

Service user involvement in cancer care: the impact on service users

Phil Cotterell MA PhD,* Gwen Harlow BA (Hons) MSc,† Carolyn Morris BA (Hons),† Peter Beresford OBE PhD,‡ Bec Hanley MA,§ Anita Sargeant PhD,¶ John Sitzia BA MPhil (Dual hons)** and Kristina Staley BA (Hons) PhD§

*Senior Research Fellow, Faculty of Health Sciences, University of Southampton, Southampton, UK, †Independent service user researcher, Consumer Liaison Group, National Cancer Research Institute (NCRI), London, UK, ‡Professor of Social Policy, School of Health Sciences and Social Care, Brunel University, London, UK, §Co-Director, TwoCan Associates, Hurstpierpoint, UK, ¶Lecturer, School of Health Studies, University of Bradford, Bradford, UK and **Acting Chief Operating Officer, National Institute for Health Research (NIHR) Clinical Research Network Coordinating Centre, London, UK

Abstract

Correspondence

Dr Phil Cotterell
Senior Research Fellow
Macmillan Survivorship Research
Group
School of Health Sciences
University of Southampton
Highfield
Southampton
SO17 1BJ, UK
E-mail: p.cotterell@soton.ac.uk

Accepted for publication

28 June 2010

Keywords: cancer care, impact on service users, involvement, service user

Background Service user involvement is embedded in the United Kingdom's National Health Service, but knowledge about the impact of involvement on service users, such as the benefits and challenges of involvement, is scant. Our research addresses this gap.

Objective To explore the personal impact of involvement on the lives of service users affected by cancer.

Design We conducted eight focus groups with user groups supplemented by nine face-to-face interviews with involved individuals active at a local, regional and national level. Thematic analysis was conducted both independently and collectively.

Setting and participants Sixty-four participants, engaged in involvement activities in cancer services, palliative care and research, were recruited across Great Britain.

Results We identified three main themes: (i) 'Expectations and motivations for involvement' – the desire to improve services and the need for user groups to have a clear purpose, (ii) 'Positive aspects of involvement' – support provided by user groups and assistance to live well with cancer and (iii) 'Challenging aspects of involvement' – insensitivities and undervaluing of involvement by staff.

Conclusions This study identified that involvement has the capacity to produce varied and significant personal impacts for involved people. Involvement can be planned and implemented in ways that increase these impacts and that mediates challenges for those involved. Key aspects to increase positive impact for service users include the value service providers attach to involvement activities, the centrality with which involvement is embedded in providers' activities, and the capacity of involvement to influence policy, planning, service delivery, research and/or practice.

Introduction

Service user involvement is an idea and activity that has been gaining in importance and priority in many different contexts over the last three decades in many countries including Great Britain (GB).¹ Yet, we are at an early stage in our knowledge and awareness of what the gains are from user involvement; what its actual 'impact' is for those becoming involved. This is a point which is increasingly being made by commentators and in the literature.²⁻⁵ It is a point that this discussion explores, building on a research study that focused on the impact of user involvement on service users affected by cancer.

Within health and social care in GB, service user involvement has been particularly understood and developed with people in mental health, HIV/AIDS, maternity and disability settings, and has been reflected in policy developments from the Department of Health (DH)^{6,7} in England, along with similar developments in Wales and Scotland.^{8,9} Of particular influence has been section 242 of the National Health Service (NHS) Act, which consolidated previous legislation on Patient and Public Involvement (PPI), and placed a statutory requirement on NHS organizations to strategically embed involvement in all activities.^{10,11}

Other developments include Local Involvement Networks (LINKs) being phased in to replace PPI Forums and the Commission for PPI in Health;¹² an undertaking from the NHS Next Stage Review (known as the 'Darzi Report') that patients and the public will remain central to the development of the NHS;¹³ and, due to failings at Stafford Hospital in England (where there were very high mortality rates for emergency admissions), a reaffirmation that patients' views need to be a top priority in shaping and guiding the services provided in all NHS organizations.¹⁴ PPI can then be seen as a core aspect within an improvement framework.

Background

The development of involvement activities in the NHS has been mirrored in cancer care for over a decade now with cancer policy initiatives

influential in this area^{15,16} and service user involvement now, importantly, forming part of core standards.¹⁷ Service user involvement in cancer services has been specifically promoted in an initiative, the Cancer Partnership Project, which paved the way for a robust system of involvement to be established. This project provided an infrastructure in which people affected by cancer and professionals working in cancer services joined together as groups within cancer network management structures to influence local cancer service development. Evaluations of this project highlight that groups are involved in an impressive range of activities suggesting that they provide much more than a consumer feedback role,¹⁸ and that they influence cancer care in a number of different ways.¹⁹

Involvement appears set to remain central to the development of cancer services with the Cancer Reform Strategy clearly affirming user involvement as an implicit component of good cancer service commissioning and delivery.²⁰ Involvement has also been occurring in palliative care, although there is a shorter history in this setting. Consequently, according to the most recent survey of hospices in the UK (although it only included 25% of hospices), under half had any form of user group.²¹ A national scoping exercise found that there was an increased activity level of service user involvement in palliative care.²² Evidence about the work and impact of hospice-based user groups is limited, although reflections on one specific group illustrate the possibility of quite significant changes including the involvement of service users in the day-to-day workings of the hospice.²³

GB government health research strategy is also now committed to involving service users in research undertaken in the NHS^{24,25} and key organizations work to promote and advise on all aspects of service user involvement in research (e.g. INVOLVE).³

Involvement in research concerns contributing a unique perspective that can change research design and/or conduct, and the generation of new knowledge. Involvement in service improvement and/or delivery concerns appraising and improving existing initiatives. Such change in

service improvement is likely to occur over a greater length of time, whereas it is possible for service users to see their impact sooner when involved in research. In this study, we included participants involved in the settings of cancer service improvement and research. We did not set out to explore how involvement in these areas differed from the other, but rather asked generic questions on the impact of involvement across settings. In fact, in this study, many participants were involved in both service improvement and research or vice versa. Whilst there may be different experiences of impact due to characteristics such as age, gender, ethnicity, sexuality and cancer type, this was not revealed in this study.

Impact of involvement on service users

Despite this raised interest and activity, there remains a need to 'evidence' the impact of involvement.²⁻⁵ invoNET (a network of people e.g. career researchers/commissioners, and service user researchers amongst others) is facilitated by INVOLVE, which supports people with an interest in building evidence, knowledge and learning about public involvement in NHS, public health and social care research (see <http://www.invo.org.uk/invoNET.asp>). A bibliography has been compiled by invoNET containing 132 references concerned with public involvement in research.²⁶ This bibliography contains 94 papers that report some aspect of impact, of which eight are in the setting of cancer research.²⁷⁻³⁴ Just three of these^{30,32,34} focus on the impact of involvement that is anything other than consultative involvement and none of them concerns a sole focus on the impact of service user involvement. There is other evidence on impact of involvement in cancer and palliative care research,³⁵⁻³⁷ but it remains difficult to establish substantive indications of impact.

It is clear then that despite a central policy orientated emphasis on involving service users in cancer services and research, only very few studies have focused on the issue of impact in cancer research. To the best of our knowledge, there have been no studies focusing primarily on the question, 'what is the impact of involvement on service

users themselves?' It is important to understand issues around personal impact of involvement for many reasons. This may be to develop our understandings of any connection between personal impact and recruitment and retention of service users in involvement activities. Also, it is important to begin understanding what wider issues the personal impact of involvement fosters.

Study design

This research, funded by Macmillan Cancer Support in their user-led grant scheme, aimed to describe the impacts of involvement on the lives of service users affected by cancer who participate in involvement activities. For the purpose of this research, involvement was defined as activities undertaken by service users with a view to informing or influencing services, policy, planning, and/or research based on their experience of being affected by cancer. Impact was broadly defined as the personal effect of involvement activities. We were aware that a small number of involved service users with non-cancer conditions were involved in groups we wanted to work with, particularly in the setting of palliative care. We wanted to include these individuals. Our funding enabled us to include participants across GB; England, Scotland and Wales specifically.

We wanted to identify and recruit involvement groups (e.g. user groups) as well as involved individuals. Groups and individual participants were eligible if they were involved in one of three different settings: cancer services, palliative care and research in cancer or palliative care. We also wanted user groups and involved individuals across local, regional and national levels in England, Scotland and Wales. Finally, we wanted to reflect a wide range of experiences and perceptions regarding the active involvement of service users. We pursued a purposive sampling strategy to obtain a range of involvement groups/individuals as outlined above. Initial user group contacts were generated by the research team and supplemented by word of mouth, advertising on relevant websites and discussion forums. In total, we recruited 64 participants.

Of the total participants, 43 (67%) were women and 21 (33%) were men. Fifty-six (87%) provided further demographic information; consequently, this contextual information is incomplete, but offers some insight into the participants who took part. Age of the participants ranged from 41 to 78 years with the average age being 61 years. Apart from two participants, everyone identified themselves in what can be termed a 'white British' category. Participants reported a wide range of different cancers including breast cancer (16); bowel cancer (5); prostate cancer (4). Three participants, in the setting of palliative care, reported that they had non-cancer conditions (Chronic Obstructive Pulmonary Disease; Still's disease; Parkinson's disease). Eleven participants identified themselves as being carers, and the same number reported that they had been carers for their partners who had died.

Involvement group members were contacted via group facilitators or group chairs where this information was public knowledge. Individuals were contacted via an intermediary e.g. lead researcher or involvement lead. Informed written consent was obtained prior to all data collection. Table 1 illustrates the types of groups included and which setting groups and individuals came from.

We conducted focus groups with eight different involvement groups, eight interviews and, to include absent members of involved groups, four participants completed a brief questionnaire about their involvement.

All data were audio-taped and transcribed verbatim. The approach to analysis was based

on a collaborative approach used with success previously.³⁷ Three members of the research team, the career researcher and service user researchers (PC, GH and CM), individually read all transcripts and noted initial interpretations. During the subsequent collaborative analysis phase, we shared our individual interpretations and our final themes were shaped by this whole iterative process. Early themes were shared with the Research Advisory Group (see below) and their insights fed into the analytic process. Key findings generated from analysis are presented below.

Ethical approval was secured from the NHS ethics service and the School of Health Sciences and Social Care Research Ethics Committee, Brunel University.

Service user involvement in the study

We used a participatory approach. By this, we mean that service users affected by cancer were involved as integral members of the research team, rather than in a tokenistic way, throughout the length of the study. We achieved this with the career researcher (PC) working with two independent service user researchers who were affected by cancer (GH and CM). The idea for the study was developed (with GH and CM). Along with shaping the outline research bid, and the full application for funding, along with (PC), they collaborated with writing the research documentation for participants; planning recruitment; developing the questions to ask; carrying out interviews

Table 1 Group type, group setting or individual and level of involvement

Setting	Groups, individuals and level of involvement
Cancer care	Cancer services user group X 2 (local) Cancer network partnership group (regional) Individual involved in cancer care services (local, regional and national)
Palliative care	Hospice user group X 3 (local) Palliative care user group (national) Individuals involved in palliative care services X 2 (local and national)
Research in cancer and palliative care	Cancer research user group (regional) Individuals involved in a cancer research user group X 6 (national) Individuals involved in research X 3 (local, regional and national)

and focus groups; analysing data; and in dissemination activities, which included the writing of a booklet based on our findings.³⁸ Working in such a way was very rewarding for all involved, and being part of the dissemination of our research findings, in outputs such as this article, has been especially satisfying for the service user researchers. Undue reliance on individual views and interpretations was avoided, in terms of data collection and analysis, by the career researcher (PC) and service user researchers (GH and CM) working closely together and providing an auditable and transparent research process. A Research Advisory Group, consisting of researchers experienced in service user involvement, cancer and palliative care (PB, BH, AS, JS and KS) provided advice and support throughout the course of the study.

Findings

We identified three overarching themes: expectations and motivations for involvement; positive impacts of involvement; and challenging impacts of involvement. Each will now be described in turn.

Expectations and motivations for involvement: "It was very much a leap into the unknown"

Participants described why they became involved in their particular involvement activity and what they expected to achieve.

Improving services

It is clear that when participants were at the beginning of their involvement activities, they had complex reasons for becoming involved. For some, treatment had not gone smoothly, it was less satisfactory than desired, and cancer care was largely negative. There followed a motivation to turn the experience around by being positive, by moving forward:

My involvement was from anger really. I saw things that could be changed very easily not, not based on money, but on common sense and on the feelings of the patient. (Sarah, cancer services user group 2)

Many service users wanted to become involved in groups to change things for the better, to be part of shaping new, and more appropriate treatment for others going through a similar experience. Gaps in service delivery were noted and it was hoped that involvement might, in some way, contribute to service improvement:

I had a, not a mission, but I was passionate about a few things when I joined. ...I had a burning desire for patients to be given more control of their treatment. That was why I first joined. (Fiona, cancer services user group 1)

Pay back

Some service users told us that becoming involved was a direct response to the 'five star' treatment they or a partner had received:

It's pay back to the hospice for looking after my wife in a very good way. (Eric, hospice user group 3)

This was a motivation that we heard about from some participants; however, it was not the overriding motivation. Mixed motivations and motivations that change over time were more common.

Lack of clarity

It is important to note that many service users were very unclear, when first joining their groups, about what they might be able to achieve. Expectations of possible achievements were very vague and under developed:

I don't think I thought about it properly, I don't know, it was very much a leap into the unknown. I just kind of thought this will be interesting. (Val, national cancer research user group)

This uncertainty continued on joining groups with group role and members remit of responsibility continuing to be vague. For some, stepping into the unknown was seen as quite exciting. However, many service users felt a degree of disappointment with the lack of focus and that their involvement had not, so far, achieved what they had hoped. The impact of

involvement was questioned; as for many, there seemed to be some distance between what they wanted to achieve and what their group appeared able to offer.

Positive impacts of involvement: "It has meant that life didn't stop, it grew"

Participants described the personal benefits of being involved in their various involvement activities.

Living with cancer

Many participants discussed how involvement had a positive impact on the actual experience of living with cancer. It was clear that involvement was used as one way to differentiate between the disease of cancer itself and the person who continues to exist despite the serious threat posed. This was explained in many ways. For some, and this seemed particularly so in the setting of palliative care, being involved helped to dispel feelings of hopelessness. Involvement in a palliative care user group enhanced self-confidence and offered a sense of belonging and of being able to contribute. Across all settings, involvement was associated with bringing something positive back into life:

It can be quite isolating and quite worrying (living with cancer)...it's been tremendous sort of socially to just get out and meet people and go to meetings and meet with people. It's been very, very positive in that respect. It's broken down some of that isolation. (Sophie, national cancer research user group)

A related point suggests that involvement, to some degree, facilitates cancer survivorship by refocusing participant's lives in a positive, purposeful and productive way. Working in groups alongside other people affected by cancer could be inspiring, particularly if others are surviving cancer and 'doing well'. Some participants were able to identify these people and utilize them as role models:

One of the personal benefits of being in the (name of group) is you meet people who have had cancer or had cancer many years ago and are surviving, live with it and are alive and kicking and doing

well. So...actually meeting people who have survived it for a long time and in a few cases cured of it, that's very powerful information in supporting your own activities and your own determination to get on with life. (Jack, national cancer research user group)

More generally, participants reported significant reactions and struggles regarding their cancer diagnosis, the process of treatment and longer term survivorship. Coming together in involvement groups, in any of the settings, with others who shared similar experiences was a reassuring and confidence boosting experience:

It has given me a sense of purpose. Has been a distraction and widened my horizons after having them shut down during cancer treatments. (Patti, national cancer research user group)

Many participants described their involvement activity as a positive way to keep active, to combat depression and loneliness, and as a way to deal with their cancer diagnosis and treatment:

In a funny sort of way, I think it has helped me to deal with treatment. It has helped me to only give it a small percentage of my intellectual thinking and my emotional feeling. It has meant that life didn't stop or life didn't change, it grew. (Marian, non-group member cancer care)

Personal and collective achievements

We heard that pursuing a new direction with user groups was exciting and brought about personal feelings of helpfulness and satisfaction:

Achievement is very important I think, within yourself. I feel I achieve things more because I am part of the user group and that sense of achievement is good. (Sarah, cancer services user group 2)

Being active in ways that could not have been imagined prior to joining the user group brought a sense of personal achievement. There were also collective achievements whereby user groups had attained objectives and succeeded in making a specific issue an organizational priority:

I enjoy the challenge of looking at it in a regional level in trying to make, and have some influence over the powers that be that are still trying to develop these services. (Brenda, cancer network partnership group)

A supportive community

It was clear that cancer diagnosis, treatment and 'just living with it' had been life-changing as well as life-challenging. Participants described their experiences using powerful language: 'you feel like you have been thrown on the scrap heap'; 'it was absolutely traumatic. I thought I was going to die'. Many spoke of involvement renewing their contact with others, as joining a supportive community where their experience was accepted and understood. Many participants relayed that groups were not support groups and differences between support groups and user groups were explained. However, there was clearly a supportive element present that was valued in all groups:

It isn't a support group but my God it's a support group (laughter). We actually enjoy each other's company. Which I think when you've had cancer is a very nice thing, is it not? (Keith, cancer services user group 1)

A member of another group explained this differently:

The support is not written in formally to the constitution of this group but it just happens. It's something that comes out of it. (Ben, regional cancer research user group)

Being with others in a similar situation was also seen as a way to 'keep cancer in its place'. Other user group members were understanding the experience and the associated feelings, and talking about these with other group members avoided the need to 'burden' family and friends:

Pam and myself have got this bond thing now and where she will ring me up because she will probably get this feeling that there is something wrong with me or I will phone her and say "what's to do"? And she will tell me. So we have like this built in buddy system thing. (Jo, national palliative care user group)

It appears that the supportive nature of groups was a factor that enabled the group to fulfil its primary functions. Working together in groups also brought about a sense of solidarity, camaraderie and acceptance. You could be

yourself, but also belong to a group consisting of others sharing similar concerns. Involvement could also be fun:

We get on socially, can have a laugh and a joke and talk about other things and then you come back and focus on what you are meant to focus on which I think is important. (Kate, regional cancer research user group)

Challenging impacts of involvement: "There is still a huge element of staff paying lip service to user involvement"

There were clearly issues and experiences that participants found diminished the impact of their involvement experience in some way.

Relationships with professionals

Involvement in groups came about because of participants' experience of cancer. As the groups were concerned with cancer and palliative care services and research, involvement necessarily meant contact with professionals working in these areas. For some, this direct contact with professionals proved a challenge, perhaps in terms of hearing negative information about one's own cancer type and potential prognosis, or in the understandable personal emphasis placed on what is discussed in meetings with professionals:

Sometimes...the other people in the room (researchers/clinicians) are...talking about issues that they deal with professionally and so they have got their professional head on but, as (service user) members, there are times when you are talking about things that are intensely personal to you and ...it's difficult to engage in the conversation unemotionally on something that has had such a profound impact on you. It means you are on a different footing to the other people in the room. (Val, national cancer research user group)

Such interactions could be distressing for participants. Others also discussed the impact of what professionals said in meetings they attended:

They were talking about a treatment for bone metastases at the end of life, chemotherapy and the comment was "of course it won't do any good, will it?" So I said "well, why give it?" And there was a

comment about a treatment using 5FU for a particular cancer that has no effect. But they give it anyway. I do find these things distressing because patients are being put through needless, pointless procedures and also it's a waste of money. It makes me annoyed; it makes me angry because I might be on the end of that one day.

I do find it difficult when I go to conferences and professionals make throw away remarks like "well once you've had cancer, of course it will always come back." That really pushes you right down again. (Les and May, regional cancer research user group)

These are examples of the personal challenge of relationships with some professionals and the more negative personal impact involvement can have. We also heard of frustrations concerned with bureaucratic staff attitudes and the sense of powerlessness that professional inaction could lead to.

Perception and credibility

Something that clearly concerned many participants was how they were perceived and treated by the various professionals and organizations they were working with. In broad terms, there was a strong commitment to influence services and/or research in order that they may be made more effective, appropriate and 'patient-centred'. Participants across the range of settings we spoke with were worried that their ability to deliver on these points was being compromised by user involvement being under valued and to some extent marginalized:

We took part in a consultation with the Department of Health on end of life care, but what happens then is they get a different version written (by the host organization)...your views get neutralized. So that what you're actually saying doesn't get through to the final report. (Cerys, non-group member palliative care)

There was a similar sentiment in another palliative care organization, but within cancer services too, there were concerns about being peripheral to decision-making:

What I'm not certain about is whether you are just a voice in the wilderness, you know, you voice some concern about some aspect of cancer services

and (name) assure us that it goes along to the management teams you know and gets taken on board but I'm not entirely sure that it does. (Mike, cancer services user group 2)

Many participants were aware and disappointed that they were sometimes referred to as 'professional users' or 'the usual suspects'. Having responded to the request to become involved, there was some confusion and annoyance at the use of these divisive terms. For some, there was a perception that staff had tokenistic attitudes about involvement:

There is definitely some resistance to certain things that have been brought up around the table...I think, sometimes, there is still a huge element of staff paying lip service to user involvement, I know there is...there are still too many staff, the management, who it's a token gesture. It's a barrier. (Sarah, cancer services user group 2)

There was a perception that participants, and their groups, were peripheral to core activities and priorities. Experiences of tokenism and of being undervalued left some service users feeling undermined and used.

There was also a call for greater networking between different groups in cancer and palliative care. Opportunities for co-operation, collaboration and development between groups were rare, but it was felt that this could strengthen and accentuate groups' positions as well as increase learning at a group level.

Discussion

These findings have gone some way to unpack the personal impact for service users who become involved in cancer and palliative care services and research. It should be noted that there are likely to be distinctive issues in this setting where most participants had faced a potentially life-threatening illness and where we know people can have significant ongoing problems associated with their cancer and treatment.^{39,40} Impact of involvement in this study has been interpreted in light of participants' cancer diagnosis and experience.

We have seen a range of expectations identified that service users have when they first

become involved and a desire to contribute to service improvement is a priority for many. Such an expectation has previously been highlighted by service users and others in this setting.^{41–45} This study has highlighted that the aims and objectives of involvement activities, in this setting, had not been clearly conveyed to those involved. For some, this was acceptable, but, for many others, the impact of this was frustrating, and when this was not any clearer over time, it became an issue of deep concern. Indeed, some service users we spoke with were talking of leaving their groups because of this lack of vision. There has been consistent and clear guidance on the need for clear vision and aims within involvement activities,^{46,47} but this issue remains problematic.⁴⁸ This relates to the problem of retention of group members; people need to know what the aim of their group is and what they can expect from their involvement activities to remain satisfied with regard to their involvement.

The role and remit of user groups need to be very clear then, as do the roles and responsibilities of involved service users to allay dissatisfaction in user groups. Disseminating clear roles and aims will also assist potential group members who may be considering involvement.

There are clear positive personal impacts associated with involvement. One aspect is how people deal with the ongoing impact of cancer and how involvement can assist with 'living well' with cancer. It is not solely a contribution to living more positively with cancer but also to flourishing in more general terms. A service user in palliative care has described how involvement has contributed to her moving on 'to carve out a new life.'⁴¹ We have presented evidence here that would also point to involvement offering the possibility to enhance life and for service users to grasp new opportunities. An important factor in user groups enabling this to occur appears to be the support and camaraderie such groups can offer. Involvement in user groups can foster collective support and a sense of solidarity. The strength of this needs to be recognized and nurtured, as it is a core element that enables user groups to thrive and for individual positive

outcomes to be fulfilled. Such solidarity has been highlighted elsewhere,⁴⁴ but we suggest that service users in such 'supportive' groups are likely to remain involved even when faced with challenging issues.

The findings also concur with earlier work⁴⁸ in that feeling that you are achieving or influencing services or research is connected to feeling positive about being involved.

Perceptions of challenging impacts of involvement were often associated with the professionals participants were interacting with. We have seen how involved people affected by cancer can hear troubling or distressing things about cancer when engaged in work with cancer professionals, as reported previously.⁴⁹ Professionals can also convey an attitude that suggests that involvement is a peripheral activity or that involvement is a low priority. This and other findings^{22,42} indicate that this can lead to frustration and a loss of motivation in service users. User groups need to occupy a more central position within cancer and palliative care services and research to be viewed as credible, in order that their capacity to influence policy, planning, service delivery, research, and/or practice is fulfilled, and in order that the personal impact of involvement is raised.

Conclusion

Involvement in the setting of cancer and palliative care services and research has been evidenced to have varied and, at times, significant personal impacts on those people affected by cancer who become involved. This study has highlighted areas that require attention and action to maximize positive impacts for those involved and, importantly, to enable involvement to be effective in terms of assisting with service improvement and research.

It will be particularly important to address these issues if involvement is to become more routine and more diverse, as is increasingly required. Departments, organizations, initiatives and individuals charged with taking user involvement forward need to focus on enhancing the personal impact of involvement. This will be

of benefit to all concerned with service improvement as well as encouraging involvement to be a more positive and effective experience and activity.

Acknowledgements

We acknowledge the generosity of participants who gave their time and those who helped to facilitate access to user groups.

Funding

Macmillan Cancer Support.

Conflict of interest

There are no conflicts of interest.

References

- Coulter A, McGee H. *The European Patient of the Future*. Maidenhead, UK: Open University Press, 2003.
- Thornton H. Patient perspectives on involvement in cancer research in the UK. *European Journal of Cancer Care*, 2002; **11**: 205–209.
- INVOLVE. Definitions of different types of impact of public involvement on research. 2007; Available at: <http://www.invo.org.uk/Library.asp>, accessed 28 September 2009.
- Hubbard G, Kidd L, Donaghy E. Involving people affected by cancer in research: a review of the literature. *European Journal of Cancer Care*, 2008; **17**: 233–244.
- Staniszewska S, Herron-Marx S, Mockford C. Editorial-Measuring the impact of patient and public involvement: the need for an evidence base. *International Journal for Quality in Health Care*, 2008; **20**: 373–374.
- Department of Health. *Patient and Public Involvement in the New NHS*. London, UK: DH, 1999.
- Department of Health. *Strengthening Accountability: Involving Patients and the Public*. London, UK: DH, 2003.
- National Assembly for Wales. *Improving Health in Wales: A Plan for the NHS with its Partners*. Cardiff, UK: National Assembly for Wales, 2001.
- Scottish Executive Health Department. *Our National Health: A Plan for Action, a Plan for Change*. Edinburgh, UK: The Scottish Executive, 2001.
- Department of Health. *National Health Service Act 2006*. London, UK: DH, 2006.
- Department of Health. *Real Involvement: Working with People to Improve Health Services*. London, UK: DH, 2008.
- Department of Health. *The Local Government and Public Involvement in Health Act 2007*. London, UK: DH, 2007.
- Professor the Lord Darzi. *High Quality Care for All: NHS Next Stage Review Final Report*. London, UK: DH, 2008.
- Colin-Thomé D. *Mid Staffordshire NHS Foundation Trust: A Review of Lessons Learnt for Commissioners and Performance Managers Following the Healthcare Commission Investigation*. London, UK: DH, 2009.
- Department of Health. *A Policy Framework for Commissioning Cancer Services (The Calman-Hine Report)*. London, UK: DH, 1995.
- Department of Health. *The NHS Cancer Plan*. London, UK: DH, 2000.
- National Institute for Clinical Excellence. *Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer. The Manual*. London, UK: NICE, 2004.
- Richardson A, Sitzia J, Cotterell P. 'Working the system'. Achieving change through partnership working: an evaluation of cancer partnership groups. *Health Expectations*, 2005; **8**: 210–220.
- Attree P, Morris S, Clifton M, Hinder S, Vaughan S. *Exploring the Impact of User Involvement on Health and Social Care Services for Cancer in the UK. Final Report*. London, UK: Macmillan Cancer Support, 2009.
- Department of Health. *Cancer Reform Strategy*. London, UK: DH, 2007.
- Help the Hospices. User Involvement Questionnaire for Hospices. 2006; Available at: <http://www.helpthehospices.org.uk/our-services/developing-practice/service-user-involvement/?locale=en>, accessed 5 March 2010.
- Payne S, Gott M, Small N, Oliviere D, Sargeant A, Young E. *User Involvement in Palliative Care: A Scoping Study Final Report to St. Christopher's Hospice*. London, UK: St. Christopher's Hospice, 2005.
- Hodgson J. Case study of service user forums at Dove House Hospice. In: Jarrett L (ed.) *Creative Engagement in Palliative Care: New Perspectives on User Involvement*. Abingdon, UK: Radcliffe Publishing Ltd, 2007: 174–183.
- Department of Health. *Research Governance Framework for Health and Social Care*, 2nd edn. London, UK: DH, 2005.
- Department of Health. *Best Research for Best Health: A New National Health Research Strategy*. London, UK: DH, 2006.

- 26 INVOLVE. *invoNET bibliography 2*. Eastleigh, UK: INVOLVE, 2009.
- 27 Andejski Y, Bisceglia I, Dickersin K *et al.* Quantitative impact of including consumers in the scientific review of breast cancer research proposals. *Journal of Women's Health and Gender-Based Medicine*, 2002; **11**: 379–388.
- 28 Andejski Y, Breslau E, Hart E *et al.* Benefits and drawbacks of including consumer reviewers in the scientific merit review of breast cancer research. *Journal of Women's Health and Gender-Based Medicine*, 2002; **11**: 119–136.
- 29 Donovan J, Mills N, Smith M *et al.* Improving design and conduct of randomised controlled trials by embedding them in qualitative research: ProtecT (prostate testing for cancer and treatment) study. *BMJ*, 2002; **325**: 766–770.
- 30 Angell KL, Kreshka MA, McCoy R *et al.* Psychosocial intervention for rural women with breast cancer. *Journal of General Internal Medicine*, 2003; **18**: 499–507.
- 31 Marsden J, Bradburn J. Patient and clinician collaboration in the design of a national randomized breast cancer trial. *Health Expectations*, 2004; **7**: 6–17.
- 32 McCormick S, Brody J, Brown P, Polk R. Public involvement in breast cancer research: an analysis and model for future research. *International Journal of Health Services*, 2004; **34**: 625–646.
- 33 Plumb M, Price W, Kavanaugh-Lynch MHE. Funding community-based participatory research: lessons learned. *Journal of Interprofessional Care*, 2004; **18**: 428–439.
- 34 Wright D, Corner J, Hopkinson J, Foster C. Listening to the views of people affected by cancer about cancer research: an example of participatory research in setting the cancer research agenda. *Health Expectations*, 2006; **9**: 3–12.
- 35 Collins K, Stevens T, Ahmedzai SH. Can consumer research panels become an integral part of the cancer research community? *Clinical Effectiveness in Nursing*, 2005; **9**: 112–118.
- 36 Cotterell P, Clarke P, Cowdrey D, Kapp J, Paine M, Wynn R. Becoming involved in research: a service user research advisory group. In: Jarrett L (ed.) *Creative Engagement in Palliative Care: New Perspectives on User Involvement*. Abingdon, UK: Radcliffe Publishing Ltd, 2007: 101–115.
- 37 Cotterell P. Exploring the value of service user involvement in data analysis: “Our interpretation is about what lies below the surface”. *Educational Action Research*, 2008; **16**: 5–17.
- 38 Cotterell P, Morris S, Harlow G, Morris C, Beresford P. *Making User Involvement Effective: Lessons from Cancer Care*. London, UK: Macmillan Cancer Support, 2009.
- 39 Costanzo ES, Lutgendorf SK, Mattes ML *et al.* Adjusting to life after treatment: distress and quality of life following treatment for breast cancer. *British Journal of Cancer*, 2007; **97**: 1625–1631.
- 40 Burkett VS, Cleland CS. Symptom burden in cancer survivorship. *Journal of Cancer Survivorship*, 2007; **1**: 167–175.
- 41 Broughton F. Conclusion: thoughts of a palliative care user. In: Monroe B, Oliviere D (eds) *Patient Participation in Palliative Care: A Voice for the Voiceless*. Oxford, UK: Oxford University Press, 2003: 196–199.
- 42 Sitzia J, Cotterell P, Richardson A. *Formative Evaluation of the Cancer Partnership Project*. London, UK: Macmillan Cancer Relief, 2004.
- 43 Paine A. Users do not want to be treated with kid gloves. Community Care. 6th–12th October. 2005: 33.
- 44 Small N. User voices in palliative care. In: Faul C, Carter Y, Daniels E (eds) *Handbook of Palliative Care*, 2nd edn. Oxford, UK: Blackwell, 2005: 61–74.
- 45 Beresford P, Croft S. *Citizen Involvement. A Practical Guide for Change*. London, UK: Macmillan Press Ltd, 1993.
- 46 Braye S. Participation and involvement in social care: an overview. In: Kemshall H, Littlechild R (eds) *User Involvement and Participation in Social Care: Research Informing Practice*. London, UK: Jessica Kingsley Publishers Ltd, 2000: 9–28.
- 47 Tedford-Gold SK, Abelson J, Charles CA. From rhetoric to reality: including patient voices in supportive cancer care planning. *Health Expectations*, 2005; **8**: 195–209.
- 48 Davies C, Wetherell M, Barnett E. *Citizens at the Centre: Deliberative Participation in Healthcare Decisions*. Bristol, UK: The Policy Press, 2006.
- 49 Gray R, Fitch M, Greenberg M, Shapiro S. Consumer participation in cancer system planning. *Journal of Palliative Care*, 1995; **11**: 27–33.