'The squeaky wheel gets the grease': a case study of service user engagement in service development

Susan Nancarrow
Wesley Vernon
Anna Johns
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Susan Nancarrow
Wesley Vernon
Anna Johns

Susan Nancarrow and Anna Johns
Institute of General Practice and Primary Care
School of Health and Related Research
University of Sheffield
s.nancarrow@sheffield.ac.uk

Dr Wesley Vernon
Head of Podiatry
Sheffield South West Primary Care Trust
Overview
This paper discusses the practicalities and limitations of establishing a service user consultation group to guide service developments, based on the evaluation of a ‘Podiatry Patient Panel’ in South Yorkshire. It describes the specific difficulties recruiting a representative panel of service users, and the gradual acculturation of the panel from a group of ‘challenging activists’ to unpaid members of the podiatry department.

Key words: User consultation, service development, podiatry, recruitment, acculturation
**Introduction**

Involvement of service recipients in decisions about service delivery has been growing since the latter part of the twentieth century. These changes have been mandated in the public sector by policies which have resulted in substantial changes to systems of public accountability and engagement (NHS Executive, 1998, NHS Executive, 1999, Department of Health, 2002, Department of Health, 2000). Three key groups of stakeholders are involved in the drive for these changes: the government; the general public and service users; and managers, clinicians and purchasers of services (Crawford et al., 2003).

The motivation to engage service users in health and social care are underpinned by a number of common themes including (Crawford et al., 2003, Hogg and Williamson, 2001);

- To improve service effectiveness and through this, improve the health of the public
- To enhance public perceptions of the quality of care, and as a way to monitor service quality
- To increase democratic accountability for the services
- To empower the service users, thus having therapeutic value for the participant and increase the rights and dignity of service user, and
- To obtain public support for service changes and legitimise the decisions of policy makers and administrators
- To ensure that the services reflect the needs and wants of service users.
- To add particular skills such as financial, legal or media.

Other authors have described additional roles for user participation such as the delivery of voluntary services and health education to patients (Brown, 1999).

Much of the literature around service user involvement focuses on the power imbalances between the service recipient and the service provider. This reflects a backlash against more traditional, paternalistic models of care in preference for models of user empowerment (Hogg, 1999, Crawford et al., 2003). It seems that attempts to engage service users in the service delivery process are at varying stages of evolution ranging from token user membership of existing groups, to sophisticated levels of partnerships between service users and providers. For instance, the United States health insurer Kaiser Permanente have extrapolated the concept of user involvement in health care from the model of ‘patient as consumer’ to engaging the ‘patient as provider’ of their own care (Bodenheimer et al., 2002, Sobel, 2003).

Crawford and colleagues provide a useful overview of the different models of user involvement in service delivery in the public sector (Crawford et al., 2003). They categorise user involvement into two main groups; involvement that is initiated by service users and involvement initiated by service providers. User initiated involvement includes complaints, user groups, user led research and political action. Provider initiated involvement can be time limited or involve on-going relationships. Time limited user involvement may use research methods or deliberative approaches such as public conferences. On-going relationships can draw on specifically developed groups, existing formal bodies or other user or community groups.

Other terminology that is commonly used to describe involvement groups differentiates between ‘consumerist’ and ‘democratic’ approaches. The consumerist model is citizen led and makes managers accountable for responding to the preferences of consumers. In contrast, the democratic approach engages consumers...
in a developmental process to challenge the “nature, distribution and eligibility for services”. In the latter, user engagement is an end in itself where the accountability is to society at large (Brown, 2000).

There are a number of discussion papers on user involvement from the health and social care sectors, however there are few published practical discussions or analyses of the actual approaches that have been adopted (Andrews et al., 2004).

This paper draws on the experiences of a user consultation group that was established in 1999 to support organisational developments within a podiatry service. The trust established the ‘Podiatry Patient Panel’ because the existing methods of obtaining user views were insufficient to address the service development issues arising in the department. Additionally, the service was undergoing accreditation (Chartermark) and needed a way to ensure it met the requirements to improve liaison with and feedback from service users. Prior to the introduction of the panel, the service had relied on feedback relayed by service providers and occasional one-off stakeholder group consultation.

The evaluation had two purposes. The growing interest in user involvement in service development meant that a number of services had approached the podiatry service to learn from their experiences of the introduction and development of the panel. The podiatry service felt that it was necessary to systematically capture the learning from their experiences, reflect on the benefits and pitfalls of the approach, and to be able to provide this information to support other services interested in implementing a similar model.

Whilst the example is taken from a health model, the learning has relevance to a range of services.

**Method**

The evaluation involved a reflective focus group with the panel members (n=5) and an interview with the service manager, both of which were tape-recorded and transcribed verbatim. Additionally, the minutes of the panel meetings were reviewed to examine the outcomes and resolutions for triangulation with the interview data. The data were analysed thematically to address the research questions and the findings were verified by a second researcher, and checked for accuracy with the service manager and deputy.

The findings are presented in two sections that describe the process of recruiting and engaging the panel members and the impact of the panel.

**Involving service users**

There are few published descriptions of the actual processes of recruiting service users to consult on service development committees. Given that individuals are often engaged to represent and reflect the views of the wider service user population, this lack of clear guidelines is an important oversight. The problems of recruiting a truly representative group are well documented, and the additional risks of using inappropriate approaches include the potential for selection bias, and ethical risks such as coercion.

**Recruitment of service users**

The podiatry service experienced some difficulties enlisting service users onto the panel. The service managers had no prior experience of establishing this type of panel so did not know what size of response to expect. To ensure that the panel
remained a manageable size, the initial recruitment attempts were relatively conservative.

The first approach involved displaying A4 sized posters on the walls of all of the podiatry clinics which briefly described what the panel was about, why it was being established, and how to become involved. The posters received few responses.

The managers then asked the podiatrists to speak directly to the service users to ascertain whether they would be interested in joining the panel, however this also met with little response because the service users reported feeling ‘unqualified’.

A lot of the negative responses were ‘oh no, I couldn’t possibly, I’m only an ordinary person’ but it’s that ordinary person that we wanted (service manager).

The podiatrists then undertook stronger lobbying with the service users to reassure them that their point of view was valuable and important for service delivery. This approach resulted in six people who expressed an interest in becoming members of the panel. The potential recruits were interviewed against loose criteria before being invited onto the panel. The panel members were not subject to police checks, but the boundaries of their access to the service were tightly defined to minimise risks to other service users.

At the time of the evaluation, three of the original members were on the panel and two new members had been co-opted. One was a colleague of an existing panel member who voluntarily attended. The second new member was someone who applied to use the podiatry services as a patient, but was refused on the basis that she was deemed ineligible. She was subsequently invited to join the panel to express her views about the service and eligibility criteria.

The ‘representativeness’ of service users
The relatively small size of the panel meant that particular attention had to be given to ensuring the social and cultural diversity of the members. The service undertook more active lobbying in some areas to achieve diversity and consequently, a range of different perspectives were represented on the panel including those of a carer, an Afro-Caribbean, people with severe medical conditions, and someone with a personal disability. The panel did not have representation from people who do not speak English, but could have accommodated this by accessing interpreters if required. Where the views of specific groups were required that were not represented on the panel, the service adopted other strategies. For instance, the service undertook specific consultation at a local Chinese centre to identify their service needs.

The panel membership was not representative of typical service users. For instance, one panel member was a retired NHS chief executive interested in maintaining service input. Some of the panel had previous experience as members of other consultative groups, such as Better Government for Older People and one had been involved in a service as an ‘expert patient’. Others were motivated by a desire to be useful and to make a difference and to represent other “people who aren’t as determined and articulate”, as Box 1 illustrates. The group described themselves as “activists” and “agitators” who were motivated to “blaze a trail”.

| Box 1: Why service users become involved; |
| To voice complaints. |
| Because they were lobbied by staff. |
To be useful and 'give something back'
   Had been members of previous committees
   Highlight issues/shortcomings with the service from a service user
   or general public perspective
   As innovators from the general public
   As advocates for service users to influence health policy and
   services in general
   To make a difference to older people’s services

The meeting processes
The aims and practicalities of engaging the panel were determined by an initial
meeting between the panel members and the head of service, which included
discussion of the length and frequency of meetings, transport and the agendas. The
managers provided some guidance as to their requirements, but allowed the panel to
determine the direction of the group.

Meeting times and venue were arranged to suit the majority of panel members, with a
flexible schedule determined at the start of the year. The agenda was also flexible
and was driven both by the needs of the panel and the service. A senior manager of
the podiatry service chaired the meetings. The panel members and managers
circulated specific issues they wanted addressed prior to the meetings, although
other points were openly discussed as they arose. The flexibility of the agenda
ensured that the panel could openly discuss and debate a range of issues, and also
meant that the most important and topical issues were raised first, before the meeting
ends.

   More often than not we just deal with issues at the meeting as they come up. That
gives a lot more flexibility and it gives you the potential to really get to grips with
things that have just cropped up over the last week and are fresh in peoples’
minds, you know, rather than having a fairly rigid agenda.

The downside of the flexible approach was that a wide range of agendas could be
expressed, it was sometimes difficult to focus the meeting to achieve specific
outcomes, and the process was time consuming.

The service met all costs associated with attending the panel, including the
reimbursement of all travel expenses; lunch for the panel members and a small gift at
the end of the year.

To ensure that the panel members had an understanding of the whole service aside
from the components they had experienced as service users, the managers devised
a detailed introductory programme which showed panel members the diverse
physical and geographic layouts of the different clinics (which are spread across a
number of different locations), the different purposes of the clinics, and the
management aspects, including the budget, service goals and targets and waiting
times.

   We took them around and showed the service in its entirety because we were
conscious that each panel member may only have their experiences of the clinic
that they’d been attending. So we took them and showed them all sorts of things
across the service – the bio-mechanics service, the diabetes side of things, the
surgery set up. We spent a day travelling about with them and they were
absolutely amazed, they’d never seen the service in its entirety. We showed them
things in the drawers, you know, bits of information about the service, about the budget and that worked quite well (service manager).

The impact of the panel
The remit of the panel was to capture the views of podiatry service users about a range of issues that are service or user driven. The panel is consulted about the introduction of any new service developments and quality management initiatives. For instance, the panel members initiated a service audit involving the administration of a user satisfaction tool that was given to service users whilst they were waiting to receive their service. The service addressed the clinical governance issues by consulting with the panel to develop clear boundaries around their remit and physical access to service users.

Panel members are invited to attend the annual service review, a one-day event at which the podiatry service is open to all of the local key stakeholders, including service users, to discuss progress, changes, outcomes and the future directions of the service. A member of the panel normally provides a report on the panel at the service review.

From the perspective of the service, the panel have provided an invaluable viewpoint about a range of issues. They have introduced a number of new and useful ideas that have led to direct innovations in service delivery as the following example illustrates;

*When we were taking the patient panel around we were down at Central Clinic and we were proudly showing them that we’ve got our non-attendance rates down from 15% to 8% and they were appalled. We were really proud of this and they were appalled that 8% of people weren’t coming – a completely different perspective. We’d normalised non-attendance and were just pleased with the improvements and they were so appalled and they were saying why is this? We said well people just don’t ring up and cancel appointments, but it doesn’t cost much and [the manager] narrated the story of the conversation with somebody who said ‘I’m not spending 5 pence on a phone call to cancel the appointment; that’s my money’. So the patient panel member said ‘use a free phone’ and as a result we’ve got that free phone. So actual developments happen through patient panel ideas (service manager).*

Consultation with the patient panel has resulted in changes to the presentation and layout of the printed information given to service users. For instance panel members altered the patient information leaflets by changing the wording and commenting on the layout and font size. In consultation about one brochure, the panel commented that the font size was too large and demeaning. The service pointed out that this was necessary for people with a visual impairment, who did not have representation on the panel.

The panel also provides a valuable lobbying tool for introducing or maintaining service levels from senior managers and service commissioners that directly reflects the view of the patient panel.

*So when we have an idea and another health professional says ‘oh no, we shouldn’t be doing those sorts of things’, ‘well actually the patient panel want it. We’ve spoken directly to patients and this is what the patients want’. You’re talking about cutting the service over there and the patient panel think that is*
appalling and it should be left alone, so it's a very powerful thing when we can quote patients directly (service manager).

The lobbying role of the panel was also recognised by the panel members.

_They need our support to alter the system, so they have to consult our patient panels saying this is what people want (patient panel member)._  

The panel are also used to provide feedback to non-health audiences. For instance, the podiatry service introduced a 'shoe standard initiative' that describes various quality attributes of footwear. They invited footwear retailers to attend an open discussion forum to launch the initiative, and had patient panel members express their views and experiences about footwear.

Additionally, from a service perspective, the engagement with the panel fulfils the 'consumerist' requirements of service user involvement that are required for quality assurance and accreditation systems.

The panel members were unanimous in their perception that they make a difference to the service. They perceived that they had been able to influence waiting times. They also felt that they had some influence over the “top brass” by influencing decision making from the “bottom up”.

_My feeling is what other mechanism is there within the structures of PCTs or acute hospitals that alerts the management or the medical hierarchy to failures in their system or shortcomings in their system? (Panel member)_

There was a perception from the panel that they were acting as a guardian for accountability for public spending. They reported that they expected to get a good service in return for paying their taxes, and one member even reported that she “could not afford to be involved in” the panel because too much money is at stake in public spending on services.

The panel members also felt a certain personal responsibility for the effective delivery of the service. For instance, one member said that he was “ashamed to be a member of the panel” as a result of a complaint about waiting times and said he hoped to “get to the bottom of it”.

_We’re like a watchdog and we’re looking at the things sometimes down a microscope, sometimes from further away, sometimes talking to people, sometimes listening and now we’re about to embark on being able to visit clinics where we can sit …and question, gently, the patient how they feel (panel member)._  

However the panel members had taken their responsibility beyond the boundaries of the panel forum and started lobbying on behalf, but not the behest of the podiatry service. For instance, panel members have voluntarily attended PCT open events to express their viewpoints about the service. They also suggested that they would go to a local newspaper to make a point about service accessibility.

_The squeaky wheel gets the grease and we start as a committee writing letters and complaining… We can actually go to the Star, pick a prime case and say you know, being like this for this long and how has it impinged on your lifestyle, you can’t do that, can’t go out to the paper shops… and we can publicise it (panel member)
The service users were enthusiastic in their belief in the importance of podiatry and were concerned about the lack of awareness of the services by other health care providers and the general public. The panel members even suggested that they could take a role in the preventative aspects of the service.

**Box 2: Service user perceptions of the role of the panel**

- To help to monitor the service.
- As a watchdog
- Give staff feedback about how they can alter their systems
- To support staff
- To promote the podiatry service and increase the understanding of the service
- To improve service quality
- To lobby funders to support the service

**Limitations of the panel**

One of the important learning points from the patient panel was the evolution of the relationship between the panel and the service. The involvement of panel members was not time limited, and over time, as they developed an increased understanding of, and role within the service, they started to see the service more from the perspective of the organisation rather than from the perspective of the service users. As a result, the patient panel started to become advocates for and extensions of the service rather than advocates for the general public.

*Panel members can become ‘native’. So what we found is we were looking for a view that would be prepared to be challenging and some of the panel members just ended up thinking we were the best thing since sliced bread and weren’t challenging anything we did. So in effect they’d become members of the department and weren’t necessarily seeing it purely as patients anymore (manager).*

The involvement of the activist created some tensions in the running of the panel because of a perception that some of the panel members attempted to use the meeting as a forum to express personal agendas.

*There’s this pitfall of the activists trying to take the panel over rather than the ordinary person (manager).*

**Conclusions and implications**

This paper has illustrated an example of ongoing, provider-led consultation with a group of service users and community members in the organisation and delivery of a community podiatry service. This example is slightly unusual in that it shows the engagement of service users to advise on a specific professional discipline (podiatry) rather than on the activities of an entire, multidisciplinary service, enabling service users to develop a closer understanding of the roles and activities within the service. Whilst this example is from a health service, a number of the issues are likely to be transferable to other community based public sector services, such as the considerations for recruitment and the processes of engaging the panel members.

It highlights a number of factors that are already known about the engagement of service users. For instance the difficulty obtaining a representative group of service
users is well documented (Sykes, 2003, Brown, 1999). The service developed a panel of users who are consulted both about service issues and freely bring their own agendas to the meetings. The people who became engaged with the process were, by their own admission ‘activists’ wanting to bring about change. They use their role as patient panel members to lobby to other decision makers about the service and on behalf of other service users. As Hogg and Williamson point, activists are found in all groups, they are the people who are more likely to become leaders, and they are more likely to be elected to positions where they speak out for the interests of their peers. Thus, it makes sense that they are the people likely to be found on user involvement groups. However, it is difficult to know whether they truly represent the views of the wider constituency.

The difficulties obtaining a ‘lay’ perspective have also been highlighted, in particular, there is a common perception that activists are often not considered to be representative of their peers (Hogg and Williamson, 2001). This case study reinforces the paradox of user involvement. In this service, the panel members were given training to increase their understanding of the whole service, providing them with knowledge about the service that would be beyond the understanding of a ‘typical’ patient. The establishment of a relationship with a group of service users, and investment of time in them to provide them with a clear understanding of the service was necessary to provide the depth and quality of feedback that the service requires. However, this process started to erode their external view. Whilst this brings the advantage of ease of discussion about a wide range of issues, the ‘going native’ of the panel means that they lost their distinct advantage as an objective member of an advisory group. Instead, they became unpaid members of the service and lost their voice as service users. The users came to the service wanting to challenge and improve the service, but they now advocate on behalf of the service as well as service users. One way to overcome this is to set clear time-limits around the involvement of the service users that are made explicit at the start of the process.

It may be possible to explain the evolving relationship between service user involvement and the service providing organisation by looking at the issues of acculturation. The differences in cultures and values between the service user and provider are well recognised (Ramsden, 1980). It may be that the process of user involvement in service delivery is a type of acculturation from which the new entrants (in this case service users) eventually become normalised. Guanipa (1998) describes five stages of ‘culture shock’ in which a new entrant to a different culture initially finds novelty in the new setting, then moves through a stage of resistance to the differences, but finally adopts some of the attributes of the new culture and perceives their original culture from the new perspective. The relevance of this model for the engagement of service users in service developments could be, firstly an understanding of the various stages that the service users are experiencing and secondly, recognition of the need to provide appropriate support through these stages. However, in order to truly obtain the fresh perspectives of the service users, their views are likely to be most valuable in the first two phases of acculturation. It is surprising, given the potential value of the first two stages of acculturation that the process is not used more widely as a management tool. Most of the management literature seems to emphasise the assimilation aspects of acculturation, rather than the enormous potential learning that could take place from the fresh perspectives.
Box 3: Key learning for practice

Recruitment of service users can be difficult and is likely to attract activists.

Time limit the involvement of the service users from the outset.

It is difficult to get representative involvement in a service user panel. To elicit views from specific group, it is probably more appropriate to use a time limited, deliberative or research approach to address a specific question.

Service user panels cannot have knowledge or understanding about the particular needs of every potential service user and it is important to be aware of the limitations of the panel.

A user panel is a valuable way to provide a different perspective on a range of service development issues.
References