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Service User Involvement in Cancer Care - Policy, Principles, Practice

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1. Foreword

This document was prepared as an 'Issues Paper' for the 'National User Steering Group' of 'National Cancer Peer Review' (NCPR).

'Peer Review' is a comprehensive NHS system for quality assurance and enhancement of cancer services in England.

The purpose of the National User Steering Group is to provide NHS managers with advice on service users' perspectives on all aspects of Cancer Peer Review policy and practice. This includes advising on the appropriate standards (called 'measures') to be used in appraising the quality of cancer care services.

The paper was drafted to assist in the 2009 revision of what are called the 'service user involvement' standards that are integral to the NCPR measures.

It is hoped that this paper might also make a useful contribution to wider debates about the value and role of user involvement in cancer care by:

- Patients and carers who are involved in working, both within and from outside the NHS, for improvements in cancer care, and who might welcome an insight into the wider context of their user involvement activities
- All health professionals who have a responsibility for ensuring that service users are involved in planning and implementing cancer services improvement
- Those who are taking up new roles as clinical leaders, service improvement managers, commissioners, and other administrative roles that are looking for an overview of the policy and practice of user involvement

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2. Introduction

This paper sets out to inform the reader about the policies and principles which underpin the current practice of service user involvement in cancer care.

The paper begins by reviewing recent developments in national cancer policy with respect to both patient care and service user involvement to improve such care.

The review of policy and principles enables conclusions to be drawn about how user involvement in cancer care can be used to underpin and promote initiatives - working with the grain of reforms - that achieve improvements to aspects of care *of most concern to patients and carers*.

2.a A point of view

My starting position is that the broad overarching goal of service user involvement is to bring about continuous improvement in the service users' experience of cancer care services. Service user experience is the primary criterion against which the outcomes of user involvement efforts are to be measured. The experience of cancer care is by definition subjective and efforts to improve the quality of care must start from patients' and carers' own experiences.

There is now significant research evidence concerning patients' and carers' experiences of cancer care, and this will be drawn upon in the following pages when the goals of service user quality improvement are identified and discussed. In a nutshell, patients and carers want care which "sees the person in the patient", and is "patient centred" (Goodrich and Cornwall, 2008, Richards and Coulter, 2007; Boyd, 2004; Institute of Medicine, 2001; Delbanco,1993).

Turning from goals to means, service users deploy a variety of methods to achieve their goals, and these are also discussed. These include gathering and using information about patient and carer experiences, responding to consultations on service improvement plans, contributing to agenda setting at Board and Commissioning levels, running demonstration projects and so forth.

My second starting position is that partnership working is the primary organisational vehicle through which service users, working in collaboration with health professionals, can most effectively achieve improvements in the service users' experience of cancer care. Partnership working lies at the heart of change efforts, whether they be at national, network or locality levels - via network user Partnership groups and locality User Forums, through service user involvement in network Site Specific groups and the network Management Board, through Commissioning Groups, and locality/trust Cancer Services Implementation Teams, as well as through service user involvement groups associated with initiatives sponsored by the National Cancer Action Team.

In brief, the conclusions of this paper are that:

1. The patient and carer *experience* of cancer care services will become an increasingly important outcome measure in the assessment of the quality of those services
2. In striving to improve patient and carer experience users should give particular emphasis to service improvement within three interrelated domains:
   - Patient-centred care
   - Supportive care
   - Transitional and self managed care

   It is in these domains that service user involvement will be assessed in terms of the contribution it makes to improving aspects of care
3. Partnership methods of working will be emphasised as the primary method through which such improvements in care can be successfully pursued through service user involvement
4. As a consequence of point 3, increasing attention will be given to strengthening the capability and capacity of partnership working.

2.b Defining key terms

It may be useful to begin by defining two key terms that will crop up throughout the following pages; 'service user involvement' and 'service user'.

In one sense, the whole of this paper represents an attempt to define what service user involvement is about, and later sections (see below, and Section 4c) examine explicitly how the term has been defined in recent policy and practice. Nevertheless, an initial definition may be helpful:

> *Service User Involvement can be defined as the active engagement of patients and carers in how cancer services are planned, commissioned, delivered and evaluated.*

As a recent Commissioning Toolkit spells out:

> *It (service user involvement) is broader and deeper than traditional consultation. It involves an on-going process of developing and sustaining constructive relationships, building strong, active partnerships, and holding a meaningful dialogue with stakeholders' (Patient and Public Involvement in World Class Commissioning, 2009)*

Service user involvement strives for continuous improvement in cancer services, and the patient and care experience of those services.

Service users are defined in this paper as:

> *Cancer patients and their carers ('carers' includes family members and friends) who are involved in working with health service personnel to improve patients' experience of cancer care services.*

2.c The rise and rise of service-user involvement

As noted above, the focus of this paper is on recent development in user involvement in cancer services – roughly since 2005 – and Section 3(a) of this paper is devoted to outlining policy and practice developments in user involvement since that date. A brief overview of earlier developments offers some historical context to what follows:

Modern patient and public involvement in the National Health Service dates from the late 1970s, with the creation of the first Patient Participation Groups and the establishment of government sponsored local Community Health Councils (the later were phased out in the 2003 in favour of Patient and Public Involvement Forums in each NHS Trust). These new bodies marked a turning point in the status of the patient in the NHS. For the first 30 years of its life, from its creation by Aneurin Bevan and the early pioneers in the 1940s, the NHS was organised along top-down, 'command and control' principles. The patient was akin to a spectator - a passive recipient of treatment delivered by expert doctors and associated health personnel. Why the patient and carer role began to change, from docile spectator to engaged activist from the 1970s onwards is a fascinating story, but tangential to our purposes here. (An interesting discussion of how the changing profile of the nation's health, along with how changes in social attitudes, medical technology etc. - helped to kick-start these changes in the 1970s - can be found in various papers published in Andersson et.al. 2008; see also Fudge, et.al. 2008). The point here is that public and patient engagement in general, and user involvement in cancer services in particular, has become

> *a central plank in the Governments modernising agenda for the NHS, covering initiatives from service improvement to creating new models of accountability in health....never before has public and patient involvement been such a political and policy priority (Andersson et al, 2008, p3)*

The influential mid-1990s Calman-Hine report linked the promotion of 'patient centred care' to the principle that patients and carers should have a role to play in the organisational development of services which deliver such care;

> *the development of cancer services should be patient focussed and should take account of patients', families', and carers' views and preferences as well as those of professionals involved in cancer care. Individuals' perceptions of their needs may differ from those of the professional. Good communications between professionals and patients is especially important. (Department of Health, 1995, p6)*

The NHS Cancer Plan (Department of Health, 2000) which led to the institutionalisation of cancer networks and other organisational reforms of cancer services (to ensure, for example, smooth patient flows and 'joined up' service provision between specialist and generalist cancer units and hospitals) built on Calman-Hine, and led to networks being mandated to introduce user involvement structures and strategies capable of informing their service delivery planning processes. The plan reported positively on a Macmillan Cancer Voices project that

> *..provides cancer users with information, support and training to be more effective in helping the NHS to shape cancer services. It enables the views of a wider range of cancer service users to be heard. Evidence from cancer service users shows that training and support are essential if they are to reflect wider users' views effectively (Department of Health, 2000)*

and lent further impetus to the growth of user involvement - as outlined in section 3a, below.

This Introduction has clarified some key terms, and the historical context for our consideration of policy, principles and practice in user involvement in cancer care.

We now move on to examine in some detail the emerging policies for cancer services.

3. Policies

3.a Service user involvement

Recent policy documents have reaffirmed the key role of service user involvement in shaping the National Health Service in general, and cancer care services in particular.

In 2007 the Cancer Reform Strategy affirmed that '*patients*, local voluntary service providers, alternative providers and other stakeholders should be involved in influencing the way in which services develop' (NHS, 2007, Ch 9, emphasis added). In the following year the Next Stage Review of the NHS (NHS 2008) stated that effective user involvement should play a central role in improving the quality of patient care and delivery of a patient centred NHS.

In the same year, 2008, Part 12, Ch 2, Section 242 (1b) of the 2006 NHS act came into force, giving further legal backing to user involvement. It placed a responsibility on Strategic Health Authorities, Primary Care Trusts, NHS Trusts and NHS Foundation Trusts in England to make arrangements to consult or involve service users (or their representatives) in:

- *the planning of the provision of … services,*
- *the development and consideration of proposals for changes in the way… services are provided,*
- *decisions to be made… affecting the operation of… services*

In 2009 service user involvement became enshrined in the new NHS Constitution. The Constitution refers to patients *rights*, and makes various 'pledges' and 'commitments' necessary to give teeth to those rights. Addressed to patients, it says:

> *You have the right to be involved, directly or through representatives, in the planning of healthcare services, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services, (and goes on):*

The NHS also commits:

- *to provide you with the information you need to influence and scrutinize the planning and delivery of NHS services (pledge); and*
- *to work in partnership with you, your family, carers and representatives (pledge).*

Recently the importance of service user involvement has become part of:

- ***Commissioning.*** World Class Commissioning competencies include 'continuous and meaningful engagement with people, patients and communities to shape services and improve health..... good commissioners will want to ensure that they have appropriate user involvement when making decisions about service provision' (NHS (2009a) Institute for Innovation and Improvement: Patient and Public Engagement Toolkit for World Class Commissioning)
- ***Peer Review.*** A key principle of the new (2008) approach to the peer review process is that patients and carers are a vital and integral part of the process, and it is expected that patients and carers will be 'active participants in the internal validation of self assessments' (NHS (2008b) National Cancer Peer Review Handbook)
- ***National studies.*** The Health Care Commission (now the Care Quality Commission) has embarked on a study of current practice in patient and public engagement in order to further develop its approach to assessing compliance with its Core Standard 17. (Richards, 2009) and the National Cancer Action Team has 'set up a project to explore how to best support user involvement... and ...consider the development of meaningful user involvement performance indicators' (Rule, 2009)

3.b The service user experience

An enduring theme within the policy literature has been its focus on the importance of the patients' experience. From a major preoccupation with the clinical pathway – with its emphasis on the timeliness and speed of access to diagnosis, first treatment etc – has been added an increasing concern with the principles and practice underpinning the supportive care pathway.

Supportive care emphasises questions of patient respect, choice, and dignity along with the importance of health professional's communication skills, their high level competence in interpersonal relations, and their sensitivity in meeting the holistic needs of the patient as a 'person'. The Healthcare Commission's 'patient focussed care' benchmarks have been incorporated in a series of 'Essence of Care' documents (Modernisation Agency (2003-2009) and 'ten priorities' for improving supportive and palliative care are being actively pursued by cancer Networks, with a view to meeting an implementation deadline of December 2009. The recent Kings Fund 'Point of Care' paper (Goodrich and Corwall, 2009) is beginning to take the discussion of supportive care practice onto the next level.

In the Next Stage Review (NHS, 2008a) Lord Darzi argued the need for clear and comprehensive information if patients are to be able to make *informed* choices about their care - via the 'NHS Choices' website - and added that the coverage of the Choices website needs to be broad, with information not only about cleanliness, infection rates and so forth, but also measurements of patient's satisfaction concerning their experience of things like being treated with dignity and respect.

The NHS Constitution picks up on this theme, emphasising the importance of 'improving care from the patients' perspective', and consultations on the new National Cancer Peer Review confirmed that clinicians were generally positive about this greater focus on patient experience when reviewing quality of cancer care.

Patient surveys are a key method for gathering service user perspectives on quality of care, as well as monitoring the outcomes of care improvement initiatives. In his first annual progress report on the Cancer Reform Strategy the National Cancer Director confirmed that 'Progress on the patient experience survey will be one of our top priorities' (Richards, 2009)

3.c Quality improvement

Improving the quality of care has also moved up the agenda for NHS reform. Lord Darzi's Review (NHS, 2008a) explicitly seeks to 'open a new chapter in the story of quality' in the NHS, confirming that *quality* measures will "go beyond mortality rates for surgery to include patient reported outcomes and patient experience of services".
His report underlines the critical importance of the patients' assessment of quality experience as noted in the previous section:

> *For the first time we will systematically measure and publish information about the quality of care from the front-line up – measures will include patients own views on the success of their treatment and the quality of their experience...and...all healthcare providers working for or on behalf of the NHS will be required by law to publish 'quality accounts' just as they publish financial accounts (from 2010).*

Darzi affirmed, then, that 'quality is at the heart of everything we do', and goes on to set out a series of proposals for enhancing the quality of patients' personal care (including compassion, dignity, respect &c) as well as support for cancer survivors, and personal care plans for all those with long term chronic conditions.

A new National Quality Board and the new NHS Evidence Service will bring clarity to quality, which will be measured and findings published. In his first Annual Report on the Cancer Reform Strategy the National Cancer Director reported that a National Cancer Intelligence Network had been established, noting that it will enhance patient choice (by promoting efficient and effective data collection throughout the cancer journey), drive up service quality (by exploiting information to drive improvements in standards) and underpin stronger commissioning (Richards, 2009).

3.d Outcomes

Implicit in the above discussion of quality is a new emphasis on assessing the *outcomes* of improvement initiatives on the service user experience. The Darzi Report noted that;

> *At present Peer Review focuses largely on processes and structures. Over time, as reliable measures of outcome become available, there should be a shift in emphasis*

It has been reported that the Cancer Reform Strategy Advisory Board has endorsed this view, and considers

> *that one of the key priorities for the future is to develop a culture where there is more of a focus on outcome measures rather than process measures, and where patient experience is seen as a key outcome measure (Richards, 2009)*

It is interesting to note that consultation on the new National Cancer Peer Review process showed that health professionals were also generally positive about the greater emphasis on outcomes within the Peer Review process.

3.e A 'patient-led' and a 'patient-centred' NHS

A final policy shift to be mentioned here – and one that will have an impact on the patients' experience – is the current vision of a 'patient-led' health service. The Next Stage Review (NHS, 2008a) emphasises the need to 'personalise' health care services – by involving patients in decision making about their treatment and care, by offering them real choices about their care, and by ensuring they have the information on which to make the best decisions for themselves in the context of their personal circumstances;

> *the NHS needs to give patients more rights and control over their own health and care...choice gives patients the power they need in the system, as NHS resources follow patients in the choices they make (NHS, 2008a)*

As already noted, the NHS Constitution has now enshrined this as a 'right'; the Constitution affirms that patients should have the right to full information about all available treatments, and the right to be involved in discussions and decisions about their care (NHS Constitution, 2009; Redding and Boyd, 2008)

The patients' right to make choices about, and exercise (more) control over aspects of their care sits well with the emphasis given to their right to be involved in the development of proposals for, and take part in decisions about, the planning, organisation and operation of services. It will also reinforce the movement to more patient-centred care. (see section 5.a below)

4. Principles of service user involvment

While recent policy pronouncements have underlined the continuing relevance and importance of user involvement in cancer care decision making, relatively little official guidance – with the notable exception of the National Institute for Health and Clinical Excellence's 'Improving Supportive and Palliative Care for Adults with Cancer' (2004) - has been given to what constitutes effective practice in user involvement. This section spells out six principles that underpin effective service user involvement.

4.a Information on the service user 'experience' is collected systematically, and used to inform action for change

Continuous improvement in the patient and carer experience of cancer care services entails lay people (together with health professionals) listening carefully to patients and carers experience of cancer care services (for example, via participatory enquiry, focus groups, patient/carer surveys, as well as drawing on their own experience of the cancer journey), and then using the results of such exercises to provide the evidence on which to base action for change. This requires that service users (through their Partnership Group &c) seek to ensure that machinery is put in place to collect patient experiences and views on a systematic and regular basis.

Examples of where collection of information about aspects of patients' hospital experiences has led to action for change is illustrated in Fig 1

Fig 1. Service users experiences of cancer care in hospitals that have given rise to demands for service improvement (Goodrich and Cornwall, 2008)

- Loss of dignity e.g. gowns that fail to maintain patient modesty; bedside curtains left open when patient receiving intimate care; mixed sex wards
- Not being treated as a person e.g. doctors and other health professionals 'talking over the patient'; being excluded from case conferences called to discuss discharge arrangements
- Unpredictable and impersonal care e.g. constant staff changes; 'agency' night staff unaware of patients individual needs
- Lack of basic care e.g. call bells left out of reach; patients being left in soiled bedding and clothes; repeated requests necessary before getting analgesics
- Difficulty in finding out who is in charge of one's care e.g. 'being passed from pillar to post' when seeking information about progress of treatment
- Lack of respect e.g. dentures, spectacles 'lost'
- Feeling like a 'parcel' e.g. repeated movement of patient from ward to ward (because admitted to 'wrong' ward following emergency admission; because of acquired infection; constant movement to specialist facilities for tests etc).
- Lack of reassurance and information e.g. 'days go by' without seeing a nurse except at medication rounds
- Care regime experienced as disjointed and fragmented e.g. different specialist health professionals don't seem to work together as a team
- Lack of real involvement in key decisions about treatment and care plans: the patient 'is the last one to learn what is to happen to them next'
- Being talked to in an upsetting manner e.g. brusquely, insensitively, dismissively

The NICE Improving Supportive and Palliative Care for Adults with Cancer (2004) summarise in general terms what patients want and expect from their experience of cancer care:

- to be *treated as individuals,* with dignity and with respect for their culture, lifestyles and beliefs
- to have their *voice heard*, to be valued for their knowledge and skills and to be able to exercise real choice about treatments and services
- to receive detailed *high quality information* about their condition and possible treatments, given in an honest, timely and sensitive manner at all stages of the patient pathway
- to know what *options* are available to them under the NHS, voluntary and independent sectors, including access to self-help and support groups, complimentary therapy services and other information
- to know that they will undergo only those interventions for which they have given *informed consent*
- to have good *face to-face-communication* with health and social care professionals
- to know that services will be *well coordinated*
- to know that services will be of *high quality*

In their recent report for the King's Fund, Goodrich and Cornwall explain what 'action for change' means in this context. They offer a definition of service user experience as;

> *the totality of events and interactions that occur in the course of an episode of care. (emphasis added, Goodrich and Cornwall, 2008, p3)*

and then go onto invoke the concept of 'the point of care' to pin down what they mean by such 'events and interactions', explaining that

> *Clinical and non-clinical staff at the point of care, and in support services, and senior leaders, including non-executives in the Boardroom, all contribute to the quality of that experience (Goodrich and Cornwall, 2003, p3)*

Action to improve the quality of the service users' experience entails a wide range of responses from communications training to organisational re-engineering, from better leadership to cultural change in health service organisations, and much more.

Lastly it is useful to remind ourselves why attention to the service user experience is important – obvious though this is to most people. The moral argument rests on humanistic and/or religious values; it is argued that humanity in care is a basic human value. The human rights argument is that all people have a right to be treated with respect and dignity. The clinical argument rests on evidence that worry and anxiety delays, and that good care and communication aids, recovery. The business case rests on evidence that service user choice of hospital or treatment centre can be influenced by the organisation's reputation for the quality of its care - and health care organisations will be constrained to attend to their reputation as patients are given greater opportunities to exercise choice within the NHS - and funding follows such choices!

4.b Valuing diversity; involving all

"Valuing diversity; involving all" is the title of a section in a recent Cancer Commissioning Toolkit which neatly sums up a further principle of user involvement (NHS Institute for Innovation and Improvement, 2009a).

Service user involvement seeks to be inclusive in two senses a) it aims to work for improvements in cancer care that reflect the needs of *all* patients and carers, and not just those who become members of user partnership groups and other cancer user groups; b) secondly it recognises that within any population there will be *particular* groups of cancer patients and carers who are 'hard to reach'; a partnership group has a responsibility to make concerted efforts to 'reach out' in order to address the felt needs and concerns of such groups.

Involving all

Partnership Groups are often concerned about how representative they are of the wider community of cancer service users. They become anxious about whether the needs and issues they address, and the service improvements they seek to promote, may be unduly biased towards their own personal experiences and particular concerns. Making sure that the changes that partnership groups pursue reflect the experience and concerns of cancer sufferers as a whole has become a key principle.

Evidence shows that patients and carers who participate in user involvement are influenced by a variety of motivations (Cottrell et. al. 2008) and that these are shaped by a wide range of personal experiences. In one sense such diversity is reassuring and offers some confidence that user involvement is not reflective of a very narrow range of experiences. On the other hand, it has been observed that the members of many partnership groups tend to be more elderly, more middle class, and to live in localities that are less than fully representative of cancer service users in general. However, achieving a perfect cross-section of local cancer service users in a partnership group is well nigh impossible. So how is the issue of representativeness to be addressed?

Service users tend to opt for one of two broad approaches to this problem. Some acknowledge that they do not, and cannot, *represent* the wider body of service users in any formal way. This group prefers to define themselves as expert 'patient involvement advisors' (Hasler, 2005) – raising issues and asking key questions of health service decision makers, and working hard to ensure they get appropriate responses (Fisher 2008, p103). Other service users take a different tack, stressing the importance of basing what they do on results from carefully designed and conducted enquiries into the experiences and priorities of the wider community of service users. These two approaches need not, of course, be seen as alternatives. It is probably best to see user partnership groups as the primary source of *evidence-based advice* to Cancer Network Boards (and other decision making forums) with respect to user issues and service user involvement, thus embracing both approaches

Valuing diversity

While conventional survey techniques can begin to address the issue of representativeness they are rarely sufficient when it comes to identifying the needs of those who are 'hard to reach'.

> *Some people have particular difficulties, not only in accessing services, but also in making their lack of access to services known to those who ....plan and provide services. Terms such as 'excluded', 'marginalised', 'hard-to-reach', 'seldom heard' and 'disadvantaged' are commonly used to describe people who are excluded from main stream social systems. (NHS Patient and Public Engagement for World Class Commissioning, p79, 2009a)*

Marginalised groups are often seen to include, for example:

- People who do not speak English as a first language
- People who experience discrimination such as racism or homophobia
- Young people i.e. teenagers and children
- People who are housebound
- People with hearing, speech and visual impairments
- People with learning difficulties
- People with little or no literacy skills

Yet these groups, as well as many others to be found in diverse, pluralistic communities like those that make up the UK, are just as much in need of cancer care services (some more so!) as are members of majority population groups. A key principle of user involvement is a commitment to ensure that *all* voices are fully 'heard', and the diversity of everyone's needs appropriately met.

Facilitating user voice amongst such diverse groups requires sensitivity and creativity – there is no one-size-fits-all formula when it comes to engaging with excluded groups; techniques have to be found that either adapt tried and tested methods of engagement or, more radically, replace them with more innovative methods.

Adapting methods of engagement like focus groups or consultation events must ensure that involvement is not prejudiced by failing to recognize, and provide appropriately for, different participant needs (e.g. crèche facilities, transport, timing of events, provision of facilities like induction loop systems, interpreters, special dietary requirements, provision of information in different languages, and so forth).

Refugees are an example here - persons who have left their own country and are unwilling to return because of well founded fear of persecution. Some will have faced racial abuse in this country, and suffered trauma (psychological, physical) in their country of origin. They may not speak much English, and they may (as a consequence of negative experiences in their country of origin) resist contact with official agencies – they may fear that information they divulge will tell against their application for asylum.

In the case of teenagers engagement activities need to take place after school or at weekends, adults involved will probably require enhanced CRB checks, will need to work in pairs, will need to comply with relevant Child Protection policies. Ensuring inclusion of teenagers with disabilities, domestic or caring responsibilities, or special leaning needs will have to be planned for. Activities and appropriate language must be adapted to take account of the particular age range in a group, and so on.

Replacing traditional methods with different, more innovative approaches, may be necessary for some groups: for example, in the case of younger children, consideration needs to be given to making things fun (e.g. running a community fun day), creative (via developing mini art projects or drawing projects) or exciting (introducing competitions and prize day contests). The Toolkit for World Class Commissioning provides useful examples and case studies of innovative approaches that have been used with children, older people and other 'hard to reach' groups.

4.c Service user involvement is concerned with organisational level interventions

As already noted action to improve the service users' experience generally entails working for organisational change. The following definition of service user involvement makes this clear:

> *Service user involvement is concerned with organisational interventions and differs from the contribution that individuals make to decisions about their own personal treatment and care (Coulter & Ellis 2007)*

Contemporary terminology can be ambiguous. It is said that the NHS should strive towards being a 'patient led health service', and that best practice in modern cancer care must ensure that everyone using health services shall be empowered to contribute to decisions about their own treatment and after-care. This kind of empowerment - at the 'point of care' - is not empowerment as it is understood in terms of service user involvement here (though User Partnerships may well pursue organisational initiatives to improve 'point of care' experiences in their work plan).

As the NICE guidance document 'Improving Supportive and Palliative Care' (2004) states:

> *An important distinction needs to be drawn between user involvement in decision-making about a person's own treatment or care and participation in the development of services for all patients. It is the latter that are the focus of service user involvement, which is about empowering people who use services to voice their experience and influence broader care*

The NICE document summarises the scope of service user involvement as making

> *contributions to the planning, delivery and evaluation of services (NICE 2004, p7)*

It is this phrase (abbreviated to 'PDE' in what follows) that will be adopted in Section 5 of this paper, when we turn to a consideration of 'practice'. PDE are large and important tasks; a user Partnership group needs to carefully think through, discuss and agree a robust user involvement strategy and work plan if it is to effectively meet this challenge.

4.d Service User involvement deploys a variety of methods to promote change; the primary method is partnership working

There are a wide range of ways in which service users get involved in 'action for change' to influence the planning, delivery and evaluation of cancer care services, for example:

- by responding to consultations on aspects of service reconfiguration planned by health professionals
- working in partnership with health professionals in, for example, a user Partnership group, or a network Tumour Site Specific group, or a Commissioning group,
- by devolution of responsibility to service users for seeing an aspect of PDE through from planning to implementation (e.g. a focus group enquiry into patient safety concerns about aspects of Radiotherapy).

The range of user involvement activities has often been conceptualised as a kind of continuum , with many models drawing in some way on Arnstein's (1969) widely known 'ladder of participation'. For present purposes it is useful to distinguish 5 levels, or 'rungs', of user involvement in the PDE of cancer services.

Level 1
Information

service users feed information into PDE processes. The information may be requested by health professionals (e.g. an invitation to out-patients to complete a questionnaire on travel difficulties in getting to a clinic), or be collected and put forward by service users themselves (e.g. providing information that they feel it is important that health professionals are made aware before (or even after!) a change to ward visiting times is implemented).

Level 2
Consultation

This level involves inviting those consulted to express a view or preference (which might be 'open ended' or involve choice from a range of pre-determined options). For example, health professionals my consult service users about their preferences concerning the design features of a new facility

Level 3
Partnership

This level involves service users engaging jointly with health professionals and, through collaborative work, progressing an aspect of PDE (e.g. joint work on the development of a patient 'information pathway')

Level 4
Delegated Authority

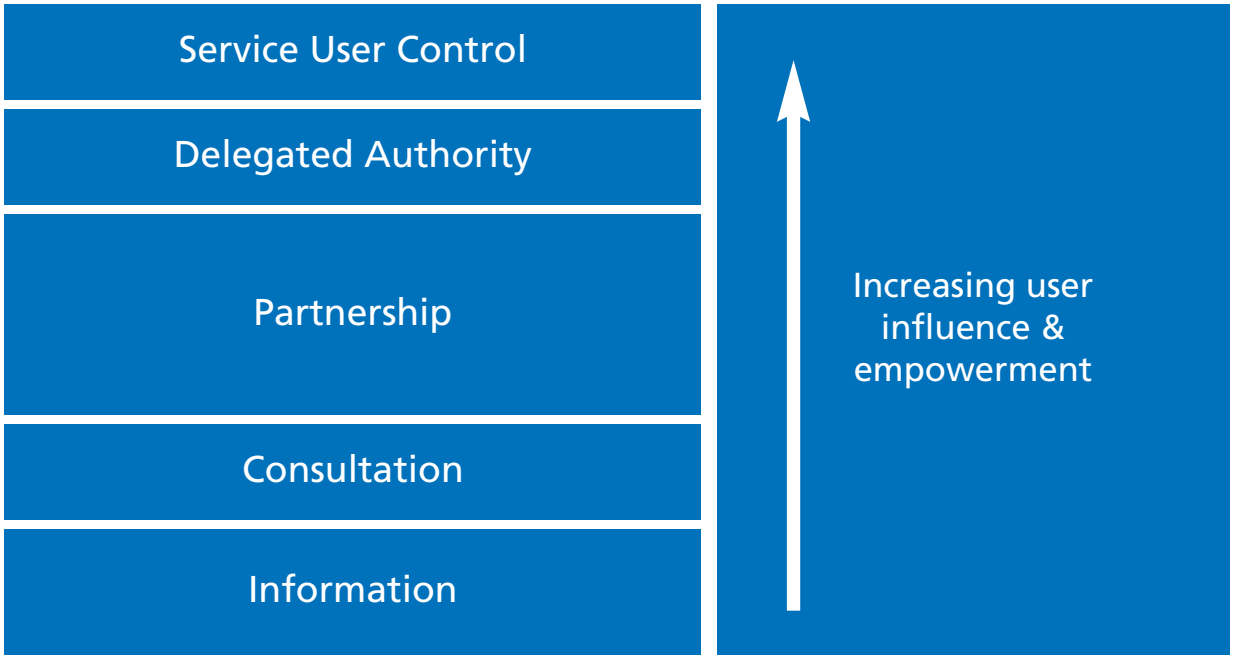
This level involves the responsibility for particular tasks, processes or decisions in PDE being delegated to a group of service users (e.g. as part of a Network's programme of user surveys and enquiries, the responsibility for planning, running and writing up a number of focus groups on the support needs of post primary treatment 'survivors' is delegated to the Network User Partnership group)

Level 5
Service User Control

This level involves service users taking full decisional responsibility for initiating and seeing through a piece of work, from planning, resourcing, implementing, monitoring and evaluating it (e.g. Service Users plan and run a Day Workshop - on 'Making Our Partnership Work')

Fig. 2 represents this five-rung model in diagrammatic form

Fig 2. A 'Ladder' of User Involvement



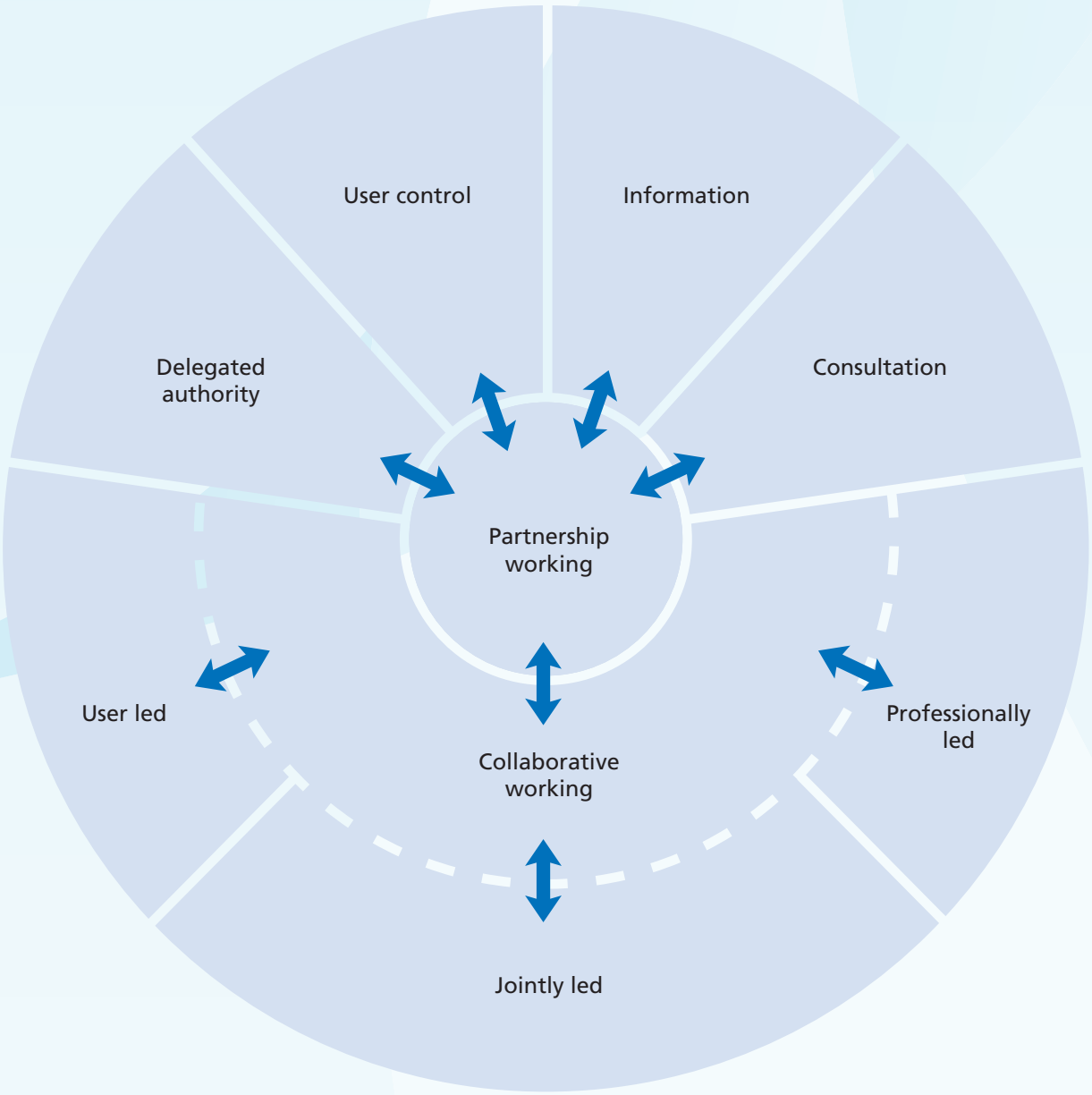
However, many user involvement initiatives entail working at a number of different 'levels' at the same time. Many service users feel that a 'ladder' model provides a misleading picture of their approach to PDE because a) it overlooks the 'holistic' and multi-dimensional nature of much practice, b) it privileges the importance of work on the 'higher' rungs of the ladder, and c) it fails to recognize that most user involvement in cancer care has adopted partnership working as the organizational vehicle through which work on most of the 'rungs' is approached (see also Tritter and McCallum (2005) for a wider discussion and critique of Arnstein's model).

The idea of a 'wheel' of user involvement thus offers an alternative, and arguably better, way of conceptualizing the nature of practice (see Fig. 3). It is, moreover, a model that is consistent with NICE Supportive and Palliative Care Guidance (2004)

> *Mechanisms at Network and provider level should be established to enable the views of people with cancer and their carers to influence the development, delivery and evaluation of cancer services.....Cancer Networks should establish and support Partnership Groups involving patients, carers and local health and social care professionals. They should take their views into account when planning services*

In our wheel model Arnstein's rungs are drawn as 'segments', each of which (as illustrated by the double-headed arrows in the diagram) is seen as a strategic option for achieving change in PDE. 'Information' for example is seen to involve both the collection of information by the Partnership group to inform priority-setting in its work plan, as well as the production of information resources that will benefit the wider body of patients' and carers'.

Fig 3. The 'wheel' model of user involvement



An important difference between the ladder and wheel model is worth drawing attention to. Partnership working, in the sense of service-users and health professionals embarking on collaborative work is signalled in the three segments occupying the bottom half of the wheel. A distinction is drawn between collaborative work that is:

- led by professionals (for example service users are invited by health professionals to join a working party they have established to develop a network- wide strategy for implementing 'information prescriptions')
- led by service users (for example service users invite health professionals to join them in a working group they are setting up to pilot new approaches to supporting patients with learning difficulties)
- jointly led (for example health professionals and service users on a Specialist (Cancer) Commissioning Group link up as equal partners to plan and implement a patient and public engagement strategy consistent with World Class Commissioning competencies

Whether we see user involvement in terms of a 'ladder' or a 'wheel' such partnership working remains the primary method of choice for user involvement in cancer services at National, Network and Locality levels (thus this particular approach is drawn bigger than the other methods in both Fig. 2 and Fig. 3). At Network level user Partnership groups are now quite well established, and service users are also increasingly involved in network Site Specific groups, Commissioning groups, Research Network groups and in the overall Network Management Board group. At locality level user Partnership groups have also become widely established as the primary method of choice for co-ordinating the involvement of service users in local needs assessment and service development. It is often through local user Partnership groups that patients and carers are invited to join Locality Cancer Implementation groups, as well as the steering groups of Trust-based Patient Information Centres, Cancer Care Centres, Service Improvement implementation groups and so forth

Partnership-working as a way of enabling and securing service user involvement has much to commend it. Depending on the profile of a Partnership's membership, leadership, organisation and facilitation, it can offer:

- *Mutual understanding;* health professionals can gain enhanced insights into what it's like to be a patient or a carer, and service users can learn about both the opportunities as well as the constrains that shape the work of a health care team
- *Creative problem solving;* opportunities are created for both health professionals and service users to take a fresh look at problems, and to suspend their usual 'mind-sets' in order to allow development of a wider vision. 'Stove pipe' thinking is reduced, holistic approaches are encouraged.
- *Trust* between partners is likely to increase, with greater likelihood of the shared ownership of goals, as well as plans and practices being modified with the agreement, and for the benefit, of all parties.
- *Collaborative working* can reduce resistance to change and encourage 'buy-in'; implementation of planned change is accelerated and goes more smoothly.

At the same time there are also downsides to partnership working and these need to be acknowledged, and if possible minimized:

- Lines of *accountability* may not always be clear
- *Slower decision-making* - at least in the initial planning stages of a particular PDE initiative
- *Opportunity costs may be unclear* - what could have been achieved with the time and resources if used differently?

Optimising the effectiveness and efficiency of partnership working is seen to be related to:

- Recruitment of an energetic, 'can-do' orientated, and diverse membership; diversity of membership relates to cancer 'experience', social, cultural and ethnic background, along with diversity in skills, knowledge and capabilities

- Involving all partners, and encouraging their engagement, as early as possible
- Allowing sufficient time for new partnership groups to 'bed in' and become established; for the shared vision to develop, for the mutual trust to evolve.
- Establishing a constitution and terms of reference that clearly spell out lines of accountability, arrangements for chairing and taking minutes at meetings, roles and decision making powers of any sub-committees/sub-groups, and so forth
- Establishing agreement on the group's purposes and strategic goals.
- Distributed (shared) leadership – opportunities for all members to 'lead' on specific matters, encouraging democratic participation in making decisions and implementation of work programmes
- Clear and open communication; and a willingness on the part of all parties to be challenged
- Building member competencies (skills, knowledge, confidence etc) through induction programmes, training, action-learning, mentoring, and buddy/mentor systems
- An underpinning of sufficient resources to secure week-by-week management, oversight and development of the partnership (administrative and secretarial support, data base updates, consultation with members, keeping members informed and 'on board', checking that they are getting out of it what they want and so forth)
- Monitoring and evaluation of the working of the partnership working, and reflecting on and using the findings of such evaluations to improve effectiveness and efficiency
- Capacity building: events and programmes that, using organisational techniques like whole-system working and action-learning to 'grow' the capacity of the partnership so that it can successfully take on more, and more challenging, pieces of PDE work (NHS (2002), Section 2; Douglas, (2009); Glasby and Dickinson, 2008)

4.e Exercising service user 'influence' and 'power', and encouraging service user 'empowerment' are central to user involvement

Clearly the types of involvement identified in Figs 2 and 3 are abstractions; and we noted above that the practice of service user involvement generally entails choosing to operate with a carefully chosen, and fit for purpose, mix of different approaches.

However, the distinction brought out in Fig 2 (the 'ladder' model) has some heuristic value. It sensitize us to differences in power and empowerment. The ladder concept provides a vocabulary through which to assess whether, in a particular Network or Locality, the user Partnership group operates more, for example, at levels 1-3 than at levels 3-6. And we can ask: is there any evidence to suggest that a particular level, or mix of levels, is going to contribute more to realising effective user involvement? In similar vein we can pose the question: when looking at the achievements of a particular user Partnership group, does their power and influence mostly relate to the 'ends' or the 'means' of PDE?

Empowerment can also be seen to be related to different forms of power: decisional power, agenda-setting power and cultural/linguistic power (Butcher et al, 2007 pp23-26). It can be helpful to review approaches to service user involvement with a view to assessing their success in deploying these different forms of power, as well as asking how (and when) they contribute to successful achievement of PDE initiatives.

4.f Effective service user involvement requires a stable resource base and professional support

The previous section noted the need for user involvement to be appropriately resourced. Experience suggests the following to be a minimum requirement:

Professional facilitation.

The NHS in general, and the policy, organisation, and delivery of cancer care in particular, can be both complex and confusing to the lay person. If service user involvement is to deliver then the support of an appropriately skilled and committed professional User Involvement Facilitator (UIF) is essential. The UIFs role is to deploy their specialised knowledge, skills and experience to support service users through helping them to a) turn their broad aims into specific and realisable objectives and b) increase their confidence and competence in the strategies and skills they will need to use if they are to achieve those objectives. Facilitation is not about teaching, or leading, or managing (though it can include elements of all three); the facilitators role is to sustain motivation and build confidence, to help clarify purposes, to create momentum, to signpost and mentor, to show how resources can be accessed, to provide recognition and appreciation, and to create an environment in which open discussion and productive action-learning can take place.

Information.

Ready access to high quality information is a key resource in effective user involvement practice. This resource includes:

- Information about evolving health policy, as this relates to cancer care
- Information about health services
- Information about cancers: prevalence, morbidity and mortality, public awareness, prevention, treatments, 'living with and beyond cancer'
- Information about heath care decision-making processes and organisational structures; the operational context through which policy is implemented and services delivered
- Information about who has responsibility for what, does what, and knows what
- Information about performance; access, for example, to organisationally and geographically specific patient experience enquiries, Peer Review reports, profiles of patient and public complaints.

Secretarial, administrative and professional support.

Such support takes two forms a) secretarial and administrative support is necessary to service both the user Partnership groups and their facilitator, arranging meetings (booking rooms, posting notices, taking and distributing minutes), assisting in organising events and workshops, updating membership lists, word processing work plans, annual reports, correspondence and so forth b) professional support is necessary if Partnership work-plans are to be effectively implemented – either through modifications to mainstream programmes, or through running pilot projects.

Finance.

In addition to employment costs (Facilitator, Administrator/Secretary, Professional support) a user involvement budget should include funds for:

- Reimbursement of service user travel, communication costs, and other out-of-pocket expenses (e.g. child minding)
- Meeting expenses (room hire, tea/coffee &c)
- Funding for education and training events, joint meetings with other user groups
- Funding for implementation of User Partnership initiatives (e.g. running events and projects, provision of specialist information/advice and so forth).

Ability to call on a budget also means that the effectiveness of partnership working can be *improved* - through investing in induction programmes, through carefully planned exercises in capacity building, through skilful facilitation, and through proper funding and resourcing of elements in the work plan. Investing time, effort and money in such activities generally proves to be worthwhile.

4.g Pursuing quality care from the perspective of 'patient centred care'

In the NHS quality tends to be defined as 'fitness for purpose':

> *Doing the right things, at the right time, for the right people, and doing them right – first time'*

Once again the Department of Health stresses the importance of the quality of the patient experience:

> *....and it must be about the quality of the patient's experience as well as the clinical result (DH 1997, 3.2)*

The first part of the above quotation implies the identification and use of 'standards' which in turn prompts the question: who sets, and defines, such standards? The answer, in the 'quality' literature pinpoints a range of models. Three of the most relevant ones here are:

- The expert model; standards are set by experts – clinical specialists or trained managers
- The democratic model: standards are set by the public, through democratic debate and political contestation
- The service user model; standards are set by service users (often called 'consumers' in a market model) (Miller, 2004)

These three perspectives overlap in practice, with standards set by a mix of professional experts, service users, general public, and managers. The 'envelope' in which standards are set in the public sector is shaped by politicians, while most of the service specific standards are set by experts (e.g. professional guidance distilled in, for example, NICE Improving Outcome Guidance documents).

Turning to patient and carer involvement, the emphasis will be different. Standards are rooted in the 'service user' model. When the service user thinks about standards, these derive not, first and foremost, from the perspective of delivering or managing a (fit for purpose) service, but from what that delivery and its management felt like for them in a direct, personal and experiential sense in a 'patient centred' way

This is not to say that users and carers turn a blind eye to objective, evidence based information about the quality (or efficient management, or effective organisational delivery) of important aspects of their medical care. Many do want, for example, scientifically grounded information about the likely outcome and safety record of particular procedures. But they are *also* exercised about how their professional carers impart such information to them as worried, confused and vulnerable individuals.

Nor is it the case that users and carers who take on user involvement roles are motivated wholly by their own *personal* experience. Some are, and they may run the risk of being seen (and perhaps marginalised) as 'axe grinders'. But most of those who give time to user involvement activities endeavour to express a general position, drawing their conclusions about what needs to change *both* from their own first-hand experience *as well* as from the experience of other service users - as garnered through a mix of a) active listening to others' experience in one-to-one conversations, b) through structured consultations and, c) importantly, through carefully designed and run focus groups, social enquiries and patient experience surveys (see for example Richard and Coulter, 2007).

The King's Fund report on patient centred care 'Seeing the Person in the Patient' (Goodrich and Cornwall, 2008) reviews a number of definitions of patient centred care and finds the Institute of Medicine (2001) definition the most comprehensive. This definition comprises 6 properties or dimensions which, slightly adapted for our purposes, provide us with a useful point of reference for present purposes:

- Compassion, empathy and responsiveness to needs, values and expressed preferences
- Co-ordination and integration
- Information, communication and education
- Physical comfort and immediate environment
- Emotional support, relieving fear and anxiety
- Involvement of patient, carers and family

Each of these dimensions can be broken down into subheadings, for example

- Physical comfort can be broken down into:
  - aspects of the physical environment – design, space, furniture and equipment, accessibility
  - the management of that environment – warmth, cleanliness, smell, noise
  - staff responsiveness to individual patients

  (Goodrich and Cornwall, 2008)

- Involvement of patients, carers and families can be broken down as follows:
  - to have their voice heard, to be valued for their knowledge and skills and to be able to exercise real choices about treatments and services
  - to be involved in the evaluation of services
  - to participate in service planning to ensure that services meet the needs of patients and carers (Goodrich and Cornwall, 2008; NICE Supportive and Palliative Care IOG, 2004)

However, gathering information about service users experience through structured techniques like patient experience enquiries - that set out to capture robust data about peoples experience - is often not straightforward. In the first place a persons' reported experience of an aspect of a service usually involves them coming to a summative conclusion about their experience based on the gap (+ or -) between their *initial expectations* of, and their *actual experience* of, the service. Another problem relates to the salience of an aspect of experience. For example one individual may express their level of involvement in decision making processes about their care as unproblematic, although further probing might reveal that this aspect of the their care was of little importance to them. Another individual, on the other hand, who deems it essential to be engaged in all stages of decision-making about their care, may report a similar experience quite negatively as her normative expectations were much higher. Access to specialist expertise in the construction and analysis of patient experience enquiries is highly desirable – either from outside sources, or from expert members of the user partnership group itself.

5. Practice

In the light of the previous discussion of policy and principles the paper now moves on to address how the *practice* of service user involvement can be used to improve the patients' experience. The two frameworks previously used to structure the discussion so far will continue to be employed here:

1. The distinction between the *goals* and the *means* of service user involvement i.e. *what* needs to be improved, and *how* can such improvements be achieved?

2. The distinction between *two types* of goals and means: a) goals and means that service users employ in order to bring about a direct and specific improvement to the patient experience, and b) goals and means that they use to improve the overall practice of service user involvement in planning, delivery and evaluation of cancer care services – to 'raise their game'.

5.a Working to improve the patient and carer experience – key elements

Figure 4 illustrates, in diagrammatic form, the key elements of the cancer patients' experience that are common to each stage along the care pathway, from referral and diagnosis, to treatment, rehabilitation, survivorship and palliative/end of life care.

Patient centred care

The circle at the centre of Fig 4 embraces the components of patient centred care – which are arguably the most influential in shaping the patients overall experience of care. According to policy and principle (backed up by considerable research) we have seen that cancer patients want:

1. Care that treats them as a *person*, and not just as a *patient*; that is to say they wish their care to be organised around their felt and expressed needs and wishes, and to be treated with dignity, sensitivity and compassion – *not* for the convenience of their health care professionals or the health care organisation which employs such professionals.

2. It follows that they wish their care to be 'holistic' in its planning and delivery – to go beyond basic clinical care to address their wider social, emotional, practical, psychological and spiritual concerns

3. Thirdly patients want to decide how much involvement they want in decision-making about their own cancer care

Transitional and self managed care

Because Fig 4 represents a stage in the patients' care experience, holistic care must also address how the patient 'enters' and 'leaves' each stage. So, in the diagram, the patients' experience of the process of entering and leaving the patient-centred care components also needs attention:

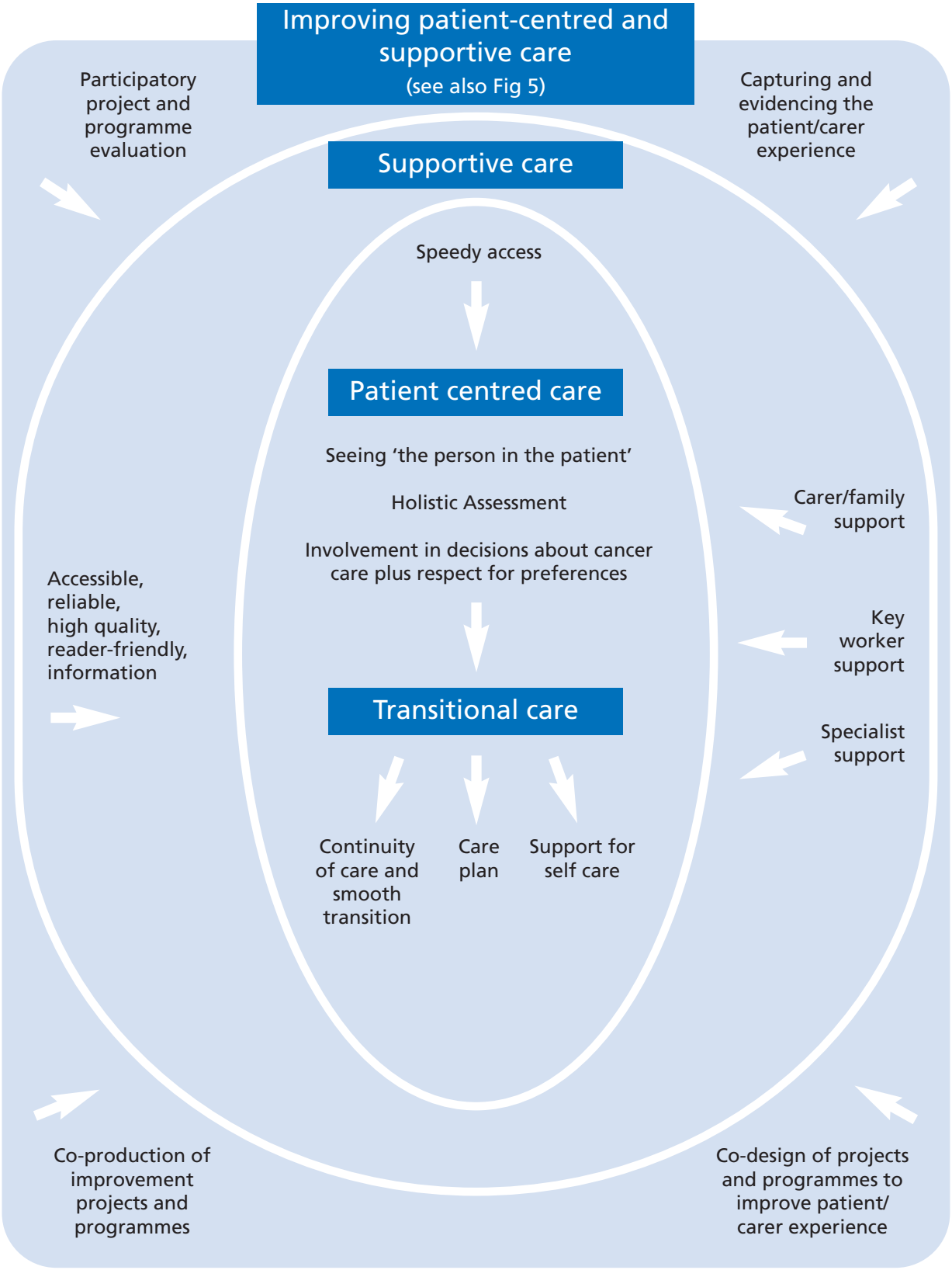
- Patients generally want *speedy access* to each new stage of their pathway – and most will want information and support if they are to navigate the transition with minimal anxiety.

- When moving on from a particular stage of care most patients hope for a) a smooth, coordinated transition to the next stage, b) the provision of a written care plan/package that summarises what happens next, and c) identification of support/information/ educational opportunities that will open up opportunities for further development of the necessary skills and capabilities for managing the transition and sustaining active self care.

Supportive care

The above elements are both logically and experientially central to the care process, but to work fully patient centred care needs to be backed up by supportive care. Supportive care, on the left of the 'patient centred care' box, comprises, first of all,

Fig 4. Promoting patient centred and supportive care



information – a crucial supportive ingredient in all stages of care. Accessible, understandable and quality information is a prerequisite to informed involvement in decision making. But in addition, of course, if patients do not know what to expect, or how to care for themselves, or when to call for expert help, then increased anxiety and worry can lead to less than optimum outcomes as well as the likelihood of increased complaints. On the right hand side of the 'patient centred care' box other forms of *supportive care* are listed – family and friends (who can offer emotional and practical help), key workers (who can act as a guide and signpost to a range of more specialist support resources: psycho-social help, rehabilitation opportunities, financial and employment advice, spiritual care and so forth), community self help, and specialist patient and carers groups.

Finally a third circle surrounds all of the above and embraces a number of key elements which, though important in shaping the experience of care, relatively few patients will give much thought to. These elements are organisational processes that service users bring into play to *improve* the patients' experience, and comprise:

- Capturing and evidencing the patient/carer experience
- Co-design of projects and programmes to improve the patient/carer experience
- Co-production of improvement projects and programmes
- Participatory project and programme evaluation

It is these elements which constitute a major part of the work of user Partnership groups and which are taken up in the next section, and are discussed as a series of steps in a user partnership 'service user improvement cycle'.

5.b Improving the patient and carer experience – through effective user involvement

Clinicians, managers and commissioners all seek to improve the patients' experience, and draw on a variety of methods to achieve this – more skilful communication, quality assurance, audit, organisational development, service re-design and so forth.

So where does user involvement fit in? Fig 5 seeks to address this question in diagrammatic form. This diagram consists of a modified version of the Kolb's experiential-learning cycle (Kolb, 1984) and provides a model of how service user partnerships can work to improve the patient experience. Elaborating on the key elements in Fig 5:

***Step 1:* Capturing and evidencing the patient/carer experience** requires a user Partnership group to find out about and understand what shapes patients' and carers' experience of cancer care services. This may, for example, involve reviewing the findings of recently conducted user-experience surveys (Care Quality Commission Surveys, 2009) or generating their own evidence through conducting their own surveys and focus groups, mystery shopping initiatives , deliberative events, discovery interviews, analysing complaints data, and so forth (Picker Institute Europe, 2009; NHS, 2009a Institute for Innovation and Improvement)

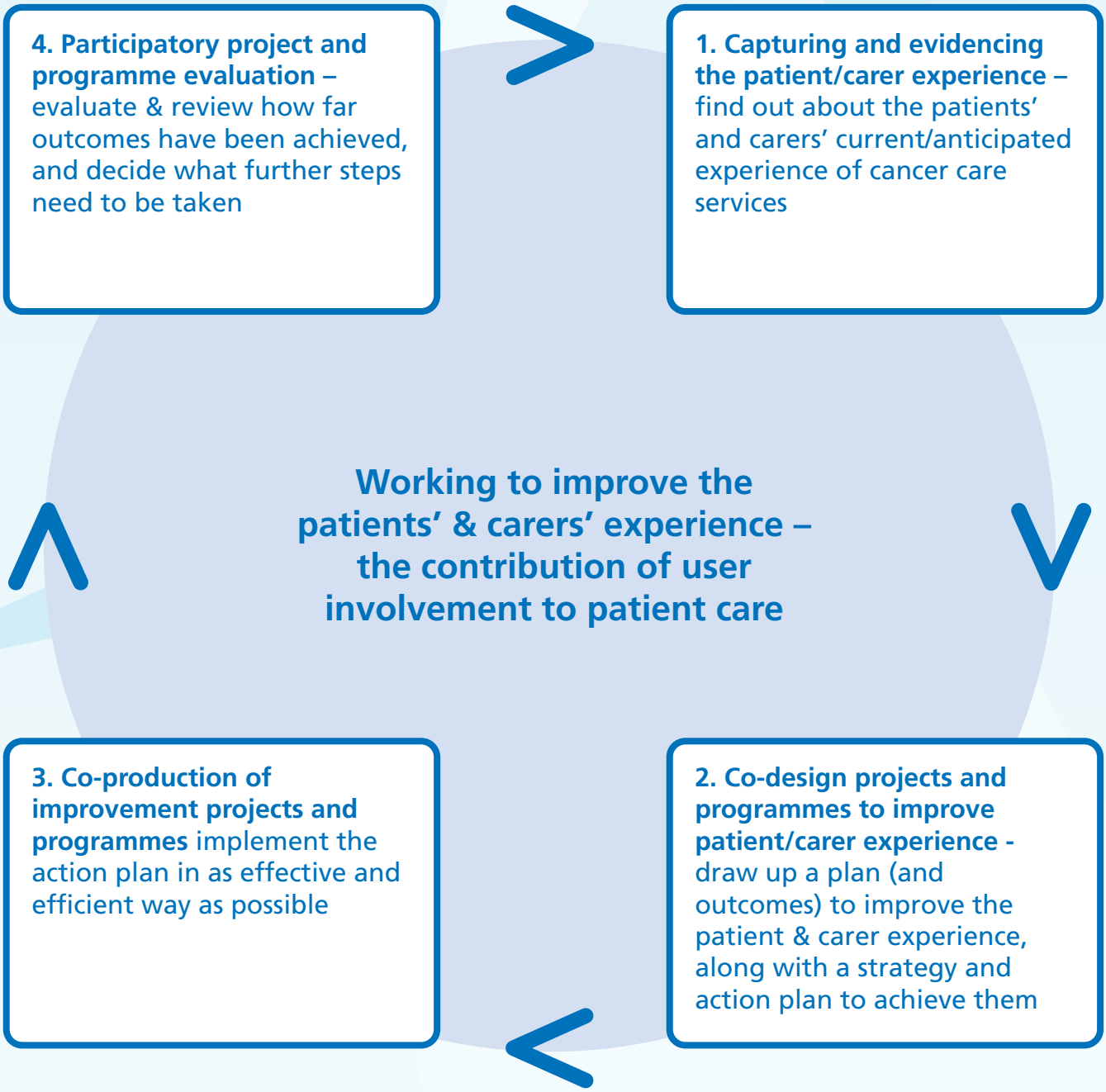
***Step 2:* Co-design of projects and programmes to improve patient/carer experience**
This involves Partnership groups drawing up a plan designed to bring about necessary improvements to the patient/carer experience. Usually this entails specifying some aims and outcomes designed to improve matters, a strategy to achieve those aims and outcomes, plus an action plan (identifying what needs to be done in concrete terms; listing timescales, resources &c) which is designed to turn strategy into changes at ground level. (NHS 2009b and 2009c, Institute for Innovation and Improvement)

***Step 3* Co-production of improvement projects and programmes** is the 'doing' stage – the implementation of the action plan in as effective and efficient way as possible. It has been recognised that implementation processes are often the weakest link in turning proposals into reality and involve careful use of techniques like project and programme management and monitoring. (Bevan et.al, 2008)

***Step 4* Participatory project and programme evaluation** involves taking stock – assessing how far the intended outcomes have been achieved, and the extent to which their achievement has contributed to improving the patient experience, as well as what, if any, further steps need to be taken.(NHS 2009d, Institute for Innovation and Improvement)

Figure 5 is, of course, another model and the usual caveats about such models apply. The 'cycle' rarely revolves with the smoothness and orderliness implied by the diagram. Practice in the real world often sees iterations of particular stages; for example the 'doing' stage may cast additional light on patient experiences which, in turn, leads to some finessing of the original intended outcomes. Again, the 'taking stock' stage should normally not be left to the end of the cycle; a robust evaluation of outcomes generally requires that base-line study (the 'before' stage of 'before-after' evaluations) be carried out in advance of the implementation stage of planned change.

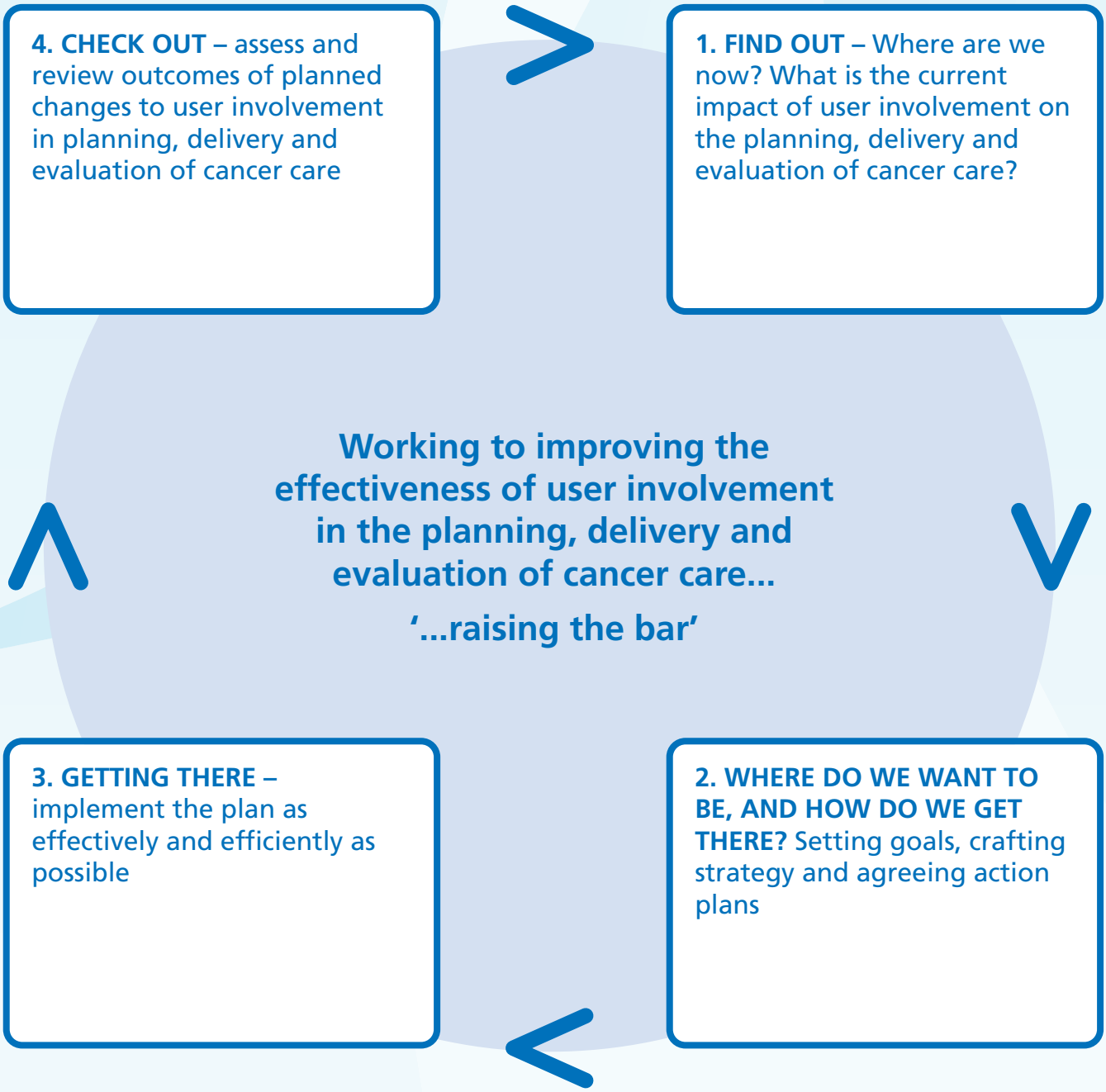
Fig 5. The user involvement improvement cycle



5.c 'Raising the bar'; improving the overall effectiveness of user involvement in 'planning, delivering and evaluating' cancer care services in order to improve the patient/carer experience

So far our discussion of practice has focussed on the 'sharp end' of user involvement practice – on practice that is intended to directly bring about concrete and specific improvements to the patients and carers experience. But there is a further aspect of user involvement practice that also deserves attention – and which supports and underpins 'sharp-end' practice. The focus here is on the organisational dimension of user involvement, on how the general capacity and capability of service user involvement can be improved. Put crudely the question is: how can groups, organisations and committees with a user involvement brief 'raise their game'? How can they do things better or differently in order to undertake work that is more effective? Figure 6 illustrates how, for example a user Partnership group (or, indeed, any other Network group that embraces an element of user involvement, can organise itself in a way that ensures the quality and effectiveness of its own work is continuously improved.

Fig 6. Improving the capacity and capability of service user involvement



Step 1 asks *'Where are we now?'*- suggesting that a User Partnership Group should make periodic assessments of the overall impact its work has had on the 'planning, delivery and evaluation' of cancer care services in its area. Is the Partnership group making a (positive) difference? Is it focussing on the priority issues? Is it working to strengthen the capability of its membership (in terms of diversity in social, cultural and ethnic background, in terms of the breadth of members experience and so forth?). Is it offering the kind of induction, mentoring and training to members which will improve the User Partnerships capacity to bring about change?

Step 2 asks, in the light of answers to the above question: *'Where do we want to be, and how will we get there?'* This parallels the 'planning' step in the previous sub-section, and involves:

1. Establishing aims and intended outcome concerning the improvement of performance of the user Partnership group in its work (e.g. building member confidence and effectiveness through induction programmes and up-skilling, mentoring, and so on)
2. Developing a 3-year strategy to achieve these improvement aims and outcomes – looking, for example, to group development and capacity building and skills development training
3. Drawing up action plans to ensure strategic aims are followed through

Step 3 is about *'Getting there'* – implementing improvement plans as effectively and as efficiently as possible. Again, use of project and programme management techniques (which specify timelines, responsibilities, resources &c) may be used to ensure effective implementation of the plan

Finally, ***Step 4*** *'Check Out'* focuses on assessing and reviewing progress made. How far has the plan to enhance capacity and capability increased the quality of user involvement interventions? What aspects of how the User Involvement Group promotes change need further attention?
Figure 6, like Figure 5 is a 'model' and the same reservations apply. A model can be no more than a 'guide' to thinking and action – signposting and identifying key things to ensure a successful journey.

6. Conclusions

This paper offers grounds for guarded optimism about the future of service user involvement in cancer care. It has been shown that key Government health policy (the National Health Service Act, 2006; the National Health Service Constitution, 2009) along with widely endorsed policy recommendations (The Cancer Reform Strategy 2007, The Next Stage Review; High Quality Care for All, 2008) lend support to the models of user involvement practice outlined in parts 2 and 3 of the paper.

As we have seen, however, such models throw up a potentially bewildering range of options concerning the best route to take if we are to improve patient and carers experience of cancer services. Clearly it is not possible to do everything that has been discussed in the previous pages; what can be done will be constrained by resources - including the numbers of service users who will get involved, and the time they are willing to give. Priorities have to be discussed and, through agreement on future work-plans, choices have to be made.

Should it be a priority, for example, to capitalise on the current enthusiasm for collecting information from patients about their experiences of treatment in order that this can be used as an evidence base for promoting change in services or re-allocation of resources? Or would it be more productive to concentrate on maximising consistent and well informed user representation on decision-making bodied like NSSGs, Trust Implementation groups, the Network Board, and specialist commissioning groups? Or perhaps most headway will be achieved through maximising the effectiveness of volunteer working, through training, group development and leadership exercises?

Alongside such organisational choices, there may also be choices to be made about the 'stages' of the patient pathway where service user involvement may have its greatest impact. Will the service user perspective have most to offer in assisting in the design of programmes to raise awareness of the importance of early detection and diagnosis of cancer? Or is bringing their experience to bear on work to improve holistic care, or enhancing support for survivorship, or improving support for carers, likely to be have a greater pay-off?

Are patient and carers interests best served if the focus of user involvement is on ensuring high standards of implementation of NHS prescribed quality standards (e.g. via the National Cancer Peer Review quality measures relating to patient care), or is more progress to be made through working to get *additional* standards developed and approved for aspects of care not currently covered by such measures?

These are examples; the list of possibilities for prioritisation could easily be extended. So how are the choices to be narrowed down? Pragmatic considerations may, of course hold sway; service user involvement is voluntary, and there is limited scope for recruiting volunteers in line with a particular, pre-defined, profile of skills interests and enthusiasms. So, the strategies and work-plans of particular groups of service users, in particular areas, are likely to reflect to some extent the priorities and perspectives of those who choose to become involved; in other cases options will be narrowed down by organisational constraints – trusts, networks and localities will be more or less supportive, indifferent or resistant to particular forms of user involvement.

Whilst acknowledging that drawing up priority goals and strategies for user involvement will be partly shaped by such factors, does our overview of current policies, principle and practice offer any systematic guidance on this matter?

The principles of user involvement in cancer care presented in Section 4, the key aspects of the patient care experience set out in 5a and the service user involvement cycle outlined in section 5b do at least suggest a framework for navigating, both rationally and systematically, the range of priority options alluded to

above, and can help in identifying a logical set of priorities. We suggest the following six 'foundation stones' of user involvement can provide the basis upon which to construct such a framework:

1. **Capturing and evidencing the patient experience** is now recognised as fundamental to virtually all aspects of user involvement. Valid data about the patients' experience:

   - should mark the starting point for project and programmes service improvement. It provides a rationale for such initiatives, and shapes the goals and strategies for change
   - provides base-line data on current service users' experience of care - that is to say what patients and carers report, via questionnaires, focus groups and other means, about their experience of the cancer journey, what happened to them, what was important to them, and so on. Such data is invaluable as a 'before' measure of 'before- after' studies of performance improvement over time.
   - underpins use of new patient-reported outcome measures of care (PROMS – patient reported outcome measures - and PREMS – patient reported experience measures); as well as data relating to how patients assess the success, eventually, of other dimensions of their experience.
   - contributes to organisational outcome data - information necessary to evaluate the outputs and outcomes of improvement projects and programmes

2. **Achieving change through alliance building and partnership working.** It has been stressed that partnership working should be the default position when working to realise the best possible experience for patients and carers as they traverse their cancer journey. Commitment to partnership working is pervasive throughout the whole of cancer services, and this should be no less the case with user involvement. The complexities of cancer care requires multi-disciplinary and co-operative partnership methods – and this applies to work relating to the patient and carer experience as much as it does to fields such as diagnostics, treatment, and palliation.

3. **Achieving change through provision of advice/ responding to consultations.** As we have seen, many aspects of the patient and carer experience are shaped by national policies and Health Department policy advice, backed up by varying amounts of guidance on their local implementation. Service users can, through their partnership groups, make a significant impact on the way policies are interpreted locally - to the advantage of local patients and carers. Drawing up 'specifications' on how policies should be implemented – from a service user perspective - can reap rewards, particularly if such advice is backed up by evidence, as illustrated above.

Comparing the gap between programme specifications (for example on the shape, use and content of individual 'care plans'), with data gathered from patient experience surveys, can strengthen service user advocacy of service improvements.

4. **Co-design of projects and programmes to improve the patient and carers experience.** It follows from the above point that work to improve the service user experience necessarily entails co-planning, co-design, and sometimes co-implementation, and co-evaluation of projects and programmes. Partnership working is not something that belongs to, and is only found in local, network, and national 'partnership groups'. It needs to be a characteristic of virtually all user involvement activity.

5. **Appropriate resourcing, support and organisational leadership is a pre-requisite to effective user involvement.** The bulk of user involvement resources – in terms of time, expertise and commitment - are of course gifted by volunteers. But as we noted in Section 4f, the contribution of such 'free' resources needs to be recognised and encouraged through organisational leadership, enabled by a professional facilitator, supported with administrative help, and backed-up with a modest budget to cover training and other working processes, as well as reimbursement of out-of-pocket expenses (for example travel, communication costs,and sometimes childcare) so that effective and sustainable involvement can be fully realised.

6. **Mainstreaming user involvement to achieve cultural change.** The above priorities will help ensure that user involvement becomes embedded as a key component of cancer service 'culture' – and constitutes a key value running through all processes with respect to decision-making, organisation, and implementation of patient care. Whether focussing on quality improvement, re-configuration of services, world-class commissioning, reaching out to 'seldom heard' client groups, staff development, ensuring inclusive provision, and so on, user involvement needs to be stitched-into every aspect of policy, process and day-to-day practice of cancer care. It then ceases to operate as an add-on and an optional extra. It becomes the norm, an accepted and functional part of the mainstream.

These, we suggest, are the six key foundation stones of effective user involvement; it is upon these that all the principles, policies and practices described in this paper rest.

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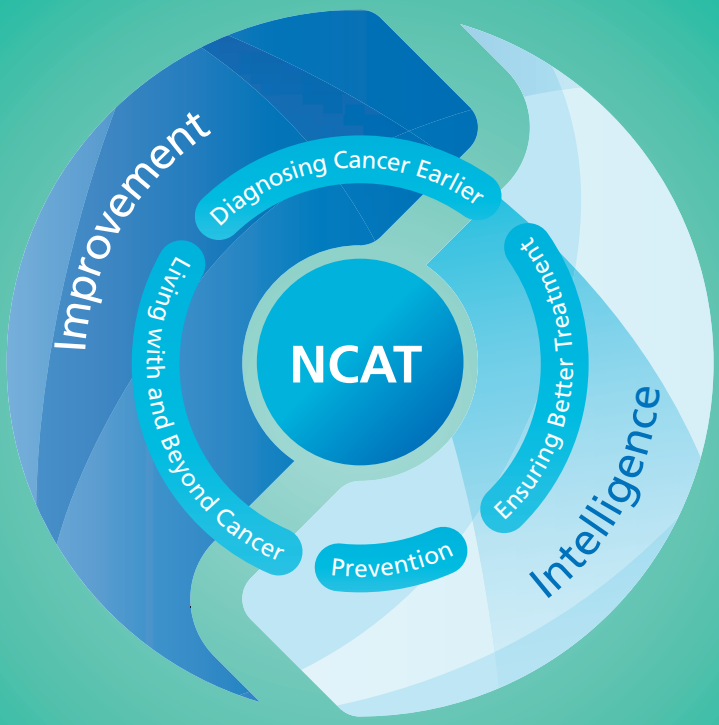

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