

# Community engagement report *for the Health Foundation*

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# Contents

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<b>Introduction</b>	4
Definitions	4
Engagement	4
Evaluation and Evidence	5
<b>Obstacles to engagement and costs of disengagement</b>	7
<b>Why many efforts to engage the public have failed</b>	13
Historical background to community engagement initiatives	13
Approach to community and engagement	15
Not engaging with authentic communities	15
Targeting social norms and identifying appropriate communities for engagement	17
Large-scale comprehensive interventions	19
Length of intervention	20
Mobilising communities for health	21
Risk and flexibility in commissioning	22
<b>Strategies and interventions for change</b>	23
<b>Barriers to the take-up of health services by communities</b>	29
General barriers to the take-up of health services	30
Community engagement in maternity services in developing countries	32
Interventions for maternal health in developed countries	34
<b>Recommendations</b>	39
<b>Background information</b>	41
<b>References</b>	42

*In approaching this report to the Health Foundation (the Foundation) we have encountered a number of problems of scope, definition and evidence. We think it helpful to set these out at the beginning to provide context to our findings.*

## Definitions

There are different approaches to defining ‘community’. In many community engagement projects there are geographically defined communities, which may cover a few streets or an entire city, or communities of interest where the members share particular characteristics or concerns. Community can also be either self-defined or defined by researchers for the purpose of their project.

This means there are many approaches to both the ‘community’ and ‘engagement’ aspects for the purpose of community engagement initiatives in health and it is not possible to assume that either word has a precise meaning.

The reviewed studies suggest that it would be useful to engage communities of interest within a particular area in which people come together in shared patterns of interaction. These communities are most likely to contain members who self-identify with each other, either as a community or more simply just as a social group. That they share strong levels of social interaction means that engagement initiatives can work to affect behavioural factors in their lives, social networks and norms that may be reinforcing unhealthy behaviour. Addressing the social aspect of their lives makes mobilising for, and owning, health a social norm. Communities that cannot be engaged in such a way may be difficult to work with for the purpose of mobilising for, and taking ownership of, health.

## Engagement

The term ‘engagement’ also, presents some difficulties. Consultation alone cannot be described as engagement and is therefore mostly excluded from our review. Engagement must, minimally, involve people and communities throughout the activity to ensure their preferences, interests, concerns and aspirations are determining the outcome. Engagement can also go beyond this to be fully collaborative with communities, partnering with them on all aspects of decisions including identifying solutions and developing alternatives. Ultimately communities can be fully empowered by having the final decision and resources within their control. This, we assume, is the objective of community engagement.

The quality of evidence for effective community engagement is variable. We have identified a large number of papers, many from ‘grey’ literature. Often these are write-ups and reports rather than proper evaluations and it is rare for there to be controlled trials of any sort. This is more a failure of research methodology than a failure of intent. For instance, community engagement does not easily lend itself to randomised trials because the intervention is with a targeted community. Also, with very limited resources often coming from the community itself, evaluation may be inappropriate or unethical.

## Evaluation and evidence

There are considerable methodological difficulties in both the design and outcomes of evaluations of complex social interventions. The Health Foundation will be familiar with the debate between quantitative randomised controlled trial approaches to large-scale interventions, which inevitably aim to eliminate the ‘noise’ of variables, and qualitative approaches, which by aiming to include real life variables, are consequently limited in power and statistical validity.

Sometimes this difficulty is presented as a failure of evidence. Actually it is a failure of research methodology to analyse and resolve multi-factorial changes.

This methodological deficit does distort research evidence and it is important to take this into account when evaluating. To use the terms of the dominant research paradigm – there may be both false positives and false negatives in the data as reported. As we suggest later, the Foundation will need to take this into account if designing an evaluation of any complex multi-factorial intervention which it might promote in the area of community involvement. In doing so it would be breaking new ground and might make a significant contribution to research methodology itself.

More thought and effort needs to be put into qualitative and quantitative approaches to evaluating community engagement and particularly into user-defined outcome measures.

We were asked in this report to pay particular attention to prenatal and perinatal maternity services. Where there are specific examples we include these in the text. There is little available information about barriers to adoption of maternity services in developed countries and on how community engagement could be used. There is, however, some information from developing countries where community engagement methods have been used effectively.

Some of the issues in developing countries, such as poor sanitation and physical access to hospitals or midwives, are not particularly relevant but what is successful and what works in terms of ways of engaging with people is common across all countries.

## 2 Obstacles to engagement and costs of disengagement

*In order to identify the purposes of, and most appropriate ways to, engage communities in the personal health issues of their members, it is important to identify the more general obstacles to engaging people in their health. Similarly, it is useful to identify the costs to health that are associated with this disengagement.*

A study carried out by the King's Fund in 2004 shows that there is a widespread belief that people should take responsibility for their own health, but that there is strong variation by social class as to whether people are sufficiently in control of their own health to be held responsible for it. The study found that 88% of people agree that individuals are responsible for their own health. More than 40%, however, agreed that there are too many factors outside individual control to hold people responsible for their own wellbeing. This figure was 54% among those in the DE socioeconomic class but only 31% among the AB class.<sup>1</sup>

This suggests that those in higher socioeconomic classes feel more in control and empowered to take active responsibility and ownership for their health. The results of a 2005 Department of Health study<sup>2</sup> into public attitudes to self-care and self-care behaviours demonstrate how differences in socioeconomic status correspond with differences in health status. The amount of self-care undertaken by those suffering from long-term conditions and the limitations on their lives caused by their condition were also explored.

The study published the following results on reported health among the general public (percentages of each socioeconomic class reporting health on the whole good–on the whole fair/poor). Interestingly, there was little difference by ethnicity.

AB	<b>82–18</b>
C1	<b>76–24</b>
C2	<b>73–27</b>
DE	<b>65–35</b>

This shows that those in higher socioeconomic classes – those that tend to feel better able to take ownership over their own health – report higher health status. Although the correlation does not imply causation it is worth noting and makes it an interesting hypothesis as to whether increasing self-perceived control and ownership of health would increase self-reported health status.

Among those with long-term conditions the percentages responding yes–no as to whether their condition limited their activities in any way are shown below:

AB	<b>34–65</b>
C1	<b>40–60</b>
C2	<b>40–60</b>
DE	<b>55–44</b>

Similarly, among those with long-term conditions, there is a strong correlation between an individual's socioeconomic class and whether or not their activities are limited by their condition. It is interesting to note this correlation between self-perceived control and ownership of health and the impact a condition can have on daily activities.

The study noted that its findings suggest that people who do more self-care feel that their health is good, very good or excellent while those who do less feel that their health is poor or fair. This suggests a link between ownership of health (to the extent undertaking self-care serves as a proxy measure for this) and self-reported health status among those with long-term conditions.

Those who say their health is fair or poor, who tend to be more disadvantaged and more elderly, are less likely to be active self-carers compared to those who say their health is good, very good or excellent. Those from lower socioeconomic groups and those with the poorest health are therefore those who require more specific attention to promote self-care and healthy lifestyles. Interestingly, the study also found that those who lived in the most deprived wards are more likely to agree that support from people with similar health problems, experiences, concerns and conditions would give them confidence to do self-care. This suggests that greater support from those with a similar life to them who they can better relate to would help them take more ownership of their health (again to the extent undertaking self-care among those with long-term conditions is a proxy measure for this).

The Patient Activation Measure (PAM), developed in the USA by Judy Hibbard, is a mechanism for measuring the skills, knowledge, beliefs, and motivations people need to become 'activated' or more effectual healthcare actors.<sup>3</sup> Activation has four levels: (1) believing the patient role is important; (2) having the confidence and knowledge necessary to take action; (3) actually taking action to maintain and improve one's health; and (4) staying the course even under stress. A study by the Picker Institute Europe of those aged over 45 with a long-term condition found a strong positive correlation between activation level and each socioeconomic group, education and age and between activation level and self-reported health status.<sup>4</sup>

It is significant that PAM levels vary considerably by socioeconomic class, age, education and self-rated health. PAM levels are linked to healthy behaviours and, as it is a changeable attribute, this indicates that if the underlying factors which the levels measure can be changed there is the potential to have a significant impact on health outcomes. The important question that follows from this is: what interventions can bring about, support and sustain changes in the knowledge, skill and confidence for self-care and healthy behaviours that PAM levels measure?

Like the King's Fund study, the survey carried out for the Department of Health found that people want to own their own health. It found that 71% of people disagree with the statement 'I don't want more responsibility over my health' while 24% agree. Of those surveyed, 95% agreed they were very or fairly 'interested in leading a healthy lifestyle overall'.

This suggests that people are generally willing to take greater responsibility for their own health and are interested in leading a healthy lifestyle, even if many people currently feel there are factors beyond their control that limit their ability to take full responsibility for their health. The challenge appears:

- to channel this willingness to take more responsibility into actually taking more responsibility and owning their own health
- to engage those who are interested in having a healthy lifestyle but do not want to take greater responsibility so that they feel willing and able to do so.

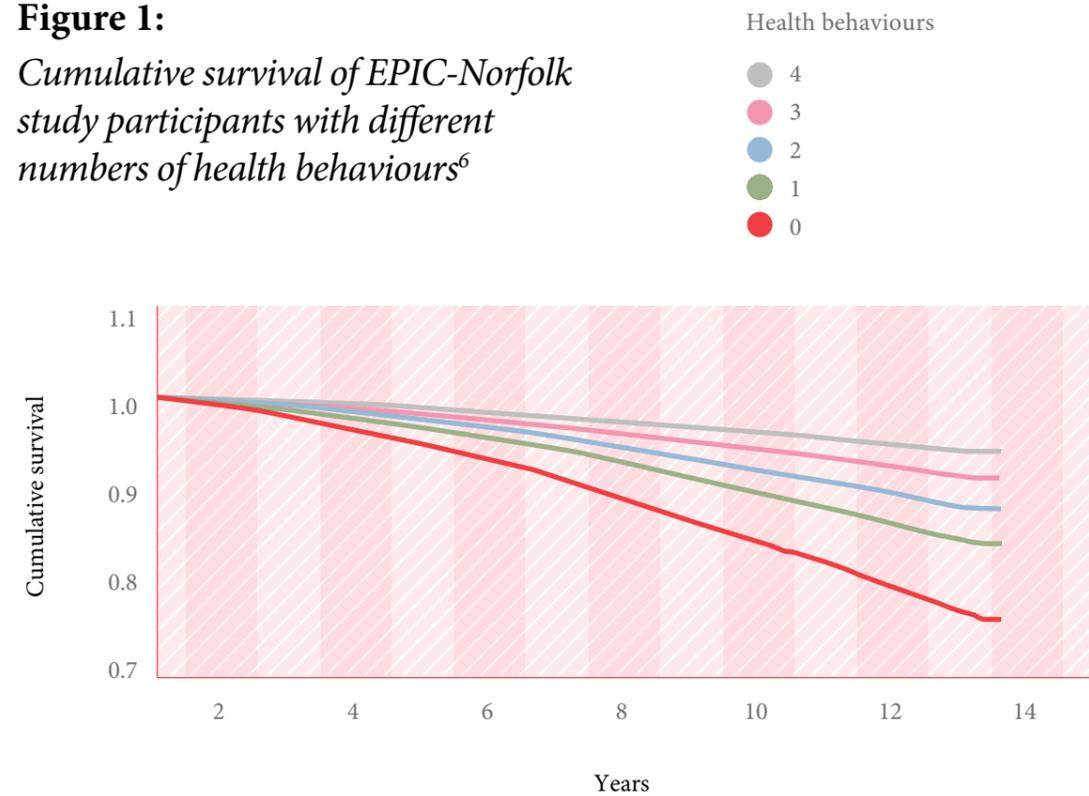
There are strong correlations between self-reported health status and social class, and between social class and self-perceived control over health. Therefore, there might also be a link between self-perceived health status and self-perceived control over health. If this is the case, successfully engaging people in their health, to increase their self-perceived control over it, could have the effect of improving their perceptions of their health and, among those with long-term conditions, lower its negative impact on their daily lives.

These socioeconomic variations in health status and perceived control are important in considering community engagement because these groups tend to be less effectively reached by most public health initiatives. However, systematic reviews have concluded that: '[community] interventions targeting high risk groups including low income communities and ethnic minority groups appeared to have considerable success.'<sup>5</sup>

Small lifestyle factors have been shown to make big differences to health outcomes. This impact is demonstrated in the following study led by Professor Kay-Tee Khaw:

Between 1993 and 1997, about 20,000 men and women aged 45–79 living in Norfolk, none of whom had cancer or cardiovascular disease, completed a health and lifestyle questionnaire, had a health examination, and had their blood vitamin C level measured as part of the EPIC-Norfolk study. A health behavior score of between 0 and 4 was calculated for each participant by giving one point for each of the following healthy behaviors: current non-smoking, not physically inactive (physical inactivity was defined as having a sedentary job and doing no recreational exercise), moderate alcohol intake (1–14 units a week), and a blood vitamin C level consistent with a fruit and vegetable intake of at least five servings a day. Deaths among the participants were then recorded until 2006. After allowing for other factors that might have affected their likelihood of dying, people with a health behavior score of 0 were four times as likely to have died (in particular, from cardiovascular disease) than those with a score of 4. People with a score of 2 were twice as likely to have died. (Figure 1) shows how the survival rates by number of health behaviors.<sup>6</sup>

**Figure 1:**  
*Cumulative survival of EPIC-Norfolk study participants with different numbers of health behaviours<sup>6</sup>*



This suggests that relatively simple healthy lifestyle behaviours can work and engaging people to make small changes could have major impacts on health. It also suggests that successful engagement efforts to mobilise people and communities for health could have major effects even if the focus is on small changes to simple and low-level behaviours.

The results show the cost to individuals' health that unhealthy lifestyles can have. However, as revealed by the surveys cited above, people overwhelmingly want to live healthy lifestyles and feel they should be responsible for their health even where they do not feel that they are currently in a position to take full control over it. The stark costs of unhealthy lifestyles combined with the desire to be responsible for their own wellbeing suggests the challenge is to build on this motivation and channel it into patterns of behaviour that promote wellness rather than sickness.

Large amounts of research on the underlying causes of ill health have shown that many key risk factors for specific conditions are rooted in unhealthy lifestyles and environments. As three leading public health practitioners have stated:

Research has clearly shown that non-communicable diseases have their roots in unhealthy lifestyles or adverse physical and social environments. Risk factors like unhealthy nutrition over a prolonged period, smoking, physical inactivity, excessive use of alcohol, and psychosocial stress are among major lifestyle issues. While there is firm knowledge on 'What should be done?' for the prevention of these diseases, the key question at present is 'How should it be done?'

The elimination of the root causes of disease requires positive action to be taken by members of communities to change their social norms and patterns of behaviour from ones promoting sickness to ones promoting wellness so that these become ordinary parts of their daily lives. Only the individuals and communities themselves can change their practices, so resources need to be targeted at this level. It requires a genuine partnership that engages with members of the community and builds on their motivations, with the main goal that the communities internalise the new health-promoting behaviours into their own norms. In this sense we believe that it is important to engage with people at the very basic levels in which their social networks shape the behaviours in their daily lives.

### 3

## Why many efforts to engage the public have failed

*As Merzel and D'Afflitti concluded in a systematic review carried out in 2003:*

The evidence from health promotion programs employing a community-based framework suggests that achieving behavioral and health change across an entire community is a challenging goal that many programs have failed to attain.<sup>8</sup>

In this section we outline why many of these projects have failed to highlight important key lessons. However, such mixed results should not be seen as disproof of the efficacy of community mobilisation as a concept but rather should demonstrate pitfalls that have caused initiatives to be unsuccessful. We propose that there are a number of key factors that have limited effectiveness and prevented success. These factors are barriers to engagement and prevent communities from taking ownership of, and mobilising for, health issues. Such projects are then community based in terms of setting rather than ownership.

### Historical background to community engagement initiatives

We begin by considering the North Karelia project which began in 1972 in a rural county in eastern Finland. It is worth considering this initiative in detail as it had significant success, has been substantially reported and provided the inspiration for numerous subsequent interventions. The project was initiated following a petition from local people requesting government action to reduce high rates of cardiovascular disease in the area.

This was one of the first significant initiatives that sought to intervene on a community level to lead to behavioural change among community members and mobilise the community for health.

The intervention began with the premise that behaviour cannot simply be changed by providing information. Rather people need to be persuaded to act in new ways and that these new ways are socially acceptable – for example, that the food is as good and activities as enjoyable. Central to achieving this was the involvement of opinion leaders from formal and informal groups to increase the credibility of the messages. These individuals were the targets of intense, persuasive communication from respected medical, and other, experts and were then encouraged to spread and support the ideas in the community.

The content of messages was carefully constructed to target and suppress anticipated counter-arguments – for example, many strongly believed that a diet high in meat fat was necessary for hard-working individuals. Additionally, any messages that could be fear inducing were accompanied by clear and attainable recommendations on how the risks could be reduced.

The project recognised that organising within the community was crucial to achieving behavioural change and, as more recent studies have found, without reinforcement in the social environment these changes are far less likely to be maintained.<sup>9</sup> Special efforts were made to build on existing social networks and identify individuals of influence for a range of different activities. Project staff and influential members of the community worked together to identify the key environmental changes needed to support the project and ways to realise them.

The project followed four steps of training to smooth the transitions in behaviour:

1. Demonstration of the new patterns of actions and responses.
2. Guided and progressively more independent practising of these new behaviours.
3. Feedback on the appropriateness of responses.
4. Reinforcement through support and encouragement that is withdrawn as the new behaviour becomes habitual.

One example of this is that many women belonged to local housewives associations, with which project staff engaged and which worked in cooperation with the project to teach new practices of cooking and food preparation following the four steps. Similar programmes were run with other groups to co-produce behavioural changes, such as for smoking cessation and means of coronary rehabilitation.<sup>10</sup>

It is interesting to note that over a five-year period, although the understanding of the risk factors for cardiovascular disease increased in North Karelia this was not statistically significant when compared to a reference area. However, when compared to the reference area there were statistically significant changes across a range of risk factors. This emphasises the importance of focusing on the social context in which individual action occurs and is maintained, rather than on increasing the knowledge of individuals. In other words, health education alone is likely to be ineffective. The project leaders concluded that: ‘essential elements for a successful community intervention programme include a good understanding of the community (“community diagnosis”), close collaboration with various community organisations, and full participation of the people themselves.’<sup>7</sup>

The North Karelia project provides a historical background to other community engagement initiatives. However, as pointed out above, the results from these have been decidedly mixed. We contend that this is because many initiatives have taken specific programme components that have been demonstrated to work without learning many of the key lessons from integrated community-led approaches. As a recent review pointed out ‘there has been a notable tendency to attempt replication [of successful trials] without due consideration of the unique people, place and time being targeted.’<sup>11</sup> In the North Karelia project, for example, many of the programme’s components worked well, but they should not be transposed to another setting directly as this demonstrates a failure to appreciate the reasons why they worked. It is the approach rather than the intervention which needs to be transposed.

## Approach to community and engagement

We believe key reasons for some community engagement initiatives failing where others succeed is their definition of, and approach to, ‘community’ and a lack of real engagement with the social context of community member’s lives. In the introduction we suggested that there have been different approaches to defining community initiatives. Many initiatives have sought to move beyond clinical approaches to health promotion and to take messages into community settings using techniques such as social marketing and providing services in more culturally appropriate settings. However, such interventions have often had relatively low success rates in producing changes on common behavioural risk factors.<sup>12-14</sup>

This is because such interventions may use community settings but they fail to engage communities in such a way that will change the social norms, attitudes and patterns of behaviour that reinforce unhealthy lifestyles. As pointed out by Swerissen and Crisp: ‘Individual action occurs within, and is maintained by a social context. Interventions that isolate individual action from its social context are unlikely to produce sustainable health gain in the absence of change to ... conditions that make up the social context.’<sup>9</sup>

## Not engaging with authentic communities

A central component of the underlying rationale for the effectiveness of community engagement is that an individual’s behaviour is significantly shaped by the norms, attitudes and patterns of behaviour that exist in their social context. This means that it is crucial for initiatives to engage with people within the social context of their community that reinforces unhealthy behaviours and particular attitudes to factors that influence health. Engaging members of a community at this level is necessary to promote healthy activities and attitudes to affect the social context and norms lying as a root cause of disengagement with health issues. A review article by Zackus and Lysack concluded that in order to be effective and long-lasting, community participation must become a successful and integral part of the community’s common experience and not be a structure imposed from the outside.<sup>15</sup> This requires an authentic self-identifying community which shares in, and identifies with, these common experiences. This is further borne out by a literature review carried out for the World Health Organization (WHO) Health Evidence Network which stated that:

In light of the evidence and other information available up to now ... while participatory processes make up the base of empowerment, participation alone is insufficient if strategies do not also build capacity of community organizations ... Advocates or external change agents may catalyze actions or help create spaces for people to learn, but sustainability and empowerment occur only as people create their own momentum.<sup>16</sup>

Many initiatives have sought to operate over large communities defined in terms of geographical areas. There are, however, problems with such approaches. A review looking at the theoretical underpinnings and results of initiatives seeking to mobilise communities for health found that many programmes 'define community in terms of geographical or geopolitical units ... which is problematic considering that these entities can be heterogeneous and characterised by a weak sense of community.

This may yield insufficient community mobilisation and inadequate programme reach.<sup>17</sup> For example, the South Carolina Heart to Heart project in the USA defined communities geographically and did not sufficiently engage with people at the community level. It alienated members of many of its target communities and was explicitly criticised by them for not taking their particular contexts and interests into account when planning interventions and for not tailoring its approach to engage with the different groups it sought to target.<sup>18</sup> As Mittlemark and colleagues observed regarding initiatives to target cardiovascular disease 'the core of a successful programme is the community organisation process'.<sup>19</sup> This requires a thorough understanding of the social context of a community and its resources before embarking on the intervention effort.

Although some successful projects have worked over large areas, such as in North Karelia, others have often been more socially and culturally homogeneous. This is important because it means norms and patterns of behaviour are shared within the group, thus requiring less tailoring to the disparate social contexts that exist in more diverse areas. For example, in the UK one of the key unhealthy behaviours that puts many people at risk of health problems in particular communities is cooking with large amounts of ghee. For other communities this is insignificant. Any initiatives that fail to recognise that the most significant behaviours underlying major risk factors differ vastly by context (for instance the role of food, its purchase, production and consumption) and target its interventions as a result – rather using, say, a general heart health intervention – will be at a disadvantage in addressing these key unhealthy behaviours that underpin the major risk factors.

Additionally, more than many programmes, the North Karelia project still targeted many of its key interventions at very specific community groups, such as the individual women's clubs, and engaged with these to co-produce particular intervention techniques. This is because it recognised that encouraging new patterns of behaviour and facilitating changes at the level of people's daily lives so they become habitual takes place in the context of the social interactions that define these events.

Not engaging with authentic communities leads to initiatives being unsuccessful, because health improvements will only occur if new patterns of behaviour are formed and then sustained after an intervention is complete. Typically this requires changes to a community's norms which underpin the behaviours of its members.

## Targeting social norms and identifying appropriate communities for engagement

Reviewing the effectiveness of types of partnerships for health promotion, Gillies found that gains had greater impact and sustainability the larger the community involvement in the practical activities of health promotion.<sup>20</sup> It was also found that the 'immediate relevance and emotional connection of the focus' was crucial. This demonstrates the importance of framing initiatives in ways that are meaningful to the targeted group, which can best be done in the context of their daily lives, their key social networks, activities, attitudes and meeting places. This means that engagement may need to take place in highly localised and specific ways – particularly in areas with high levels of diversity and disparate social contexts – in order to reach a group of people who share a strong sense of identity and among whom a common 'emotional connection of focus' can be made.

The Minnesota Heart Health Program, a large-scale project focusing on cardiovascular disease, had participation rates for screening programmes of approximately 60% with about 30% receiving face-to-face interventions.<sup>21</sup> However, the results showed little change in healthy behaviours as a result and the evidence suggested the effect on people's attitudes to health was minimal. For example, only 4.1% of smokers participated in smoking cessation programmes in the intervention communities, little more than the 3.1% in comparison areas.<sup>22</sup> The findings demonstrate the difficulty of engaging populations in activities that are sufficiently intensive to result in sustained behavioural change. Although in Minnesota large numbers of people received screenings and information, this alone did not sufficiently engage them in health issues.

The approach to community engagement advocated in our paper is one where communities play a far greater role than they have in many of the unsuccessful projects. Many projects use 'community' to refer to a setting for interventions.<sup>23</sup> These often covered large geographically defined areas and may sometimes utilise the resources of communities, such as community institutions, in their intervention and may seek input from community members, for example, through advisory councils to try and refine messages to the target groups. However, they focus on bringing about change in an individual's behaviour to reduce risk factors, largely by targeting individuals. They have often not sought to engage with communities at a deeper level to mobilise them for action as a group and encourage the communities themselves to take on a role of co-producing health.

Merzel and D’Afflitti found that community initiatives in HIV prevention did not show the schemes demonstrated by many other initiatives. They found that the major difference between the HIV projects and other unsuccessful ones was that HIV initiatives emphasised changing social norms regarding risk behaviours so that patterns of behaviour promoting risk avoidance were seen as normal and acceptable and part of the socially reinforced ordinary patterns of behaviour within the target communities. They concluded:

The accomplishments of the HIV programs indicate that obtaining considerable community input for the development and delivery of interventions and focusing on changing social norms as a means of altering individual behaviour should be considered critical aspects of community-based health promotion. At the same time, the nature and degree of the risk involved and the targeting of relatively smaller, more homogenous social groups distinguish HIV programs from other health promotion efforts.<sup>8</sup>

They suggested that the key reason these programmes were more successful than other efforts was that:

... the targeted communities and subgroups for the former were relatively small and more homogenous. Under such conditions, extensive intervention tailoring and concentrated efforts to change the normative environment may be more feasible and effective than when the community is large, diverse, and difficult to define in terms of risk. Thus, getting identifiable social groups to change specific behaviours with discrete levels of individual risk may be more achievable than developing multiple interventions designed to motivate numerous subgroups of varying risk found within a broad geographically defined community.

Community members, particularly peers, should be closely involved in intervention design and delivery, and messages should be tailored to target audiences ... to help change norms and teach skills needed to reduce risk behaviours. Addressing social norms promoting at-risk behaviours is one of the most critical elements. Although the HIV interventions had more community input in terms of intervention design and implementation than many other community-based prevention programs, it is worth noting that the HIV programmes appear to have relied on informal methods of community involvement.<sup>8</sup>

As the HIV studies show, success in community approaches appears linked to:

- the input of the target group in developing and delivering programmes
- a focus on changing social norms within target groups as a means of altering behaviour
- targeting smaller, more homogeneous groups.

This helps ensure greater reach into, and impact within, target groups as it is more affecting of their daily lives.

The use of informal methods is also significant. Unlike some other interventions, the HIV programmes did not try to create new formal structures, rather they sought to use the existing informal settings in which members of communities live their lives. As the WHO literature review found the most effective strategies to change norms and mobilise communities for health are those which build on and reinforce authentic participation, a sense of community and local bonding and seek to empower people as members of their communities.<sup>16</sup> Again, this stresses the need for community engagement initiatives to start where people are and build on the resources that are there, rather than starting from scratch trying to create mechanisms to reach and engage individuals.

## Large-scale comprehensive interventions

The evidence shows that it is difficult to engage large proportions of a population sufficiently intensively to get the level of involvement and subsequent behavioural change by individuals to have a major impact. Comprehensive intervention approaches which target large geographically defined areas have had little or no success in producing long-term sustainable outcomes. For example, the Minnesota Heart Health Program sought to recruit participants to educational programmes targeted at an individual level, but struggled to recruit and then shifted to a mass media approach that had very limited effectiveness.<sup>17</sup> This shows that initiatives can face pitfalls if they use the community as a setting to attempt to bring in people, rather than engage with the members of communities to co-produce changes in favour of healthy behaviours.

The evidence suggests that interventions across a large geographical community struggle to create change in people’s actual lives. Numerous smaller-scale interventions focusing on the local networks where people are in their daily lives, rather than on a large collaborative programme, are likely to have more success – particularly in socially and culturally diverse settings. This follows the rationale of the HIV programmes which were successful because they engaged with people in these contexts and were therefore able to affect the way in which their behaviour and choices are determined.

Narrowly targeted engagement initiatives, rather than widespread ones that may not reach this far down into the unhealthy behaviour-creating contexts, are likely to be most effective. They allow for different strategies to emerge in engagement with different groups. This is important as if each community has its own social norms and patterns of behaviour and has authority and legitimacy in the eyes of its members, it is the community itself that is in the best place to know the messages and activities that will change the sickness-promoting patterns of behaviour to ones of wellness.

Large-scale initiatives focusing on single objectives which look to form large collaborative partnerships often lose the interest of their resident members during extended planning sessions. These members then tend to leave the partnership, which then evolves into an issue-oriented initiative with limited non-professional involvement. Although they may use community-level settings they fail to engage with the members of the communities.<sup>18</sup> This lack of engagement then prevents communities addressing the norms that lie at the root cause of sickness-promoting behaviours. Such initiatives are then reliant on changing people's attitudes on an individual level without reinforcement within the social contexts in which they live.

## Length of intervention

The nature of community engagement for health means that even well-designed projects may take a long time to demonstrate positive results. The focus is to change social norms and practices and this is a long process. It involves engaging with communities to jointly identify important health issues and priorities, and their root causes. It then involves working in partnership to come up with ways to address these root causes and facilitate and promote new healthier behaviours. These activities need to be produced and run by the communities and have a deep enough and lasting effect to be internalised into the communities ordinary processes and the social norms and patterns of behaviours of its members. Even in initiatives such as the North Karelia project, which produced clear, positive outcomes, these took time to develop and become established.<sup>19</sup>

A review carried out by Roussos and Fawcett found that: 'demonstrable improvements in health of the population typically only result when the community action is sustained over the long-run'.<sup>20</sup> They identified a number of strategies as being central for achieving this. Programmes or programme components should be integrated into the regularly planned activities of groups in the community. These provided key channels of influence because sustained change was found to be more likely where engagement took place within peer groups and existing community organisations. Specific community changes should be identified, in an ongoing manner, to affect community health improvement. This was important as targeted intervention on one issue facilitated higher rates of change in communities than general community health initiatives without a specific focus. Providing adequate context-sensitive technical assistance to groups was important to enhance the competencies of its members where this was relevant to activities they sought to undertake.

## Mobilising communities for health

A recent study of local community groups in four municipalities in Finland looked into the main common factors across those groups which were most engaged in health-promoting activities.<sup>21</sup> Four factors that led to greater engagement in health and action by community groups were identified, of which the first two were most significant:

1. The extent to which the group values health.
2. The extent to which the group perceived its competence, such as its work being appreciated and whether it believed its activities were having an impact on people's health and wellbeing.
3. The extent to which the group perceived opportunities were available to it, such as being involved in local decision making on health issues and cooperation from those locally in positions of power and influence.
4. There was also variation across municipalities, which the authors suggested was down to different policies in each setting. For example, it found that in a municipality where local groups were less active in health only 14% of the decision makers considered that emphasis on health promotion action was important in making choices on service providers.

These findings show key facilitators to mobilising communities for health. Firstly, it is clearly important that communities value health. Most communities will value the health of members to some degree, the studies cited in section 2 show people do value their health and want to live healthy lifestyles. However, communities will also value numerous other things and may value many of these to a greater extent than health. The challenge is then to engage with the communities to increase the relative value of health and make it more important to them as an outcome. The study also shows it is important that a community has a sense of competence in the health activities it is taking on to promote further action in, and greater ownership of, health. Similarly, the study emphasises that, in addition to feeling able to have an impact in its activities, feeling able to have an impact in the way in which health issues are addressed locally facilitates greater engagement in health issues.

## Risk and flexibility in commissioning

Institutionalised attitudes towards risk provide a barrier to commissioners and other funders engaging with communities to mobilise for health. With ownership of health comes ownership of the risk. Among many commissioners and funders there is inertia due to deeply ingrained organisational risk aversion. If the control and responsibility for activities is passed to communities then the risk of failure is no longer controlled by the commissioner. It is inevitable some community-led initiatives will be poorly managed when produced by the community involved – this is another reason why in section 4 we advocate raising the scope of activities and responsibility of communities incrementally over time working towards their ultimate ownership of production. If a commissioner is more innovative and goes beyond what has traditionally been done by their organisation to commission communities to lead services and this fails, the reputational and professional loss to them is likely to be far greater than if they had taken the safer option of continuing to commission the same sort of services their organisation always has, even though these may not be particularly effective at reaching the groups who need a service most. These entrenched structural problems can be a significant barrier to genuinely empowering communities to give them ownership of health services.

Commissioners at times need to be more flexible with communities than they might be with traditional service providers, as the communities take on new responsibilities and ways of doing things and seek to innovate in providing services to their members. Funding communities to provide services may often require a larger initial outlay as they develop their capacity to produce them. However, in the longer term communities have a greater advantage in terms of leveraging in funds from their members and external sources beyond the initial commissioning organisation. Promoting their ownership of the health of their members can help re-orient their priorities so that they value health and focus more of their time and resources on this – providing double dividend in the long run. It is important that initiatives are robustly evaluated. Some will be unsuccessful and should not be re-commissioned. Commissioners need to be in a position to know which initiatives have been unsuccessful and learn from these to ensure future services do not repeat any pitfalls. However, commissioners need to be sensitive in evaluating community initiatives and to involve the community in the evaluation. It is important that they use appropriate methodologies and are not perceived to be intrusive in a manner that could alienate communities and create a barrier to future engagement.

# 4 Strategies and interventions for change

*In section 3 we reviewed why many community engagement initiatives have failed to bring about major changes in healthy behaviours and lifestyles. In this section we seek to identify how strategies and interventions can successfully bring about change in practice.*

The implications of the evidence on community engagement initiatives were well put by Darwen with Blackburn Primary Care Trust (PCT) when reviewing the literature on community interventions to inform its public health programme: ‘relatively limited and focused scope and remit, both in terms of target problems and geographical area coverage. A limited remit should not be seen as a weakness; rather this helps to focus effort and resources, especially in the early stages.’<sup>22</sup> The report also acknowledged that by starting with smaller, simpler successful steps this could facilitate an incremental approach to a wider remit being taken on.

Many of the obstacles to successful community engagement initiatives are interwoven. Taken together they demonstrate the central importance of engaging with people where they are, in ways that are meaningful to them given the context of their lives. If this does not happen initiatives will fail to engage communities and will not lead to increased mobilisation of their members for health. This is the difference between an initiative being community based and truly community engaging. It is important that community-based health promotion interventions are tailored to that particular community’s needs, different communities will respond differently to an intervention. This means that there is no such thing as a model ‘effective intervention’. This is borne out by the WHO’s finding that interventions which empower communities cannot be standardised across different groups, but must be created within a local context.<sup>16</sup> We should not seek to create a template intervention in which we then seek to engage the community, as this puts the cart before the horse. There are ways to approach engagement that have had clear success. However, it is common to these that the engagement precedes the specific interventions so that communities can design, control, produce and ultimately own them.

Real community control is necessary if the sickness-promoting norms are to be changed and new health-promoting norms created and maintained. Co-production of the intervention by communities, so that they take on greater responsibility for, and ultimately ownership of, the activities is crucial. Communities know best what is important and of value to them, and what has meaning and significance to their members. As a result, they know what will be persuasive to their members and how to integrate new health promoting behaviours into their members' lives. It is in this social context of communities that norms and the behaviour of individuals are anchored, and hence here that they can be changed and sustained.

We will now illustrate how communities can successfully be engaged in health issues. To do this we will first present a case study of a community engagement project in the London Borough of Newham. We will use this example to show how community engagement strategies can be designed to overcome these problems successfully. We will then draw on the published and grey literature to explicate how it practically demonstrates that community engagement initiatives can meet identified criteria for success and have real effects on the health of participants.

Since 2005, the Newham Primary Care Trust Patient and Public Involvement Team has been working with a local voluntary sector infrastructure organisation, the Black and Ethnic Minority Community Care Forum, which had some experience in promoting health projects in the local area, to develop and test the Communities of Health initiative, which involves a scheme to accredit groups with Community of Health status. Working with a second tier voluntary organisation at the strategic level helped to give the initiative a greater network of contacts to reach into target groups and added legitimacy to many it targeted who have not engaged with the health service or have negative past experiences of it. As a study by the Community Development Foundation noted, trust has to be established by practitioners who might be tested by people to determine their credibility and whether they can be relied upon, it was found this was far easier if practitioners could join up with those already accepted by the people with whom they sought to engage.<sup>23</sup> Elsewhere second tier organisations have specifically been identified as a significant resource of local knowledge and deep networks in communities.<sup>24</sup>

The purpose of the programme in Newham is for the Communities of Health to take an element of ownership of the health of their members, with support from the health service where needed. Communities of Health relies on creating health impact in a community context across a continuum of activity ranging from general social interaction to health-focused activities – for example exercise classes and healthy eating groups. The approach is to take people towards health through the medium of their social context.

The Patient and Public Involvement Team and the Black and Ethnic Minority Community Care Forum agreed to work to deliver the following by 31 May 2008:

1. A framework for the Communities of Health assessment process.
2. To use information gathered in the research stage and formulate the first draft of the assessment framework, including a signposted process for organisations to use before, during and after the initial diagnostic period.
3. To identify the skill sets required by the health trainers/navigators.
4. To define the assessment process.
5. To identify the health trainers/navigators to take place in the pilot project.
6. To train the health trainers/navigators to carry out the initial diagnosis against the framework.

Of the seven organisations so far accredited – and a further four are due for accreditation by autumn 2009 – one organisation had a 200% rise in participants in healthy activity over the period from November 2006 to April 2008 and across the remaining organisations this increase was 28%. Overall there was a 46% increase in participation in healthy activity, from 3,111 people to 4,545, representing a 9% increase in person hours of lifestyle changing activity. The seven accredited organisations increased their health programmes by an average of 18% over the period. Among 10 benchmark groups, between the start of their involvement with Communities of Health in November 2006 to April 2008, increases were recorded in:

- health creating activity (eg exercise and weight loss activity, healthy eating, smoking cessation)
- health sustaining activity (eg social networking activity such as tai chi for the elderly)
- health ownership activity (eg talks and discussions on the subject of health or health services).<sup>25</sup>

Communities of Health estimates that across the sample the impact equals 2,000–5,000 years in additional life expectancy, on top of the improved self-esteem and sense of ownership over health that is reported by members – many of the groups involved want to do more because of the recognition they are receiving from the NHS.

The increases in activity have not just been directly linked to PCT funding as Communities of Health also increases the profile of health as an issue in culturally sensitive ways. This has led to subtle shifts in the internal resource allocation of groups – financial, time, commitment, skill utilisation – in the direction of health. Participation in Communities of Health activities has also helped the groups leverage additional funds from elsewhere.

Communities of Health uses simple and accessible evidence, such as the *Small Changes, Big Difference* dataset mentioned in section 2, with its target groups to help show what differences can be made by minor changes in lifestyle and behaviours. It then supports the groups to design and implement activities that would facilitate these. It always starts with small attainable steps which the groups can easily complete. This attainment helps encourage an empowering sense of being able to control their own health and to take on further responsibility for it in a continuous process of increased responsibility for, and ownership of, health. This incremental approach is central to promoting the empowerment of the community and mobilising it to health ownership.

The approach of Communities of Health is not just to target existing community organisations. It requires some antecedent social networks to utilise, but these communities can simply be lunch clubs, people who regularly meet up to go to football matches, employers in the area, firemen who eat together on their break and so on. A useful way for it to prioritise its target groups is to begin by analysing detailed public health data in relation to social patterns and characteristics in the area to find out the pressing health needs corresponding to particular communities. Having identified the health issues, and those most affected (eg in terms of age, ethnicity), the next step is to figure out where these people go so that they can be reached – hence having local knowledge is crucial to the success of this approach. Focus groups can be an important addition to this, although they may simply be grabbing some people from a coffee morning rather than formal exercises. It is important to find out what makes people and their communities tick – what has an important role in their lives that can be a way to reach them. As such, focus groups that target very specific groups can get the necessary knowledge that must itself be highly specific in order to reach these specific groups of people.

Following this, Communities of Health goes to these places, such as faith groups, social groups, or workplaces or any other setting, and talks to influential people there. Many communities have expectations that have been shaped by their past experiences that health professionals will simply want to come in to give a talk and then leave without any further engagement. Communities of Health tries to overcome negative perception by talking to them on equal terms explaining the health problem in their community and suggesting a range of possible things that the community could lead and do. It is important that as part of its approach Communities of Health does not try to overwhelm communities, but points to small and attainable steps that can be made and have a real impact on people's health. It serves as a facilitator initially to co-produce programmes, but these are fundamentally led and shaped by the communities themselves who progressively take greater ownership of them.

Communities of Health can also provide a useful platform for public engagement in health more widely, such as engaging with communities to improve the appropriateness of service design and to broker dialogue in the area over health issues. In Newham, Communities of Health took the lead role in the recent *Healthcare for London* consultation. As a platform for their consultation they went out to members of the Communities of Health network. The results showed more diversity in responses, more relaxed and confident discussions better engaged in the process and a far higher number of responses.

This method of engaging communities and encouraging them to be active in the health of their members and to produce services can help leverage in funds from elsewhere. A February 2008 estimate by Communities of Health was that from an initial investment of £190,000 some 40 groups have spent on average £5,000 a year more on health-related activities from their own resources, due to their involvement in the Communities of Health programme.<sup>26</sup> Additionally, the accreditation scheme can have the effect of raising the profile of accredited community groups, which helps leverage in further funds from other bodies and it can increase the esteem in which they are held in the wider area.

A case study of Communities of Health's engagement with a community of white, working class men in their 50s, who are traditionally a hard group to reach with health messages, demonstrates their approach. Communities of Health ran a small focus meeting to find out who this group might listen to. They discovered that the men wouldn't listen to doctors, nurses, health promotion professionals or community development workers. However, the men were big West Ham United fans who would meet up with friends to go to the games and watch other football matches together at the pub. Having found that the club had authority for this group – that it was the centre around which they organised much of their lives – Communities of Health went to West Ham and booked one of their hospitality spaces. Here, Communities of Health held a discussion circle to get this group involved; rather than using a doctor or dietician to run a pedagogical seminar and, with the men now involved, they began running programmes with them. West Ham offered use of their pitch to the men as a reward for making the changes to their lifestyles, which provided a major incentive to this community of people to stay in the programme and sustain their changes to healthier lives.<sup>26</sup>

Communities of Health is an innovative approach that appears successful at encouraging communities to engage with, and take ownership of, health issues and mobilise communalities into health-promoting activities. Potentially there are significant ways it can promote community engagement in health beyond just mobilising communities and their members for their own health. Communities of Health could help provide a focal point for community involvement in service organisation and design beyond helping communities set up and run services. It has the potential to facilitate improved dialogue between the PCT and members of communities to ensure that any consultations on service organisation engage the community far more. It already has the trust of communities that it has worked with and is able to develop a large network of contacts in the local community. The trust it has enables communities to get far more engaged in the consultation process as it gives a greater legitimacy and assures community members. This is important as commonly identified barriers to successful consultation are beliefs like 'they're only interested in us when they want something' and 'they'll never do anything regardless of what we say' and it could also address consultation fatigue by better coordinating engagement activities.

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## 5 Barriers to the take-up of health services by communities

Similarly, Communities of Health has the ability to go to people and engage with them on their own terms. Alongside having generated trust, its work and experience with communities means it knows how to reach different groups of people and the appropriate methods to communicate health issues effectively in ways that are meaningful to them. Additionally, by discussing the issues with people in their particular community, rather than seeking their views simply as input as individuals and users, also enables the discussion to focus on what resources each community has and how these can best interact with the health services that providers and commissioners are looking to supply to ensure that the health system for the area is as efficient and effective as possible. The increased rate of and diversity in responses to the *Healthcare for London* consultation and Newham PCT, for example, has included Communities of Health as part of its bids for funding to run pilot projects. This all suggests the potential to not just to promote communities to own their own health and run activities and services, but to also contribute to community engagement in the organisation and structuring of health provision.

Communities of Health can also promote community engagement in health because its involvement with groups can demonstrate to commissioning and funding bodies that a particular organisation can be trusted to deliver services because it has done so in the Communities of Health scheme. If it is progressing towards or has attained accreditation, this demonstrates the commitment a community group has to providing health activities/services – that it has experience in

doing so and puts significant resources into this. This can help the organisation prove to funders that it is a safe bet – it knows how to deliver activities and will effectively manage its budget. All this could help contribute to a greater shift in the role of communities in health in which communities are fully engaged and empowered because of their own mobilisation for health and because funders recognise the capacity the groups have to deliver effective health activities

To directly address key factors that promote the mobilisation of communities for health identified in section 3, the style of approach we have outlined above has many strengths. It takes advantage of an existing authentic sense of community, which numerous studies have found to be a key facilitating factor. The initial engagement revolves around the perceived value of health, which promotes its relative importance to the community as a focus for action. The initial activities are designed with the community such that they best use the resources already in the community that can change behaviours. Control is given to the community and at each stage the steps are sufficiently small and attainable that the members can easily meet them. They are also provided with the necessary support to do so, which promotes the psychological empowerment and a sense of urgency among community members with regard to control of their health. In turn this empowerment and ownership of health can be a continuous process over time whereby successful small changes increase feelings of empowerment over health, encouraging members to take further steps to own their own health.

*This paper has focused on community engagement in health as a driver of improved personal health. This has mostly led to an emphasis on engaging with communities to promote healthy behaviours and lifestyles and a sense of ownership of personal health, and to community engagement as providing a way of overcoming barriers to healthy lifestyles. However, the nature of the barriers to the take-up of health services by communities also shows that effective community engagement has considerable potential to contribute to overcoming them. In developing this theme we will pay particular attention to the barriers to the take-up of maternity services and what evidence there is in this area of health improvement.*

Numerous barriers to the take-up of health services have been identified in published studies. Most of these have been qualitative studies which focus on the adoption of health services across a narrow range of people, either specific groups with low take-up rates or those with specific conditions.

However, common barriers to the take-up of health services emerge across the groups and conditions focused on in the literature. In outlining the key findings on barriers we have particularly drawn on those that have been identified regarding the take-up and accessibility of maternity services, although there are few studies among published or grey literature from which these can be extracted.

## General barriers to the take-up of health services

The general barriers to the take-up of health services by communities that can be found in the published literature are interrelated and there is a great deal of consistency across different conditions that might otherwise provide reasons to take-up health services. Although little data exist across the literature the following broad categories are consistently discernable:

1. Personal factors: personal conceptualisations of conditions, such as fear of a condition and its consequences, are associated with both personal denial of suffering from it in the face of symptoms and often tendencies to try to manage the symptoms by maintaining a limiting lifestyle rather than accessing health services.<sup>27-31</sup>
2. Social and cultural factors: the social and cultural norms and attitudes of particular communities are strongly linked to the factors above as many of the attitudes and patterns of coping were specific to the communities involved in studies.<sup>27,29</sup> Additionally, cultural insensitivity of services provided also acts as a barrier to the take-up of services.<sup>30,32</sup> Some studies have found evidence of cultural ignorance and underlying beliefs among many health professionals which could have significant impacts on the services they provide.<sup>31</sup>
3. Knowledge and awareness: unsurprisingly there were low levels of knowledge and awareness about risk factors, causes and treatments for given conditions among those failing to take-up services, this was particularly the case where conditions had low visibility within a community.<sup>27</sup> Problems for communities to obtain information in their language also limits knowledge about particular conditions and the services available to them.<sup>32</sup> As we have indicated knowledge may be a contributor to behavioural change but is insufficient to bring it about.
4. Experiences and expectations: expectations of health services formed from past experiences can prove a barrier to accessing services in the future. Having experienced culturally insensitive services and/or professionals, feelings of negative attitudes and being blamed form specific barriers to individuals. Additionally, negative experiences if prevalent in a community may have a detrimental impact on access and engagement with services by other members of the community.<sup>31</sup>

As suggested above these factors are not isolated and any strategy to address them should not view them as such. For example, culturally insensitive services may provide a direct barrier but also a wider one where they lead to negative expectations in a community. Communities communicate; personal attitudes and conceptualisations of conditions are inseparable from the social and cultural context in which an individual lives their life. Similarly, language may be a barrier to knowledge and awareness but is also a symptom of culturally insensitive service provision.

Many of these barriers form before a person has any direct contact with the health system. This suggests that to address these barriers people need to be reached where they already are, and engaged with to try to change the norms and attitudes which lead to low take-up of services. Additionally, engagement is needed to ensure that services adequately take account of cultural sensitivities so that this does not also provide a barrier to uptake. This engagement of communities for health needs to change established behaviours in both communities and service providers that impose barriers to the take-up of health services. This is to help change norms and attitudes that lead community members not to seek care when it is needed into ones that promote health and health-seeking behaviours and to ensure that the care that is available is not inappropriately designed and implemented so that communities are discouraged from accessing it.

As a recent review of the literature on access to primary healthcare concluded:

Access to primary healthcare can be viewed as the fit among personal, sociocultural, economic and system-related factors that enable individuals, families and communities to have a timely, needed, necessary, continuous, and satisfactory health service ... In a culturally and socioeconomically diverse environment, the interplay of these factors can be very complex, and access must be evaluated from many perspectives, including health needs, and the material and cultural setting of the vulnerable groups.<sup>33</sup>

## Community engagement in maternity services in developing countries

Many of the interventions we report are from developed countries and few have sought to deeply engage with and mobilise communities for maternal health issues. This has happened far more in developing countries.

A community engagement initiative in rural Malawi, in which the Health Foundation is involved with, found that although studies had suggested that women as individuals did not have a comprehensive awareness of the problems that affect them:

... this capacity can be accessed and channelled through women meeting and collectively discussing these issues ... [and that] this process enables women to clearly identify their maternal health problems, recognise their importance, and generate motivation to address them. Thus women's own perceptions of their problems could form a vital resource for communities and policymakers.<sup>34</sup>

Although there are many barriers to take-up of services in developing countries, such as Malawi, that do not exist in the same way in the UK, such as financial costs and the availability of services, there are common barriers underlying low take-up rates. As in the UK, many health promotion and education interventions directed at pregnant women had taken place at the level of health facilities with little evidence that these had effectively reached and had an impact on many communities.<sup>35</sup> The Malawian study operated on the premise that improving preventive and care-seeking behaviours, increasing knowledge and changing attitudes was necessary, rather than providing information and delivering programmes at a health facility level for which there is little evidence of effectiveness. Although long-term data on outcomes from the initiative have not yet been published, the initial study found reason to believe 'that a great deal of this capacity already exists in communities.'<sup>34</sup> The key challenge is to channel this effectively and build upon what already exists where the people are in their communities, rather than design initiatives which do not take this into account and so do not utilise the capacities and potential resources already in the communities themselves.

The Malawian initiative was based on a successful project in Nepal that sought to engage with local women's groups to identify the major maternal and newborn problems in their communities and to develop community-driven strategies to address these. The initiative had significant success with 30% fewer newborn deaths and 80% fewer maternal deaths than in control areas. The table below outlines the strategy used to engage with the women's groups.

Phase	Meeting	Aim
Introduction	1	Introduce the study to the group
	2	Discuss why mothers and newborn infants die and how the intervention will work in the community
Problem identification	3	Ascertain how women understand maternal and neonatal problems
	4	Find out about maternal and neonatal problems in the community
	5	Understand the frequency of maternal and neonatal problems and to identify strategies to obtain information in the community
Problem prioritisation	6	Share information from other women in the community and to prioritise three important maternal and neonatal health problems
Planning together	7	Discuss possible strategies for addressing the priority problems
	8	Discuss involvement of other community members in developing strategies
	9	Discuss preparation for a meeting of community members
	10	Hold a meeting involving other community members to discuss the activities of the women's groups, the priority problems identified by the groups, and possible strategies, and reach consensus

There have been successful efforts to mobilise communities for maternal health for specific at-risk communities. Two case studies, one in Nepal and one in India, sought to mobilise communities for the reproductive health and maternity service needs of married adolescents. Although the results were mixed when it came to improving knowledge of pregnancy care and delivery, they had success in other areas. The authors concluded that:

Women in the community mobilisation sites were more likely to know where maternal care services are available, more likely to receive antenatal care, to seek routine care at government services, and to have deliveries in a medical facility or with a trained medical professional ... Where the community mobilisation approach was particularly strong compared to the traditional approach was in tackling social and attitudinal changes among women, their households and their community. Community mobilisation approaches gave young women the confidence and skills to articulate their reproductive health concerns and demand services, increased young men's understanding of maternal care, improved husbands' willingness to support their wives' maternal care needs, and fostered better inter-generational communication and support between mothers-in-law and daughters-in-law. Further, in working with local health care providers, peer networks, and key adults, the community mobilization approaches enhanced the availability of quality sources for reproductive health information, counselling, and services for young married women.<sup>36</sup>

The key way in which the initiative sought to mobilise the target communities was by working largely through local organisations to produce and implement the intervention programmes, to facilitate ownership of the programmes by these groups and to promote their long-term sustainability.

## Interventions for maternal health in developed countries

An early initiative developed in Ireland involved community mothers supporting disadvantaged first time mothers. The community mothers worked under the guidance of family development nurses who provide a resource person, confidante, and monitor, in a partnership for 15–20 community mothers each supporting five to 15 first time mothers.<sup>37</sup> This programme influenced the development of similar schemes in the UK, for example the Thurrock community mothers programme in southwest Essex.<sup>38</sup> It found that by the end of the study children in the intervention group were more likely to have received all of their primary immunisations, to be read to (daily), to have played more cognitive games and were exposed to more nursery rhymes. Mothers and babies had more appropriate diets and at the end of the study mothers were less likely to be tired, feel miserable, want to stay indoors, had more positive feelings and were less likely to display their negative feelings.<sup>37</sup>

However, many similar studies elsewhere have had less success. A study in the USA which compared the effects of a lay home visiting initiative for pregnant adolescents with the effects of a more traditional clinic-based programme had mixed outcomes. The programme sought to support disadvantaged teens through the use of paraprofessional home visitors who were similar to the teens in race and socioeconomic status. The programme recruited teens and encouraged early prenatal care, provided teen mothers and their families with practical help and increased community awareness regarding infant mortality and adolescent pregnancy. When compared with a traditional clinic-based programme it reached 76% of high-risk adolescents under the age of 18 compared with 46% who were in the traditional clinic-based programme. It also showed that 53% of participants began prenatal care before the fourth month of pregnancy compared with 33% in the traditional programme. However, it had slightly lower birth-weights, with 90% of babies born at over 2.5kg compared with 94% in the traditional programme.<sup>39</sup>

An intervention in Canada targeting pregnant women with complex needs highlights the difficulties to overcoming barriers to full take-up of services by disadvantaged individuals. The study randomised women into groups receiving:

- the current standard care programme
- the current standard care programme plus nursing support
- and the current standard care programme, nursing support plus paraprofessional home visitors.

It found that completion rates did not vary by intervention and despite retention efforts a higher proportion of women with complex lives and multiple risk factors did not complete the study. The authors concluded that:

For women with complex health, lifestyle and social issues, lack of retention may reflect incongruence between their needs and the programme ... even under a universal system of care and with supplementary prenatal support, optimal birth and early childhood outcomes will not be achieved until programs and resources are implemented which better meet the needs and preferences of all women. Program planners should be aware that recruitment and retention strategies will be more effective among women with complex lives and multiple risk factors when tailored to the needs of this clientele.<sup>40</sup>

In light of the evidence on strategies to improve access to antenatal care for all women a literature review carried out by Lewisham PCT concluded that:

... it is probable that no one strategy exists to reduce low birth-weight nationally or locally. However, improving access to antenatal care for all women in Lewisham is likely to have a number of positive outcomes which will include early identification of problems which may contribute to either pre-maturity, growth restriction or both.<sup>41</sup>

The review stressed it was important that health providers consider social factors equally alongside medical factors when assessing the needs of a pregnant woman and planning with them the support they may need during and post-pregnancy. It specifically identified the importance of collaboration between professional, voluntary and service-user groups to:

- improve and enable earlier access to maternity care
- ensure that women are informed pre-conceptually or early in pregnancy of how to be as healthy as possible and that support can be accessed
- ensure systems in maternity, such as referral to smoking cessation services, are as appropriate and effective as possible
- design care pathways for women who may be at increased risk of having a low birth-weight baby including social, as well as medical, interventions.<sup>41</sup>

A systematic review of access to antenatal care supports the role of communities. It identified that community organisations which already have established links with individuals in at-risk communities have successfully mediated contact between women from socially disadvantaged groups and health service providers. It also noted that midwives working in local Sure Start programmes have facilitated multi-agency working benefiting at-risk women.<sup>31</sup>

Sure Start local programmes have improved accessibility by: offering home visits, drop-in clinics, and evening and weekend sessions; greater continuity of care; running tailored sessions for particular at-risk groups, such as teenagers, ethnic minority women, homeless women and asylum seekers; and following up people who drop out to offer additional assistance to help them attend and access the programme's services. A key way in which Sure Start local programmes have done this is by using expertise from community groups to co-produce specific services funded by the Sure Start local programme.<sup>42</sup>

A consultation by Health Link in southeast London sought to identify the main issues among local women with low rates of accessing maternity services. The key issues were:

- problems accessing basic information about pregnancy – such as on healthy diet, fetal development – or the information provided was not meaningful to them and failed to register as useful or informative
- the majority would prefer a midwife rather than a doctor to be their first point of contact and many had strong cultural preferences for female-only care
- women moving around a lot had difficulties registering with general practitioners (GPs) and many asylum seekers found it difficult to find a GP who would take them on
- continuity of care was repeatedly raised as was a desire to get to know the people involved in delivering their baby
- difficulty accessing information outside of the English language and lack of interpreters was a further barrier – for example, attending scans without an interpreter could cause misunderstandings and anxiety and made people less willing to attend
- staff had poor awareness of disability and mental health issues – many mental health service users felt stigmatised by health professionals who they perceived as not wanting them to have children at all and disabled women often had difficulties with physical access to facilities.<sup>32</sup>

The evidence suggests that engaging communities could lead to real improvements in the appropriateness of service design to help overcome some of the barriers women have in adopting maternal health services. The evidence also suggests that, although there are aspects of maternity care that necessarily require professional expertise, there are significant resources in communities that can be built on to co-produce specific maternity services to overcome many barriers.

# 6

## Recommendations

We make the following recommendations both about how the Health Foundation should explore the possibilities of community engagement to improve health but also what features of community engagement interventions have the most likelihood of contributing to success.

1. Understand and define for the purpose of the programme what you mean by 'community' and 'engagement'. There are no simple definitions but being clear about the group with which you are working and the aspects of engagement you wish to use is essential for success.
  2. Ensure the authenticity of the community with which you are working; do they identify with each other and recognise themselves as a community or group with shared activities and aspirations?
  3. Find and work with the leaders, or those with leadership potential, in that community.
  4. Do not think external people can lead but aim to enable support and sustain local leadership.
  5. Transfer the power and resources to the community. Without this change in the balance of power no co-creation can take place.
  6. Transfer of power and resources also means transfer of risk. This is a major barrier to change. You must have an effective risk recognition and management programme which is capable of absorbing and responding to unanticipated risks.\*
  7. Be realistic about your objectives. Community engagement succeeds by incremental steps.
  8. Allow time for change to happen and build sustainability into the planning from the start. Effective interventions are those which in the long term the community owns entirely for itself.
  9. Ensure that you have user-reported outcome measures. And measure them.
  10. Avoid setting provider outcome measures which may not be achievable and then by failing to achieve them define the programme as a failure.
  11. Ensure your research methodologies are capable of dealing with multi-factorial outcomes and that they are practicable with community users. There is an opportunity to design new and more effective research methods for measuring effectiveness in community engagement.
- There are particular issues for community engagement programmes with pregnant women. Being pregnant does not make you a member of a community, though it is clear from Sure Start that pregnant women and mothers of young children do gain support and advice from each other. However, women are pregnant within their other communities – family and friends, locality, faith or ethnic community – so it is particularly important to identify the authentic community with which individuals identify if a community engagement strategy is to have any hope of succeeding.

\*The authors are looking at further work on the transfer of risk in empowerment programmes.

# 7

## Background information

Contact details for networks, programmes and individuals.

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