

Engaging communities for health improvement

A scoping study for the Health Foundation

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Produced as a scoping paper by the Health Foundation in 2009.

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Executive summary

This publication was produced as a background scoping study for the Health Foundation. It was to help us to decide what we might do to strengthen community engagement in health.

The report fed into our design for the 2010/11 round of Closing the Gap, which focuses on transforming the dynamic between those who use services and those who provide them. We have published it as it may have wider use for people working in this area.

It is argued that there are at least four roles for community engagement in healthcare:

- to determine local needs and aspirations
- to promote health and reduce health inequalities
- to improve service design and the quality of care
- to strengthen local accountability.

The report reviews relevant policy, conceptual and methodological issues, summarising the evidence base and giving examples of relevant initiatives.

Good community engagement projects share the following characteristics:

- clarity of purpose
- a clearly defined community profile
- identified leadership
- specified goals
- a plan for engagement
- learning from previous experience
- a thought-through recruitment strategy
- carefully selected methods for encouraging participation
- attention to issues of payment
- a realistic timetable
- attention to capacity and resources
- training for community members and professional staff
- cultural awareness
- focus on consensus building
- · a communications strategy
- a plan for monitoring process and outcomes
- independent evaluation and dissemination of the results.

Introduction

The Health Foundation is considering making funds available to support demonstration projects that use community engagement strategies to improve health and healthcare. This scoping study aims to help clarify what the Foundation could usefully do in this field. It has the following objectives:

- to outline potential gains from community engagement in health and healthcare
- to describe current approaches to community engagement in the UK
- to outline what is known about the effectiveness of community engagement
- to identify people working in the field and other relevant experts
- to suggest a role for the Foundation in helping to build and strengthen community engagement.

A companion paper by Blomfield and Cayton outlines the theoretical background to the topic.¹ The purpose of this report is to complement their paper by focusing on practical examples and extracting general learning points to inform the Foundation's planning and future work.

Terminology and scope

Various terms are used to describe the phenomenon of involving groups of people in tackling issues of relevance to their local communities. These include community development, community mobilisation, community empowerment, community involvement and community engagement. Differing views on which of these terms is most acceptable exist. For the purposes of this report I have decided to follow the lead set by some key players – the Improvement Foundation, Turning Point and the National Institute for Health and Clinical Excellence (NICE) – all of whom use the term community engagement.

The Shorter Oxford English Dictionary (OED)² gives a number of definitions for 'community': 'an organized political, municipal, or social body'; 'a body of people living in the same locality'; 'a body of people having religion, profession etc in common'; and 'a sense of common identity'. The term encompasses not just geographical communities, but also people sharing a common identity by reason of their faith, ethnic origin, occupation, organisational affiliation, health status, disability and so on.

The OED is not quite so helpful in relation to 'engagement' because the term has numerous meanings, including some quite contradictory ones, for example, 'bind by a promise of marriage'; 'enter into combat'; 'provide occupation for'; and 'come into contact with or fit into a corresponding part so as to prevent or transmit movement'. The most relevant definitions for our purposes are 'attract and hold fast a person's attention'; 'enter upon or occupy oneself in an activity, interest, etc'. Thus the act of engagement can be transitive and intransitive, active or passive, done by or done to. In respect of healthcare, NHS organisations might

want to attract the attention of local communities, and members of local communities may decide to get actively involved with them. So engagement seems a satisfactory term because it can be used to describe the motivations and actions of all parties.

There are divided views on the appropriate focus for community engagement. Some people advocate an exclusive focus on working with groups of disadvantaged people in specific locations, such as a housing estate. This builds on a long tradition of community development work espousing a holistic or social model to empower communities. Community members are encouraged to set the agenda to tackle the issues that they deem most important. Of course, these issues may not necessarily involve health or healthcare directly, but helping people to take action to improve their lives may strengthen community cohesion or social capital which may in turn have an impact on health.

Healthcare provider organisations, on the other hand, tend to see their responsibilities to engage with their local communities somewhat differently. Their concern is to respond to the healthcare needs of people living in their catchment area and to improve their services by learning from the experience of service users, so they cast a wider geographical net. Their main contacts tend to be with representatives of organised community groups or individual service users, with a specific focus on their health and social care needs and experiences. This report encompasses both these perspectives.

A Californian organisation has produced a useful conceptual framework for community engagement in health using the model of a ladder of participation.³

Ladder of community participation

Health organisation initiates and directs action

Takes the lead and directs community to act

Health organisation informs and educates community

Shares information with the community

Limited community input/consultation

Selects specific, periodic community input

Comprehensive community consultation

Solicits ongoing, in-depth community input

Bridging

Community members serve as conduits of information and feedback to and from the organisation

Power-sharing

Community and health organisations define and solve problems together

Community initiates and directs action

Community makes decisions and shares information with the health organisation

The authors warn against the use of this framework as a hierarchy where the first rung of the ladder is seen as the least desirable. Instead it is conceived as a planning tool to help organisations decide where to start the process of community engagement and where they hope to get to. Goals and starting points will differ according to the context and capacity in the local community.

Policy context

The UK policy pendulum tends to oscillate between initiatives designed to strengthen command from the centre and those that aim to encourage local initiatives. At present it appears to be swinging in the direction of local community engagement. This is evident in recent policy documents from each of the four UK jurisdictions - England,⁴ Scotland,⁵ Wales⁶ and Northern Ireland.7

Recent White Papers and other policy documents have emphasised the need to strengthen local communities by empowering people to influence the decisions that affect them. For example, the 2008 White Paper, Communities in control: real people, real power, included the following statement:

We want to shift power, influence and responsibility away from existing centres of power into the hands of communities and individual citizens. This is because we believe that they can take difficult decisions and solve complex problems for themselves. The state's role should be to set national priorities and minimum standards, while providing support and a fair distribution of resources.8

Historically, UK healthcare policy has stressed the national, universal nature of the NHS, but this is undergoing some modification as the impact of devolution opens up differences in emphasis between the four UK nations. Within England there is now an attempt to encourage greater devolution and localism while maintaining universal entitlements and a strong steer from the centre. This sentiment was encapsulated in Lord Darzi's NHS Next Stage Review:

The proposals will allow NHS services everywhere to reflect the needs of their local communities ... The NHS should be universal, but that does not mean that it should be uniform. Clear minimum standards and entitlements will exist, but not a one size fits all model.4

Public and patient involvement is seen as central to this easing of central command and control. The NHS Constitution includes the following commitment to citizens:

You have the right to be involved, directly or through representatives, in the planning of healthcare services, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services.⁹

Community engagement in health

The main responsibility for consulting and engaging with local communities about their health and healthcare needs is laid firmly on the shoulders of primary care trust (PCT) commissioners. The NHS operating framework for 2008/9 says:

Commissioners have a responsibility to ensure that their local communities have the opportunity to be fully engaged in the decisions they take, and to take greater efforts to communicate what they are doing and why to their populations. 10

In recent years the Labour government introduced a number of specific initiatives and policy instruments designed to focus attention on community engagement:

- PCTs, NHS trusts, strategic health authorities (SHAs) and local authorities have a statutory duty to involve patients and the public by consulting and informing them¹¹
- World Class Commissioning emphasises PCTs' responsibilities to provide local leadership for the NHS, to work with community partners and engage with public.¹²

A great deal is expected of commissioners – both PCTs and practice-based commissioners – in respect of engagement with their local communities.¹² They are expected to make careful assessments of local needs, use their commissioning power to ensure that local services provide high-quality care and that they are responsive, and they must conduct their business in a transparent manner being held accountable to local communities for their decisions.

NHS commissioners must work with local authorities, voluntary organisations and other agencies in local strategic partnerships to develop Local Area Agreements on how to improve the health and wellbeing of local communities.¹³

• NHS foundation trusts are expected to engage with their local communities and recruit local people as members who can elect trust governors.14

- All local authorities must now have a Health Overview and Scrutiny Committee who must be consulted when major changes are planned.¹⁵
- Since September 2008 each local authority has been required to establish a Local Involvement Network (LINk) to represent the views of local people on health and social care.¹⁶

The goal is to ensure that the NHS is more locally accountable and shaped by the people who use it. NHS organisations are expected to forge new relationships, both internally and externally, in the hope that user involvement will move from the margins to the mainstream of every organisation that is responsible for planning, commissioning and providing health services.17

Doing the job properly involves keeping in touch with the views of all local residents, not just the small minority who turn out for public meetings or volunteer to sit on committees. In particular commissioners must reach out to minority or disadvantaged groups whose views are seldom heard and often ignored. This is no easy task. A recent survey found that many PCTs were struggling to engage patients and the public in commissioning.¹⁸ Many said they lacked the skills, experience and confidence to do this effectively. If they are to prioritise this as they must, PCT staff will need help in the form of budgets, leadership, techniques and technology.

The Labour government's goals appeared to be in tune with public sentiment, at least in theory. The vast majority of people – 90% in one survey¹⁹ - think local people should have a say in how the NHS is run, and they expect to be consulted. However, only 22% say they'd like to be actively involved in planning or delivering services,20 and in practice only 1-2% do get actively involved when invited to do so.21 So engaging with local communities is more difficult than it may at first appear.

Review methods

The scoping study draws on an extensive web search using terms such as 'community engagement', 'community development', 'community mobilisation', 'community involvement', 'community empowerment', 'patient and public involvement' 'health', 'healthcare' and 'commissioning' (see below for a discussion of the terminology).

I have also followed up leads in reports and journal articles, but in the short time available it was not possible to carry out a systematic review of the extensive academic literature. A list of the organisations whose websites were identified by this means is included in the appendix.

Scrutinising websites to identify practical examples and tease out the learning from them has not been an easy task and I am acutely conscious of having only scratched the surface. There are, of course, many thousands of community initiatives up and down the country. Many of these have not published their experiences and many do not even have websites. Those engaging specifically with health and healthcare issues are the subset that I have tried to find, but it is very possible that many good examples have been missed. I hope readers of the report will draw my attention to major omissions so these can be rectified.

The report includes brief descriptions of a few projects selected to illustrate the variety of approaches. Many of the other projects listed in the appendix could have served equally well as case studies, but a description of each would have made

the report too long and unwieldy. Instead I have tried to incorporate themes from their experience in the general learning points outlined in the conclusions.

There are at least four reasons why community engagement in health and social care is seen as worthwhile:

- to determine local needs and aspirations
- to promote health and reduce inequalities
- to improve service design and the quality of care
- to strengthen local accountability.

The following sections elaborate on these four objectives, briefly summarising the evidence base and giving examples of relevant initiatives. The report concludes with a consideration of the characteristics of a successful community engagement project.

OBJECTIVE 1:

Determining local needs and aspirations

Health needs assessment has been defined as 'a systematic method for reviewing the health issues facing a population, leading to agreed priorities and resource allocation that will improve health and reduce inequalities'.22 It is the first step in a commissioning cycle that includes assessing needs, reviewing services and identifying gaps, analysing health risks, deciding on priorities, determining strategic options, implementing contracts, developing providers and managing provider performance.

There is nothing new about needs assessment public health departments have been producing statistical analyses and epidemiological profiles for many years and these have informed commissioning plans and local health improvement strategies. Nowadays, however, there is an expectation that the statistical analyses and options appraisals will be accompanied by, and take account of, extensive consultation with local people. Commissioners are expected to ensure that their local strategies are built on an in-depth understanding of the needs and aspirations of all sections of the local community.

There is evidence that World Class Commissioning has helped to drive change in the organisational culture of PCTs and boost the status of patient and public engagement, but most PCTs are not yet in a position to demonstrate whether and how engagement with local communities has influenced their decisions.¹⁸ Furthermore, there is as yet no evidence that this form of engagement leads to improvements in health outcomes.

Consulting local people

The best local consultations are carefully planned and involve a number of different methods to ensure that the diversity of perspectives is understood and that all sections of the community have an opportunity to give their views. Feeding back the results once the consultation process is complete is equally important and should be programmed in from the start, with attention paid to how these will be disseminated to interested parties.

example Liverpool's Big Health Debate

In the process of developing its outside-of-hospitals strategy, Liverpool PCT organised a threestage community consultation, beginning in July 2006. The first phase of engagement took the form of an online questionnaire and ballot-box paper questionnaire, accessible from the Big Health Debate website, surveys in general practitioner (GP) surgeries and a 24-hour freephone line, which elicited 10,000 responses.

The PCT made visits to more than The views of people from 40 community groups and then organised a one-day deliberative event for 150 participants (100 members of the public and 50 healthcare professionals and representatives from community groups). This Big Health Debate Live! was held on 30 October 2006. This introduced participants to the case for change and provided an initial response to the concepts involved.

A further survey of more than 600 regular users of primary care services provided additional information supplemented by a multidisciplinary workshop for health and social care staff and three road shows for health professionals.

specific priority groups were sought by means of 13 specially organised discussion groups. These included people from the Chinese, Sikh, Somali and Yemeni communities, homeless men, Irish travellers, people with sensory disabilities and mental health service users.

The conclusions of the consultation, which had involved a total of 11,000 people, were incorporated into the PCT's health strategy. An update event was organised in October 2007 to revisit the strategy and inform people about the actions that had ensued.

Community audit

Some projects are now going beyond traditional methods of professionally-led consultation to involve local community members in leading the process. Turning Point, which has been working on engagement in social care for some years, is promoting a new concept called Connected Care. The idea originated from research carried out by Turning Point and the Institute for Public Policy Research (IPPR) in 2004. Connected Care is Turning Point's vision for integrating health, housing and social care in the most deprived communities, with the community playing a central role in the design and delivery of those services.

The aim of Connected Care is to provide a framework to help commissioners that:

- prioritises integrated services that meet the needs of individuals
- enables local people to design and deliver their own services
- provides better access to services for everyone in the community
- engages those who cannot or will not use services
- achieves greater diversity of provision and draws upon the strengths of the third sector
- fosters the development of a skilled, innovative and professionally coordinated health and social care workforce.

The Connected Care programme is promoting community audits in which local people are recruited to find out what other local people think about their health needs and aspirations. The idea is to support local people in developing their own needs assessment or community profile. The community audit is not just an information gathering tool, but also the first stage in engaging the community.

example Connected Care in Hartlepool

The first national Connected Care pilot took place in Owton Ward in Hartlepool. The ward is ranked as one of the most deprived nationally, with most residents living in social housing. However, it has a well-developed community and voluntary sector with strong residents' associations and organisations that are delivering a number of services locally.

The first stage of the project involved a community audit to determine the needs and aspirations of local residents and their perceptions of current services. Auditors were recruited from the local community and trained to carry out the audit. They were supported by Turning Point, Hartlepool PCT and by academics from the University of Central Lancashire (UCLan). The process was evaluated by researchers from Durham University.

A local community organisation was selected to recruit, coordinate and host the team of nine community auditors recruited from the local community. The training package, which was delivered by UCLan, covered research methods, interview techniques, facilitating focus groups and

recording and analysing data. The workshops were accredited giving the community auditors the opportunity to gain a university qualification.

The audit involved an initial survey, followed by one-to-one interviews, focus groups and a 'Have your say' event. In total, 251 people participated in the process. A detailed report of the audit was published in January 2006. This included the main findings presented thematically under five headings: information, choice, access to services, continuity and coordination between services, workforce and quality provision.

Durham University's evaluation pointed to a number of important issues and learning:

- recruitment of community members proved quite difficult; it was undertaken by the host organisation and drew largely on existing community association staff and volunteers
- payment of volunteers can be a tricky issue and a flexible approach was adopted
- team-working and individual's needs and capacity required careful handling

- qualitative research methods were found to work best
- a supplementary professionally-led process was undertaken to provide the perspectives of harder to reach groups and to deliver the report within the desired timescale
- the audit team was involved in data gathering but not substantially involved in the process of analysis and report writing
- the host organisation and audit team were central to the organisation of the launch event and presentation of findings which helped to reinforce community ownership
- the existence of a range of champions, including policy makers, professionals, community organisations and their members, was important
- training should focus not only on research design and methods but also on the concept of Connected Care itself so that everyone involved understands the bigger picture.²³

OBJECTIVE 2:

Promoting health and reducing inequalities

Most of the national and local organisations with a specific focus on community engagement in health list improving health and reducing inequalities among their goals. This is also a high priority for the government. The Department of Health (DH) has set out a strategy for improving public health which includes action to achieve the following goals:

- tackling inequalities in health
- reducing the numbers of people who smoke
- tackling obesity
- improving sexual health
- improving mental health and wellbeing
- reducing harm and encouraging sensible drinking
- helping children and young people to lead healthy lives
- promoting health and active life among older people.²⁴

Community engagement is seen as an essential component of this strategy, as well as the provision of individual advice, education, mass marketing and secondary prevention activities, such as screening.

Social capital and co-production

The theoretical underpinning for collective approaches to health promotion is connected to ideas about building community cohesion or social capital. Social capital is a way of describing the norms, networks and interactions (sense of belonging) that facilitate collective action. Many commentators consider it essential for economic development and for fostering inclusion and social cohesion. Many believe it holds the key to understanding and tackling social inequalities in health.²⁵

There is also a belief that co-production (involving lay people directly in working alongside professionals to create and deliver services) will have more effect on people's health and wellbeing than merely informing, advising or consulting them.²⁶

The theories are appealing, but testing them is extremely difficult. Few studies have compared the effectiveness of community-based approaches against other methods of health promotion, for example national legislation, mass communication or direct provision of lifestyle advice.

Health promotion in minority groups

Some of the most successful projects have emerged from communities that have a clear identity and focused goals rooted in an understanding of specific health needs. Many of these involve minority ethnic groups.

example Apnee Sehat

Apnee Sehat (our health) is a social enterprise pathfinder project that is tailoring lifestyle programmes to meet the needs of Britain's South Asian community. The project began in 2005 in South Warwickshire with the support of South Warwickshire hospitals and the PCT, the National Diabetes Support Team and the DH Equality Director, Surinder Sharma, in response to a community request for lifestyle support.

The project, which has involved a multidisciplinary effort by a number of organisations across traditional boundaries, has achieved national recognition for its innovative approach in supporting preventive healthcare for this target 'high risk', 'hard to reach' group.

Based in Coventry, Apnee Sehat currently works with communities in Royal Leamington Spa, Warwickshire and Coventry to raise awareness and screen for vascular disease risk so as to reduce the danger of strokes, heart attacks and diabetes. They encourage lifestyle changes through the provision of education, self-care and screening programmes. They educate the community about risk factors pertinent to their genetic predisposition and lifestyle choices, and they deliver services, including community specialist clinics, that are culturally sensitive, easily understandable and transferable.

Narrowing the gap

There is evidence from independent studies that carefully targeted health promotion programmes and social marketing can reduce health risks in certain groups, but there is very little evidence on the extent to which they reduce health inequalities between groups. ²⁷⁻⁵⁹ Approaches that help communities to work as equal partners, or delegate some power to them, may lead to more positive health outcomes, but the evidence, as yet, is not strong. ²⁶ The Healthy Communities Collaborative (see p 21) certainly looks promising, but independent evaluation is required.

This whole area was recently reviewed by NICE. The resulting guidance lists the following recommendations for effective community engagement to promote health:

- coordinate implementation of relevant initiatives
- commit to long-term investment
- foster openness to organisational and cultural change
- be willing to share power, as appropriate, between statutory and community organisations
- develop trust and respect among all those involved
- support appropriate training and development for those working with the community including members of that community
- introduce formal mechanisms which endorse partnership working
- support effective implementation of area-based initiatives
- recruit community members to act as agents of change
- organise community workshops and events
- *employ experienced consultants*
- develop and implement an evaluation framework.²⁶

example Health Action Zones

One of the most extensive and ambitious attempts to develop community engagement initiatives across the country was the Health Action Zone (HAZ) programme launched by the government in 1997. Twenty-six HAZs were set up as seven-year pilot projects. They were meant not only to improve health outcomes and reduce health inequalities, but also to act as trailblazers for new ways of working at a local level.⁶⁰ The outcome of all this effort was mixed. Many of the HAZs succeeded in focusing local attention on health improvement and inequalities, but there was disappointingly little evidence of an impact on reducing the health gap between social groups.

The national HAZ evaluation pointed to a number of factors that had affected their progress:

- changes in national policy
- changes in HAZ priorities and uncertainties about their future
- variable understanding of the problem of health inequalities
- changes in local organisational boundaries and lack of coterminosity of agencies
- the nature of local labour markets leading to high staff turnover in some areas and inflexibility in others
- the key role played by specific individuals in promoting or inhibiting the work.⁶⁰

One of the perennial problems in policy development is that previous initiatives – even major ones such as the HAZ programme – tend to get forgotten when a new one appears. But much can be learnt from the experience of programmes such as this, and it is especially helpful that it was independently evaluated. Any organisation wanting to engage local people in health improvement activities would do well to study the HAZ experience.

Measuring impact

Many community engagement approaches to health promotion appear promising but they lack adequate evaluation. This is a serious problem because all strategies to tackle health inequalities need to be based on rigorous evidence if the government's goals are to be achieved.

Sir Michael Marmot's recently published review of progress in tackling health inequalities over 10 years since the publication of the Acheson Inquiry provides a great deal of evidence of a persistent gap between rich and poor in relation to a plethora of health indicators. 61 The report takes an epidemiological approach and has very little to say about community engagement. It is strange, in view of the general enthusiasm for community approaches, that they have been overlooked in this major review but this may be a reflection of the lack of published evidence on effectiveness and impact.

example Healthy Communities Collaborative

The Improvement Foundation's **Healthy Communities** Collaborative (HCC) has made strenuous efforts to measure the impact of its work. HCC aims to combine quality improvement and community development in the hope that this will both build social capital and reduce health inequalities. The programme has grown from an initial three sites in 2002 and now includes more than 50 projects involving a wide range of partners.

The HCC uses the collaborative model led by local people. They are supported and enabled to improve their communities through partnerships with statutory and voluntary organisations. The focus of the work is to make positive changes in health and wellbeing. To achieve this, all participants are taught how to use tools to effect change. Outcomes include improvement in a specific topic area and benefits to the community itself, which ignites the desire to affect other topics.

Key features of the HCC are as follows:

• An expert reference group develops 'change principles' that when followed will secure the greatest gain in the chosen topic.

- Learning workshops are held during which the teams learn of best practice on the topic and are supported to understand this in a local context.
- Action periods take place where they meet regularly and use the Plan-Do-Study-Act (PDSA) learning cycles to test ideas for change and improvement. Teams are encouraged to test ideas on a small scale and continue taking small sequential steps.
- Improvement tracking, with data collected monthly, occurs.

Putting these key features together in a framework makes it easy for teams to get started, achieve results rapidly and demonstrate success. They aim to bring about a creative environment in which testing ideas and measuring improvement become the norm.

HCC has achieved some notable successes.⁶² An early focus of the programme was on reducing falls in older people. In three sites, covering a population of 150,000, there has been a 32% reduction in falls (730 fewer falls over two years). The HCC estimate that

this amounts to a reduction in hospital costs of £1.2m, in ambulance costs of £120,000 and in the costs of residential social care by £2.75m.

There was also evidence of an improvement in social capital within the communities involved in the reducing falls programme, resulting in:

- 12% increase in people's perception of whether their area was a good place to live
- 12% increase in people's perception of whether individuals show concern for each other
- 22% increase in the number of people who knew where to get advice about falls
- 48% increase among participants in the proportion who thought they could change and improve things in their communities.

Current projects include community-based programmes to improve diet and nutrition and reduce obesity; to improve early identification and assessment of people at increased risk of cardiovascular disease; and to raise awareness and promote earlier identification of cancer.

OBJECTIVE 3:

Improving service design and the quality of care

Many community engagement projects have service improvement and redesign as a central focus. Since almost everyone uses the health service on a fairly regular basis, most discussions about health needs inevitably come round to people's concerns about the quality of local service provision and gaps in the availability of particular services.

Engaging local people and service users in quality improvement requires considerable effort on the part of NHS organisations. In general, most people do not come forward to talk about their experiences or give their views without a great deal of encouragement.

Commissioners reaching out

There is some evidence that most members of the public do not know how they could get involved in shaping local services if they wanted to. In the Healthcare Commission's 2005 survey of users of local health services in 100 PCTs, only 3,597 out of 34,494 respondents (10%) said they knew how to get involved in making decisions about local health services (for example, by attending meetings or joining a local patients group); 17% said they were not sure and the overwhelming majority (73%) said they did not know how to get involved.⁶³

This highlights the need to improve communications and to focus efforts on actively encouraging people to get involved. It is possible that a more concerted push on the part of healthcare organisations will lead to an increase in the numbers of people who volunteer, but staff will need to be very clear about what role they expect them to play and how they will welcome and support service users wanting to participate.

Some successful projects have stemmed from commissioners' desire to understand and reflect the diverse needs of their local communities. In certain cases these have been reflected in commissioning plans, leading to changes in the pattern of service provision. Once again, however, we lack the evidence that these changes have led to improved outcomes.

example NHS Tower Hamlets

The PCT in Tower Hamlets has led the way in responding to the needs of its community. NHS Tower Hamlets has particular challenges when it comes to engaging with its local population: nearly half of the population is from non-white ethnic communities, one third originates from Bangladesh and there are also significant Vietnamese, Chinese and Jewish communities; at least 78 different languages are spoken. They have made great efforts to engage with local community members and in 2009 the PCT was rated first in London and

second nationally for its work on improving health services.

When reviewing services for people with diabetes it recognised that it needed to reach out to the Bangladeshi population because diabetes is more prevalent among South Asians than in the population as a whole. The PCT has employed two multilingual link workers as lay diabetes educators. They run education classes in Bengali within the diabetes centre, GP practices and community settings, greatly enhancing the service provided.

They also opened a second retinal screening service at Spitalfields Health Centre, chosen because it was more convenient than the existing centre for many of the Bangladeshi population. The opening of this new service was accompanied by an intensive publicity campaign within the Bangladeshi community using contacts in local mosques, community centres, voluntary organisations and shops, as well as poster campaigns.

OBJECTIVE 4:

Strengthening local accountability

New models of service provision

Another important development in Tower Hamlets has produced an entirely new model of service provision. The Bromley by Bow Centre is frequently cited as one of the most innovative examples of a community-based facility with a new type of health centre at its core.

example Bromley by Bow Centre

The Bromley by Bow Centre is an innovative community organisation in East London. Working in one of the most deprived wards in the UK, it supports families, young people and adults of all ages to learn new skills, improve their health and wellbeing, find employment and develop the confidence to achieve their goals and transform their lives.

The centre was established in 1984 when Reverend Andrew Mawson became the Minister of the local United Reformed Church. He found a dwindling, elderly congregation and recognised that if the church was to survive it needed to adopt a different approach. He persuaded his congregation to open the building up to the local community. Local artists became involved and agreed to teach their skills in return for rent-free workshops, the church started a nursery and was used for various events, from Eid and May Day celebrations to the Chinese New

Year and a harvest supper. As a result, the building became a focal point and meeting place for the entire community, laying the foundations for the centre's subsequent development.

As it grew beyond the church, the Bromley by Bow Centre developed as a secular organisation in its own right and became a registered charity in 1994. It then expanded rapidly, with the biggest change happening in 1997 with the opening of the health centre. The entire site kept evolving, with new buildings added to existing ones and the park restored as an asset for the entire community.

Today, the Bromley by Bow Centre is an organisation with a turnover of more than £3m a year and in excess of 100 staff. It is the third largest provider of adult education in the Borough of Tower Hamlets and has launched numerous spin-off

businesses. They centre works with 2,000 people each week, including families, young people, vulnerable adults and the elderly.

A GP partnership lies at the heart of the centre providing a vital service to the local community. Together they have developed the healthy living centre model which has become a national exemplar for an entrepreneurial approach to integrated healthcare. The GPs rent the Healthy Living Centre premises from the centre and deliver primary healthcare to over 5,000 patients in this community and a further 7,000 patients from the XX Place practice in Stepney. The practice is fully integrated with centre activities at every level, from senior management to project delivery. The model hinges on a common approach to service delivery which focuses on the widest possible network of support and intervention for patients.

Public accountability for commissioning decisions is very important because PCTs now control the major part of the NHS budget and they are required to consult, involve and inform local people in respect of their commissioning decisions. There are three main domains of public services for which public accountability is felt to be essential:

- financial accountability value for money
- accountability for performance quality of services
- political and democratic accountability responsiveness to service users.64

The traditional model of public accountability was upwards to parliament or Whitehall, but nowadays this is clearly insufficient. Allowing the electorate the chance to express their views at the ballot box once every four or five years is not enough to ensure that public services respond adequately to people's needs and desires, so the DH is trying to strengthen healthcare commissioning and increase its responsiveness by requiring commissioners to consult with, and report back to, local communities.

Recognition that the centrally funded and directed NHS suffers from a democratic deficit has led to calls for new forms of local participation. The renewed emphasis on community engagement is part of this shift in thinking. Mechanisms such as Local Strategic Partnerships, Local Area Agreements and Comprehensive Area Assessments, coupled with the legal duty to engage with and consult local people, have been introduced in an attempt to ensure that services retain public support and respond to local perceptions of needs and priorities.

Commissioners are supposed to be held to account for the quality of services delivered to local residents. Quality metrics and other performance indicators are to be published in the form of quality accounts and PCTs must also publish prospectuses setting out what they have done to address any problems identified. The whole system is overseen by a complex mix of organisations, including SHAs, the Care Quality Commission, Monitor, the Audit Commission and professional regulators such as the General Medical Council, the Nursing and Midwifery Council and the Health Professions Council.

Scrutinising services

With this proliferation of top-down supervisory bodies it is no wonder that PCTs struggle to look outwards to their local communities. The structure of regulation seems designed to foster conformity with centrally-derived rules and targets rather than flexibility and responsiveness to diverse local populations. The establishment of Local Involvement Networks (LINks) and Overview and Scrutiny Committees (OSCs) is meant to encourage them to do this but these bodies are relatively immature and still finding their feet.

The Centre for Public Scrutiny argues that effective scrutiny should:

- provide a 'critical friend' challenge to executive policy makers and decision makers
- enable and voice the concerns of the public
- be carried out by independent-minded people
- drive improvements in public services. 64

This is an area that LINks and OSCs can work together to ensure community scrutiny and accountability.

example Partnership between LINks and OSCs

The NHS Centre for Involvement (NCI) has published a document outlining the potential for collaboration between LINks and OSCs as a way of strengthening local accountability. ⁶⁵ Both organisations are expected to play the 'critical friend' role and both have a legal right to ask for information about the performance of health and social care organisations and to expect a response to any criticisms or recommendations, so working together should make sense.

The NCI argues that since LINks and OSCs have limited resources to support their work, they should collaborate to identify local priorities and explore issues in more detail before making recommendations to health and social care organisations. There are signs that this collaboration is already beginning to develop in some areas. For example, in Bristol, Cumbria, East Sussex, Gateshead, Hull, Isles of Scilly, London Borough of Merton, Newcastle, Northamptonshire, Nottingham, Sandwell, Somerset

and Stockport, LINks and OSCs have agreed protocols for joint working involving a variety of options for developing partnerships. The organisations have different powers and remits and different types of members and support arrangements, so they are likely to have different viewpoints on some local issues and in some cases priorities may conflict. In many cases, however, joint working ought to provide the basis for stronger local accountability.

The NCI warns that progress to date has been patchy; some areas have developed close and effective partnerships, but in others progress has been slow. They have developed the following checklist to guide good practice in this area:

- understand the responsibilities, roles and structure of OSCs and LINks in the area
- work with local health and social care organisations to keep up to date with what they are doing and what their priorities are

- OSCs and LINks should communicate regularly, both formally and informally
- agree 'rules of engagement' or protocols and review them regularly
- encourage support staff to communicate with each other on a regular basis
- agree joint planning meetings or events to identify local priorities
- be realistic about setting priorities, identifying those that can be addressed or influenced and those that cannot
- focus on outcomes not just processes
- build in time within work programmes to address issues that may arise throughout the year
- agree at times to differ the roles are complementary not competitive.

Deciding on spending priorities

Taking decisions about the quality, availability, design and funding of local services can lead commissioners into controversial waters, especially when this involves denying services to particular groups or individuals. Judicial reviews, and the threat of them, are becoming increasingly frequent. PCTs and other commissioning bodies must develop coherent principles to guide their decision making. These will have most legitimacy when they are developed with the active involvement of local people and the rationale for decisions is communicated effectively. This form of community engagement, sometimes referred to as deliberative democracy, is relatively underdeveloped as yet, but it is likely to come to the fore as we enter a period of funding squeeze over the next couple of years.

There are several theories on what ought to be done when tackling sensitive issues such as priority setting or rationing of healthcare. One of the most useful, 'accountability for reasonableness', suggests that decision makers should pay attention to four conditions or principles to maximise the chance of achieving local buy-in:

• Publicity – the public has access to both the decisions and the rationales for priority setting.

- Reasonableness the rationales should be acceptable by 'fair-minded' people as a way of providing value for money while meeting health needs for a defined population under resource constraints.
- Appeals there must be ways to challenge decisions and resolve disputes, and these must offer an opportunity to revise decisions, for example in the light of new evidence.
- Enforcement action to ensure the first three conditions are met through either voluntary or mandatory regulation.⁶⁶

Various techniques can be used to secure active engagement of local people in priority setting, including citizen's panels, citizen's juries, neighbourhood committees and deliberative forums. There is some evidence that these can lead to improved knowledge and understanding among those directly involved and the results of their deliberations can be influential, but they are often costly and time consuming to organise. Whether the benefits justify the costs requires further research, but their usefulness depends in large part on what local policy-making bodies do with the resulting recommendations.

example Oxfordshire PCT Priorities Forum

PCTs are under a statutory duty to promote the health of the local community. They are also under a duty not to exceed their annual financial allocation. These legal requirements mean that, from time to time, difficult choices have to be made. The Oxfordshire PCT Priorities Forum makes recommendations about which drugs and treatments should be low and which should be high priority. It provides an advisory service to the Oxfordshire PCT's clinical executive team to help them make difficult decisions on prioritisation. The forum includes lay members of the local community as well as clinicians and managers.

The forum is supported by the South Central Priorities Support Unit which provides an independent service to all PCTs in the region. They undertake literature searches and produce evidence-based reviews, which are then submitted to an individual PCT's priorities committees.

The South Central Priority Setting Unit and the Oxfordshire Priorities Forum have developed an ethical framework to guide their decision making. This gives priority to evidence of clinical and cost effectiveness, equity, healthcare need and capacity to benefit, and patient choice. The framework was discussed with local people, agreed

by the PCT's board and published on their website.

Oxfordshire PCT uses the ethical framework together with the evidence-based reviews to aid their deliberations when considering whether to fund referrals for treatments that are exceptions to previously agreed policy and not covered by contracts or NICE guidance. This does not eliminate public protests when individuals are denied treatment that they believe will be beneficial, but it does enable the PCT to demonstrate that its procedures conform to the requirements of accountability for reasonableness.

Engagement methods

A wide range of methods has been advocated for securing community engagement – from informing and consulting through to full community control.

There is no shortage of techniques and case studies but, in general, we lack a critical literature and sufficiently rigorous evaluations to provide definitive guidance on which techniques are most appropriate in each and every circumstance. Nevertheless, there is much to be learnt from the experience of those who have tried it and several specialist organisations, including Involve and the NCI, have produced helpful guidance.

Working with communities

Good involvement practice is described as being continuous, inclusive, well-informed, fit for purpose, transparent, influential, reciprocal and proportionate. However, this is much easier said than done. Local authorities have had longer and broader experience of doing it than healthcare organisations. Drawing on this experience, Involve's guidance suggests that effective engagement with local communities means paying attention to the following:

- understanding the local community
- tapping into existing networks
- learning from informal relationships
- targeting under-represented groups
- allowing people responsible for strategy and delivery to work together
- taking an action-focused approach
- maintaining a long-term perspective
- understanding that the method is only part of the story – purpose + context + people + method = outcome
- setting clear objectives
- bringing people together around issues that connect them
- adapting to local circumstances and context
- listening and learning
- having good communications and visible results
- supporting participants to take part (information, logistics, incentives)
- ensuring diversity of voices
- capturing and sharing learning to improve practice.⁷⁰

Engaging service users

The Involve guidelines are useful for organisations, such as local authorities, with a broad remit that can allow local communities to determine priorities, but commissioners and providers of healthcare often have a more specific requirement for community engagement with a clear focus on service improvement. Some healthcare provider organisations have made efforts to involve users of their services in their quality improvement efforts and their experience is instructive. Evaluative studies have suggested that effective user involvement in this context requires:

- adequate resources
- a facilitative organisational culture
- good quality information
- professional champions
- staff training (by users)
- user training (by staff)
- payment and/or employment of users (sometimes)
- representative structures
- recognition and understanding of power differentials
- acknowledgement of, and sensitivity to, likelihood of mental distress
- high-quality, meaningful and measurable involvement processes. 26,71-73

This can be quite challenging and few healthcare professionals have received relevant training. In addition many of those with responsibility for patient and public involvement feel unsupported.⁷⁴ And it is not as if there's a great clamour on the part of service users to get directly involved. Many organisations struggle to get people to join patient groups or attend meetings.

A key issue is the extent to which active sustained involvement is essential, and what it is realistic to expect people to do. Most service users who actively participate in planning and service development value the experience, but only a tiny minority get involved in this way. 26,67,68 These people undoubtedly have a valuable contribution to make, but they cannot be expected to represent the diversity of views in the larger population of service users. For example, it may be unrealistic to expect busy people to give up much time to work with staff to improve customer service and care delivery or be consulted about complex service developments that do not affect them directly. These people may, however, be willing to give their views and they are likely to welcome information and feedback on what organisations are doing to improve services. The views of active participants need to be balanced by information gathered from people who are unable or unwilling to get directly involved but are nevertheless willing to give their views in surveys, focus groups or by other means.

Tools and techniques

A wide range of tools and techniques have been developed to assist in working with groups of people. Some of the most commonly used participatory methods are listed below.

For a more detailed description of each method, its strengths and weaknesses and when it should be used, see www.peopleandparticipation.net.

Participatory methods

Techniques for use with large groups	Techniques for use with smaller groups	Online techniques for use with those who have internet access
21st-century town meeting	Appreciative inquiry	Blogs
Area forums	Citizen advisory groups	ePanels
Citizen's summit	Citizen's panels	Online consultations
Community development	Citizen's jury	Online forum
Consensus conference	Café consultation	Twitter
Deliberative polling	Customer journey mapping	Webcasting
Fun days/festivals	Deliberative workshops	Web chat
Future search	Delphi survey	Wiki
Open space events	Focus groups	
Opinion polls	Mystery shopping	
Surveys	Participatory appraisal	
	Participatory strategic planning	
	Planning for real	
	User panels	

Principles for effective involvement

The NCI at the University of Warwick works with NHS organisations to help them develop patient and public involvement programmes. Their organisational development programme provides strategic and practical help to trusts and gathers case studies and learning for wider dissemination. The NCI has developed the following set of principles for effective patient and public involvement.

Be clear about what involvement means. People in all parts of the organisation need to:

- have a shared understanding of what is meant by involvement and its purpose
- be clear about the difference between working for and working with patients and the public
- be clear about the different possible purposes of collective involvement
- make sure there are adequate resources including money, time and people (skilled staff, engaged and informed patients and the public).

Focus on improvement. Involvement is a means of improving services, not a problem to be solved. Organisations must:

- engage with patients and the public and demonstrate change as a result of that engagement
- embed a systematic approach to involvement that links corporate decision making to the community
- ensure commitment and leadership from the board, its chair, trust chief executive, directors and clinical leads
- support staff and equip them with the necessary skills.

Be clear about why you are involving patients and the public:

- by being clear about the objectives of the work, its rationale, relevance and connection to organisational priorities
- by being honest about what can change, what is not negotiable, and the reasons why
- by finding out and using what is already known about people's views and experiences.

Identify and understand your stakeholders:

- by defining who needs to be involved and who needs to be informed
- by considering who is likely to be affected by the implications of the matter in hand
- by ensuring that your involvement activity is relevant to your stakeholders' interests
- by making sure all stakeholders are appropriately involved.

Involve people:

- by finding out how people prefer to be involved
- by creating opportunities for people to be involved
- by making sure your methods suit the purpose of the involvement exercise
- by making a concerted effort and bespoke arrangements in order to reach out to people whose voices are seldom heard
- by sharing information and knowledge, so that people can easily understand the issues
- by making it clear to people what you are doing and why, including what you can and cannot change
- by clearly letting people know that their views will feed into decision making processes
- by providing feedback to people about what you have learned from them and what action(s) you intend to take as a result of their involvement
- by ensuring that patients and the public have the support they need to get involved.

What makes a good project?

This section draws together the learning from the various projects and reports reviewed during the course of this scoping study to describe the characteristics of an effective community engagement project.

Clarity of purpose

Those proposing to engage with local communities should be clear about why they are doing it. Reasons might include the following: to determine local needs and aspirations; to promote health and reduce inequalities; to improve service design and the quality of care; to strengthen local accountability.

Clearly defined community profile

The most effective projects start with a clear idea of the nature and make-up of the community they want to engage and key stakeholders within it. It should be possible to specify who the target community is and why their engagement is considered important. Known characteristics of the community should be described including, if appropriate, the names of host organisations or community partners. Apnee Sehat (p 17) is a good example of a project that works with a specific group (members of the Sikh community) and has clear focused health improvement goals (reducing the risk of strokes, heart attacks and diabetes).

Identified leadership

It should be clear from the outset who is responsible for leading the project. This person/people may be located in a healthcare organisation, voluntary organisation or in a community group; in many cases all three will be required. Most of the successful projects stress the crucial role played by effective champions. For example, the evaluation of the community audit organised by Connected Care in Hartlepool (p 15) stressed the crucial role played by various champions, including the PCT, local community associations, and a national voluntary organisation – Turning Point.

Specified goals

Project proposers should be able to specify the goals of the project at the outset and what they hope and expect to achieve. Ideally the goals should be SMART, ie specific, measurable, agreed upon, realistic and time based. Careful consideration should be given at the outset to how flexible or fixed you want the goals to be. For example, can the project accommodate community-defined goals if community members decide that issues other than health are a higher priority? It may be possible to combine the general aim of community mobilisation and empowerment with a more specific focus on particular health topics. The Bromley by Bow Centre (p 24) is an example of a project that successfully combines both.

Engagement plan

A project plan should set out how community members will be approached and what will be done to ensure that all relevant people are informed, consulted and invited to participate. Ideally the plan should be developed with the active involvement of community representatives. Liverpool PCT's Big Health Debate (p 13) managed to engage large numbers of people in its consultation and planning process.

Building on previous experience

There is a great deal of knowledge about community engagement, much of it stemming from outside the health sector. It makes sense to study the experience of other projects before plunging in. The many national, local and academic organisations that specialise in this field (see appendix) are useful information sources. The HAZs (p 19) are a useful source of learning and the results of the national evaluation have been published.

Recruitment strategy

If people from the community are to be employed in the project, either on a paid basis or as volunteers, a recruitment strategy should be specified. Connected Care in Hartlepool (p 15) found this was more difficult and took longer than had been anticipated.

Participation methods

Techniques for promoting and securing local participation should be carefully selected and clearly specified. Involve's People and Participation website (p 33) is a useful source of information and guidance on tried and tested techniques.

Payment policy

Consideration should be given to the issue of financial incentives, including the possibility of paying community members for time spent working on the project, fees and expenses. This has proved a sensitive topic in some community engagement projects. Connected Care in Hartlepool (p 15) solved it by adopting a flexible approach to meet specific individual needs.

Timetable

Project proposals should include a realistic timeline. In practice many community engagement projects underestimate the amount of time it takes to achieve their goals. Tackling entrenched problems, such as health inequalities, is likely to require a long-term commitment.

Capacity and resources

Expecting community members to devote a great deal of time may be unrealistic. An assessment should be made of the likely extent of voluntary contributions and what skills people can bring to the project, in addition to a clearly worked out budget for professional staff time and resources. Sometimes working in partnership with other organisations will make sense, as in the arrangements worked out by LINks and OSCs (p 27).

Training

Community members and professional staff may need training to help them perform identified tasks. This needs to be timetabled and budgeted for. Voluntary organisations and university departments may be able to help as in the case of Connected Care in Hartlepool (p 15), where UCLan provided the training.

Cultural awareness

If the target community includes people from minority groups, it is especially important to be aware of cultural differences and to seek guidance from members of those communities. NHS Tower Hamlets (p 23) was able to develop new facilities to meet the identified and previously unmet needs of particular minority groups.

Consensus-building

It is crucial that all involved share a common understanding of the goals of the project, its rationale and planned direction of travel. Plenty of time should be set aside for consensus building. Involving local people in the development of a clear ethical framework to guide decision making has been helpful to Oxfordshire PCT (p 29) when making its allocation and exceptional treatment decisions.

Communications

Clear communication and transparency are important elements in any community engagement programme. It may be appropriate to seek help from communications professionals in developing a strategy and implementing it. Liverpool's Big Health Debate (p 13) went to great lengths to increase understanding of the consultation process and its outcomes.

Monitoring and outcomes assessment

If the project has set itself SMART goals, including measurable outcomes, it should be relatively easy to monitor progress. Process and outcome indicators should be carefully selected to ensure that they are feasible, specific and reliable. Monitoring process and outcomes is important for keeping on track and informing funding bodies and, in particular, for maintaining the commitment of those involved. The Healthy Communities Collaborative (p 21) is a model in this respect since regular monitoring of progress towards their health and community empowerment goals is a feature of all their projects.

Evaluation and dissemination

All those involved in community engagement should have an interest in developing the knowledge base, so independent evaluation should be built into projects wherever possible. Many of the best projects have involved academic organisations in formative and summative evaluations. Completed evaluations should be published with a clear plan for disseminating the learning.

Appendix: List of sources

National organisations

Association of Public Health Observatories (APHO)

www.apho.org.uk

Centre for Public Scrutiny

www.cfps.org.uk

Charities Evaluation Service

www.ces-vol.org.uk

Community Development Exchange (CDX)

www.cdx.org.uk

Community Development Foundation (CDF)

www.cdf.org.uk

Community Empowerment Division, Dept of Communities and Local Government

www.togetherwecan.direct.gov.uk

Community Health Exchange (CHEX)

www.scdc.org.uk

Federation for Community Development Learning

www.fcdl.org.uk

Health Link

www.health-link.org.uk

Healthy Communities Collaborative,

Improvement Foundation

www.improvementfoundation.org

Improvement and Development Agency for Local Government (IDeA)

www.idea.gov.uk

Involve

www.involve.co.uk

National Council for Voluntary Organisations (NCVO)

www.ncvo-vol.org.uk

NHS Centre for Involvement

www.nhscentreforinvolvement.nhs.uk

National Institute for Health and

Clinical Excellence (NICE)

www.nice.org.uk

National Social Marketing Centre

www.nsms.org.uk

National Support Team for Health Inequalities

www.dh.gov.uk/en/Publichealth/

Healthinequalities/index.htm

New Economics Foundation (NEF)

www.neweconomics.org

Pacesetters Programme

www.dh.gov.uk/en/Managing your organisation/

Equalityandhumanrights/

Pacesettersprogramme/index.htm

Patient and Public Involvement

Specialist Library

www.library.nhs.uk/ppi/

Picker Institute Europe

www.pickereurope.org

Turning Point

www.turning-point.co.uk

Local organisations

Bradford and Airedale PCT www.bradfordairedale-pct.nhs.uk

Bromley by Bow Centre www.bbbc.org.uk

Community Health Action Partnership (CHAP) www.chalk-ndc.info/doing/ndc-health/chap.htm

East Midlands Community Dialogue Project www.communitydialogue.typepad.com

Grimsby Open Door www.guardian.co.uk/society/2007/aug/15/ guardiansocietysupplement.health

Heart of Birmingham PCT www.hobtpct.nhs.uk

Herefordshire PCT www.herefordshire.nhs.uk

Liverpool PCT www.liverpoolpct.nhs.uk

Murray Hall Community Trust www.murrayhall.co.uk

St Matthew's Project, Leicester www2.le.ac.uk/departments/health-sciences/ extranet/research-groups/Nuffield/project_profiles/ eqh.html

NHS Tower Hamlets www.towerhamlets.nhs.uk

Organisations with a specific focus on ethnic minority communities

Apnee Sehat www.apneesehat.net

Black and Ethnic Minority Community Care Forum

www.bemccf.org.uk

Communities in Action Enterprises www.communitiesinaction.org Community Health Involvement and Empowerment Forum (CHIEF) www.chiefcic.com

Delivering Race Equality in Mental Health www.nmhdu.org.uk/our-work/promoting-equalities-in-mental-health/

Social Action for Health www.safh.org.uk/safh_php/index.php

Universities

Department of Social Policy and Social Work, Oxford University www.ox.ac.uk

International School for Communities, Rights and Inclusion, University of Central Lancashire www.uclan.ac.uk

Personal Social Services Research Unit, London School of Economics www.lse.ac.uk

School for Health, Bath University www.bath.ac.uk

School of Applied Social Sciences, Durham University www.dur.ac.uk/sass/

School of Health and Medicine, Lancaster University www.lancs.ac.uk

School of Population, Community and Behavioural Sciences, Liverpool University www.liv.ac.uk

Social Policy Research Unit, York University www.york.ac.uk



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