‘Taking off the suit’: engaging the community in primary health care decision-making

Elizabeth Anderson MSc RGN,* Michael Shepherd MSc PhD† and Chris Salisbury MD FRCGP‡

*Research Associate, Academic Unit of Primary Health Care, University of Bristol, Bristol, †AWARD Senior Research Fellow, Cardiff Institute of Society, Health & Ethics, Bristol University, Bristol and ‡Professor of Primary Health Care, Academic Unit of Primary Health Care, University of Bristol, Bristol, UK

Correspondence
Elizabeth Anderson
Academic Unit of Primary Health Care
University of Bristol
Cotham House
Bristol BS6 6JL
UK
E-mail: e.j.anderson@bristol.ac.uk

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Abstract

Objective To explore the process of public involvement in planning primary health care.

Background Recent policy in the UK promotes public involvement in planning health but there have been difficulties in engaging communities in the process. Surveys of health service organizations have found that there has been a failure to adapt to new approaches. It has become important to understand why this has occurred if policy initiatives to encourage involvement are to succeed.

Design Qualitative study. Data collected through individual interviews and focus groups.

Setting Two new primary healthcare developments in deprived areas in Bristol and Weston-Super-Mare.

Participants Thirty-six professionals and 23 local residents in Bristol; six professionals and three local residents in Weston-Super-Mare.

Results Three themes were identified: process, partnership and power. The main findings were that exceptional people with a shared commitment to public involvement were necessary to motivate others and develop partnerships. Local people were drawn into the process and with increased confidence became powerful advocates for their community. Creative and varied methods to involve the public were important in achieving balance between professionals and lay people. However, conflicts over practical decisions arose from a lack of clarity over who had power to influence decisions.

Conclusion Most of the participants were enthusiastic about their experience of public involvement in planning primary health care. Features crucial to sustainable involvement included a commitment from leaders within statutory agencies, support over a long period to build the confidence of local people, willingness to use informal approaches that are in tune with local culture, and a recognition of the concerns of both service users and providers.

Introduction

Participation and involvement are contested terms that are used interchangeably in many discussions of patient and public participation in decision making in health.[1,2] Recent government policy in the UK has promoted the importance of involving the public in the planning of health care[3] and interest extends beyond the UK as internationally efforts are made to understand the implications of public participation.[4] It is often conceptualized as a hierarchy ranging from narrowly defined market research-based approaches to more inclusive community empowerment models.[5] This is not always a helpful or informative representation[6] and UK health policy has often been vague about the meaning of involvement it aspires to.

There are a number of interpretations for the rise of participation in decision making as a policy.[5] First, it can be seen as a way to improve services so that they match the needs of local communities more closely. Secondly, it can be argued that involvement represents a technology of local accountability and that local health service decisions are legitimized by involvement.[7] Thirdly, there is some evidence that participation has some direct health benefit through building a sense of self-worth and empowerment.[8,9] While governments of the last two decades have often returned to this topic and have promoted public involvement through a number of different initiatives including the Patient's Charter, Expert Patient Programme and the development of Patient Forums, there have been notable difficulties in implementation. Surveys of health service organizations[5,10] have found that the health service has failed to adapt to new approaches.[11] Prior to the NHS Plan, interest in public and service user involvement was sporadic, despite the rhetorical support of government, and few healthcare professionals had developed the experience or the skills to be able to work with service users in the way that the government had envisaged.[12,13]

In a recent systematic review, Crawford *et al.*[14] found evidence, drawn mainly from case reports, that involving patients in planning and developing health care has contributed to changes in service provision. Many of the studies identified were in relation to mental health or learning disabilities, with few based on experience of lay involvement in planning primary health care. The areas where there was most involvement were those with existing service user movements, and where there was already a significant level of joint planning and provision of services, most often with local authorities, but increasingly also involving the voluntary sector.[15]

The establishment of Primary Care Groups included the first systematic attempt to introduce local opinion into decision-making processes in primary care, through lay membership of Boards. It can be argued that this has been enhanced in the subsequent establishment of Primary Care Trusts in 2000, with additional lay membership, Patient Forums and a duty to consult.[16] Primary Care Trusts are statutory organizations, funded directly by the Department of Health, which are responsible for commissioning and delivering the majority of health care for their local populations. They reflect the UK government's aim of making decision-making bodies more flexible and responsive to local needs.[17] An alternative view would be that these formal processes promote a particular form of involvement based on shared understandings of discourse and behaviour which may exclude significant sections of the population.[18]

We wanted to find out whether these viewpoints held any validity in practice. We conducted a qualitative study to examine the process of public involvement in the planning of two innovative projects to improve primary health care. The majority of our data were collected in South Bristol on an estate with high levels of material and social deprivation, where a 'Health Park' has been established as the site for a range of health and social services including a health centre,[19] an NHS Walk-in Centre and a Healthy Living Centre.[19] Healthy Living Centres were innovative ventures, funded by the

National Lottery, and designed to mobilize community activity to improve health in deprived areas. They were intended to encourage health promotion in the widest sense by stimulating co-operation between health and social agencies in the statutory and voluntary sectors and between professionals and the local community. Service users were expected to be involved in all aspects of development and delivery of these projects, in line with a strategy which is credited with securing local support and capacity building in a disadvantaged community.[20]

The Health Park reflects this philosophy. It is a joint venture of health and local authority agencies, managed by a partnership group which includes the Primary Care Trust, City Council and local representatives. Public involvement is a fundamental aim. This would include seeking the views of all sectors of the population through a variety of means, and involving local people at all stages of making decisions about how services should be provided. In parallel with the development of the Health Park in Bristol, similar developments, including a Healthy Living Centre linked to a general practice were being planned in a disadvantaged estate in the neighbouring town of Weston-Super-Mare (WSM). This is also based on a philosophy of public involvement but unlike the project in Bristol had been evolving slowly over a long period, initially as a health improvement project focusing on coronary heart disease, which soon transformed into a broad community health development project funded jointly by the health service and local authority.

First, we aimed to establish how far the explicit goal of public involvement had been achieved in Bristol and to identify the processes involved (particularly facilitators or barriers to involvement) and factors that would enhance sustainability.[21] Secondly, we wanted to compare our findings from Bristol with the experiences of the project in WSM in order to see if similar patterns had occurred.

Methods

Design

This was an exploratory study in that we sought to investigate more thoroughly two existing projects in order to understand more clearly the phenomenon of public involvement explicit within each.[22] Each project was viewed as a case, within which different perspectives were explored in depth and compared.[23] We used a qualitative design to enable us to draw on individual's experiences of lay involvement. Data were collected using open interviews[24] and focus groups.[25] A topic guide was used for the initial interviews. This was used flexibly during data collection to allow the participants to express their views in their own terms and was revised and refined as the data collection progressed to reflect themes as they emerged during data collection. The data analysis from the first project preceded the data collection from the second and provided specific themes that we could explore in a different setting.

Sample

In Bristol, we used a stratified, purposive approach to sample from groups of professionals and local residents with varying levels of involvement. 'High' level involvement included those individuals who had been involved in the outset as strategists and regularly attended meetings relating to planning aspects of the Health Park. 'Medium' level involvement included people who had attended one or a few meetings, but had relatively little strategic involvement. 'Low' level involvement referred to those who have never had a direct input into the process of planning but who might have been involved in some of the consultation processes.[26] In Bristol a total of 40 subjects were interviewed individually, 36 professionals and four local residents. Data for 19 local residents were also obtained through four focus groups based on existing community groups.

Professional interviewees came from a range of backgrounds, including clinical professionals, managers and community workers. There was a mix of age, gender and experience of working in the area. There was also a range of involvement, both in terms of participants' level of involvement in the project and the time at which they were most involved (Table 1). Informants from the local community also included people with a range of involvement in the project. Only four of these participants had high-level involvement and were interviewed. Two others who had medium-level involvement were also interviewed. The remaining data were drawn from a series of four focus groups (Table 2).

In WSM, we ran two focus groups, one with professionals and one with local people. These were all individuals with high levels of involvement drawn from the members of the Project Steering Group and Residents Group. In WSM, the public focus group consisted of three local residents. The professional focus group consisted of six participants, including a general practitioner, a practice manager, two curates, the Healthy Living Centre project manager and the buildings administrator.

Table 1 Characteristics of professionals in Bristol by level of involvement ($n = 36$)

Characteristic	High	Medium	Low	Total
Male	11	1	3	15
Female	11	9	1	21
Total	22	10	4	36
Age (years)				
21–40	5	6	0	11
41–60	17	4	4	25
Total	22	10	4	36
Occupation or agency				
Doctor	1	1	2	4
Nurse/HV	0	2	2	4
Community worker	3	0	0	3
Manager of HP unit	1	5	0	6
Administrator of HP unit	1	2	0	3
Health authority/NHS trust	5	0	0	5
Local authority	8	0	0	8
Voluntary sector	2	0	0	2
Other	1	0	0	1
Total	22	10	4	36

HV, Health Visitor; HP, Health Park.

Table 2 Characteristics of local residents in Bristol focus groups by level of involvement ($n = 19$)

Characteristic	High level	Medium level	Low level	Total
Male	0	1	5	6
Female	0	2	11	17
Total	0	3	16	19
Age (years)				
18–20			3	3
21–40		0	6	6
41–60		1	3	4
>60		2	4	6
Total		3	16	19

Analysis

All interviews and focus groups were recorded and fully transcribed for analysis. All three researchers were involved in interviews, E.A. and M.S. undertook focus groups. Analysis was undertaken collaboratively by E.A. and M.S. We analysed the data using a constant comparative method.[27] E.A. and M.S. read transcripts and identified themes separately before discussing and agreeing major issues. These provided a framework to code the data using ATLAS-ti version 4.[28] The codes and themes were refined and cross-checked by L.A. as the analysis progressed and corroborated by M.S. Finally, the themes were organized to explain different aspects of public involvement.[23] Names were changed within the text to maintain anonymity and participants given an identification number.

Results

We identified three main themes: partnership, process and power. The main findings from WSM are reported separately within each theme.

Partnership

A critical theme was the relationships and partnerships that evolved as people learned to communicate across traditional boundaries. In the early stages of the project there were a number of professionals in strategic roles who were crucial to its progress and who shared a particular vision. They described themselves as:

> an influential bunch of professionals…(and)…a group of people I felt very at home with and we were able to think out of the box. (P4, other professional, Bristol)

> a tiny band of brothers. (P31, community worker, Bristol)

The group were mentioned by name by many of those who were interviewed. They ensured that local involvement was a key aim of the development. They were accessible and flexible, rather than remote and directive. Talking about one of the professionals a local resident said:

> …he didn't have a posh office downtown that we had to go to down there, he actually came to where people was…. (MS1, local resident, Bristol)

This approach of adapting the process to local needs provided symbolic recognition of the importance of doing things differently. One of the professionals described both the mental and physical preparation for going to meet the local residents as '…taking off the suit' (P8, local authority, Bristol). A few local people were also highly involved from the start of the project. Many were already active and became skilled in presenting their case and became increasingly politicized by the process. These individuals were eventually able to gain access to authority at the highest level:

> …so that recently they went and had tea with the Prime Minister and so that's how high they can get, right to the top. (MS2, community worker, Bristol)

In Weston, one of the local residents involved in the Healthy Living Centre had also become involved in local politics through community activities and in Bristol one manager reflected that:

> …there has been some very assertive and well-informed residents who have taken really key roles in that and have gone on to become lay members on PCTs and that kind of stuff. It's pretty extraordinary when you think about it and fantastic! (MS3, manager, Bristol)

As the Bristol project progressed, the strategists who were initially involved moved on, giving way to those who would implement the development. It was at this stage, we found that conflicts arose. The most serious of these, over the planning of the reception area, was graphically described by several informants:

> …they wanted to put them (the reception staff) behind Perspex and local people were really furious and said well Christ we have worked together for two and a half years to put this together and you are still telling us you want to be behind bars. (MS2 community worker, Bristol)

The dispute became very bitter and people began to withdraw. Unlike the 'band of brothers', those involved now were less committed to the philosophy of involvement. An underlying factor was that the receptionists felt that they had not been included in the decision-making process in the early stages and they did not necessarily share the same vision for a project in which local people were full partners. In Weston, we found a similar issue challenged the project in the transition from conception to delivery:

> …we didn't get a consensus on the processes that we're going through and people who had a vested interest in exerting a bit of power at that time just took the opportunity. (Professional Focus Group, WSM).

However, the partnership in Bristol survived the troubles of the reception area and at the time that this study was conducted was functioning at both policy and operational levels with involvement from local authority, health services and the local community. The role of community workers who supported residents in the groups and advocated for them in their absence was crucial in that their links to the agencies gave them credibility, while their commitment and professional skills enabled them to develop links in the community and establish a solid reputation locally.

Process

We found that involvement of local people took place on at least two levels. Most people kept in touch with both projects through newsletters and special events, where their ideas might be

collected. But a few people went on to become deeply involved in the planning and decision making. They would meet regularly with professionals from the local and health authorities and contributed to formal policy-making bodies. For these individuals, we found that there was a pattern to their involvement in the decision-making process. It often began with some personal motivation, provoked perhaps by experiences that brought them into contact, often conflict, with the healthcare system. Their interest was supported by community or health development workers and welcomed by managers keen to build up the number of local people involved with the formal process of representing their community and they began to attend meetings.

If the managers were welcoming, we found that the meetings themselves could be a frustrating experience for local residents who found them both tedious and daunting. As the development of the Health Park in Bristol progressed, the nature of the tasks became more operational, aimed at getting services running, and the effort towards involvement made by the professionals at the beginning of the project proved hard to sustain. More traditional decision-making processes began to re-appear as the business of delivering health services became a priority and local views appear to be less valued. The meetings were now more formal and intimidating for local people therefore limiting participation. This was recognized on both sides:

> They are frightened to speak in a group if the people may be more clever than them so therefore what they say is considered rubbish. (P28, local resident, Bristol)

> It needs a sea change in the way the process is organized to ensure maximum user involvement. Formalized meetings will not appeal to local people who have never experienced doing things this way, and why should it be the template? (MS5, community worker, Bristol)

For those who could endure the meetings familiarity led to the growth of confidence and an ability to challenge the process of decision making. As individuals became more comfortable in the formality of a 'meetings culture', they were more likely to be assertive when faced with authority figures:

> …this last time, I got really fed up and let them have it…they just never seem to get on with it and do things. (MS6, local resident, Bristol)

The experience in WSM was very similar, with local people becoming involved incrementally. A threat to withdraw medical services from the estate further brought the community together, acted as a collective motivator and started the move towards achieving a Healthy Living Centre. However, unlike the Bristol project, the length of time from inception to the laying of the first stone for the new Healthy Living Centre permitted the group to gradually establish more robust organizational structures to support public involvement. The original Project Steering Group and Residents Group became a Board of Directors (including a majority of lay members) and an Advisory and Consultation Group. Terms of reference were clarified, and the need for training and support for all Board members was recognized from the start.

For most local residents, events to raise awareness of the projects in WSM and in Bristol focused on 'fun'. They were successful ways to get local people interested and provided opportunities to capture their ideas. Examples included the use of video-booths, use of creative arts, competitions and one of the local general practitioners conducting tape-recorded interviews in public at an open day. These were memorable community events, mentioned by many of those involved in interviews and focus groups. They became important ways of getting information across and bringing a sense of united purpose to the projects.

Part of the process was to maintain regular contact with local people and respond to their need for support and encouragement. This was achieved through the community workers engaged in the projects and amounted to a process of patiently nurturing empowerment in both individuals and the community. Because they understood the local perspective, the culture and the social structure, they were able to access the right networks:

> …because they (the men) haven't got very good networks the message about what is going on say like what's going on in the health park won't get out through the men but it will get out through the women. (P5, community worker, Bristol)

Power

We found that despite the rhetoric of a new approach to public involvement in planning primary care services, people still felt that traditional models of power were upheld:

> GPs still sort of end up holding that sort of level of power that, even though you probably don't appreciate that they have, but if GPs don't support something its very difficult to actually get it off the ground. (MS7, manager, Bristol)

Local people felt that they could not compete with the statutory agencies involved and that their views were eventually marginalized:

> We had a committee (for health issues) which was mostly local people but then we got quite a few social workers and…it started to get taken out of the hands of the local people. It was a local initiative, then it started to get quite political…. (Public Focus Group 4, Bristol)

In the early stages, the managers and professionals involved had sought to increase the influence of local people in the process by consciously agreeing to cede a certain level of power to local people and remodel the decision-making process. For more conventional planners, this was a confusing and apparently anarchic approach:

> …it never felt very clear to me about what the remit of the various groups involved in the process actually were. It just felt that all the people were finding their way through a maze on the hoof…. (MS 8, Manager NHS, Bristol)

The ability to control the form and extent of participation remained with the statutory agencies and the effort expended seemed dependent on how well it 'fitted' with other agendas. For example, in Bristol, when managers were under time pressure to respond to Department of Health timetables for opening a Walk in Centre on the Health Park, they failed to include local residents in putting the bid together. This may have been an indication of the absence of policy coordination at the Department of Health and a lack of real commitment at local level. One community worker commented that public involvement was still '…seen as window dressing' by the health service.

Despite the loss of the early enthusiasm in the 'band of brothers' period, the continuing involvement of local residents established participation as a stable part of the project culture. This was reflected strongly in WSM, where there was a more traditional and formal approach to the organization of the project. Whilst there may be negative effects in that the focus on the more formal processes can be exclusive, by the end of the project residents regularly participated in interviews for prospective employees and a residents' panel is now a feature of the appointments process.

In the Health Park in Bristol too it was clear that local views are now an important consideration, one manager commenting that:

> …the council doesn't go back to KW and say well we're the Council and we are so much bigger and more powerful than you that you have just got to do what we say, it is much more of a dialogue. (MS 9, local authority manager, Bristol)

Discussion

We identified three themes: partnership, process and power. These are interlocking and our findings demonstrate a complex inter-relationship that can affect participation.[29] This was often compounded by the fact that there were variations in the interpretation and application of 'public participation' by different agencies and individuals. We also illustrate the importance of understanding local culture and using a variety of approaches to create conditions where involvement can take place,[6] even though this is difficult to sustain without the commitment of appropriate resources and ongoing support.[30] We observed, particularly in Bristol, a combination of pressure from above (intervention from Government), meeting pressure from

below (local activists supported by community workers) producing conditions that can challenge the structural basis of health decision making.[31]

Almost all of those interviewed for this study were enthusiastic about their experience of public involvement in planning primary health care, while recognizing the difficulties it entailed. This widespread support in principle has been contrasted by the lack of resources and skills which act as a barrier to effective activity.[5,10] We demonstrate the importance of learning on the part of both health services and community members and we highlight the importance of those who can work across boundaries and facilitate involvement.

Limitations

Our study has limitations. Most of our data came from one area in Bristol. However the main findings were supported by the data from WSM as the comparative case, and provide an insight into the complex process of public involvement in planning primary health care. Our sampling strategy was designed to capture views from professionals with a range of experience and attitudes. This was generally achieved but it was difficult to recruit local people for focus groups or individual interviews, especially in WSM. Obtaining the community perspective remains problematic for researchers as well as for policymakers. Other research[32] has found that citizens are willing to take part in decision making about healthcare issues, provided they are confident that their views will really be considered and that the decisions take place in a transparent environment. We see from our results that minor setbacks, exemplified by conflict over the reception area, can have adverse effects on willingness to participate whilst trust remains fragile. Our difficulty in recruiting focus group participants may also mean that the views of the more motivated members of the community will be over-represented and policy change may not be driven by, or meet, community need.

Partnership

The cases we studied exemplify the notions of partnership put forward by the current Government as a feature of their overall 'third way' approach which promised to change the relationship between the individual and the state.[33–35] Since 1997, discourses of 'partnership' or 'joined-up government' have run through policy initiatives. Healthy Living Centres and neighbourhood renewal schemes blur the boundaries between areas of departmental responsibility.[36] Partnership working means that a range of agencies, including the National Lottery, the Treasury, The Office of the Deputy Prime Minister as well as parts of local government now take an interest, fund or work closely with health service organizations in delivering health-related services. At a local level, partnership working between the local authority, health service and other agencies demonstrates progress towards performance targets. Working in this way brings primary care trusts into close contact with organizations which have different objectives and approaches to decision-making. This leads some analysts to conclude that the consequence is a decline in the traditional medical influence over local health policy as the alternative perspectives of partners become more influential.[31]

Our findings stress the importance of achieving a balance between the views of local people and health professionals and to be clear about the purpose and limitations of public involvement. The rhetorical use of terms such as 'partnership' implies improved consultation that will lead to greater convergence between public and professional views. Instead it may highlight conflicts or shift decision making away from public forums.[37] This may be because of an unwillingness to relinquish entrenched power or an increased ability to resist it among local communities. It may also be due to perceptions of professional responsibilities or the need to weigh public views against other sources of evidence.[30] Similarly, the influence of local people may be limited by financial constraints and the need to distribute limited resources equally across a wider area.

Although tensions often exist between local authority and local health service providers because of different cultures, our findings show that these two groups were able to work together in a generally constructive way. This was perhaps driven by the shared agenda to regenerate and improve the health of a disadvantaged area, and resources were gathered from a number of sources to make collaboration meaningful. However, the majority of local residents in Bristol and WSM remained relatively passive participants in the process of public involvement, attracted by 'open days' or through contact as patients or workers.

Process

By far the majority of public involvement in health services to date has consisted of managers and (rarely) clinicians gathering local views through some sort of research-based process such as questionnaires or focus groups and using that information in a mediated form in decision-making.[5,10] This indirect process fits comfortably into the traditional quasi-rational decision making of health service organizations and has been criticised as 'ceremonial' and 'a technology of legitimation'.[31,38] The 'traditional' model was apparent in both of the projects studied, for example at community events where creative methods were used to collect information and opinion. But there were also additional processes, such as participation in policy and working groups, in which local people were involved directly in decision making. The latter 'active' or 'direct' approach to involvement is less easy and less predictable for health service organizations, but means that local concerns expressed by people who actually experience them can be reinforced by their peers in decision-making forums.

It has recently been suggested that a model of involvement that is conceptualized as a spectrum rather than a hierarchy of approaches might be more helpful when making policy decisions in relation to engaging communities.[6] There was evidence from our study that this is very pertinent to healthcare planning where critics have argued that public involvement has rarely developed beyond consultation.[39] The use of a variety of different strategies, sometimes in parallel, meant that the majority of the community were involved albeit passively and at a lower level whilst a small number of lay people became actively involved in decision making, contributing to the management of services and resource decisions.

Certain individuals were invaluable in this process. Community workers helped local people and the health professionals to communicate. Their role was to advocate, translate and mediate between local people and professionals, acting as what has been identified in the literature as 'boundary spanners'.[40] They were trusted by both the agency representatives and local participants who they supported and it was their intervention that enabled involvement and made the partnership function. With their support, individuals achieved empowerment, so community concerns were increasingly brought to the fore. There were also a small number of committed individuals amongst the professionals who shared a vision, motivated others and sustained enthusiasm driving the process of public involvement in the early stages. They worked across boundaries, challenged traditional models of consultation and decision making, and treated local people as equals.

Power

Even within a broadly democratic approach, control over the process of decision making and the form of involvement means that health and local authority managers are able to regulate the participation of local people, even where involvement is direct. By adhering to agendas, requiring formal papers and through the position of chair, meetings can be manipulated to exclude local views. This use of power disables real participation, allowing organizations to claim that they are open, while effectively excluding those most affected by decisions.[41,42]

Even where meetings were more open, we found that people were reticent about participating. They felt less able to articulate their views than the professionals. This perception

that the knowledge of specialized experts is intrinsically of greater value can lead to the neglect of important sources of lay knowledge particularly relevant to local decisions.[43] Many studies conclude that the views and ways of thinking of clinicians hold enormous sway over decision making in clinical and non-clinical arenas, gathering their legitimacy from their ability to determine the nature of health discourses.[31,44,45] However, we found that residents can become attuned to functioning within this culture if they are empowered and supported. Then they are able to engage in the process and subvert it, by 'let(ting) them have it'. They will ignore (implicit) meeting convention, shifting the focus away from narrowly defined health agendas to broader social objectives that contribute to reducing inequalities in health and may lead to the reshaping of power relationships.[44,46,47]

Conclusion

Government policies that place partnership at the centre of public services create opportunities for new approaches to decision making that incorporate community views with those of professionals from a range of backgrounds. Features crucial to sustainable involvement include a commitment to a shared vision from leaders within statutory agencies, support over a long period to develop partnerships and the development of local people willing to participate. Understanding the local culture and employing attractive and informal approaches which are in tune with local culture, and recognition of the concerns of both service users and providers are equally important. Our research shows that organizations such as Primary Care Trusts who have a duty to involve the public in planning health care will need to adopt decision-making processes that facilitate involvement from partners and local people.

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