

# Exploring the influence of service user involvement on health and social care services for cancer

Pamela Attree PhD,\* Sara Morris PhD,<sup>†1</sup> Sheila Payne PhD,<sup>‡</sup> Suzanne Vaughan BA (Hons) § and Susan Hinder PhD<sup>¶</sup>

\*Research Associate, School of Health and Medicine, Division of Health Research, Lancaster University, <sup>†</sup>Public Involvement Manager, NIHR Research Design Service for the North West, School of Health and Medicine, Division of Health Research, Lancaster University, <sup>‡</sup>Help the Hospices Chair in Hospice Studies, School of Health and Medicine, Division of Health Research, Lancaster University, Lancaster, <sup>§</sup>Postgraduate Research Student, Medical Education Research Group, University of Manchester Medical School, Manchester and <sup>¶</sup>Freelance Researcher, RaFT Research and Consulting, Clitheroe, Lancashire, UK

## Abstract

### Correspondence

Pamela Attree  
School of Health and Medicine  
Division of Health Research  
Bowland Tower East  
Lancaster University  
Lancaster LA1 4YT  
UK  
E-mail: p.attree@lancaster.ac.uk  
<sup>1</sup>Principal investigator.

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**Keywords:** cancer care, partnership, service user involvement

**Background** Service user involvement in health and social care is a key policy driver in the UK. In cancer care it is central to developing services which are effective, responsive and accessible to patients. Cancer network partnership groups are set up to enable joint working between service users and health care professionals and to drive service improvements.

**Aims and objectives** The aim of this study was to explore the influence of the cancer network partnership groups' service user involvement activities on cancer care.

**Design** This was a qualitative study involving documentary analysis and in-depth case studies of a sample of partnership groups.

**Setting and participants** Five partnership groups were purposively selected as case studies from Macmillan regions across the UK; documents were collated from a further five groups. Forty people, including core group members and key stakeholders in cancer services, were interviewed.

**Results and conclusions** The evidence from this study suggests that cancer network partnership groups are at their most influential at 'grass roots' level – contributing to patient information resources, enhancing access to services, and improving care environments. While such improvements are undoubtedly important to patients, the groups' aim is to influence strategic changes, for example in cancer care commissioning or macro-level policy decision-making. The evolution of open, participatory relationships between service users and professionals, and recognition of the value of experiential knowledge are seen as key factors in influencing cancer care. The provision of dedicated resources to strengthen service user involvement activities is also vital.

## Introduction

Cancer network partnership groups in the UK are regional organizations set up to enable joint working between service users and health professionals, with the aim of developing more effective patient-centred cancer care. Their remit is to promote collaborative working, shared decision-making and shared ownership of service developments.<sup>1</sup> The model is based on the Cancer Partnership Project, funded by Macmillan Cancer Support and the Department of Health, which provided support for cancer network partnership groups and facilitated service user involvement in the planning and delivery of cancer services. An independent evaluation of the project was conducted in 2004, finding that the majority of people involved felt strongly that the groups were making a difference to local NHS cancer services in ways which went beyond traditional consumer feedback.<sup>2,3</sup> The evaluation also illuminated some of the complexities and tensions inherent in the partnership model.

The study described in the present paper provided an opportunity to revisit the cancer network partnership groups, to examine the influence of their service user involvement activities on cancer care and to explore some of the issues they face in extending their influence.<sup>4</sup> The term 'service user involvement' in this study refers to the engagement of people affected by cancer (including patients, ex-patients, their informal carers and families) in the planning, organization and delivery of cancer services. The findings are explored using data drawn from in-depth case studies of a sample of groups.

## Background

Service user involvement in health and social care has become a key policy driver in the UK, reflected in policies such as the *NHS Plan* in England and similar policies in Wales and Scotland.<sup>5-7</sup> A stated aim of such policies is to ensure that services are patient-centred and take account of patients' and carers' views and preferences.<sup>8</sup> In relation to cancer care, service user involvement is central to planning and devel-

opment, emphasized in policy documents such as the *NHS Cancer Plan* and the recent *Cancer Reform Strategy*, which set out a 5-year plan for cancer services in England.<sup>9,10</sup>

The perceived benefits of engaging people affected by cancer in the planning, delivery and evaluation of cancer care are wide ranging. Service users are seen to bring a unique perspective to the task, grounded in their personal experiences of the disease.<sup>11,12</sup> Burton identifies two main types of benefits of service user involvement (although there is inevitably some overlap between the categories) – developmental, which refers to the perceived benefits for participating individuals; and instrumental, relating to the improved quality of decision-making about services.<sup>13</sup> In this paper, we focus solely on the instrumental benefits of service user involvement for health and social care services for cancer. A companion study by Cotterell *et al.*<sup>14</sup> also funded by Macmillan Cancer Support, examined the benefits of involvement for participating individuals.

In order to explore service user involvement, we draw on a simplified version of Arnstein's framework<sup>15</sup> refined by Charles and Demaio,<sup>16</sup> which describes three levels of participation – consultation, partnership and lay control. Consultation represents the lowest form of participation in decision-making. It provides people affected by cancer with an opportunity to express their views on care. Next is partnership, in which decision-making is shared between lay people and professionals, often in committee settings. Lay control, the highest rung of the ladder of participation, occurs when service users are in full control of the decision-making process and involves a transfer of power from traditional decision-makers to service users.

The framework also describes three decision-making domains in which users can participate: treatments, services or resources provided to patients; service delivery resource allocation decisions – that is, what services are delivered, how, where and by whom; and macro-level health care allocation and policy decisions at regional or national level.

Despite the increase in interest and activity in service user involvement in health and social care, little direct evidence of its effectiveness has been produced.<sup>17–22</sup> Evaluating the influence of service user involvement is not a simple task as it varies according to its purpose, the people involved, the degree of involvement, the methods employed to support involvement, and the context. There may be rapid change, or it can take a considerable time for service users' views to be translated into differences in practice.<sup>23–25</sup> There have been attempts to measure impact, largely in terms of service user involvement in research,<sup>26</sup> and the NHS Centre for Involvement recently carried out a systematic review of research into patient and public involvement in healthcare services (awaiting publication). One of the difficulties is that there is an absence of widely recognized measurement criteria for judging the success or failure of service user involvement.<sup>25</sup> Consequently, much of the discussion concerning service user involvement in health and social care looks at what makes for an effective *process*, rather than measuring the outcomes of involvement activities.<sup>27</sup> Rather than thinking about outcomes as such, Earl *et al.*<sup>28</sup> focus on spheres of 'interest, influence and control', identifying those people, groups, and organizations that an initiative is attempting to influence. The research team drew on this approach in designing the methods for this study.

## Methods

The study employed a primarily qualitative design, drawing on two main sources of evidence: documentary data produced by the cancer network partnership groups, leading to in-depth case studies of a sample of groups, which form the basis of this paper.

We were keen to encourage service user involvement in the study and did so from the project's inception. In planning the research we consulted with the North West Users Research Advisory Group and a local cancer network partnership group. The research team included experienced service users, as did the Research Advisory Group convened by Macmillan

Cancer Support. Service user researchers were provided with training and support throughout the research process. They also contributed to data interpretation, the writing of the final report to the research funders, and the preparation of this paper.

Ethical approval for this study was received from the North West Research Ethics Committee. Managerial permission at NHS sites was obtained from the relevant care organizations hosting the partnership groups, in accordance with NHS research governance arrangements.

Five cancer network partnership groups were purposively selected as case studies from Macmillan regions across the UK (see Table 1 below). For the documentary analysis phase of the study, five further groups were selected from each of the regions using a stratified random sampling technique. The aim was to ensure that a wide range of groups were included in the study, based on network region, length of time in operation, urban or rural location, and population diversity.

A total of 92 documents were collected from 10 partnership groups. Types of documents varied, with minutes of meetings being the most common.

We planned to carry out 6–8 interviews in each case study site; in round 1 with two 'core' partnership group members such as the service user partnership facilitator and chair person. These participants were identified using information found during the documentary data collection phase of the study or via Macmillan Cancer Support. Interviews in round 2, with key people involved in cancer care locally who were in a position to comment on the groups' influence on cancer services and/or policy, were arranged using a 'snowball' technique.

Interviews took place between July and November 2008, and were conducted by two service user researchers and a research associate. All interviewees were given an information form about the study and asked to complete a consent form, in accordance with ethical procedures.

Study participants provided basic demographic details. Checklists were used to guide the interviews and ensure that the most important

**Table 1** Interviews: rounds 1 and 2

Case study site	Round 1: core members of partnership groups	Round 2: key stakeholders in cancer services
Central and South West England	Facilitator 3 service user representatives	Clinical nurse specialist Research associate Voluntary sector manager Patient organization representative
East Midlands and Northern England	Facilitator 2 service user representatives	Peer review representative Oncologist Lead cancer nurse General practitioner Voluntary sector manager
London, Anglia and South East	Facilitator Lead cancer nurse 3 service user representatives	Development manager 2 lead cancer nurses Development coordinator
Scotland	Facilitator Service user representative	Senior research fellow Cancer information nurse General practitioner Clinical services manager Nurse consultant Regional coordinator
Wales	Facilitator Service user representative	Development coordinator Senior NHS professional Consultant in palliative medicine Cancer services manager General practitioner

topics were covered. Partnership group members were asked about their role in relation to the partnership group, the aims of the group, who the group was trying to influence, what they saw as evidence of success, specific examples of change as a result of the group's activities, and the group's future priorities. Key people involved in cancer care were asked about their role in relation to cancer services, their relationship with the partnership group, their views on the group's influence, specific examples of change as a result of the group's activities, and their views on the partnership group's future priorities. All interviews were tape recorded and transcribed verbatim; permission for this was sought from participants prior to interviews commencing.

### Case study: round 1 interviews

For round 1, user partnership facilitators identified by Macmillan Cancer Support were first

contacted by a member of the research team and provided with an outline of the study. Arrangements were then made to interview the facilitators, who also negotiated access to the partnership group chairs on the research team's behalf.

Thirteen semi-structured, face-to-face interviews were carried out with core representatives of partnership groups, involving 16 people in all (see Table 1). In two case study sites job share arrangements were in operation for chairing the partnership groups and joint interviews were carried out.

Of this group, one person described their ethnicity as African; all other participants were white British. Eight interviewees were female and eight male. The average age of the interviewees was 58 (range: 37–75).

At the end of this first round of interviews, participants were asked to identify key contacts in their geographical area who could comment on the group's influence on cancer care.

### Case study: round 2 interviews

In preparation for round 2, key stakeholders in cancer services were sent an introductory letter, followed by a telephone call to arrange interviews. Semi-structured interviews were then carried out with 24 local stakeholders in cancer care, either in person or by telephone (see Table 1). Efforts were made to include participants from both primary and secondary care services, together with the voluntary sector (such as hospice staff). It proved difficult, however, to identify respondents from primary care who were in a position to comment on the partnership groups' influence. The majority of interviewees in this second round were therefore from secondary, acute cancer services.

Of this group, one person described their ethnicity as Asian/Asian British; all other participants were white British. The average age of interviewees in this group was 47 (range: 26–63).

Documents were analysed iteratively using standard thematic analysis techniques to identify common issues and themes.<sup>29</sup> Analysis was undertaken independently by two researchers; differences of opinion were discussed by the research team until a consensus was reached, to ensure consistency and rigour. Qualitative evidence from the interviews was also thematically analysed using an iterative approach to interpreting data both within and across case study sites. Meetings were held with service user members of the research team to discuss emerging analyses and findings. Quotations in this paper were selected to illustrate the main study themes and consideration was given to the representation of different 'voices', both service user and professional.

### Findings

#### Partnership group aims and objectives

Cancer network partnership groups share a primary aim, which is to improve cancer services through drawing on the experience and knowledge of those affected by cancer. Participants in this study were not always in agreement about whether groups' priorities should be operational

or strategic, however. A senior health professional, for example, emphasized the need for partnership groups to shape cancer care developments at a strategic level, rather than deal with 'small issues on the frontline'. At the same time it was recognized that service user members often need 'quick wins', in order to maintain their interest and enthusiasm.

#### Partnership group activities

##### *Improving resources and services for people affected by cancer*

Good quality information is seen as an essential prerequisite for patients to be able to participate in decision-making about their care.<sup>10</sup> Yet there is limited research evidence that involving service users in the design of patient information materials results in leaflets that are more relevant to patients, and generally more readable and understandable.<sup>20</sup>

The partnership groups in our case study sites were particularly active in seeking to improve the type and quality of information available to patients and carers. Requests for help with leaflet design, for example, were received from both health professionals and patient support groups; moreover, partnership group members worked closely with cancer network information officers. Groups typically contributed to new information resources for patients and carers (including web-based sources), and identified gaps in information pathways. For example, a service user representative explained:

We do sit down and look at the cancer pathway. And some of us are involved in different teams, and we can say, 'Hang on a minute, don't we need a piece of information at this juncture of this patient's journey? Are you going to let the patient leave this hospital without them knowing what happens next in their treatment?' 'Oh', says somebody, 'Of course, never thought about it like that.' So we have the power to fill the gaps of saying, 'Hang on a minute, I'm the patient.' (Participant 34)

This type of project was seen by the health professionals involved in the study as important to group morale, because service users can see



that they have 'made a difference' to patients in a tangible way.

Improving access to cancer services also plays a key role in partnership groups' activities, particularly in networks with large rural populations. Transport to treatment facilities is a major concern for patients, and has formed the basis of a number of successful campaigns. One group, for example, protested at the need for patients to travel long distances for Positron emission tomography – computed tomography scanning, and were successful in negotiating access to treatment closer to home. When a new gastrointestinal cancer service was planned, the group again highlighted patients' concerns, as a cancer services' manager described:

What was interesting is you could say, yes we've got the surgeons, the HDU [High Dependency Unit] beds, the pre-op assessment, but they [service users] came from a different perspective and said, 'Right, what's the bus service like?' (Participant 22)

Good access to care is not only about improving transport facilities or campaigning for local services. Importantly, service user partnerships have worked to enhance access to 'out of hours' care for patients. For example, a consultant in palliative medicine detailed the impact of one partnership group initiative:

[The group members wanted to ensure] that patients and carers had access to advice and support 24 hours a day...So the sorts of services that they didn't find effective or helpful were ones where there was a sense of the drawbridge coming down at nine o'clock in the morning and then being pulled up tight shut at five o'clock. So I think they were quite proactive in pushing that agenda forward. (Participant 21)

This study suggests that service user partnerships were influential in making environmental improvements to cancer services, both in enhancing existing provision, and planning the layout and design of new services. The following quotation illustrates the importance of service user involvement in pinpointing issues important to patients that might otherwise be overlooked:

We recently had a new cancer centre built at our main hospital...and our [service] users were very involved with... the design once it had been built of

inside of it, you know the cosmetic stuff and this sort of thing... But silly things like when you go for radiotherapy you obviously are gowned up, and there's changing rooms where you take your clothes off and put your gown on. Well there were no mirrors in the changing rooms. And [it's] such a simple, simple thing. So we were instrumental in making sure that mirrors were put into the changing rooms. (Participant 04)

#### *Planning and commissioning cancer care*

One of the difficulties in involving people affected by cancer in commissioning services is that it is seen as a complex task requiring specialist expertise and knowledge.<sup>30</sup> In this study a service user representative suggested that, despite group members' involvement in cancer network board meetings (the body which decides overall strategy for cancer services) there is a reluctance to make direct approaches to decision-makers. Another service user explained:

...we haven't got a handle on the big commissioning stuff yet. But we're learning about the process. We need education like they [health professionals] do I'm afraid, about commissioning. But we can actually say...can we think about where this service might be? (Participant 34)

Initiatives which improve service users' understanding of the issues involved in planning and commissioning care can help to overcome this perceived barrier. A partnership facilitator suggested, for example, that service user participation in network board meetings serves an educative purpose, and provides useful preparation for future involvement in commissioning decisions. A group in one case study site carried out a training exercise to prepare service users to take an active role in commissioning decisions. In another, service user members took part in a meeting in which funding priorities for patient information materials were discussed. The following comment from a partnership facilitator illustrates the symbolic importance of service users 'having a place at the table' where funding decisions are taken.

We know that the government want to get more [service] user involvement in the commissioning processes. And we're hoping that... you know sort

of sitting in at the board meetings will actually stand us in good stead for that...So it's a good education for all concerned. (Participant 04)

There are examples of service user influence on the allocation of NHS resources, although these are limited. In one case study site, for example, members' views were perceived as influencing the allocation of £200 000 of new funding for palliative care services. A senior professional described the process as one in which the weight of the consumer voice was exploited:

What they've [service users] been able to do is put pressure into the system, but using quite cleverly 'this is the customers' view', and 'ignore us at your peril'. [...] So we've actually put a lot of money last year into out-of-hours palliative care. And where clinicians have wanted to spend it on the sexy machine that goes beep, the fact that the customers are saying no, out-of-hours care is not good enough, that's been quite an irresistible message. (Participant 24)

Historically, NHS professionals are seen as having a monopoly over specialist, technical knowledge – the tendency therefore is for decisions to be led by expert opinion.<sup>31–33</sup> The educative effects of service user participation can potentially help to close this perceived gap and equalize knowledge bases.<sup>33,34</sup> Indeed, partnership working is dependent on professionals sharing knowledge.

However, the significance of the acquisition of technical expertise by service users should not be overstated. If the rationale for including people affected by cancer in partnership groups is their subjective experience of the disease, it may be more important to ensure that both types of knowledge, experiential and technical, are accorded equal value.<sup>33</sup>

#### Extending the influence of the cancer network partnership groups: key issues

##### *Recruitment, representation and legitimacy*

Recruitment is an enduring problem for cancer network partnership groups. As study participants pointed out, membership is demanding in terms of the time and commitment required, while the nature of cancer as an illness can mean that sustained participation is difficult.

Perhaps more significantly, the representativeness of group membership was also seen as problematic by some stakeholders. The evidence from this study suggests that it can be particularly challenging to engage some population groups, such as certain black and minority ethnic communities, in which the topic of cancer is not openly discussed. Concerns about representativeness stem from the perspective that legitimacy of the service user voice in governance arrangements can only be obtained by the representation of multiple stakeholder interests;<sup>35</sup> indeed, lack of representativeness is frequently cited as problematic.<sup>36</sup> But, as Pickard *et al.*<sup>32</sup> have pointed out, the search for the 'typical service user' can be self defeating and stifle progress; it may be sufficient for service users to act as 'lay examples' in partnership groups. The focus then shifts to pluralistic approaches to decision-making, and diversity and inclusion in local networks.<sup>35,37,38</sup> Martin, for example, argues that representative validity can be achieved by the 'interestedness', 'diversity and particularity' of service users' experiences, allowing them to speak to issues that are 'universally relevant to the broader constituency of patients and the wider public' (p. 1761).<sup>36</sup>

##### *Attitudes and structures*

Many of the participants in our study commented on the 'participatory relationship' as important in the process of influencing services.<sup>13</sup> In many cases, the attitude of professionals was perceived to have been changing over time. A partnership facilitator noted that:

...initially, particularly the clinicians and the consultants, they felt as if it [service user involvement] was a bit of an infringement on them and they weren't happy with it. But over the course of time it has been a hearts and minds exercise with these people, and ... I think now we're proving the value of [service] user involvement. And they're seeing it first hand for themselves. So instead of us approaching them [health professionals] saying, well, we think we should be involved in this, they're now approaching us saying, well, we think you should be involved in this. So the tables have turned – ever so slowly but nevertheless they have turned. (Participant 04)

Service users were invited to become involved in other parts of the cancer network (such as site-specific and cross-cutting groups) and were approached to join steering groups. These were relatively recent developments, but were seen as important in influencing the clinical management of patients, and as a means of enhancing the credibility of service user involvement in decision-making about services in general.

While the well-documented barriers to partnership working between health professionals and service users<sup>1,39</sup> have not been entirely overcome, participants in the study perceived a more open, participatory relationship as key to achieving influence. A service user representative from a partnership group said, for example:

I certainly get the impression that there is a group of more traditional clinicians... who ... do not recognise the movement towards a... user-led health service, or a user participative health service... And I suppose that would be another indicator of ... how I'd know things are changed, when I see them according value to what the patient perspective is and what people say about it. (Participant 35)

Attitudes towards the legitimacy and value of user involvement, whether positive or negative, were clearly an issue for respondents and were put down as markers of progress (or lack of it). Participants in the study also noted other indicators of value in structural arrangements, such as the sustainability of sources of funding, resources to provide training and to support posts such as user partnership facilitators. Respondents argued that the UK government's policy rhetoric about the value of service user involvement in service planning and development should be underpinned by the provision of dedicated resources.

## Discussion

The evidence from this exploratory study suggests that cancer network partnership group members perceived that they had made meaningful contributions to service development, particularly in improving information for patients, enhancing access to services and mak-

ing changes to care environments. The primary focus on practical, operational issues, and the pursuit of short-term goals, may, however, be at the expense of developing a wider, more strategic role. This could be attributed to challenges which partnership groups face, such as funding insecurities, recruitment difficulties and maintaining service user participation, all of which militate against the development of longer-term strategies.

Current UK government policy highlights the importance of patient and public engagement and working with community partners in achieving World Class Commissioning for cancer services.<sup>40,41</sup> Critics suggest, however, that the process of commissioning is currently largely uninfluenced by service users.<sup>42</sup> (Note, however, that Macmillan Cancer Support and the National Cancer Action Team are currently conducting a pilot study which aims to embed service user involvement in cancer commissioning.) Evidence from the present study confirms that, with a few notable exceptions, realizing the aim of engaging people affected by cancer in planning and commissioning care remains an aspiration rather than a reality.

As the authors of an earlier evaluation of the Cancer Partnership Project predicted, the majority of partnership groups have evolved from establishing their place in the cancer networks, through a reactive phase, and are now moving towards a more proactive mode of working.<sup>2</sup> However, in some cases the operational model remains closer to one of consultation than of genuine partnership. A senior professional argued, for example, that:

... the initial suggestion may have come from a comment from somebody, or one or two users of a particular local service, who may or may not be involved with the partnership... As the particular proposal or development has been worked up and taken forward, then the partnership group may be asked for their opinion, or probably more directly you know would they support it rather than even, 'What are your thoughts on this?' Because it tends to be quite late in the day, and ... those developing the service wouldn't want at that stage for it to be undermined... So it's put in terms of, 'Would you



mind supporting this?' And so it's a measure of how – I hesitate at the word genuine – but how meaningful that is. (Participant 15)

The extent to which partnership groups' priorities are driven by service users is still open to question, therefore, although the majority of study participants felt that progress had been made towards meaningful partnership working.

### Limitations of the study

This was a relatively small scale qualitative study. Although care was taken to identify as wide a range of groups and respondents as possible, it is likely that both the core members committed to partnership group working and those key stakeholders identified as having been influenced by the groups would express positive opinions about the influence of service user involvement. It was also apparent from our research that much service user involvement in the cancer network takes place outside the auspices of the partnership groups, for example in the tumour-specific groups. It is a limitation of the study that it did not recruit members of these groups.

### Conclusions

The evidence from this study suggests that service user involvement in cancer network partnership groups is currently at its most effective at an operational level, in improving the type and quality of information available to patients, access to services, and care environments. At a strategic level, however, in terms of planning and commissioning cancer care, the evidence of their influence is less compelling.

With regard to levels of service user participation,<sup>16</sup> the emphasis of the cancer network partnership groups (as the name implies), is on partnership working in committee settings. There is no evidence of NHS professionals ceding control of the decision-making process to service users. If we examine the decision-making domains in which service users can participate,<sup>16</sup> while there is evidence of the influence of the groups on services and resources provided to patients (and such factors are undoubtedly of

great importance to people affected by cancer), apart from a few notable exceptions there is little indication of service user influence in the domains of service delivery resource allocation, or macro-level health care allocation and policy decisions. One of the ways in which service users can be encouraged to participate in higher-level, strategic decision-making is through adequate preparation, education and training. It is also important, however, that service users' experiential knowledge is recognized by professionals as a valuable resource in itself. The development of more open participatory relationships between health professionals and service users was seen by respondents as key to influencing the planning and implementation of cancer care in ways which are responsive to those people most affected.

Although cancer network partnership groups have undoubtedly achieved a great deal in the last 4 years, this study suggests that there is room for improvement if service user involvement is to be at the core of planning and development in the cancer networks, rather than at the periphery. The evidence suggests that there may be a gap between the policy rhetoric and the reality on the ground, so although there is much talk about the importance and value of service user participation, this does not always translate into meaningful influence over care planning and implementation.<sup>34</sup>

Cancer networks are seen as 'early innovators' in promoting the engagement of people affected by cancer in service planning and development; however the evidence from this study highlights the need for sustainable sources of funding to strengthen service user involvement activities, and to sustain the momentum built up in recent years. Participants in this study argued that the UK government's policy statements about the value of service user involvement in service planning and development should be underpinned by the provision of dedicated resources.

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### Conflicts of interest

None.

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