion groups and contact any members of the group not seen to be participating, to ensure that there are no technical problems and to provide any other assistance necessary. We anticipate that the first day of activity on the online discussion group will be used to make sure that everyone has logged in and can use the board. We will introduce the groups' purpose informally to allow participants to gain familiarity with the ways of posted information.

Discussion board software has been used to develop the online platform for the focus groups. However, we have adapted the way it looks and functions in order to simplify it, and make sure it is suitable for this research purpose. The format looks similar to a word document or email rather than having the traditional discussion board format which might be confusing for those less familiar with such e-communication. We have removed unnecessary tools such as the use of emoticons, traditional web-forum FAQs and the ability to edit old posts and any other elements that unnecessarily clutter the visual presentation and which may interfere with easy use of the focus group. We have adjusted the board so that it shows continuous posts rather than going onto numerous pages, again for simplicity of use. Only PenTAG researchers will be able to start new threads. There will be a "help" button on the top of the discussion board which can be used to send an email to the team at PenTAG if any problems with use are encountered. This is a specially set-up email address that can be accessed by all members of the team.

As the groups will be asynchronous and involve writing rather than real time speaking, this also allows for considered responses to be made in response to questions both from the moderator and from group members. Those for whom English is not their first language will

also have chance to compose their responses. As moderator, staff from PenTAG will ask questions based on a semi-structured discussion guide in order to ensure that all topics of interest are covered. They will also respond to contributions from members of the group to gain clarity or to explore topics of interest that emerge and actively encourage participations to contribute. The online discussion groups will be active for a period of two weeks. Members will be emailed each time a new comment or question is added to their group to aid participation. In addition, after the focus group has closed, members will be invited to send by email any comments which they did not get a chance to articulate in the group.

We recognise that even with close moderation of the online discussion and the provision of assistance to those participants who require it, it is possible that the discussions will not produce as much or as rich data as expected. We assess this risk to be slight given that the characteristics of the participants (familiarity with discussing issues online and across different project and national domains) will likely match those previously identified as being positively associated with a successful online focus group (Bloor et al. 2002). Furthermore, the utilisation of online focus groups with health professionals, whilst not widespread, has a sound record of producing data that would otherwise have been difficult to obtain (Kenny 2005; Murray 1997). In order to minimise the potential for problems with the method, we shall also draw upon the expertise of Dr Inocencio Maramba (Faculty of Health & Social Work, University of Plymouth) who has substantial experience in the design and implementation of interactive online technologies for consultation in the field of health.

4.2.2 Telephone interviews

At initial telephone contact with all identified potential participants (see Section 4.1 and Supplement 1), we will identify those people who are only willing or able to participate through telephone interview. We will schedule hour long telephone interviews which will be recorded and transcribed. Participants will be given a copy of the transcript and offered the chance to clarify or add to the statements made within a specified time frame. The interviews will be structured around the same topic guide as the online focus group in order to produce transcripts that facilitate an integrative analysis of the focus group and interview data. Numbers will be finalised when lists of potential participants have been drawn up, which will take place once the programmes and interventions to be included in the effectiveness review by WMHTAC have been finalised.

4.3 Security

Only invited members will be allowed to access and contribute to the online focus groups. Each group will be password protected, while members of the focus group will also design a password to log onto their own account.

As moderator, PenTAG staff will have the ability to remove any offensive or aggressive comments should they occur.

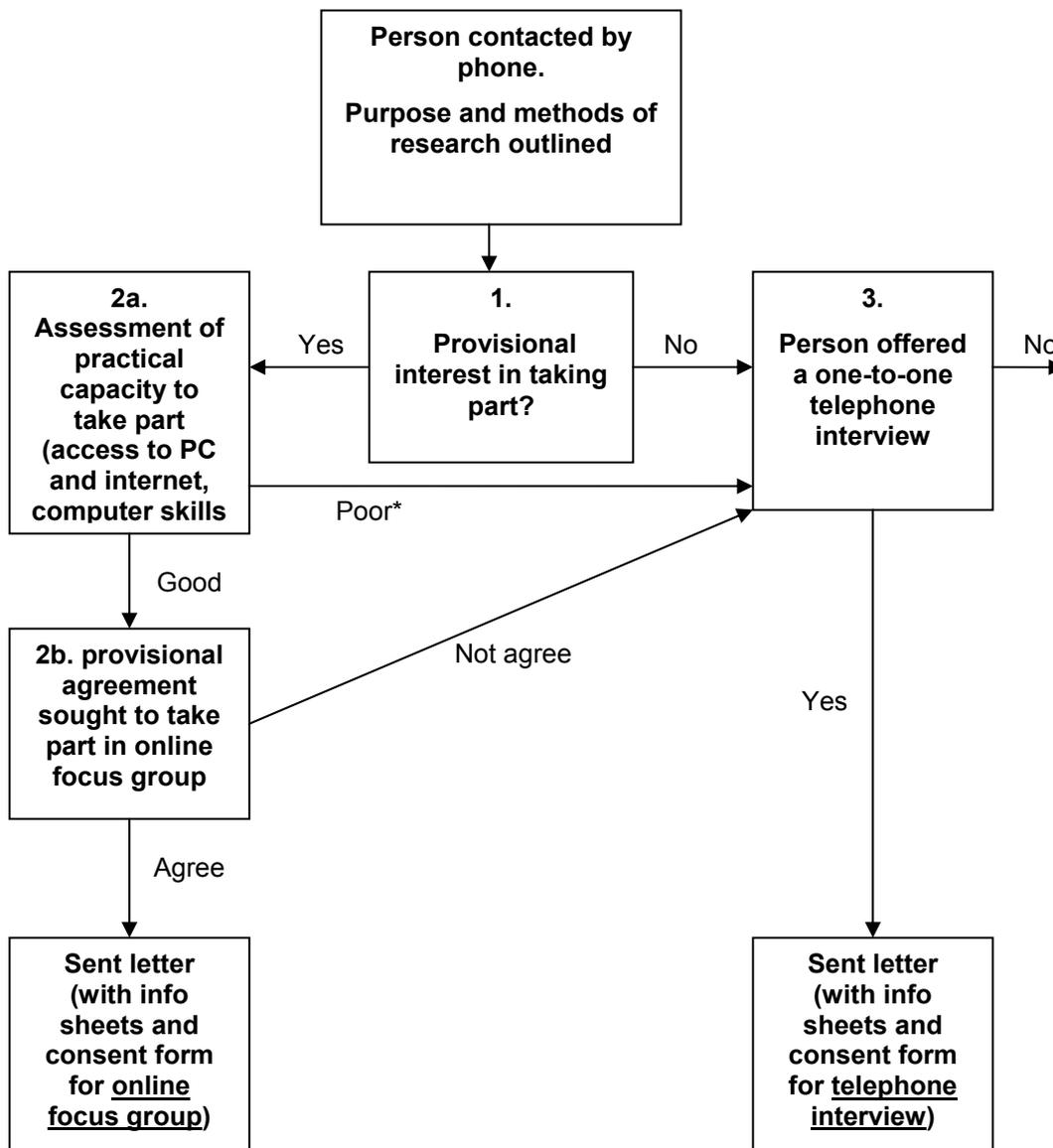
4.4 Data analysis

Data will take the form of the written input into each discussion forum, together with any subsequently emailed accounts and comments, and the transcripts of telephone interviews. These will be subject to thematic analysis. The transcripts will be read and re-read in order to identify and code key themes emerging from the data that relate to factors perceived to have enhanced or mitigated against their programme's success. Initial coding schemes will

be developed by two researchers independently coding one focus group script. Discrepancies in coding will be resolved through discussion. Once coding is agreed, the transcripts for the remaining groups will be analysed. An audit trail will be kept that shows the decisions about and development of the codes, and categories will not be collapsed too early to avoid premature closure of meaning. Processes of consensus and disagreement within groups will be explored. Similarities and differences both between participants within groups, and between groups will be examined.

While online focus groups do not allow for non-verbal elements of conversation to be assessed as they are in traditional focus groups, we will be alert to any textual forms that may have parallels (for example, bold or underlined text to denote emphasis etc.). These will be maintained in the analysis and if quoted in the study report.

Supplement 1: Flow diagram showing how people will be invited to participate in either the web-based focus group discussion or for a telephone interview



* judged on basis of whether their level of access to the internet, and/or experience of using PCs or e-mail etc., is likely to make it difficult for them to participate fully (or at all) in the online focus group.

Supplement 2: Guide for initial approach by phone to participants

- Introduce self: name, role, institution.
- Explain why the call is being made, i.e. to recruit participants for research into the barriers to and facilitators of the successful implementation of multi-risk factor cardiovascular disease programmes.
- Provide further information on the format and dates of the online focus group (refer to the protocol and information sheet as appropriate). Ask if the potential participant would be interested in taking part in the research.

If not: Offer the potential participant the option of a one-to-one phone interview. If this is also declined, thank the potential participant for their time and assure them that we shall not contact them again with regard to this project

- Explain the research in greater detail, namely:
 - Its place within a linked series of reviews for NICE.
 - The aim of obtaining insight into implementation issues that remain unreported in programme evaluation studies.
 - The online focus group – rationale for using this method and what participation will involve.

If provisional agreement to take part is obtained, continue.

*If provisional agreement is **not** obtained, enquire as to why this is, e.g. technical issues, lack of familiarity with the research method, motivation. Address these issues if possible, but if not, offer the potential participant the option of a one-to-one phone interview.*

- Enquire as to whether the potential participant has the practical capacity necessary to take part in the online focus group.

If not, discuss with potential participant how these issues could be addressed. If the issues cannot be addressed, offer the potential participant the option of a one-to-one phone interview.

- Inform potential participant that interview or online focus group information sheets (as appropriate) and consent form will be sent by mail. Advise potential participant that being sent these documents does not oblige them to take part in the study.

Thank the potential participant for their time and advise them that they are welcome to contact the research team with any further queries.

Appendix 3 Participant email following initial telephone contact

Dear XXXXXX

Re: Population and Community Programmes to Prevent Cardiovascular Disease: A qualitative study into how and why some programmes are more successful than others

Further to our telephone conversation, please find attached an information sheet regarding our research into the barriers and facilitators for the successful implementation of CVD prevention programmes. If you are still interested in taking part in the research, **please complete and sign** the attached consent form and return to me at the address below. The online discussion forum will take place over a period of two weeks, starting on November 10th.

Any suggestions of other people who have been involved with the planning, design, management, or evaluation of multi-risk factor CVD prevention programmes who we could contact to take part in this research would be very gratefully received. **We are particularly interested in contacting front-line staff** in order to better understand their experiences of programme delivery.

Please do not hesitate to contact me or another member of the research team (pentagresearchteam@pms.ac.uk) if you have any further questions.

Dr Ruth Garside
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Appendix 4 Participant information sheet

This study forms part of a series of linked research projects commissioned by the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom to assess the effectiveness of programmes that are aimed at primary prevention of cardiovascular disease (CVD) at a population level through the reduction of multiple risk factors. The research will be used by an independent Programme Development Group (PDG) to develop guidance to improve such CVD prevention programmes. The PDG will consider evidence a range of research as well as the views and experiences of people involved in such programmes.

We are particularly keen to hear from people like yourself who have unique stories to tell about their involvement in planning, managing, delivering or evaluating such CVD prevention programmes. We want to hear about your experiences and opinions which will provide insights into why some programmes are more successful than others and what features act as barriers to, or facilitators of, successful implementation and outcomes. It will also offer you the opportunity to share ideas and experiences directly with those who have been involved in different CVD prevention programmes from a number of locations nationally and internationally.

This research is being undertaken in addition to the usual stakeholder consultation which NICE conducts as part of the guidance development process, and in which you may also already be involved.

This information sheet aims to provide the information you will require to make an informed decision as to whether or not you would like to participate in the research which will take place in early November 2008.

The Purpose of the Research

This research is funded by the UK's National Institute for Health and Clinical Excellence (NICE) as part of their Public Health guidance programme. Details of this project can be seen here:

<http://www.nice.org.uk/guidance/index.jsp?action=byID&o=11881>

A number of elements will contribute to this research upon which the Peninsula Technology Assessment Group (PenTAG) are working in collaboration with the West Midlands Health Technology Assessment Centre (WMHTAC) at the University of Birmingham. WMHTAC will be undertaking systematic reviews of the evidence for the clinical- and cost-effectiveness multi-risk factor CVD prevention programmes, and developing a computer model to estimate the cost-effectiveness of such interventions. PenTAG will undertake a systematic review and synthesis of qualitative research about factors which militate against or enhance the success of interventions that aim to reduce CVD.

In order to deepen understanding of *how* and *why* some multiple risk factor programmes to reduce CVD are more successful than others, we also want to hear directly from those who have been involved in commissioning, planning, delivering or evaluating CVD programmes. It is this phase of the research in which we would like you to participate.

Who we are

The Peninsula Technology Assessment Group (PenTAG) is a multi-disciplinary research team within the Peninsula Medical School. We conduct a range of applied and methodological research which spans the synthesis of existing research, economic and disease modelling, and also primary empirical research into the effectiveness and cost-effectiveness of health service treatments and programmes to improve health.

You can find out more on our website:

<http://www.pms.ac.uk/pentag/>

What do you want me to do?

We want to gather information about your experiences and understandings of crucial factors that affected the success of population-level CVD prevention programmes that you have been involved with.

In order to do this, we would like you to take part in a "virtual" focus group discussion. This means that you will be asked to contribute to an online discussion forum over a two week period. Each group will contain 8-15 members. The members will have been involved in similar aspects of such programmes (for example, programme managers will be in the same group, those engaged in evaluation will be in another group and those involved in programme design will be in another, and so on). In addition, a member of PenTAG will take part in the discussion as a moderator, adding questions and clarifying as necessary. We hope that this format will stimulate discussion between members of the group, creating an "online conversation".

In order to ensure that this discussion can develop, we anticipate that the online group will be active for 2 weeks. This means that the conversation does not have to be in real time, allowing you to log in and out whenever it is convenient and allowing those resident in different countries to take part. In addition, members can return to the group numerous times over this period to respond to what else has been said. Each time a new comment is added by a member of your group, you will receive an email alert. Whilst the format of the online group is not prescriptive, it is proposed that key areas such as programme implementation issues and contextual factors that act as barriers or facilitators will be discussed.

Although the online group may be unfamiliar to you as a forum, we believe it to be the best way to enable discussion and debate between participants who are widely-dispersed and who would not normally have the opportunity of engaging with one another. We estimate that your participation would require a time commitment of approximately 2 hours (around 10-15 minutes per day) over the 2 week period, although the decision about the amount of time spent reading and contributing to the online group rests entirely with you. The online group has been designed to be straightforward to use and we hope that you will find it to be a rewarding means of contributing your expert knowledge to the study.

Participation in this research is voluntary. If you choose to take part you will be asked to sign a consent form, but doing so does not remove your right to withdraw from the research at any time. However, please note that in view of the nature of the online focus group, where a number of participants may respond to your contribution, it will not be possible to retrospectively withdraw postings that you have made to the group.

Privacy and Confidentiality

Access to the online focus group will be password-protected. Your online presence in the focus group will be indicated by user name only, allowing you to be anonymous to other members of the group if you wish.

Your identity will be known to researchers at PenTAG who will treat this information as confidential.

We would like to use direct quotes from you in any reports from this research that we write. Such reports might go to NICE, be available online or be submitted to academic journals. We will ensure that any identifying details about the project (such as your name, or the location and timing of the programme) are removed from any published information. In order to participate in the online focus group you will need to sign a consent form in which you can consent (or withhold consent) for quotations to be used in this way. However, you should be aware that the contributions that you make to the online focus group may contain information about a particular programme (or your role within it) that could allow other participants to infer your identity; in this respect, the maintaining anonymity is your own responsibility.

We hope that your experience of being part of this research will be a constructive and informative one and that the results will contribute to learning and best practice within the NHS and elsewhere. However, we realise that contentious issues may be discussed in the course of the online focus groups. The following section provides details of research management procedures. This research is governed by the University of Exeter's Code of Good Practice in the Conduct of Research (2002), which also contains an explicit protocol for the investigation of research misconduct. You are encouraged to contact and discuss with

the primary investigator (whose contact details are at the end of this information sheet) any concerns that you may have regarding the conduct of this research.

Research Data Management

The primary investigator (Ruth Garside) and research colleagues are bound by the University of Exeter's Code of Good Practice in the Conduct of Research to maintain confidentiality regarding all issues discussed in the course of this research, *unless* the participant explicitly states that they are satisfied to be identified with a particular statement.

It is acknowledged that ensuring absolute anonymity in this research may be problematic; for example, a participant's identity may be inferred if they reveal details about a programme (such as its location and timeframe) with which they were involved, even if the programme itself is not named. If you prefer for your identity to be known within the online focus group, your own name can be used as your user name. We can anonymise this in any subsequent publication if necessary. If you are happy for your identity to be known in the report of the research, there is an option on the consent form for you to grant permission for this.

The nature of the research also means that despite the best efforts of the researchers to provide a secure online environment, the potential exists for an external party to break the Computer Misuse Act (1990) in order to gain access to personal information such as the Internet Protocol (IP) address and other identifying features of the computer and server that are used to access the online focus group. Every effort has been made in the design of the discussion forum to minimise this risk.

The transcription of the online focus group in which you participate will be accessible in its entirety throughout the time in which the focus group is running. This allows you to both check back on the proceedings of the group in order to help frame further contributions, and also clarify any statements you have made by contacting the primary investigator. The entire transcript of the focus group in which you participated will remain available for a period of 7 days after the group ends in order to provide time for you to further clarify statements should you wish to do so.

We are also happy to receive additional information from you by email or by phone after the focus group time has finished.

Data Storage

The digital transcripts of the online focus groups will be stored electronically on the University of Exeter's intranet server and as a CD back-up. The University of Exeter's intranet server utilises a secure password access system and files stored on CD will be password-protected using the Microsoft XP operating system. These files may be accessed via the primary investigator's (or colleagues') home computers in the course of data analysis, but will not be stored on these computers. The focus group transcripts will identify participants only by the user name that they have chosen. Any printouts made of transcripts will be for the purposes of data analysis only; these printouts will be stored in a locked desk within a locked office at PenTAG (Noy Scott House, Barrack Road, Exeter) and will be disposed of using the confidential waste system upon the completion of the analysis.

In accordance with the University of Exeter's Code of Good Practice in the Conduct of Research, in order to maintain the transparency of the research the password-protected

computer files of the online focus group transcripts will be stored for a minimum of 5 years on the University of Exeter's intranet server.

Access to the online focus group data will be restricted to the primary investigator and research colleagues at PenTAG, Peninsula Medical School.

Ethical Approval

This study was given a favourable ethical opinion for conduct in the NHS by the Essex 1 Research Ethics Committee.

If you have any further questions, please contact the primary investigator:

Ruth Garside,
Peninsula Technology Assessment Group (PenTAG),
Peninsula Medical School (Universities of Exeter & Plymouth),
Noy Scott House, Barrack Road, Exeter. EX2 5DW
E-Mail: Ruth.Garside@pms.ac.uk
Tel: (01392) 406970

Appendix 5 Participant consent form

Participant Consent Form: Online Focus Group

Population and Community Programmes to Prevent Cardiovascular Disease: A qualitative study into how and why some programmes are more successful than others

Participant ID number:

Primary Investigator: Ruth Garside

Tel:(01392) 406970 **E-Mail:** Ruth.Garside@pms.ac.uk

1. I confirm that I have read, and understand, the Participant Information Sheet: Online Focus Group (version 1.4, dated 01/10/08) for the above study. I have had the opportunity to consider the information and ask questions, and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I understand that the digital transcript of the online focus group to which I contribute in the course of this research will be kept for a period of at least 5 years (with the file password-protected and no identifying data being held in the same location) in accordance with the University of Exeter's Code of Good Practice in the Conduct of Research (2002).
4. I understand that I shall be able to choose a 'user name' in order to protect my anonymity whilst participating in the online focus group and that access to this group will be protected by way of a secure log-in process. I also understand that every effort has been made in the design of the online focus group to maintain participant's anonymity, but that in common with the transmission of all data on the Internet, complete anonymity cannot be guaranteed if an external party breaks the Computer Misuse Act (1990) in order to access data which they are not authorised to do.

5. I understand that all researchers at PenTAG are bound by the Data Protection Act (1998) and the Research Governance Framework for Health and Social Care (2005) to maintain confidentiality regarding all personal information obtained in the course of this research. I understand that my contribution to the online focus group will be anonymised in publications arising from this research unless I explicitly state that I am satisfied to be identified with a particular statement.

6. I agree to take part in the above study, and hereby assign the copyright in my contribution to the research to the University of Exeter.

Please tick either:

- I give my permission for the information I shall give to be used for research purposes only (including research publications and reports) **without** preservation of anonymity
- I give my permission for the information I shall give to be used for research purposes only (including research publications and reports) **with strict** preservation of anonymity

Please tick if appropriate:

- I give my permission for direct quotations from my contribution to the online focus group to be made in the write-up of this research

Participant

Name: *Signature:* *Date:*

Researcher

Name: *Signature:* *Date:*

When completed: 1 copy for research participant and 1 copy for researcher

Appendix 6 Participant email sent if unable to make contact by telephone

Dear XXXXXX

Re: Population and Community Programmes to Prevent Cardiovascular Disease: A qualitative study into how and why some programmes are more successful than others

PenTAG is involved in a series of linked research projects commissioned by the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom to assess the effectiveness of programmes that are aimed at primary prevention of cardiovascular disease (CVD) at a population level through the reduction of multiple risk factors. The research will be used by an independent Programme Development Group (PDG) to develop guidance to improve such CVD prevention programmes. The PDG will consider systematic reviews of quantitative and qualitative evidence, economic modelling, as well as the views and experiences of people involved in such programmes.

More information about the project can be found here:

<http://www.nice.org.uk/guidance/index.jsp?action=byID&o=11881>

As part of this research, we shall be holding an **online discussion forum** through which people involved in the design, management, and delivery of CVD prevention programmes can share their experiences and contribute to the development of guidance related to implementation. We understand that you were involved in **[NAME OF PROGRAMME]** and **we would like to invite you to take part** in this online discussion forum, which will take place over a 2-week period starting on November 10th.

Full details of the research are provided on the information sheet (attached). If you would like to participate in this research, please complete and sign the attached consent form and return to me at the address below.

As we hope to involve people who were involved in all levels of design, management and delivery, it would also be helpful if you could **provide names of other people involved in [NAME OF PROGRAMME]** who you think it would be useful for us to include in our research. **We are particularly interested in contacting front-line staff** in order to better understand their experiences of programme delivery.

Please do not hesitate to contact me or another member of the research team (pentagresearchteam@pms.ac.uk) if you have any further questions.

Dr Ruth Garside
Research Fellow
PenTAG
Peninsula Medical School
Universities of Exeter and Plymouth
Noy Scott House
Barrack Road
Exeter EX2 5DW

01392 406970

Appendix 7 Registration email sent to online forum participants

Dear XXXXXX

Re: Population and Community Programmes to Prevent Cardiovascular Disease: A qualitative study into how and why some programmes are more successful than others

The online discussion forum for this research starts Monday November 10th

You should have received a username and password (by email) that will allow you to log-in to the forum (<http://ehealth.chiirup.org.uk/CVDResearch/>). Please contact us if you experience any difficulties with logging in or using the forum – we will be happy to offer you any assistance you need in order to get 'up and running'.

We have assigned you to the [INSERT NAME OF SUB-FORUM] group within the forum – if you feel that this group does not reflect your area of expertise regarding CVD Prevention Programmes, we would be grateful if you could email or phone us in order to discuss assigning you to a more appropriate group.

In order to keep you up-to-date with the discussion taking place on the forum, you will automatically receive notification by email when a new post is made. If you do not wish to receive this notification, please contact us.

Thankyou for returning your signed consent form. Please do not hesitate to contact us (pentagresearchteam@pms.ac.uk) if you have any further questions.

Dr Ruth Garside
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Appendix 8 Topic Guides

Managers

Planning and inspiration

How did you first get involved in the project?

Where you aware of theory behinds the programme?

Implementation

Did the actual programme look like the plan programme?

(prompts: How did it differ?
 Why did it change?)

What were the main challenges of day to day management of your programme?

What factors contributed to successful or less successful collaboration between professional groups/ organisations?

What factors contributed to successful or less successful staffing?

(prompts: Training
 Findings
 Retention
 Staff morale)

How was community engagement undertaken?
(what went well/ badly?)

Legacy

Once the formal period for the intervention was over, was there anything left?

(prompts: What was it?
 Was it different to the original?)
 If not, why not?)

Programme deliverers

Planning and inspiration

How did you first hear about the programme?

Were you made aware of why the programme was taking place in your area?

How did you get involved?

(prompt: On top of other duties, dedicated time etc)

Implementation

Were you able to reach the people at whom the programme was aimed?

What methods were planned to reach the target groups? Were they successful? Why/ why not?

What factors contributed to successful or less successful collaboration between professional groups/ organizations?

What factors contributed to staff satisfaction?

(prompts: Training
Independence/ community
Retention
Staff morale)

How was community engagement undertaken?

Legacy

Once the formal period for the intervention was over, was there anything left?

(prompts: What was it?
Was it different to the original?)
If not, why not?)

Planners and evaluators

Planning and inspiration

How did you first get involved in the project?

Where you aware of theory behind the programme design/ implementation?

Evaluation

What were the main challenges of evaluating such a programme?

Were there benefits of the programme that the evaluation was not able to measure?

Did the evaluation conclusions reflect staff and community perceptions of the programme?

Do you believe that the programme was successful?

Appendix 9 Reminder email sent to participants

Dear **XXXXXX**

Re: Population and Community Programmes to Prevent Cardiovascular Disease: A qualitative study into how and why some programmes are more successful than others

The online forum is now live at: <http://ehealth.chiirup.org.uk/CVDResearch/>

Discussion to date has addressed issues such as the background to the establishment of particular community CVD prevention programmes and the frameworks that have informed their design.

For discussion in the forum to work to its full potential, it is important for participants to familiarise themselves with the experiences of other contributors. Similar to meeting in person, an online forum requires some 'small talk' before people settle down to the business at hand – so please do not feel that your postings have to be in some way 'definitive' in these initial stages. We would welcome your contribution and encourage you to check back regularly so that you can respond to other participants' postings.

If you are having any difficulties accessing or using the discussion forum, please do not hesitate to contact us by phone or email:

Dr Ruth Garside 0044 (0)1392 406970

Dr Mark Pearson 0044 (0)1392 403056

E: pentagresearchteam@pms.ac.uk

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Appendix 10 Email invitation to comment on focus group discussion

Dear XXXXXX

Re: Population and Community Programmes to Prevent Cardiovascular Disease: A qualitative study into how and why some programmes are more successful than others

Thank you very much for your interest and participation in the above project.

The online discussion forum has now closed.

For your information, we are attaching a transcript of the discussion that took place in the forum to which you were assigned.

We are aware that the period of time for which the forum was open may have meant that you did not have the chance to say all that you wanted.

If you would like to add to, or clarify, any of your contributions we would be very happy to see these. In addition, you may wish to **respond to comments made by others** that you were not aware of at the time.

Please return any contributions you may have to us by email. All contributions to the forum have been numbered – it would be helpful if you quote this number if making reference to specific posts.

Please send your contribution to pentagresearchteam@pms.ac.uk by 12th December 2008.

The attached documents contain the forum discussion in each of the topic areas – double-clicking on the file name will show the discussion in Internet Explorer, or the files can be opened directly from MS Word if you prefer.

Please do not hesitate to contact me or another member of the research team if you have any further questions.

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Appendix 11 Email invitation to hold a telephone interview

Dear XXXXXX

Re: Population and Community Programmes to Prevent Cardiovascular Disease: A qualitative study into how and why some programmes are more successful than others

Thank you very much for your interest in the above project.

The online discussion forum has now closed, but we recognise that some people did not manage to participate. If you want to contribute, **you can still participate in the research through a telephone interview in early January 2009.**

The interviews are designed to give you the opportunity to discuss your experience of ***planning/ delivering/ evaluating/ managing (delete as appropriate)*** a community CVD programme with a view to identifying the barriers and facilitators to effective programme delivery. We envisage key topics to address will include programme management, community engagement and the effects of local contexts, but the interviews are designed to allow you to cover the topics that *you* feel are of particular importance. **Interviews will last a maximum of 1 hour and will be arranged for a time convenient to you.**

Please contact me by phone or email (details below) to arrange an interview for the week beginning January 5th, or soon after.

I look forward to hearing from you.

Dr Ruth Garside
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Appendix 12 Bibliography

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