

Review of the literature on service user and carer involvement in cancer research in England

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Setting the scene

Service user and carer involvement in NHS cancer services

Since the early 1970s, with varying intentions and degrees of fanfare, successive governments have risen to the challenge to reform the NHS into an organisation accountable to, and directly influenced by, the local populations it serves. The first step towards direct service user involvement came with the establishment of Community Health Councils (CHCs) in the NHS reforms of 1968-74, an enterprise seen as a fairly radical challenge not only to the 'paternalism' of the doctor-managers who then controlled NHS services but also to the public's own strong disinclination to criticise the NHS.³⁻⁶ A more sweeping transformation began in the early 1980s when the 'Griffiths Report' paved the way for the Thatcher government to introduce legislation and policies to develop competition among NHS service providers,⁷ and in so doing cast NHS patients and potential patients in the role of 'consumers' with 'choices' and 'rights' regarding service provision. These reforms were spurred on by the NHS winter crisis of 1987-88 (which saw hospitals around the country closing beds in order to balance their budgets after years of extremely tight financial settlements combined with growing demand and spiralling technology costs) that generated huge amounts of adverse publicity and fuelled low opinion poll ratings. The 1991 *Patient's Charter* is regarded as the culmination of this 'consumerist' policy, having a strong emphasis on patients' rights, patient choice and information for patients.⁸

The Labour government elected in 1997 pledged to replace this consumerist 'internal market' with an NHS 'accountable and open' to patients and the public and 'shaped by their views', as a part of wide-ranging NHS reforms set out in the White Paper *The New NHS*.⁹ The *NHS Plan* launched the 'Patient and Public Involvement' (PPI) policy stream,¹⁰ and subsequently Section 11 of the Health and Social Care Act 2001 placed a statutory duty upon NHS organisations to 'involve and consult' local people. The NHS Reform and Health Care Professions Act 2002 later introduced the framework of 'PPI Forums' (committees comprised of patients and the public working to influence and monitor services), and Patient Advice and Liaison Services (PALS) (a professional service to assist patients, act as patients' advocates and provide data for service improvement) within each of the 600-odd NHS organisations in England.

This policy movement was evident in cancer services, with the 1995 Calman-Hine report and the 2000 *NHS Cancer Plan* stating that cancer services must develop to be patient-centred and to take account of patients' views and preferences, and indeed that patients needed to be 'empowered' in order to improve services.^{11 12} Guidance issued by the National Institute for Clinical Excellence in 2004 was forceful and unambiguous: people affected by cancer should be directly, meaningfully involved in service planning and delivery, and it is the responsibility of service providers and cancer networks to ensure that this happens.¹³

The service user and carer involvement that has appeared in NHS cancer services might be characterised as a mix of 'bottom-up' initiatives (i.e. initiated by people 'on the ground' using or working in or using NHS services) and 'top-down' initiatives (i.e. initiated by policy makers or senior officials at national or local level), though the evidence suggests more of the latter than the former. Merryn Gott and colleagues, studying the Trent health region, found that user involvement consisted of a haphazard assortment of relatively small-scale but nevertheless meaningful projects, such as the inclusion of service users on a local Palliative Care Forum.¹⁴ The common message from service users was "[Professionals] all say they are going to do something but there has been hardly any work".^{14 p.26} A similar picture was painted by another regional study, this time from the Avon, Somerset and Wiltshire cancer network area, though here the majority of reported 'involvement' activities seemed to consist of consultation in one form or another (e.g. questionnaires about service provision).¹⁵

In summary, these wide-ranging regional studies found limited evidence of formal user involvement in cancer services and little designated funding for such activities. Rarely did user involvement activities form part of an integrated system of user involvement in cancer services. This conclusion is supported also by the evidence review on user involvement conducted to inform the NICE guidance on supportive and palliative care.¹⁶

This lack of integration has been tackled, at least in part, by the 'Cancer Partnership Project' (CPP), perhaps the most prominent and concerted programme to advance service user involvement in cancer services. This initiative was developed jointly by Macmillan Cancer Relief and the Department of Health following a national consultation with cancer service users, charities and service co-ordinators, among others.¹⁷ Launched in 2002, the CPP aimed to establish 'partnership' groups in each of the 34ⁱ cancer networks in England, partnership groups typically being a collaborative, democratic group of patients, carers, clinicians and NHS managers working at the level either of an individual trust/locality (e.g. the Northamptonshire Cancer Services Partnership), or a cancer network (e.g. the Humber and Yorkshire Coast Cancer Network Patient Involvement Group). To some extent the CPP was building upon an existing model of local cancer User Groups or Partnership Groups, a number of which had arisen independently from the mid-1990s onwards (e.g. in the Sussex Cancer Network). Some indications of the scale of this involvement activity are available. A Macmillan internal project to 'map' user/partnership groups listed 27 trust/locality groups and network groups as being active in England in late 2002.¹⁸ A study by Crossbow research published in July 2003 reported that of 154 'community' and 'self-help' groups sampled, 87

ⁱ There are currently (June 2006) 33 cancer networks in England, following the merger of networks for the North Midlands and the Black Country from 1st April 2006. The new Network is known as the Greater Midlands Cancer Network. However, at the time of evaluation there were 34 networks, and so, for example, we make reference to the '31 non-CRP pilot networks'.

(56%) were “aware of and involved in” NHS user groups or partnership groups.¹⁹ An external evaluation of the CPP published in May 2004 reported that by the end of 2003 at least one type of partnership group had been established in 30 of the 34 networks.²⁰

The CPP evaluation report concluded that in the large majority of networks the ‘partnership’ model was proving undeniably effective in providing a mechanism for service user involvement and influence, a conclusion also reached by Andrew Gallini in his study of the partnership group in the Sussex Cancer Network.²¹

The CPP report found that groups were engaged in five main activities:

- Groups acted as an easily accessible ‘reference group’ for NHS staff and others who were seeking service users’ views on a particular issue or document (e.g. the wording and distribution a local patient survey questionnaire).
- Group members worked alongside NHS professionals on more substantial, longer-term service redesign or development projects (e.g. in the architectural design of a new cancer centre).
- As a consequence of the concentration of user involvement experience and expertise, groups acted as local catalysts for NHS service user involvement and as ‘hubs’ in extensive networks of involvement in and representation on other groups and committees in the NHS, public sector and broader community (e.g. PPI Forums, local Cancer Action Groups, cancer network management boards, cancer network site-specific policy groups, research project steering groups).
- Groups initiated and led projects concerned with patient information and communication. Partnership Groups had developed booklets, leaflets, and template letters for a wide array of purposes, and some had established sub-groups dedicated to patient information. Several groups had undertaken work on the issue of ‘breaking bad news’. At least one group had a ‘breaking bad news’ working party, another had been involved in training for NHS staff, and others had worked on drawing up and ensuring the implementation of breaking bad news policies and standards.
- Groups worked to exert direct influence upon the local NHS and other agencies that impacted upon the lives of people affected by cancer. The tactics used were many and varied, and included lobbying to secure service user membership on decision-making groups, talking to influential actors, press and publicity, road shows and conference talks. Access to services was a common focus for this influencing, with groups working to bring about positive changes to car parking arrangements for example, or public transport provision.

Other initiatives to note include the newly established national palliative care user group, supported by the charity Help the Hospices.²² It is worth noting also that the Department of Health is establishing a commissioned ‘Centre for PPI (Patient and Public Involvement) Excellence’, the role of which will include the collection and dissemination of evidence on PPI.²³

User involvement initiatives are also being reported from other countries, with similar emergent issues to those identified in the UK. The involvement of cancer patients in policy-

making activities in Canada, for example, was initiated in 1989 as part of the Cancer 2000 project for national cancer systems co-ordination.²⁴ Regional initiatives followed. In Ontario, the 'Life to Gain' cancer policy planning process 'ring-fenced' one-third of all committee and working group seats for cancer patients, establishing consumers as full participants in the process.²⁴ From 2002 onwards, the same province initiated a patient involvement strategy in the development of new, regional supportive care networks; however, an evaluation concluded that the 'attempt' had 'failed', finding a significant gap between intentions to involve patients in health planning and their actual involvement.²⁵ User involvement also appears in Australia, with organisations such as Cancer Voices New South Wales facilitating involvement in service planning (www.cancervoices.org.au). The Cancer Council of Western Australia launched a Consumer Participation Project in 2001 that has trained around 50 people affected by cancer to participate in health services development in various ways, for example as policy advisors (www.cancerwa.asn.au). An international review of user involvement in cancer services is long overdue.

In conclusion, the evidence base directly relating to service user involvement in NHS cancer services is somewhat narrow but nevertheless has indicated that mechanisms for involvement are evolving, and seem to be evolving fairly equitably across England. Nevertheless, a recent comparative analysis of patient engagement in personal healthcare in six developed countries found the UK results to be less positive than those from the other countries, and reached the discouraging conclusions that efforts to promote involvement have done little to change clinicians' relationships with patients, that patients lack support from health professionals for engagement with their healthcare, and that engagement will not improve until clinicians recognise and support patients as 'active partners' in their care.²⁶

Service user involvement in health research

Service user involvement in health research emerged in the 1980s in a number of specific fields and most prominently in mental health, HIV/AIDS, maternity care, and breast cancer.²⁷⁻³⁰ Its roots might be seen to lie in the disability protest movement that from the 1960s onwards sought to replace the traditional model of medical care and welfare, in which the 'problem' of disability is located firmly within the individual, with a new 'social model' in which the problem of disability is located within society:

It is not individual limitations ... which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation. Hence disability ... is all the things that impose restrictions on disabled people, ranging from individual prejudice to institutional discrimination; from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on. The consequences of this failure do not simply and randomly fall upon individuals but systematically upon disabled people as a group who experience this failure as discrimination institutionalised throughout society.^{31 p.32-33}

The disability movement placed great importance on disability research, as it considered that whoever controlled the research controlled the evidence upon which disability policy was

based. As traditional, academic research until then had done little but support the oppression of disabled people, the movement argued, so a radical, separatist model of research was necessary. 'Emancipatory disability research' emerged, a model in which control of the research agenda, funding and process lay with disabled people and organisations of disabled people.³² This 'user-controlled' research is conceived of "In political terms as an agent of change ... working to liberate disabled people, rather than as a neutral system of inquiry to produce more information."³³

The radicalism of the emancipatory disability research movement, in terms of being a 'new way' of doing research, was reflected again in the 'survivor research' movement in mental health;³⁴ but in the 'acute' health sector this radical shift was seen perhaps singly in the field of HIV/AIDS. In the 1980s, the importance of AIDS as a public health issue and the need for rapid evidence to guide policy triggered the use of 'insiders' in order to access hard-to-reach groups and to elicit information on private and sensitive aspects of behaviour. There appeared "... a new legitimacy for the previously unconventional in research; those with personal knowledge ... were listened to, and actively involved, as never before."³⁵ Again, research was seen by the 'service users' – in this case gay communities and groups - as a critical issue. In the United States, the first meeting of Gay Men's Health Crisis, in 1981, for example, had been to raise funds for research,³⁶ whilst in the UK a founding objective of the Terence Higgins Trust in 1982 was, "...to institute, promote, undertake, encourage and assist research into the causes, origins, transmission and treatment of AIDS [and] HIV."³⁷ The Terence Higgins Trust collaborated with academic doctors and trialists on the Concorde trial, for example, a comparison of AZT treatment *before* versus *at onset of* AIDS-related symptoms. AIDS activists were involved in protocol development, recruitment and retention of participants, and in managing the release of results, which indicated that early AZT was not beneficial (INVOLVE 2002a). In terms of user involvement in clinical trials, the AIDS epidemic, it has been argued, should be considered a decisive turning point:

AIDS trials are distinctive not only because of the militancy of many of the patients, but because their representatives have mobilized to develop effective social movement organizations that evaluate knowledge claims, disseminate information, and insert lay people into the process of knowledge construction. The activist representatives of AIDS patients not only facilitate the flow of information to and among them, but also press demands about what should be studied in the first place and how the research protocols should be worded. Highly technical details such as the entry requirements for trials, the types of controls employed, and the endpoints to be used in studies have all been the subject of vociferous debate.^{38 p.34}

Other than cancer, which is discussed in section 2.2, the final field with early user involvement activity of mention is maternity care, where again involvement focused on clinical trials. User involvement was led by the Association for Improvements in Maternity Services in 1985 when, with other organisations, it supported a Medical Research Council proposal to compare chorion villus sampling with amniocentesis in a randomised trial.³⁹ This trial was co-ordinated by the Oxford-based National Perinatal Epidemiology Unit, which since then has brought together researchers, clinicians and patient organisations in the planning of further trials.^{27 40}

The profile, volume and extent of service user involvement in health research today without question are far greater than they were two decades ago. The Department of Health has funded INVOLVE, an advisory group on user involvement, since 1995 (www.invo.org.uk), and has supported user involvement in a wide variety of national research programmes and activities; for example, in the NHS R&D Forensic Mental Health programme, service users sit on the main Advisory Committee and are involved in the reviewing and commissioning of projects.^{41 42} The Medical Research Council has established an Advisory Group on Public Involvement as a key mechanism for bringing consumer perspectives to its work,⁴³ and user involvement has been espoused by a number of medical research charities; perhaps best known among these is the Alzheimer's Society award-winning 'Quality Research in Dementia' programme, which actively involves people with dementia and their carers in setting the research agenda, awarding grants and assessing outcomes (www.qrd.alzheimers.org.uk).

In fact, numerous individual initiatives for user involvement in health research can be found, such as alliances formed by academic research groups with local consumer organisations better to pursue collaborative research, e.g. the Health Services Research Group at Aberdeen Robert Gordon University,⁴⁴ service user involvement in patient safety research,⁴⁵ and the institution of a 'Patients' Editor' and 'Patient Advisory Board' for the influential *British Medical Journal*.⁴⁶

Nevertheless, it remains difficult to gauge how much service user involvement is actually going on at the level of individual research projects. Work to estimate the 'incidence' of involvement in health research projects is under way both at the University of Sheffield (Boote, *personal communication*) and at Worthing and Southlands Hospitals NHS Trust (Kelley, *personal communication*).

The question of 'impact' of involvement – what difference does involvement make? – is perhaps that most keenly debated. For many years it seemed that little attention was paid to the question of outcomes of involvement, perhaps because the argument was put so strongly that involvement was a democratic right (i.e. almost regardless of outcome). Increasingly, however, 'outcome' is becoming a primary focus in evaluative and reflective work in this field, and the consensus seems to be that involvement does have tangible and positive outcomes. A recent evaluation of user involvement in 11 research studies in primary care, for example, concluded that there was tangible positive impact on both the processes and outcomes of the studies, and personal benefits to the service users involved.⁴⁷

The organisation and funding of cancer research in England

'Cancer research' is a broad field that includes many different types of research activities:⁴⁸

- **Basic research** is laboratory-based research into the causes and nature of cancer, typically attempting to gain a better understanding of the molecular basis of malignancy and currently with an emphasis upon genetics and genomics. Prominent research centres include the Institute for Cancer Research (London), the Beatson Institute for Cancer Research (Glasgow) and the Paterson Institute for Cancer Research (Manchester).

- **Drug discovery.** Part of the process of basic cancer research is the identification of target molecules for drug development. In the UK this work is mainly performed in the private sector.
- **Translational Research.** Translational Research is the process of using research results, discovered in scientific laboratories, to develop new ways of treating or diagnosing diseases, primarily new anti-cancer drugs. In 2001, a new National Translational Cancer Research Network (NTRAC) was established to develop translational research in the NHS, which from 2006 will be developed into a network of Experimental Cancer Medicine Centres.
- **Clinical Trials.** Once a new treatment has been identified as potentially beneficial to patients with a particular condition, the treatment must be tested on humans. Clinical trials are used to evaluate new treatments (or modified forms of existing treatments) by testing them in the clinic to compare their efficacy and toxicity profiles with those of established therapies. They usually follow the format of randomised controlled trials (RCTs). In RCTs, a suitable group of patients is identified and split randomly into 'experimental' and 'control' groups. The experimental group receives the treatment under investigation. The control group receives the best-known treatment to date.
- **Epidemiology and Public Health Research.** This type of research uses national cancer 'registries' to evaluate progress in the prevention and treatment of cancer. Cancer registries collect information on the number of people who develop the different forms of the disease each year (incidence), and their survival rates, and also the number of people who die from cancer, and how these figures change over time.
- **Research into Improving Patients' Quality of Life.** This area includes psychosocial studies related to supportive, palliative and end of life care and health services research. Research of this type utilises observational and experimental methods of data collection.

Cancer research in the UK is funded by an estimated 250 charities, numerous Government bodies and the pharmaceutical industry. There are no accurate data for the total amount of money spent on cancer research; the Government spent around £190 million in 2000/01, the medical research charities some £200 million, and the pharmaceutical industry at least £134 million.⁴⁹

The National Cancer Plan, published in July 2000,¹² set out how the government intends to improve the quality of cancer care in the NHS. A key part of the plan was the establishment of the National Cancer Research Institute (NCRI) in April 2001. The NCRI consists of 19 partner organisations. It is a partnership between government, the voluntary sector and the private sector, with the primary mission of maximising patient benefit that accrues from cancer research in the UK through coordination of effort and joint planning towards an integrated national strategy for cancer. All the major organisations that fund cancer research are involved. Key to the NCRI's role was the development in 2001 of two national research networks, both funded by the Department of Health: NTRAC, mentioned above, and the National Cancer Research Network (NCRN).

The National Cancer Research Network

The NCRN was set up to provide the NHS 'infrastructure' to support randomised controlled trials of cancer treatment and other well-designed studies. Its aims are to:⁵⁰

- Improve patient care;
- Improve the co-ordination of research;
- Improve the speed of research;
- Maintain and enhance the quality of research;
- Improve the integration of research and cancer services
- Widen participation in research.

The NCRN comprises 33 Cancer Research Networks across England, with a co-ordinating centre based at the University of Leeds. Each network receives funding for a designated Clinical Lead (part time) and Network Manager (full time) plus an allocation of £200,000 per annum (at 2003/04 prices) per one million catchment population. Funding typically supports research staff, such as research nurses, data managers and medical staff sessions and is used to access pharmacy, pathology, radiology and other areas of support required for high quality research.

At local level, research networks operate alongside the local Cancer (service) Network. So, for example, the Sussex Cancer Research Network is positioned alongside the Sussex Cancer Network.

Network research staff recruit patients into clinical trials within the NCRN 'Trials Portfolio'. The NCRN website (www.ncrn.org.uk) defines an NCRN Portfolio study as either:

- (a) Any cancer clinical trial or well-designed study which is supported or funded by a member of the NCRI (e.g. Medical Research Council, Cancer Research UK, Department of Health); these studies are automatically part of the NCRN Portfolio; or
- (b) Other, well-designed, non-NCRI-funded trials that are 'accredited' by NCRN by means of an internal quality assurance process.

The initial aim of the NCRN, set by the Department of Health in 2001, was to double the number of cancer patients entered into clinical trials and other well-designed studies by April 2004 (from 3.75% to 7.5%). This target was achieved ahead of schedule, with actual accrual at the end of the NCRN's first three years in excess of 10%. The NCRN 'network' model rightly is regarded as a successful model for the advancement of clinical research, and has been adopted for the introduction of new clinical research networks in stroke, diabetes, dementias and neurodegenerative diseases, medicines for children, and primary care, under the auspices of the UK Clinical Research Network (www.ukcrn.org.uk).

Service user and carer involvement in cancer research

Involvement in the design of clinical trials

A substantial proportion of documented service user and carer involvement in UK cancer research is in the design of clinical trials. 'Pioneering' work appeared primarily in the field of breast cancer. A key stimulus was the publication in 1990 of interim results from a charity-funded study of survival rates for women with breast cancer who had received complementary therapy at the Bristol Cancer Help Centre.⁵¹ This report suggested that women who attended the centre were three times as likely to relapse and twice as likely to die as women receiving conventional treatment only. Heather Goodare, one of study's participants, writes that the women in the study only learnt of the results through sensationalised media reports, which caused 'extreme distress' to the participants.⁵² The findings were later discredited – the 'Bristol' cohort had more severe disease to start with than the 'conventional' cohort – but by then the participants had launched their own campaign;⁵³ in Goodare's words, "... the women in the trial had become 'activists' – the first patients to challenge the results of a trial in which they had participated."⁵⁴ p.1277 The Charity Commission upheld a complaint about the conduct of the two charities that had funded the study, leading to new medical research guidelines,⁵⁵ and a new group, the Consumers Advisory Group for Clinical Trials, emerged in late 1994 to encourage patient and carer involvement in the design of breast cancer clinical trials.⁵⁶

Subsequent service user involvement in cancer clinical trials has focussed on the 'interface' between researchers and participants – aiming to improve recruitment processes, for example, or participant information leaflets – and on the core trial design itself, with perhaps an emphasis on 'quality of life' assessments. Jane Bradburn and colleagues, for example, used focus groups with breast cancer patients in a trial of community versus hospital follow-up care, and protocol changes were made in line with the patients' suggestions, such as inclusion of additional qualitative psychosocial measures, and the inclusion of direct contact with a specialist breast care nurse.⁵⁷ Focus groups also formed the starting point for user involvement in the design of the HRT trial. Issues identified from the focus group discussions were then debated at a meeting between researchers, patient representatives from the different support groups, and members of the Consumer's Advisory Group for Clinical Trials. Every patient and researcher was allocated 5 votes which they could use to indicate the 5 priorities they considered to be the most important, and this open voting system was action points to be incorporated into the national HRT study design were prioritised.⁴⁰ The ProtecT trial took conducted an 'action research'-type study within a trial of treatments for prostate cancer, with interviews with participants and recordings of recruitment appointments used to explore views about involvement in the study, interpretations of study information, and the acceptability of randomisation and treatments. Findings were fed back into the trial design, and accrual gradually rose from 30% to 70% of eligible patients.⁵⁸

However, cancer trials with active service user involvement appear to be the exception rather than the rule. A survey of all UK clinical trial co-ordinating centres published in 2001 identified only 8 cancer trials that had any user involvement.⁵⁹ Whilst involvement most often was in

drafting or reviewing information for patients, involvement was also frequent at the protocol development stage.

It is worth mentioning here the relatively large body of research work that has looked at patients' attitudes to clinical trials with respect to participation as 'subjects'. This work identifies and explores the 'factors' that determine participation in trials, and participants' understanding of trials; much of this research has focused on cancer clinical trials. One key area of study has been patients' understanding of the concepts of 'randomisation' and 'equipoise'; there is strong evidence, for example, that many participants in randomised trials do not in fact understand that their treatment has been allocated at random and instead believe that their treatment has been 'allocated' (by their own clinician) on the basis of their individual therapeutic needs.⁶⁰⁻⁶³ Another interesting recent example is the work of Jenkinson and colleagues in identifying which factors determine patients' willingness to enter a trial; 'patient information' and 'safety' were not considered important factors by this sample of patients, whereas patients' views about the importance of trials and beliefs about the value of patient involvement were likely to be predictive of whether or not patients' would enter a study.⁶⁴

Involvement in the NCRI and cancer research networks

The emergence of the NCRI and of cancer research networks has provided a framework for systematic user involvement in cancer research at both national and local level. The NCRI Consumer Liaison Group (CLG) was established in June 2000 "... to provide a national overview of consumer concerns and to act as a central resource for guidance on consumer issues in cancer research."^{50 p.61} The principal role played by CLG members, the majority of which are people affected by cancer, is to sit on the 24 NCRI Clinical Studies Groups, each of which covers a specific cancer site. These groups develop new clinical studies and take them forward for funding, and these studies then duly become a part of the NCRN national research 'portfolio'. In this way, there exists a mechanism for consumer involvement in each and every NCRN study that is developed under the auspices of the NCRI Clinical Studies Groups, that is the large majority of national, multi-centre clinical trials undertaken in the cancer research networks.

Members of the CLG are also involved in several NCRI Trial Steering Committees and the NCRI Boards, and contributed to a series of NCRI/NCRN 'think-tank' meetings to consider strategic issues and the 'next steps' in user involvement in cancer clinical research.⁶⁵ The think-tank report provided a useful summary of NCRI/NCRN thinking regarding the value of service user involvement in research:

It is anticipated that an increased involvement of consumers in cancer clinical research will enhance the overall quality and relevance of the research conducted, by enabling consumers to be an integral part of the research process from the identification and prioritisation of research questions, the design of the research project, the development of patient information sheets and other publicity material, the management of the project, and the dissemination of the results. The incorporation of consumers' perspectives should result in cancer clinical research projects which are more acceptable and relevant to patients, and

thus more successful and credible. Consumer involvement should therefore be viewed as essential, not preferable, in cancer clinical research.^{65 p.2}

One of the key recommendations of the think-tank was 'Preparation of a plan for the development of research consumer groups'. The Consumer Research Panels (CRPs) initiative, which is the subject of this current report, was established in consequence.

A precursor of the current CRPs initiative was the North Trent Consumer Research Panel. This panel was set up in 2001 by the North Trent Cancer Research Network in response to a growing need to more systematically incorporate the views of service users in its research programme. The panel is formed of around 30 cancer patients and carers, and its key objective is to develop alliances between researchers, professionals and consumers to ensure that a consumer perspective is present in all new studies and at all stages of the research process.⁶⁶⁻⁶⁸ Despite an external evaluation that found the panel was achieving its objectives,⁶⁹ the most significant challenge facing the panel today is to secure sufficient recurring financial support to maintain the panel.⁶⁶

Involvement in supportive and palliative care research

Supportive and palliative care research appears weak in terms of user involvement, with research activity focused on 'satisfaction' with services and 'quality of life' for people requiring palliative care.⁷⁰⁻⁷² Commentators have ascribed this convention primarily to a concern for proper ethical conduct on the part of professionals, who consider these service users to be vulnerable and in need of protection; this key theme arises both in the service and research contexts.⁷³⁻⁷⁶ Payne, for example, expresses the suspicion that service user involvement in palliative care research is a higher priority for researchers and the research agenda rather than for service users themselves.⁷⁷ Equally, Small & Rhodes' influential work exploring service user involvement in palliative care warned that, for people facing the end of their lives, becoming involved in practice or research could be too burdensome and might also be exploitative.⁷⁸ A review of 138 published qualitative research studies in palliative care over the span of one decade confirmed that there has been a tendency to collect data indirectly from carers, rather than directly from patients themselves; just 26% of studies collected data directly and no collaborative or participatory methodologies were employed in any study.⁷⁹ In fact the sole reference to collaboration in this review was in terms of collaboration between academic and practice-based researchers rather than in terms of researchers and service users.

However, an alternative opinion is that service users in palliative care can and do want to have greater involvement (Beresford et al, 2000:12);⁸⁰ the 'Build' project is one example of a constructive involvement strategy in palliative care, in this case enabling people with Motor Neurone Disease (MND) to become actively engaged in the planning of the services they receive.⁸¹ A recent editorial in the journal *Palliative Medicine* highlighted some of the challenges and some of the benefits that service users can experience from involvement in palliative care research.⁸² A practical example is provided by Croft and colleagues.⁸³ This participatory study of specialist palliative care social work included both an advisory group made up of service users and service user members within the project steering groups; different steering groups operated over the course of the project with different service user

members as a pragmatic way of involving service users who are likely to be very ill. Steering group members were significantly involved in the project, offering their perspectives both on practical issues (e.g. interview schedule development) and on 'business' issues (e.g. the general progress of the project). Similarly, Cotterell's exploration of the experiences of people with life-limiting conditions with regards to service provision was guided by a service user research advisory group which, despite a fluctuating membership, worked over a considerable period of time and was considered to have made a significant contribution to the project, particularly with respect to data interpretation.⁸⁴ A joint reflection on this project highlighted the not inconsiderable challenges to involvement for service users with life-limiting conditions but emphasised the substantial positive influence of involvement and strong commitment of the people involved.⁸⁵

Key issues in service user involvement in cancer research

The three bodies of literature reviewed above – user involvement in cancer services, user involvement in health research generally, and user involvement in cancer research – have each separately identified the key issues in user involvement in that particular field. The commonality between these is very striking; and indeed we find these same issues cited again and again in the 'involvement' literature, be it the literature on involvement in NHS services generally (including the systematic reviews conducted by Crawford *et al.*, by Simpson & House, and by Smith *et al.*),⁸⁶⁻⁸⁹ on involvement in cancer services specifically, on involvement in NHS research generally,⁹⁰ or on involvement in cancer research specifically² (including the important recent systematic review by Hubbard *et al.*⁹¹). These issues can be grouped into themes, and are presented in summary form in the sections below.

The purposes and scope of involvement

- While there is general consent that user involvement is important, at the same time there is much **confusion about the meaning** of the term and about user involvement as a concept.
- This confusion is well founded: user involvement has been allied to a range of **social movements**, including 'citizen participation', empowerment, and consumerism, to corporate governance and to shifts in patient / professional relations, and to shifts in research approaches and debates on the nature of 'evidence'.
- There is some scepticism about the government's **motives** for espousing user involvement; some people think it is meaningless rhetoric, others that it is simply a government strategy to legitimise its decisions.
- There is a lack of **popular interest** in user involvement; it is seen by the majority of both users and professionals as a marginal activity.
- **Clarity of purpose** in individual involvement initiatives varies, and the success of an initiative seems directly related to clarity of purpose and feasibility of objectives.
- There is uncertainty about which exact involvement **activities** are appropriate and useful. Many commentators state that service users should be involved at all stages of the research process, whereas opponents point out that this might not be feasible, affordable or the best employment of users' expertise.

- There are numberless ongoing debates about the **terminology** of user involvement, notably the term for ‘correct’ term for ‘service user’: service user, consumer, lay person, patient, public, etc.

Models and mechanisms for involvement

- Appropriate models for involvement remain the subject of debate. Broadly speaking, the service user lobby argues for **direct involvement**, i.e. users participating directly in decision-making bodies. However, it has been argued, because some professionals are resistant to direct involvement, more commonly user involvement is **indirect**, meaning that users’ views are elicited (e.g. via a survey) but decisions as to their uptake (or not) remain solely with professionals.
- ‘**Collaborative**’, professional-led models of involvement appear most commonly in cancer research and service provision.
- NHS public and user involvement activities often are **not well integrated** into other efforts to improve services and good practice is not shared across organisations.
- While **funding** is made available to support short-term or pilot involvement initiatives, long-term funding to support sustained, ongoing involvement mechanisms (other than the statutory PPI Forums) appears very difficult to secure. Overall, resources for involvement are scarce.
- Professional support is essential to the success of user involvement; but there is a **legacy of scepticism** among professionals, which is only reinforced when user involvement is associated with complaints procedures or clinical governance.
- The most common forms of involvement in research are:
 - People affected by cancer participating in research organisations, programmes and networks with a view to influencing their direction and work generally; Hubbard refers to these as strategists.⁹¹
 - Service users as member of project-level **advisory groups**, or advisory groups formed only of service users, often having specific input into participant materials and recruitment strategies.
 - Service users as **reviewers** of research proposals or protocols, or of project reports or publications.
 - Involvement in the development and testing of **data collection instruments**, such as questionnaires.
 - Involvement as **co-researchers**, working alongside professional researchers at some or all stages of data collection, analysis and reporting. Sometimes this involvement is in ‘participatory research’, a specific methodology that aims to empower people through direct involvement in the research process.

The involvement ‘process’

- **Motivations for involvement.** **Service users’** motivations vary, but often people want to ‘give something back’ to the NHS and feel that they have valuable insights and experiential knowledge to contribute. Some NHS and research **professionals** are

motivated by a genuine belief that involvement makes a positive contribution; others are involved with service users only because they are obliged to be, e.g. by the funder, or by the researcher's employer.

- **Recruitment** to user groups typically is inclusive, transparent and non-selective, but recruitment of users to professional groups, such as research advisory groups, is often the opposite. **Retention** has been identified as an issue in long-term initiatives that rely on a small 'core' of active users; tangible achievements are key to sustainability.
- Involvement in cancer research is much more common in the field of **breast cancer** than in any other single field of cancer research.⁹¹
- Service users typically do not see themselves as being '**representatives**' in any formal sense, yet this is how professionals like to regard them. **Representation** and **tokenism** are however common concerns in 'corporate-level' involvement groups, which typically attract low numbers of people from black and minority ethnic communities and from 'hard to reach' social groups.
- **Principles of 'successful' involvement** at research project level have been developed by Telford and colleagues using a consensus approach.⁹² Hubbard *et al.*⁹¹ highlighted three factors in particular for successful involvement: training and information; resources; and changes in attitudes and roles.
- **Training** is often provided within a collaborative research project, but this training (a) tends to be limited to research training for service users, rather than also including training for professionals about involvement, and (b) can be limited to 'formal', methods-oriented training sessions, despite evidence that training is most effective when coupled with information and ongoing support. Research programme-level training in the UK has been documented for the NCRI CLG, Macmillan Cancer Support's research programmes, and the North Trent Consumer Research Panel.
- **Resources.** There is strong consensus that involvement must be properly resourced, with funding available for training, support staff, administration and information provision, as well as expenses related to meetings and research work. A specific issue is **payment to service users**: there is consensus that as a minimum all service users' expenses must be met in full; 'best practice' is that service users are in addition paid a reasonable rate for their time and work.⁹³ The requirement for additional resources means that it costs more to work in collaboration with non-professionals than to work within a conventional, professionals-only model.

The impacts of involvement

The main issue in debates of user involvement remains that of 'impact' or 'benefit' of involvement. While there is a relative absence of good-quality evidence about impacts, anecdotal evidence and expert opinion suggests that **a range of impacts can be identified**, and that user involvement typically **results in positive change**.^{4 15}

- **Benefits to NHS services.** Direct benefits to NHS services have been ascribed to user involvement, primarily with respect to patient information and service accessibility. Involvement is considered to have a wider impact on the organisations involved, altering staff attitudes and the general organisational culture.

- **Benefits to research.** Broadly speaking, the evidence suggests that involvement in research appears most effective in the early stages of the research process:
 - At the **priority setting** stage, when public views on research priorities – which differ from researchers’ views – can influence the research topic and research questions, with the result that research programmes address to a greater extent the issues regarded by service users as most relevant.
 - At the **commissioning** stage, when service users’ perspectives can help refine selection criteria and processes. However service users’ reviews have been found to closely match professionals’ views, and so have minimal effect on commissioning panels’ decisions.⁹¹
 - At the **study design** stage, when user involvement can improve participant information, recruitment strategies, and data collection materials and methods.
- **Benefits to the service users involved.** Documented **personal gains** from involvement include a sense of achievement, increased confidence and assertiveness, and better knowledge of services and research. Personal **empowerment** is quite often cited as a specific outcome, though commonly the meaning and consequences of ‘empowerment’ remain unclear.
- **Assessment of outcomes.** One reason for the lack of evidence of impacts is that evaluations or critical reflections of involvement appear infrequently, and furthermore employ conventional evaluation methodologies that attract criticism in this context. Common criticisms are that the assessment is ‘too subjective’ (e.g. it asks the people involved what they think, or an initiative is evaluated by the people who established or were involved in the initiative), or that the follow-up period was too short, or that outcomes cannot be wholly attributed to the involvement activity, or that the cost effectiveness of the activity has not been evaluated.

Conclusions

Service user involvement has been evident in cancer research for some 15 years. Conventionally restricted to relatively small pockets of research activity, involvement has in recent years gained a profile in national research institutions and structures. There is growing momentum to expand current initiatives still further, and this movement should bear in mind the various ‘barriers’ to high-quality, effective user involvement that previous work has identified. Moreover, commentators remain uncertain of the effectiveness of involvement, and health and research professionals too have a ‘legacy of scepticism’ regarding user involvement.

This is an exciting time in this field, with a number of funded, high-quality involvement and research initiatives in progress. We await with interest reports from, among others:

- The Macmillan Listening Study, a large piece of work to explore what people affected by cancer think about cancer research and to identify their research priorities (University of Southampton, School of Nursing and Midwifery);

- An evaluation of public influence in the NHS Health Technology Assessment R&D Programme (University of London, Institute of Education, Social Science Research Unit);
- Further reports from a three-year study of the experiences of people affected by cancer, including people affected by cancer involved in research (Stirling University, Cancer Care Research Centre).

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