



User Involvement in Palliative Care: a scoping study

Final Report to St Christopher's Hospice

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STRUCTURED ABSTRACT

Title

User Involvement in Palliative Care: a scoping study

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Aims

1. To review the research, policy and practice literature to identify what is known about user involvement in palliative care.
2. To identify methods of accessing user views which are suitable for use in palliative care.
3. To elicit the views of key informants (users, advocacy groups, researchers, practitioners and policy makers) on user involvement in palliative care.
4. To offer examples of best practice and advise how these might be further developed and sustained.

Design

Phase 1 - a review of the literature, to identify what is known about user involvement in palliative care and other areas (**Aim 1**) and the methods used (**Aim 2**) and to subject the evidence to critical appraisal.

Phase 2 – to obtain the views of key informants using telephone or face-to-face interviews and at site visits, to identify a sample of people who have expertise about user involvement in palliative care (**Aim 3**).

Phase 3 - a consensus building meeting was arranged in which service users, carers, professionals and 'experts' who were identified during Phase 2, were offered preliminary findings and were invited to comment on their strengths and weaknesses to help shape the findings of this scoping study (**Aim 4**).

Sample

Phase 1 – Stage 1 literature search located 2046 'hits', refined at Stage 2 to 507 papers, with 53 papers finally selected at Stage 3.

Phase 2 – Interviews conducted with service users (patients n=19), service users (carers n=6), professionals (n=22), 'experts' (n=4) – total respondents (n=51).

Phase 3 – Participants at consensus meeting - service users (patients n=17), service users (carers n=12), volunteers (n=2), professionals (n=13), ‘experts’ (n=4), project team (n=8) – total attending (n=54).

Key Findings

Phase 1

- There is an increasing body of literature about user involvement in palliative care.
- User involvement initiatives from health care areas outside palliative care provide examples of alternative approaches to access hard to reach service users and community development projects.
- The literature is predominantly written by health and social care professionals, with very little written by service users.
- Most literature is in the form of descriptive accounts of initiatives, projects, conferences or other practical activities. Few of these activities have been evaluated in any way except for simple 'satisfaction' measures.
- There is remarkably little evidence of the efficacy of user involvement for participating patients and carers, or professionals, or for the organisations, apart from anecdotal accounts.
- The literature review sheds little light on what motivates the minority of patients to become involved in these initiatives and what sustains their involvement despite well recognised barriers.
- None of the literature examined why the majority of patients and carers decline to participate in user involvement opportunities.

Phases 2 and 3

- People (service users and professionals) were keen to share their experiences of user involvement and participate in a consensus meeting.
- We found evidence of diversity in approaches but most common were questionnaire surveys and forums/groups.
- Key individuals, both service users and professionals, were highly influential in initiating and sustaining user involvement in specific organisations and networks.
- For those patients and carers already engaged in user involvement activities, there appeared to be intrinsic (eg. feeling of empowerment, being valued) and extrinsic (eg. improvement in services and facilities) motivations and rewards.
- It is less clear what the rewards are for organisations except to comply with government directives.

Recommendations

- User involvement should be part of a new notion of citizenship. There should be recognition that we may all be service users at some time. People may occupy multiple roles and that over the lifespan, roles and identities in respect to health care services may vary.
- Creative and novel ways need to be explored to involve those who are too ill, too tired or unable to attend meetings. There is a need to build relationships between community groups and services, for local voices to contribute (Cancer Networks may offer one way forward here).
- Developing practical initiatives which capture service user’s stories and experiences, especially those people who are frail and very ill, using novel information technology, can contribute to widening participation.

- The development of greater participation by current carers and bereaved carers who appear to be under represented (for example, only they can comment on the death experience) using outreach schemes, should be considered.
- We need to help people express themselves in different ways and consider how to incorporate these into service planning. Currently there is a dominance of views elicited in writing such as those obtained from satisfaction surveys.
- The availability of dedicated resources, leadership and openness to change are key factors in sustainability.
- Organisational cultures in hospices and specialist palliative care providers need to be supportive of user involvement and show a willingness to respond to suggestions.
- Further consideration of how to develop organisational cultures that are respectful and open to service users feedback are required, and mechanisms to track the outcomes of their suggestions.
- There needs to be clear lines of accountability in the managerial structure of organisations to implement changes otherwise user involvement initiatives may appear to be tokenistic.
- A programme of information and education for professionals engaging with services users needs to be developed.
- Some training courses are already available for service users to help them understand health services and committee procedures and these have advantages but there are concerns about potentially ‘professionalising’ patients and carers.
- Consideration should be given to the problems associated with the current heavily reliance on relatively few highly motivated individuals. This places heavily demands on a few patients and carers. The reliance on a few key professionals makes organisations very vulnerable to their loss and jeopardises the sustainability of user involvement.
- Criteria should be developed to indicate when patients and carers can no longer be regarded as current service users.
- Further research is needed to investigate the efficacy, and costs and benefits of user involvement from the perspectives of: 1) patients and carers, 2) professionals, and 3) organisations.

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1.0 Introduction

This study was commissioned at the instigation of the Steering Committee on User Involvement of the National Council for Palliative Care during 2003 and was funded by St Christopher's Hospice in 2004. User involvement is widely promoted within health and social care policy as an effective means of developing patient-centred services and to ensure that research programmes address the concerns of patients and carers. This report is predominantly concerned with the development of user involvement initiatives in relation to services rather than research. For the purpose of this project:

- **User involvement** is taken to mean the way people, who use public services, are involved in making suggestions and taking decisions about how different services are run and developed. User involvement is about how service users are involved in shaping or building the future of public services.

Involvement can be direct or indirect:

- **Direct involvement** might include a service user group writing an information leaflet about a public service or a health problem.
- **Indirect involvement** might include a professional group asking a service user about what they think of the plans the professionals have already decided are important.

We have adopted an inclusive model of service users who are regarded as including: patients, carers, health and social care professionals, support workers, the general public, people who may potentially be affected by health screening or other factors in the future, members of voluntary organisations and advocacy groups, other stakeholders.

1.1 Background

Healthcare providers and policy makers only began seeking the views of patients or trying to involve them in developing services relatively recently. It remains uncertain whether patients' views are given adequate weight to influence policy decisions. Some fields have a longer history of user involvement than others. For example, services in mental health, maternity, rehabilitation and learning difficulties have been exposed to pressures from the public and specific pressure groups such as MIND and SCOPE (formerly MENCAP) for longer. The disability rights movement provided an influential critique of rehabilitation services and challenged the social construction of disability (Seymour 1998). There are also numerous disease, gender and culture specific pressure groups that aim to highlight the special needs of their members. The growth of these advocacy, pressure and self help groups is usually traced to social changes in the latter part of the 20th century and a rise in consumerism (Small and Rhodes 2000). More recently, British government policy has encouraged general healthcare services to elicit the views of users and to involve them in planning and developing services.

Drawing upon analysis of NHS structures, Small (2004) has argued that the emergence of a user voice in health decision making can be traced to organisational changes and to new conceptualisations of citizenship in the UK. A simplified account can be characterised in three periods of NHS development:

1948-1989 **Hierarchical structure** based on geographical regions with top down directives during which period citizens could vote for politicians who decided policy but generally British health service planning and provision was paternalistic and centrally directed.

1989-1997 **Market economy** model in which patients were positioned as consumers who could make choices but in reality choice of health care was limited by availability and decisions were made predominantly via GP fundholders.

1997- present **'User led' health care system** was the rhetoric of the 'New' Labour government in which patients and the public were positioned as the 'active citizen'. There are now formal requirements to consult service users at all levels of NHS activity.

Crawford and colleagues (2002) in a systematic review found little high quality evidence about the benefits of involving patients in decision making. Most published literature is based on case study designs and reflects the opinions of project managers. Interestingly, the review did not include patients' informal caregivers. This was a major failing because patients, especially those with chronic conditions or disabilities, may be heavily reliant on the care provided by friends and relatives although informal caregivers may have different views from patients. While listening to local voices and working in partnership with advocacy and support groups has a long history in areas such as the disability rights movement, mental health services, learning disability and childbirth services, services for people with physical health problems have been slower to emerge.

According to Oliviere (2001) it is an agenda with which palliative care wants to engage. A seminar conducted at St Christopher's Hospice in 1999 involving patients and carers of palliative care services found considerable support for developing user involvement initiatives (Beresford et al 2000). However, careful thought needs to be given to ensure that such initiatives are tailored to the unique circumstances of palliative care, where patients have advanced disease and are likely to be physically frail with high levels of symptom burden, are psychologically vulnerable and socially isolated (Doyle et al 1998). Likewise, carers may be facing difficult physical and psychological challenges as the patients' health deteriorates (Payne et al 1999).

It is within this social context that recent attention has focused on listening to the voices of cancer patients and latterly to patients with end stage conditions using palliative care services. Both initiatives were funded by the charity Macmillan Cancer Relief. Bradburn (2003) describes the development of a project to obtain the views of cancer patients across the country. This initiative has been influential in providing feedback to services and in policy developments such as functioning as a reference group to the NICE (2004) Guidance in Supportive and Palliative Care.

In two concurrent projects, Clark et al (2004) have examined the written accounts dying patients produce about their end of life experiences and the narratives written by health and social care professionals and other writers about the deaths of cancer patients. Their analysis concluded that professionals' interpretation of the needs of advanced cancer patients which emphasised symptoms management remained framed within biomedical culture and that professionals struggled to acknowledge individual autonomy and to meet the diversity of individual end of life needs. Analysis of patient's written narratives revealed the large volume of accounts produced by cancer patients compared to those dying of other diseases. The authors also noted that while patients accounts described conventional concerns of professionals such as symptoms, communication and treatment, they covered broader social aspects of dying which were not apparent from professional accounts. This report serves to highlight how contemporary accounts of dying are produced and the differences between the concerns and perspectives of professionals and patients but what remains missing are the accounts of the family witnesses – the carers whose voice remains largely absent. It also concentrates on the articulate, those with sufficient education

and time to write, and those who are made aware of their dying status while they still have enough energy to write.

The National Council for Palliative Care defined palliative care users as: people with life threatening illnesses and conditions; their families, partners and friends; and people who become bereaved (NCPC 2000). However, the attitudes and needs of these groups can not be assumed to be homogeneous and it is crucial to address how these various perspectives can be accessed and reconciled. There are particular problems in defining the remit of palliative care service user as it is likely to include those accessing general and specialist palliative care provision and to include patients with diagnoses of conditions other than cancer (Gott, 2004). Moreover, it can not be assumed that patients who are nearing the end of life will necessarily see any benefits or purpose in participating in the development of services which they are unlikely to live to partake of (Payne, 2002).

There are many levels of involvement from tokenism and potential manipulation to empowerment and user-led services. Hoyes et al (1993) have proposed a dimension from high to low involvement (see Figure 1).

Figure 1 Dimensions of Involvement (Hoyes et al 1993)

High

- Users have authority to make decisions
- Users have authority to make selected decisions
- Users' views are sought before decisions are finalised
- Users may take the initiative to influence decisions
- Decisions are publicised and explained before implementation
- Information is given about decisions made

Low

To involve palliative care patients in user involvement initiatives also requires re-thinking traditional methods of involvement. Many of these people are very ill, easily fatigued and their time is likely to be at a premium. Therefore joining a steering committee, which was identified as the principle means of involving users in developing cancer services (Gott et al 2002), may not be feasible if people are too unwell to travel, have communication difficulties, or do not want to meet other people who's disease is more advanced than their own (Small and Rhodes, 2000). Similarly, satisfaction questionnaires, which are often used to gather user views, exclude people who have difficulty writing and also do not offer the possibility of on-going dialogue, something that has been identified as important by users (Gott et al 2000). New modes of involvement such as 'citizen's juries', whilst certainly exciting, may not be appropriate for palliative care patients as they require regular commitment.

It has been argued that innovative methods of involvement are required. These need to facilitate communication between users and professionals whilst not requiring users to leave their home (or other place of care) if they do not wish to do so. Technologies with the potential to facilitate discussion in this way, potentially between large groups of people, include the Internet and telephone. However, prior to implementing an initiative of this type there is a need to learn from projects with experience of using these technologies. To

further understand the barriers and potential of different methods of user involvement for palliative care, a scoping study of the literature and current practice was undertaken.

2.0 Aims

A key aim of the current project is to consider user involvement initiatives developed both within, but also outside of palliative care and to evaluate their applicability to palliative care. Examples of user involvement from other countries have been sought and relevance for the UK examined. Gathering this material together and subjecting it to critical appraisal for the first time ensures that the upsurge of interest in user involvement is translated into a practical agenda of involvement appropriate to those in palliative care contexts.

1. To review the research, policy and practice literature to identify what is known about user involvement in palliative care.
2. To identify methods of accessing user views which are suitable for use in palliative care.
3. To elicit the views of key informants (users, advocacy groups, researchers, practitioners and policy makers) on user involvement in palliative care.
4. To offer examples of best practice and advise how these might be further developed and sustained.

2.1 Objectives:

1. To prepare a summary of the research, policy and practice literature highlighting its relevance to the palliative care context.
2. To make recommendations about appropriate methods of eliciting user involvement from various stakeholders within palliative care.
3. To offer models of best practice both to establish and sustain user involvement and seek feedback on the acceptability of these models.
4. To advise the National Council for Palliative Care on the development of guidelines for facilitating user involvement and make suggestions for further research and for organisational development.

3.0 Design and Methods

3.1 Study design

This scoping study was conducted over one year and used a three phase design. Phases 1 and 2 were conducted concurrently.

- Phase 1 - a review of the literature, to identify what is known about user involvement in palliative care and other areas (**Aim 1**) and the methods used (**Aim 2**) and to subject the evidence to critical appraisal.
- Phase 2 – to obtain the views of key informants using telephone or face-to-face interviews and at site visits, to identify a sample of people who have expertise about user involvement in palliative care (**Aim 3**).
- Phase 3 - a consensus building meeting was arranged in which service users, carers, professionals and ‘experts’ who were identified during Phase 2, were offered preliminary findings and were invited to comment on their strengths and weaknesses to help shape the findings of this scoping study (**Aim 4**).

3.2 Phase 1 Literature Review Methods

Our approach to reviewing the literature was informed by the principles of systematic review methodology described by the Cochrane Collaboration (NHS Centre for Reviews and Dissemination 1996). However we considered the Cochrane systematic review methods to be largely unsuitable because of the broad range of methodologies that were likely to be encountered. Instead, we used critical appraisal methods developed for analysis of literature published on evaluative and mixed methods research (Hawker et al 2002). We conducted the review using the following discrete stages:

- Search Strategy
- Inclusion Criteria
- Assessment of Relevance to research aims 1 and 2
- Data Extraction
- Data Synthesis

The first four stages of the review followed standard systematic review methodology. The final stage utilised both quantitative and qualitative data analysis techniques to present aggregated and interpretative findings.

3.2.1 Search Strategy

The aim of the search was to provide as comprehensive a list as possible of primary studies and other reports, both published and unpublished, which complied with the inclusion criteria described below. We searched the health and social care literature and those from related disciplines for:

- Research studies from peer reviewed sources;
- Theoretical papers from peer reviewed sources;
- Research papers from non-peer reviewed sources;
- Professional and policy documents;
- Other relevant published/unpublished literature.

Electronic databases searched:

The following electronic databases were searched and appropriate ‘hits’ were downloaded using ‘Endnote’ software. Database searches were started in May 2004 and a final updating search was conducted at the end of December 2004. The list below identifies the databases that were searched - for some this was an ongoing process and searches were made over the period. Additional sources of data were tracked via the Internet and current contents were accessed via on-line journals. As this was a scoping study, hand searching of journals in the library was not undertaken and following up citations was not routinely undertaken.

- CINAHL
- Medline
- BIDS – IBSS(International bibliography of social sciences)
- Web of Science
- PsychInfo
- AMED (Allied and complementary medicine)
- BNI (British Nursing Index)

- Caredata (social work and community care literature)
- Cochran database of systematic reviews
- EMBASE (biomed and pharmacology)
- EBMR (Evidence based medical reviews)
- Index to theses (UK theses)
- Internet search of Joseph Rowntree Foundation, The Kings Fund, INVOLVE
- Broad search of 'grey literature'

Known 'experts':

Email and telephone contact was made with academic experts and researchers with experience of user involvement to identify potential literature. The people who responded included:

- Professor Gordon Grant (Cognitive Disability)
- Professor Mavis Kirkham (Midwifery)
- Professor Susan Read (Nursing Practice Development) - all the above based at The University of Sheffield
- Dr Tony Stevens (Consumer Liaison Lead NCRN)
- Mr Andrew Gallini (Lead cancer nurse with special interest in user involvement),
- Dr David Wright (Research Fellow to Professor Jessica Corner, University of Southampton).

Search terms:

For each database combinations of the following key words/terms were used:

- User Involvement
- Consumer Involvement
- Lay Involvement
- Palliative Care
- Hospice Care
- End of Life Care
- Terminal Care
- HIV/AIDS
- Older people
- Mental Health
- Learning Disabilities
- Maternity
- Service development
- Service Planning
- Health Service
- Elderly/Aged
- Learning Disorder
- Cancer
- Dementia
- Consumer participation
- Consumer satisfaction

While we can claim that our search strategy was broad and inclusive, we can not claim that it was exhaustive. The purpose of our literature review was to present a

scoping of the available evidence rather than undertake a comprehensive systematic review.

3.2.2 Assessment of Relevance to Research Aims 1 And 2

We undertook a three stage process of screening identified material (as shown in Appendix A). The aim of the assessment of relevance was to examine the located studies to identify those relevant to the research aims and objectives. This involved a number of decisions which will be made as explicit as possible (Hawker at al. 2000). All papers were assessed by the Research Fellow (AS).

Stage 1

After undertaking a search of academic databases, internet and grey literature using key words the references and available abstracts were both electronically downloaded and manually typed into the Endnote bibliographic software, in which a 'library' of single references was established. As new references were discovered during the period of the study these were also added to the single reference library database. Duplicate references were removed from the database providing a total of 2046 references available for review. At the first stage, abstracts were scrutinised for key words. Each reference and abstract was then read by the Research Fellow and assessed for their relevance to the study. All references and abstracts that were not directly relevant to the aims and objectives of the study were excluded.

Stage 2

To identify and extract the relevant literature to be reviewed from the initial search findings inclusion and exclusion criteria were established. At the second stage, the following selection criteria were applied.

Inclusion Criteria

A decision was made to use broad inclusion criteria to ensure that the review encompassed as much potentially relevant information related to user involvement as possible. These were established at the outset and they were limited to published and unpublished documents:

- That describe the user involvement process / methods within palliative care and other health/social care settings
- That describe the perspective of service users, professionals, researchers, of involvement initiatives within palliative care and other health/social care settings
- That describe the effects of involving users in planning and shaping health care, palliative care services and research
- That describe the outcomes of user involvement initiatives
- That define user involvement
- That address the context of user involvement within palliative care
- That address the context of user involvement with vulnerable adults (mental health, learning disabilities)
- Published between 1990-2004.

Exclusion Criteria

Papers and documents:

- That measure satisfaction levels or preferences without describing the process of involvement or how it was used to change/develop a service or research
- That discuss decision making between patients and health care professionals about treatment, care and future planning
- That discuss palliative care services in clinical terms (treatment, care)
- That do not address the specific contexts of user involvement
- That discuss medication.

The application of these inclusion and exclusion criteria resulted in the selection of 507 items of literature for review.

Stage 3

During the third stage, the exclusion criteria were refined to remove papers reporting on user involvement concerned with research participation and methodologies related to these. The research team developed an assessment form (adapted from Hawker et al 2000), which was used to rate each paper and determine its 'acceptance' or 'rejection' (see Appendix B). It covered four criteria including:

- Relevance to research questions – 8 items
- User involvement domain – 8 items
- Source of data – 4 items
- Study type – 7 items

There was space for additional comments at the bottom of the form. Using the selection criteria on the assessment form, 362 items of literature were reviewed. During the early part of stage 3, a 4% sample was independently assessed by Helen Ross (a researcher). By December 2004, 145 items of literature were not available for review because they were unobtainable. A final total of 53 items of literature were assessed to be of relevance to the study aims. At completion of this stage, a 10% sample was scrutinised by Sheila Payne to establish the reliability of assessment.

3.2.3 Data Extraction

Data were extracted from 53 items of literature for a bibliometric analysis. A hand search of the included literature was undertaken to ensure accuracy in the collection of the bibliometric data. Analysis was undertaken using the MS Excel programme. Literature were analysed in terms of:

- The user involvement domain/relevant area of health care
- The nature of the document
- Who the literature were written by
- Country of origin

3.2.4 Data Synthesis

As we were conducting a scoping study not a meta-synthesis or secondary analysis which would form part of a conventional systematic review, our data set was subject to two levels of interrogation: a quantitative analysis of all 53 included papers and a descriptive analysis. Results are presented in a bibliometric analysis and in the form of an annotated bibliography, followed by a synthesis. In addition, service users, carers, professionals and experts were invited to comment on the initial themes identified in the literature at a consensus building meeting held on the 25th January 2005 at St. Christopher's Hospice.

3.3 Phase 2 Methods for Interviews with Key Informants

3.3.1 Gaining ethical approval

An application for ethical approval was submitted to the Central Office Research Ethics (COREC) for Multi Centre Research Ethics Committee on the 4th May 2004. Ethical approval was granted by West Hertfordshire NHS Research Ethics Committee on 16th August 2004 (Reference Number 04/Q0203/29) subject to adding that ethical approval was provided by West Hertfordshire ethics committee to each information sheet.

Informed consent

All participants were initially sent an information sheet about the study, with a self completion form stating whether they were interested in being contacted by the researcher. They were asked to return this form to indicate their interest in being interviewed. The researcher telephoned each potential participant to confirm their interest and discuss the study. A letter, information sheet about the interview and consent form were sent to participants. Participants undertaking a telephone interview returned their consent form independently. Participants undertaking face to face interviews completed their consent form with the researcher present. Each participant was informed that they could stop the interview at any time and withdraw from the study.

3.3.2 Sample Selection and Recruitment

In collaboration with the National Council for Palliative Care Steering Committee on User Involvement we identified a sample of service users and service provider representatives who had expertise about user involvement in palliative care. Participants were asked if they would consider inviting people they knew who might be interested in joining the study. Only one participant joined the study using this method.

Further recruitment of participants was undertaken in several ways:

- Word of mouth recommendations
- Hospice Information Directory 2004
- Liaison with national organisations
- Attendance at conferences

The sample selected and the outcomes of recruitment invitations are presented in Table 1.

Table 1 Sample selection and outcomes

Method of recruitment	Organisations approached	Successful	Unsuccessful
NCPC	Marie Curie Cancer Care National representative and Belfast Hospice NCHSPCS Service user forum Sue Ryder representative	✓ ✓ ✓	
Hospice Directory 2004	Dove House Hospice Dorothy House Hospice St. Ann's Hospice The Sussex Beacons Mildmay Mission Hospital	✓ ✓ ✓	✓ ✓
Liaison with national organisations	MNDA Representatives Sheffield MS Society -Local S.U representative Black Cancer Care – Manchester	✓ ✓	✓
Attendance at a conference	One service user	✓	
Word of Mouth recommendations	St. Christopher's Hospice Bradford Cancer Support Centre Prince of Wales Hospice The Rowans Hospice Wath GP patient participation group St Gemma's Hospice Phil Cotterrel (PhD research with service users) at Worthing and Southlands NHS Trust	✓ ✓ ✓ ✓ ✓	✓ ✓ ✓

3.3.3 Data Collection

Data collection was conducted between August 5th and December 7th 2004. Data collection was undertaken in two ways: by interviews with service users, health professionals and experts and by observation of service user forums. The manager or lead clinician at each service was invited to participate or nominate a member of staff who might be interested in being approached for an interview.

Semi structured interviews were undertaken using a pre-designed interview protocol to elicit the following information about user involvement in palliative care (see Appendix C: health professionals version; Appendix D: patients and carers version):

- How do people understand the term user involvement?
- How do people become involved in user involvement initiatives?
- What different user involvement models are being used?

- Examples of good policies and practices
- Perceived and actual barriers to user involvement in palliative care.
- How can user involvement be assessed?

Site visits and observation of user forums were undertaken to elicit how each meeting was organised, facilitated and who attended.

3.3.4 Data Analysis

Fifty one semi-structured interviews were undertaken. Interviews were transcribed verbatim by an external transcribing agency and checked for accuracy. The sound quality of 6 interviews was extremely poor and they could not be transcribed.

Written notes were made during 3 of these interviews.

Each participant was given a code and identifying information was removed from each transcript to anonymise the data. The interviews were thematically analysed by reading each transcript and by using QSR NVivo computer software to develop thematic codes and collate data. Field notes from the site visits were also analysed.

Excerpts of transcribed text have been included to illustrate certain themes discussed in the report. These quotes were selected on the basis of two criteria. First, they illustrate the issue being discussed and second, an attempt was made to utilise a spread of participants rather than rely on a few individuals. After the excerpt from an interview the participant is identified in brackets, with a number and by their status as professional or service users.

3.4 Phase 3 Consensus Meeting Methods

The third phase of the study involved the preparation and undertaking of a consensus building meeting held at St Christopher's Hospice in Sydenham, on 25th January 2005.

3.4.1 Identification of Participants

Participants who had been interviewed as part of Phase 2 were invited to attend the consensus building meeting by letter. Members of the St Christopher's service user forums, day care and bereaved carers were also invited to attend. Potential additional participants were identified during Phase two interviews. A number of previous participants were unable to attend the meeting due to prior engagements and other responsibilities.

3.4.2 Planning and Preparation

The consensus building meeting required careful planning. The researcher worked closely with staff at St Christopher's Hospice. Key organisational issues were identified including:

- Confirmation of attendance by participants
- Dietary requirements and meal planning
- Over night accommodation
- Transport of participants to and from the venue
- Support staff for service users at the hospice
- Oxygen and wheelchair facilities

- Preparation of an initial report describing user involvement processes and experiences using everyday language
- Re-writing the information sheet and consent form, to enable understanding by the widest readership

3.4.2.1 Confirmation of attendance and individual requirements

Participants were sent invitation letters between 6-8 weeks prior to the meeting with accompanying reply slips. The reply slip asked participants to identify whether they wished to have overnight accommodation and/or transport arranged. Accommodation and travel arrangements were made by the Research Fellow. A degree of flexibility was built into the arrangements to allow for changes in health or circumstances. One participant required the use of an oxygen concentrator and wheelchair access. Two participants required special diets without wheat or milk.

3.4.2.2 Information letter, consent form and the preliminary report

Due to the expected participation of three service users with learning difficulties, it was felt a different information sheet and consent form (Appendix F) were required (than that originally approved by the MREC) (Appendix E). A new information sheet and consent form were written in a much clearer format and using simple everyday language with pictures to enhance the understanding of the text. A preliminary report was written in the same simple style using pictures to enhance the understanding of the text (see preliminary report). Copies of each were sent by post to all participants, to enable them to have time to read them prior to attending the consensus building meeting.

3.4.3 Features of Consensus Meeting

The day was planned to enable participants to voice their opinions and experiences about user involvement. Group work was planned as a method of enabling participants to be heard and for their opinions to be feedback into the larger group. The day was punctuated by frequent refreshment breaks to ensure people did not get over tired or uncomfortable.

Group work

To enable participants to engage with the material from the preliminary report and share their experiences and perceptions about user involvement, two small group discussions were planned. The participants were allocated into four groups prior to the meeting. Each group had a facilitator and a note taker from the research team. The groups were asked to consider two questions.

- Do the findings capture your experience?

This was asked by the facilitators at the beginning of the morning group work.

- How should we take this forward?

This was asked by the facilitators at the start of the afternoon group work. At a plenary session representatives from each group presented a summary of the key points from the discussions.

Post-it notes

During the day participants were also invited to write anonymous comments upon post-it notes supplied in the information packs. A large board was identified as the place on which to place the post-it. These were collected over the lunch period and general themes identified.

3.4.4 Data Extraction from the Meeting

Data were extracted from the group work notes and from the post it notes. They were grouped conceptually and themes derived.

4.0 Findings

4.1 Phase 1 Literature Analysis

The findings of the literature search will be presented in three ways:

- a. A bibliometric analysis
- b. An annotated bibliography
- c. Qualitative content analysis

4.1.1 Bibliometric analysis

The domain or area of health care discussed within the selected literature in relation to user involvement

Table 2 reveals the quantity of literature located by the domain or area of health care referred to within the contents of each document. Mental health literature was dominant at all stages in the process of selection. Mental health care was one of the earliest proponents of user involvement initiatives, and this is mirrored in the literature identified. The category of 'other' consists of a combination of literature relating to primary care and service provision, which were not identified in the key word search of the literature databases, but fulfilled the selection criteria.

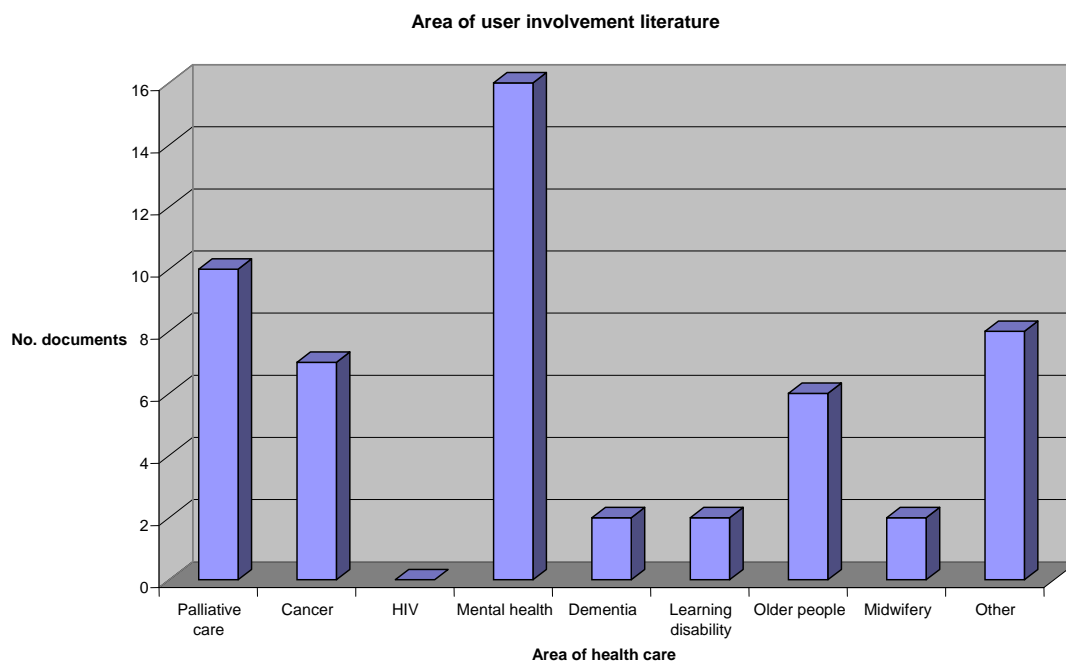


Table 2 Area of user involvement literature

Palliative care provides the second highest proportion of literature, but as can be seen from Table 3 the selection consisted of a range of descriptive, context specific accounts and project reports. There are few papers recording research or case studies. The amount of palliative care literature identified in this category reflects our search criteria rather than being indicative of a higher concentration of activity in this area.

The type of the literature selected

The following analysis reveals the typology of literature accepted for review. It is clear that despite the small number of relevant literature available, a range of different information has been sourced. Descriptive papers are most common in this selection of literature, due to their focus on the processes and information required for undertaking user involvement initiatives. Some empirical research and case studies are present.

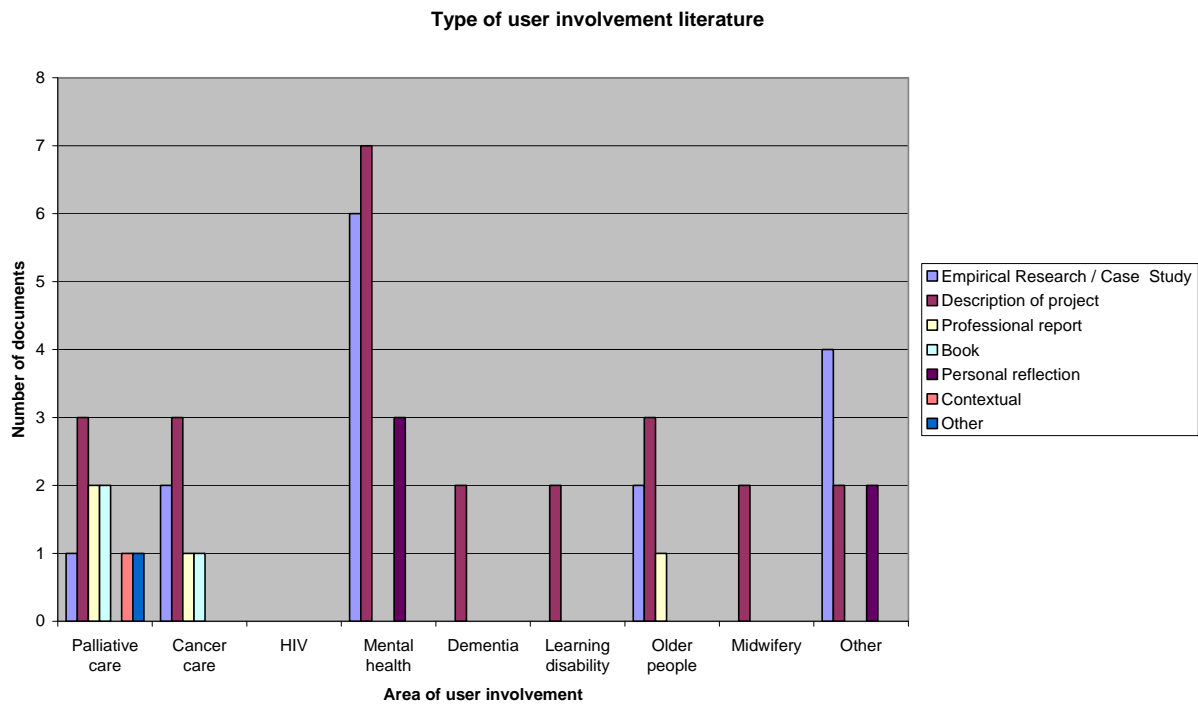


Table 3 Type of user involvement literature

The source of documentary data

Literature written by professionals and service users were selected for analysis. The majority of the literature was written by health professionals and academic researchers. A small percentage of documents were written by service users or written jointly between a professional and service user.

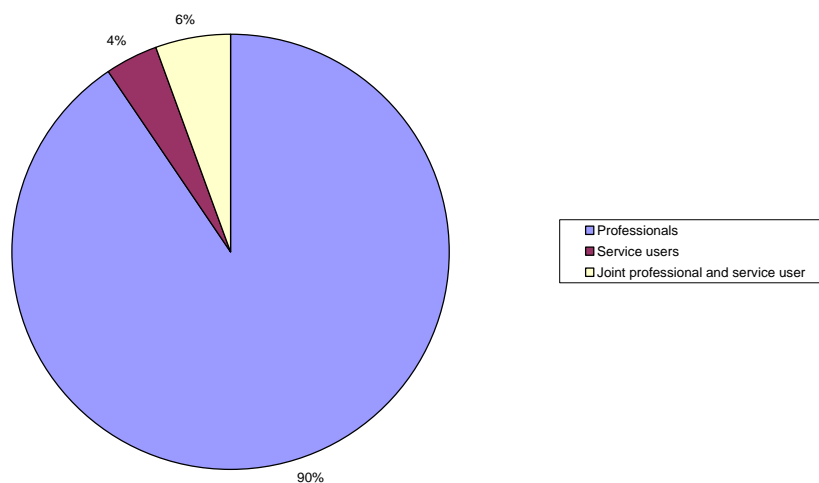


Table 4 Backgrounds of authors of the literature about user involvement

Table 5 A breakdown of the literature by area of health care and type of document

Papers /documents	Empirical Research Study inc. Case/pilot study	Description of a project	Professional Report	Book	Personal Reflection	Discussion specific to contextual issues	Other	Total
Palliative care	1	3	2	2		1	1	10
Cancer	2	3	1	1				7
Mental Health	6	7			3			16
Dementia	2							2
Learning disability		2						2
Older people	2	3	1					6
Midwifery		2						2
HIV	0		0	0	0	0	0	2
Other	4	2			2			8
Total	17	22	4	3	5	1	1	53

The country of origin of literature

The literature was analysed by the country of authorship. It is clear that the United Kingdom has provided the majority of the literature identified. This is due to the contextual relevance of the data, although literature from the USA, Canada and Australia, has also met the inclusion criteria. We did not include non English language publications in our initial search.

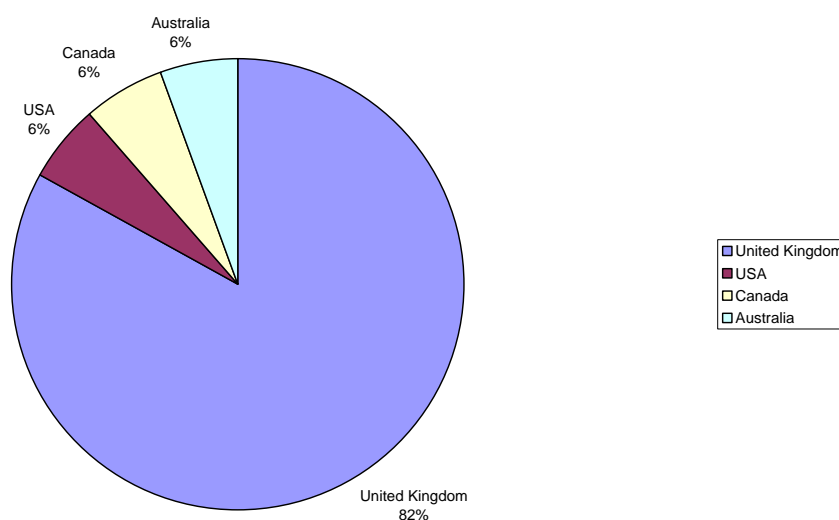


Table 6 County of origin of user involvement literature

4.1.2 Annotated Bibliography

In the annotated bibliography, the literature has been divided into thematic subsections which combine the information about different aspects of user involvement from across the different health and social care domains.

Contextual issues for user involvement in palliative care

Oliviere, D. (2001) User involvement in palliative care services. *European Journal of Palliative Care* 8 (6): 238-41.

This paper discussed the socio-political context of user involvement within health care and also offered an historical overview of user involvement within palliative care. It is one of the few papers that discussed and defined who could be considered a 'user' and what 'involvement' is understood to mean, before considering how to obtain the collective voice of palliative care service users. Oliviere considered the potential limitations and dilemmas for undertaking user involvement with people who are seriously ill, dying or bereaved and the implications these have in the balance between evidence based practice and user centred palliative care. He concluded that user involvement is neither cheap nor is it optional.

Monroe, B. and Oliviere, D (Eds.) (2003) *Patient participation in palliative care: A voice for the voiceless*. Oxford, Oxford University Press.

This is an edited collection by a range of authors who considered user involvement in terms of patient participation. Chapters were written by professionals, with a brief final chapter written by a service user. Small describes the socio-political context for user involvement in relation to palliative care, and there is an interesting chapter by Bradburn who considered the importance of the experiential knowledge held by service users. She briefly described several user involvement initiatives undertaken within cancer and palliative care services. Davie and Noble drew on their work with service users participating in palliative care education by describing how final year medical students interviewed bereaved service users about their experiences. They noted that service users need to feel safe and supported in their participation. Ahmedzai and Hunt discussed the role of service users involved in the design and implementation of new quality of life measures. Broughton, a service user, concluded that user involvement is about translating collective experience into better services.

Methods of user involvement in palliative care

Chowns, G. (2004) Breaking new ground? *INVOLVE newsletter* Spring 2004.

Chowns and her colleagues developed a video entitled 'No, you don't know how it feels' in participation with children of parents who have life threatening illnesses, some of whom are facing death. The paper presents the perceptions of some of the children who took part.

Kraus, F., Levy, J. and Oliviere, D. (2003) Brief report on user involvement at St Christopher's Hospice. *Palliative Medicine* 17 (4): 375-377.

The paper described the function of user involvement at St. Christopher's Hospice. Each method of user involvement is briefly described including patient satisfaction surveys and service user's forum. The paper described the distribution of satisfaction surveys, and that they are also left at strategic points throughout the hospice. The decision making path and feedback mechanism are described and three examples of outcomes are provided. The service user forum is described in relation to: its

frequency, selection of service users and management of the service user forum day. Issues about, time, training, processes and responsibilities are briefly discussed.

Small, N. and Rhodes, P. (2000) *Too ill to talk: user involvement in palliative care*. London Routledge

This comprehensive book considered user involvement and palliative care, focusing upon interviews with people who have Multiple Sclerosis, Motor Neurone Disease and Cystic Fibrosis. Small and Rhodes provided an excellent overview of the literature. Examples of user involvement initiatives were referred to, such as the Fife users panel, set up by Age Concern Scotland. From the interviews undertaken with service users, providers and support groups and independent organisations, it becomes clear that there is a challenge in setting up and maintaining different user involvement initiatives, due to the critical balance between the impact of diagnosis, coping and facing the future. The book presented the challenges and debates that people face at an individual level, including taking decisions and responsibility about care. At a wider social level user involvement can be the creation of a collection of voices to inform service development and information needs.

Beresford, P., Broughton, F., Croft, S. Fouquet, S. Oliviere, D., Rhodes, P. (2000) *Palliative care: developing user involvement, improving quality*, The Centre for Citizen Participation, Brunel University: 18.

This is a summary report of the first national seminar bringing palliative care service users and workers together. The report described the day as a mixture of presentations and seminars. The report contained quotes by service users and representatives from service providers. Key issues that were identified from small group discussions are presented. A list is also presented of what participants want for user involvement in the future.

Methods of user involvement outside of palliative care

Consultation workshops

Lamont, L. and Levenson, R. (2001) Patients, Carers and Staff: Talking to each other to improve health-care service delivery. *Health Expectations* 4: 140-143. The authors described the processes involved in developing and hosting a one day workshop bringing an NHS Trust, mental health service users and voluntary organisations together to discuss communication issues that the Trust could address. Hypothetical scenarios were used to aid discussion but these were not described. The authors concluded that good preparation and attention to practicalities are important. Ownership by the organisation and support from key senior managers enabled the event to be valued as important and the workshop demonstrated it was possible to get good value out of what appeared to be a small initiative.

Bullivent, D. and Reeve, J. (1996) Back to Basics. *Health Service Journal* 106 (5485): 28-9.

This very brief report described a one day consultation workshop for Plymouth Hospitals in which members of the public were invited to participate. The aim of the meeting was to listen to service user's views about the hospital and its cancer services. Information was presented about how the meeting was facilitated and key issues that arose.

Wilson, B. (1992) Establishing a people-centred health service in Gwent Wales *Journal for Healthcare Quality* 14 (30): 32-5

The paper presented the socio-political and strategic context of health care within Wales before describing an initiative to make Gwent cancer services more people centred. A clear description was provided of the recruitment of participants, development and undertaking of a two day seminar to discuss cancer services. A mixture of health professionals and service users participated. Findings and future outcomes from the initial seminar are reported.

Development of clinical guidelines and service standards

van Wersch, A. and Eccles, M. (2001) Involvement of consumers in the development of evidence based clinical guidelines: practical experiences from the North of England evidence based guideline development programme. *Quality in Health Care* 10 (1): 10-6.

The paper reported a study designed to explore service user involvement in clinical guideline development. Four different methods of user involvement were observed and assessed: incorporating an individual patient in a guideline development group; 'one off' meeting with patients; workshops with patients; and incorporating a patient advocate in a guideline development group. Service users were involved in the development of asthma and angina guidelines. Results indicated different levels of involvement from service users depending on the type of user involvement process. The authors concluded that the patient advocate was a feasible method of facilitating consumer involvement and that they had a different status in multidisciplinary discussion groups. They also suggested that obtaining wider access to service user views needs consultation outside of meetings with a range of different approaches.

Whitfield, S. and Lewison H (1994) User involvement in setting standards for maternity care. *British Journal of Maternity* 2 (11): 555-8

The paper discussed user involvement consultations over a two year period with maternity services users within a London health authority. The role of a maternity services liaison committee was described in developing maternity service standards for two maternity service providers. There was some description of the process and an example of two quality standards presented. The authors concluded that the development of service standards requires the input of health professionals as well as service users for the results to be meaningful.

Raynes, N. V. (1998) Involving residents in quality specification. *Ageing and Society* 18: 65-78.

The paper described a project undertaken across the city of Manchester involving older people from 45 participating nursing homes and residential homes. Details were provided of the development and implementation of the project which aimed to gather the views and opinions of older service users about future service contracts for nursing and residential care. Eighty six residents were invited to attend project meetings. Details of organisational requirements such as transport and care needs of the service users are provided. Clear information about how the service user's views were used to compare current and revised quality standards, and how these were incorporated by the council in purchasing services was presented. Unplanned positive outcomes were also described. The paper concluded that planning had to be meticulous but that the process improved management awareness of client needs and established partnership in decision making between service purchasers, providers and clients.

Patient councils and liaison committees

Lawn, O. (1996) Supporting Programme (Sheffield hospital's development of a patient's council as a forum for comment on services). *Health Service Journal* 106 (5512): 35.

The author was a non executive director of an NHS Trust at the time of writing. The one page article very briefly discussed the setting up of a patient council to provide a forum for patients and local community to comment on hospital services at a large general hospital. Descriptive information was provided, about how members were selected, and what they undertook. There was also a brief list of outcomes from the patient council's involvement.

Fletcher, G. (1995) Maternity service liaison committees -- ensuring the consumer voice is heard. *Changing Childbirth Update* (1): 2.

This one page document was written by the Chair of a Maternity services liaison committee. It described how a maternity service liaison committee developed and improved consumer representation. Members were drawn from the different areas covered by the maternity service. They were recruited through advertising on posters and flyers around the hospital and clinics, a radio interview and newspaper article.

Barnes, M. and Wistow, G. (1994) Learning to hear voices: Listening to users of mental health services. *Journal of Mental Health* 3 (4): 525-540.

The paper reported on an evaluation of a community based user involvement project to enable long term users of mental health services to participate in a user's council. Descriptive details were provided about the project. Twelve interviews were undertaken with health and social care professionals and informal interviews with a number of service users in a range of venues, but total numbers were not provided. Service users' and professionals experiences and perceptions were discussed. Discussion also focused on the impact of user involvement, provision of support and managing user involvement.

Community partnership development

Cornwall, A., Lall, P., Kennedy, K. and Owen, F. (2003) Putting partnership into practice: participatory wellbeing assessment on a south London housing estate. *Health Expectations* 6 (1): 30-43.

The paper described the development of a community project designed to improve well-being on a densely populated housing estate. The process of inviting participation, broadening residents' involvement and developing an action plan were described. The role of the facilitator was discussed as well as the involvement of health and social services representatives. This paper described the uses of a wide range of innovative methods including the involvement of local children using a 'problem wall' and 'solution tree' on which a picture of a leaf and a brick was taken by children to discuss with parents a problem and a solution and then brought and placed on tree or wall. A feedback event and the outcomes of the process were described. It was concluded that community participatory approaches are slow and intense processes, but they are valuable for stimulating change and developing commitment.

Crowley, P., Green, J., Freake, D. and Drinkwater, C. (2002) Primary Care Trusts involving the community: is community development the way forward? *Journal of Management in Medicine*. 2002 16 (4-5):311-22.

The paper described a case study of an initiative to promote community participation in decision making about local health services. A range of methods were employed: 82 interviews were undertaken with stakeholders and community activists and 114 self completion questionnaires were returned. Findings revealed the greatest community involvement was through consultation with local groups who identified their main concerns. An illustrative case about access to the deaf community in the Trust was presented. Description of the involvement of the deaf community and the outcome of their involvement was provided. Perspectives of service providers were also discussed. Observations suggested it is the hard work of community workers that makes things happen. It was concluded that initial needs assessment indicated a need for partnership rather than consultation, and that community action can open up significant dialogue with a range of minority voices, marginalized by other approaches.

Small, R. D. and Sudar, M. (1995) Islands of brilliance. building relationships between mental health professionals, families, and people with a mental illness. *Psychosocial Rehabilitation Journal* 18 (3): 37-50.

The paper discussed a partnership model of user involvement between mental health service users and professionals in Langley, Canada. The paper described the development of a consumer bureau to provide talks and education for the community on mental health issues. Partnership was developed between health professionals, people recovering from mental health problems and family members. The paper discussed the importance of trust and equality between members, how the bureau managed the different perceptions and experiences of family members and some of the barriers. The benefits of this form of user involvement were presented, although it was concluded that attitudes towards mental health change slowly, the experience for those involved was very positive.

Aronson, J. (1993) Giving Consumers a Say in Policy Development - Influencing Policy or Just Being Heard. *Canadian Public Policy-Analyse De Politiques* 19 (4): 367-378.

The paper focused on government initiatives in Ontario, Canada for involving older people in consumer participation. The socio-political context was presented before the consultation processes and organisation. The perceptions of older service users were discussed as well as the challenges and barriers experienced by older people attending forum meetings with service providers. Expectations and attitudes of service providers as well as bureaucratic language and a fixed agenda were seen to repress service user's voices. The paper discussed the difference between service driven user involvement and independent user involvement groups in achieving change and being heard within the political arena.

Pilgrim, D. and Waldron, L. (1998) User involvement in mental health service development: how far can it go? *Journal of Mental Health* 7(1): 95-104.

The paper reported an action research project developed to take service users from a position of opinion providers, to a point where they were actively involved in negotiating change. Service users were drawn from statutory and voluntary sectors and worked together in a group to develop priorities, known as 'the hobby horse'. The paper described how each participant took responsibility for acting on an item on the list. The outcomes from these actions were described, including the local authority appointing a mental health advocate, and development of an information

book. The paper explained how the facilitator role provided a teaching role for negotiation skills. No definition of user involvement was offered. The findings were discussed in relation to the socio-political context of user involvement and it was concluded that the ultimate constraint on user involvement was the presence of available finances.

Service evaluation

Rutter, D., Manley, C., Weaver, T., Crawford, M., J. and Fulop, N. (2004) Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Social Science & Medicine* 58 (10): 1973-1984. The paper described two case studies investigating the factors involved in influencing the implementation and degree of user involvement in two Greater London Mental Health Service Trusts. Details were given about the size and make up of each Trust, data collection and the selection of participants. The findings indicated the factors that influence user involvement including: barriers, representation, payment and independence. Findings indicated that managers retained the option to consult service users whilst feeling under no compulsion to respond to their views. Service user groups varied but service users experienced frustration and lack of power to influence change. It was concluded that consultation rather than partnership was represented by the two Trusts with the balance of power firmly with the service providers. It was suggested that transparency about expectations and limitations was required for collaboration to be sustainable.

Rose, D. (2001) User Focused Monitoring. *Mental Health and Learning Disabilities Care* 4 (6): 207-10.

This paper in described how 61 mental health service users were trained to become interviewers for a large evaluation of mental health services call User-Focused Monitoring. The interviewers were randomly sampled and recruited from day centres and other projects. The paper described the recruitment process, the development of the questionnaire, training and selection of the interviewees and the interviews. Focus groups were used to ensure evaluation questions were rooted in service user experience of community and hospital services. The experiences of two participants were presented. It was concluded that the views of service users were complex but they have important contributions and suggestions to make.

Bowl, R. (1996) Legislating for user involvement in the United Kingdom: Mental health services and the NHS and Community Care Act 1990. *International Journal of Social Psychiatry* 42 (3): 165-180.

This paper reported findings from two linked pieces of research; 1) A telephone survey of social service officers in 31 Local Authorities across England and Wales and 2) An in depth study of three contrasting local authorities involving 135 mental health service users, 9 establishments and 6 user forums. Observations and interviews were undertaken to explore user involvement and decision making structures. No definition of user involvement was provided. The findings focused on devolution of power, representation and the role of forums. It was concluded that local authorities need guidance on user involvement to increase participation and to address staff skills and attitudes to user involvement.

Ingleton, C. and Faulkner, A. (1995) Patient involvement in audit in palliative care: views of the professionals. *Journal of Cancer Care* 4 (4): 153-6.

The paper reported one aspect of a larger evaluation study. It presented findings from interviews with palliative care staff about their perceptions of whether service

users should be involved in audit processes. Although there was a general consensus that patients should be involved, concerns were raised about the vulnerability, poor concentration and sense of indebtedness that patients might feel which could compromise their participation. It was recognised that the methods used may need reconsideration, such as the length of questionnaires and the types of questions asked and that using qualitative methods may be more helpful.

Sitzia, J., Cotterell, P, et al. (2004) *Formative evaluation of the cancer partnership project: Final Report*. London, Macmillan Cancer Relief

The paper presented the final report from an independent evaluation commissioned by Macmillan Cancer Relief and the Department of Health. The report was a formative evaluation of Cancer Partnership Projects across England. A mapping exercise was used to collect information on service user/partnership groups activity from 34 cancer networks. Six cancer networks were selected to interview a range of service users and NHS staff about aspects of their involvement. Twenty nine people were interviewed about their involvement. Key findings and recommendations echoed comments and findings in other papers. The paper suggested that user involvement was an evolving and organic process which required ongoing commitment and resources by cancer services. Education and awareness raising of user involvement was also necessary to improve the shift towards patient centred care through genuine collaboration.

Hard to reach service users

O'Keefe, E. (1999) Public participation and marginalized groups: the community development model. *Health Expectations* 2: 245-254.

The paper described a project 'HealthLINK' developed to consult house bound people within the London Borough of Camden about their views on planning and monitoring health and social care. The paper described in detail the different processes undertaken to identify participants. Questionnaires were sent to 150 people. Eighty replies were received, the majority of participants being 70 years or older with disabilities. Information was provided about the establishment of group meetings and feedback mechanisms. Other consultation methods were also described. It was suggested that the expertise of older service users needs to be nurtured through development of trust over time. The development of sustainable user involvement was labour intensive, time consuming and required ongoing resources. It was concluded that each service user's views are a resource, but that it takes skills to transform diverse points of view into competent networks of people who can plan for more equal partnership with commissioners and providers.

Patmore, C. (2001) Can managers research their own services? An experiment in consulting frail, older community care clients. *Managing Community Care* 9 (5): 8-17.

This brief management orientated paper reported upon an experimental interview programme to enable frail older service users to be consulted about their services. Two local authority offices used a stratified sample of older service users, who were subsequently screened according to set criteria before being sent letters requesting an interview. Managers appeared to prove effective interviewers, and conducting the interviews reminded them of everyday realities for service users. It was concluded that this approach to consultation created a large volume of diverse and extensive information which informed service development. A related finding was the need to improve social support to all isolated older people who were depressed or at risk of

depression from their disabling conditions. The merits of different approaches of consulting older service users were debated.

Carter, T. and Beresford, P. (2000) *Age and Change - Models of involvement for older people*. York, Joseph Rowntree Foundation.

The paper presented findings from a project considering different models of involvement for older people. The report was based upon conversations with older people from a variety of groups and organisations and the identification and brief description of user involvement initiatives across the country. Strengths and weaknesses were highlighted for the different forms of user involvement. There was discussion about issues of inclusion and exclusion in relation to particular approaches ability to achieve change. The report discussed issues of race and gender in relation to how these affect user involvement initiatives

Barnes, M. and Bennett, G. (1998) Frail bodies, courageous voices: older people influencing community care. *Health & Social Care in the Community* 6 (2): 102-111.

This paper reported on a project funded by Age Concern Scotland which set up seven user panels in Fife to enable housebound and frail older people, who are usually unable to leave their homes without assistance, to participate in a user involvement initiative for community care planning. Participants were recruited because they were representative of the older population, with the largest number of people being between 86-90 years old. Detailed description of the organisation was given. The aim of the project was to identify issues that older people felt were important. Interviews were undertaken with panel members, using interview schedules developed with other older people. Results revealed that despite the resource intense nature of the panel, members reaped many benefits from involvement including: enhanced self esteem, being listened to, learning from others and increased social contact. It was noted that the success of the project could be measured by reference to objective changes within service agencies and the interest it evoked.

Using pictures and photographs seek user views with hard to reach groups

Allen, K. (2000a). Drawing out views on services: ways of getting started. *Journal of Dementia Care* 9 (1): 22-25.

The paper described one aspect of an action research study trying to explore the views of people with dementia about their services. This paper focused on the processes and methods involved in finding the right technique to use with service users. The use of visual stimuli such as pictures and developing a conversation were described. Pictures prompted the telling of a story to which key workers could ask questions about their own service if relevant. The importance of the key worker being able to identify responses and develop opportunities was also discussed.

Allen, K. (2000b). Drawing out views on services: meeting the many challenges. *Journal of Dementia Care* 9 (2): 26-29.

In a companion paper, the many challenges in exploring the views of service users with dementia were discussed. In addition the role of the researcher and the anxieties and developments of the service staff in developing their skills and confidence were highlighted. The paper explained the difficulty for staff in finding starting points and creative approaches with service users to managing their own anxieties. It was argued that it was important to make a start rather than wait for the perfect idea or

method. It was found that keeping records of service user's behaviours were helpful, to enable staff to become alerted to changes and to share these with colleagues. It was felt that being flexible and seizing the moment was important, since sometimes plans to facilitate communication failed due to the service user's feelings and state of mind. It was concluded that the developmental process of engaging with user involvement had a transformative effect on staff and improved communication on an everyday basis.

Woolrych, R. (2004) Empowering images: using PhotoVoice with tenants with special needs *Housing, Care and Support* 7 (1): 31-5

The paper discussed innovative use of photography called 'photovoice' in enabling service users with special needs to express their views about their accommodation. The photographs were used to record what people liked and disliked about the service. The paper also described how 'photovoice' had been used with older tenants in sheltered accommodation and for a series of regional and national conferences. Examples were given of how digital cameras and computer training have empowered service users. This was supported by a discussion about different levels of participation in which the use of taking photographs had a place in representing service users views.

User involvement with education initiatives

O'Sullivan, M. and Donovan, A. (2003) How to be heard: you can't just expect mental health service users to turn up and participate. *Mental Health Today*. May p31-33

This descriptive paper was written jointly by a professional and mental health service user. In it they discussed the development of a 5 day training course to developed service users knowledge and confidence in Derbyshire. The project developed out of a local service user conference, leading to a service user strategy implementation group within the local mental health Trust. Specialist training was provided to develop assertiveness and to do interviews for radio, TV and newspapers. One author wrote that she felt less intimidated by the end of the course when writing the next article for her group and that she found the welfare rights information helpful in relation to payment for user involvement initiatives. The authors concluded that the project had been successful in attracting the attention of other authorities as a framework of training service users in other fields.

Turner, P., Sheldon, F., Coles, C., Moutford, B., Hillier, R., Radway, P., Wee, B et al. (2000) Listening to and learning from the family carer's story: an innovative approach in interprofessional education. *Journal of Interprofessional Care* 14 (4): 387-395.

The paper reports on a three month evaluation of workshops in which nursing, medical, social work and rehabilitation therapy students interviewed carers about: 1) their experiences of caring for their family member or friend; and 2) the end of life care received from health and social care professionals. The aim of the workshops was for students to learn about the reality facing patients and their families and to learn about interprofessional working. The paper briefly discussed the initial setting up of the workshops and issues surrounding the involvement of carers, and workshop organisation. Carers were recruited through the hospice and its bereavement, home care and day care services. The perceptions of students and carers were sought in the evaluation and discussed in the paper.

Service development and information development

Last, A. (2003) User involvement. Pick and choose. *Health Service Journal* 113(5852): 28-9.

This paper described how service users with learning disabilities were involved in interviewing a new lead officer for disability services in a West Midlands PCT. Procedural aspects of the preparation for the interview including: the available time, planning, preparing service users and developing the questions were discussed. The importance of a facilitator in enabling the service users with learning disabilities on the panel to make decisions about candidate scores and framing the questions, to help identify the preferred the candidate were outlined. The paper concluded with a discussion about how to involve service users throughout the whole process of staff recruitment. It ended by reminding readers that good user involvement takes time and effort.

Bhui, K., Aubin A. and Strathdee, G. (1998) Making a reality of user involvement in community mental health services. *Psychiatric Bulletin* 22 (1): 8-11.

The paper discussed user involvement within an inner city mental health service. There was a short description of the development of three way workshops with users, carers and health professionals, designed to establish the content of printed information leaflets for outpatient appointments. The authors concluded that that they always learned from their service users but that service users were not always right and that professionals need to retain some responsibility for decision making.

Blacker, S. and Chapman, K. (1998) Issues in collaborative practice. Partnering to create patient education resources on breast cancer. *Cancer Practice* 6 (2): 129-31. This brief descriptive paper was about the development of information for women with breast cancer at a hospital in Canada. A multidisciplinary response to service user requests for information enabled development of an information package. A small pilot study of 20 newly diagnosed women given the pack, achieved a 40% response rate which indicated the package was perceived to be very helpful. It was concluded that multidisciplinary partnership with services users enabled timely, cost effective and patient focused information packages to be developed which became an integral part of the institution's standard care provision.

Sabin, J. E. and Daniels, N. (1999) Public-sector managed behavioural health care: III. Meaningful consumer and family participation. *Psychiatric Services* 50 (7): 883-885.

The paper discussed a multi-pronged user involvement strategy in Massachusetts. It discussed different methods of user involvement, provided some descriptive details about each method and lessons learned. A consumer council, a family advisory council and a peer education group provided guidance to practice and directly influenced key members of staff in different organisations. More details were given about other initiatives. The authors concluded that access to the key service purchaser, and careful management of the user involvement processes can not guarantee that consumers will be heard or be able to effect change.

Service users crossing the professional boundaries

Dixon, L., Krauss, N. and Lehman, A. (1994) Consumers as Service Providers - the Promise and Challenge. *Community Mental Health Journal* 30 (6): 615-625.

The paper described a project in which service users were employed as advocates in an interdisciplinary outreach mobile community treatment team for homeless people

in the United States. The advocates knowledge and experience of illness, medication and available services were helpful because they could discuss these concerns and provide information to other service users. Consumer advocates were seen as valuable because of their personal knowledge of the health and social care systems and life styles of service users, and the type of information needs users have, as well as knowledge about how to engage with service users and build trust where professionals could not. Discussion also focussed on the roles, boundaries, responsibilities and support needs of the consumer advocates. Issues arose when advocates became ill themselves. Conclusions drawn by the authors suggest more work needs to be done to address boundary definitions and supervision.

Truman, C. and Raine, P. (2002) Experience and meaning of user involvement: some explorations from a community mental health project. *Health & Social Care in the Community* 10 (3): 136-143.

The paper reported on a qualitative evaluation of a community project for mental health service users using a participatory framework of user involvement. It described service users activities including: volunteering at a community gym, having opportunities for training and becoming an advisor to other service users. Focus groups and interviews with gym users explored meaning of user involvement. The findings suggested that there was a clear organisational structure for service users to progress from patient to staff member. However, some service users found the boundary between being a service user and being seen as a staff member stressful, as was working with people with similar illnesses. It was concluded that meaningful and successful user involvement enabled service user to develop their skills at their own pace in an environment which was supportive. However, facilitation was identified as being more complex than just providing the right structures.

Perceptions of professionals and service users about user involvement

Craig, A. (2004) Public involvement in health care: Every voice counts, not just that of patients *British Medical Journal* 328 (7437) p462

In a letter to the BMJ the author presented his perception of user involvement. He stated that in his experience user participation in primary care practices could 'foster trust, responsibility, and partnership between users, practitioners and managers'. He suggested support of practice participation can assist in meeting regulatory requirements as well as developing lasting structures for user involvement. He believed investment as well as good intention are needed.

Summers, A. (2003) Involving users in the development of mental health services: a study of psychiatrists' views. *Journal of Mental Health* 12 (2): 161-74.

The paper presented a study based on 14 interviews with general psychiatrists investigating their expectations and perceptions of user involvement. In general user involvement initiatives were perceived to be 'politically correct', although interviewees hoped that services would be improved by them. Responses were analysed by allocating participants into three response types: the optimists, rationalist and sceptics. It was concluded that psychiatrists were willing to think about user involvement from a utilitarian perspective and that this stance could be used to negotiate some of the tensions and complexities of user involvement

Berger, E., Carter, A., Casey, D. and Litchfield, L. (1996) Consumer note. What's happening with consumer participation? *Australian New Zealand Journal of Mental Health Nursing* 5 (3): 131-5.

This paper presented perspectives of consumer representatives, organisers and members of the Pioneer Clubhouse. It described how the authors began their consumer participation initiatives and how they set up a pool of representatives to attend committee meetings and elect a consumer representative coordinator. The evolution of the project was described, as well as how it informed mental health services through organised workshops and consultations with people with disabilities. It concluded that consumer involvement was an evolving process and that participation by staff and users managed to breakdown a 'them and us' division. It regarded user involvement as essential for implementing best practice.

Lammers, J. and Happell, B. (2003) Consumer participation in mental health services: looking from a consumer perspective. *Journal of Psychiatric & Mental Health Nursing* 10 (4): 385-92

The paper presented findings from a qualitative research study in which 15 mental health service users in Victoria Australia were interviewed about their perception of user involvement. Five carer participants were also interviewed. The difficulty of recruiting carers was noted. Findings were discussed in relation to opportunities and barriers for participation of service users and carers. A range of experiences were recorded. Of note was that service users felt excluded by the language used at management meetings, and carers felt their participation was minimal. Tokenism was seen to be caused by professionals need to meet policy expectations. It was concluded that health reforms were driving user involvement, but that the different needs of service users and carers were not being acknowledged. There remained an inherent difficulty in empowering both groups at once.

Connor, H. (1999) Collaborative or chaos: A consumer perspective. *Australian & New Zealand Journal of Public Health* 8 (3): 79-85.

The paper reflected upon collaboration and partnership between mental health service users and mental health nurses in Australia and New Zealand. Participation from both a personal and general perspective considered the range of different levels of participation, as well as potential constraints and barriers. These included issues of: payment of service users, peer support, communication and feedback mechanisms to ensure user involvement was accountable. A list of essential factors to facilitate consumer participation was provided, and the paper concluded that consumer involvement was a journey towards equality, respect and rights.

Faulkner, A. (2003) The emperor's new clothes. (Critical discussion of mental health user involvement in academic and clinical research). *Mental health Today*: 23-5.

A short paper based on the author's experiences as a mental health service user, who was also a working health professional within the mental health field are presented. The author discussed issues about how she was perceived both as a professional and as a service user by members of the panel she was a representative on. The motives behind user involvement were questioned and a list of principles for successful user involvement is provided.

Gott, M., Stevens, T., Small, N. and Ahmedzai, S. (2000) *User involvement in cancer care: exclusion and empowerment*. Bristol, The Policy Press.

This publication reported the findings of a study undertaken in the UK investigating the nature, impact and extent of user involvement in cancer care. Representatives of

local self help groups, service providers and key informants from national organisations were interviewed. Interviews focused on organisational, process and policy aspects related to the support groups and services. The study findings are reported in relation to the perspective of service providers and the perspective of service users. There was little consensus about the definition of user involvement amongst both service providers and service users. Perceptions of service providers and service users are discussed in relation to communication, support and barriers to user involvement and mechanisms for involvement.

Gray, R., Fitch, M., Greenberg, M. and Shapiro, S. (1995) Consumer participation in cancer system planning. *Journal of Palliative Care* 11 (4): 27-33.

The paper reported on an empirical study undertaken in Ontario, Canada that investigated patient and family representation within the Life to Gain cancer strategy. Semi structured interviews were undertaken with 19 participants. Information was provided about participants perceptions of their involvement. There was general satisfaction with participation, and a strong sense of motivation for greater user involvement, despite unhelpful power issues compromising user involvement. Participants identified support, help with terminology, and a change in the time and location of meetings from that of a professionally driven agenda, as helpful in enabling effective participation.

Reference and tool kit books

National Council for Palliative Care (2004) *Listening to users: helping professionals address user involvement in palliative care*. London, National Council for Palliative Care

This document provided guidance and advice to palliative care services and health professionals about addressing user involvement. The document provided a clear explanation of what user involvement can mean and how this can be translated into practice. A list of key issues to consider is provided, as are recommendations about what factors can contribute to how user involvement can be sustained. Examples and a brief description of how different forms of user involvement initiatives are undertaken by named palliative care services are given and these are complemented by stories from service users.

Tritter, J., Daykin, N., Evans, A. and Sandias, M. Eds. (2004) *Improving cancer services through patient involvement*. Abingdon, Radcliff Medical Press

This book presented a tool kit for considering, establishing and evaluating user involvement within cancer services. The book was based upon findings from a three year Department of Health funded study evaluating user involvement within the former Avon, Somerset and Wiltshire Cancer Network. The book represents an excellent resource. It was clearly written, raised important questions to be considered and presents user involvement as an ongoing cycle involving different stages. A complete tool kit, offering advice on running a workshop, designing materials, the educational requirements of services users and professionals and ethical considerations were outlined. A set of tools developed and validated during the research are presented in the appendices.

Chambers, R., Drinkwater, C. and Boath, E. (2003) *Involving patients and public: how to do it better*. Abingdon, Radcliff Medical Press.

The authors have written a book which acts as a reference manual and tool kit for health and social care professionals and voluntary organisations when considering

what approach to use for user involvement. It covered methods and process as well as ethical issues such as obtaining consent. Examples of practice were provided to highlight approaches, and questions raised for the reader to consider. The language was clear and simple.

Less common user involvement methods

Citizen juries

Lenaghan, J. (1996) Setting priorities: is there a role for citizens' juries? *British Medical Journal* 312: 1591-1593.

The paper described a pilot study undertaken within Cambridgeshire in which 16 randomly select jurors sat for four days on a citizens jury hearing evidence from expert witnesses and were then asked to consider how priorities for health care should be met. The process and issues around citizens' juries are discussed. Jurors developed their own criteria for purchasing healthcare and debated the importance of balancing quality and quantity. Jurors were also given a questionnaire to complete. Most felt there should be public involvement in developing guidelines for priority setting, but it was also felt people would need more information if they were to participate. The jurors were reimbursed for the four days. It was concluded that this was one method that can be used in combination with more traditional approaches to involving the public in priority setting.

Use of performance

Ruga, W. (2002) Performance review. *Hospital Development* 33 (10): 15-6.

This short paper, written by an architect, described the problems of using performance as a mode of user involvement in representing service user's views about the design of a new cancer service. The performance involved a man and woman talking about their experiences of having cancer. The author discussed the problem of needing an interpreter to convey its message to the bidders of the contract to build the new cancer unit, thus highlighting the problem with this approach.

4.1.3 Qualitative Content Analysis

A content analysis and synthesis of the literature was undertaken to identify: key authors, the timeline of the literature and dominant themes within the literature. The selected literature is drawn from 1992 to 2004, which spans a range of policy changes and initiatives in health and social care in the UK. Selected literature from Canada, Australia and the USA has been considered to contribute to an understanding of user involvement. Key themes were identified across the literature, using a qualitative content analysis. They will now be discussed.

Who writes about user involvement and who gets heard?

From the bibliometric analysis it is clear that professionals including academic researchers, health and social care professionals and managers have written 96% of the extracted literature, with only 4% being written either independently by service users or in conjunction with a professional. The majority of papers were written by academic researchers and by medical professionals. Their work is generally published in peer reviewed journals or in books. This shapes how user involvement is written about and what is contributed.

There is a distinction between peer reviewed journal articles, which are written to a tight methodological format and the books written by professionals on user involvement. The journal articles often provide some socio-political or theoretical context before explaining the methodology used to study user involvement using a variety of methods, or describing the establishment of user involvement initiatives. There is some critique and some reflection on the methodology used to investigate user involvement, rather than about user involvement itself. Bhui et al (1998) who are mental health practitioners questioned the assumption that the user is always right. Some critique of user involvement is provided where the perceptions of professionals about user involvement have been sought (Summers 2003, Gott 2000). However, there was little critique of user involvement and most papers were based on the assumption that user involvement is 'good'.

A range of books have been written by academic researchers and health and social care professionals. The only critical analysis of user involvement has been provided by Small and Rhodes (2000) although Tritter and his colleagues (2004) also address definitional aspects of user involvement. In comparison an edited book by Monroe and Oliviere (2003) offer predominantly descriptive and contextual accounts. Tool kits for user involvement have been developed by academic researchers (Tritter et al 2004) and by general practitioners (Chambers et al 2003). The tool kit books fulfil service delivery needs driven by policy directives within health and social care to increase user involvement, and therefore their remit is largely educational. Both books address the context behind user involvement, but offer no conceptual critique.

A reference booklet produced by service users and professionals at the National Council of Palliative Care (2004) draws upon a range of models of user involvement in practice in palliative care settings. This offers a guide, but no process information and readers would need to go to both Tritter et al (2004) and Chambers et al (2003) for advice and methodological guidance.

Documents written by health and social care professionals, service managers and service users were found in professional journals, not all of which are peer reviewed and in non academic literature. The content of such documents are often descriptive accounts of user involvement initiatives and the experiences of those involved, rather than offering a critical appraisal. The location of these accounts include the letters pages of journals (Craig 2004), in brief commentaries (Lawn 1996, Faulkner 2003, Fletcher 1995) and a few longer articles.

The service users who have contributed to the literature come from mental health and palliative care domains. The mental health service users write about their experience and the successful initiatives they have developed. There is descriptive process detail as well as personal reflection. Any critique of user involvement is in relation to the barriers experienced by the service users. The contribution by palliative care service users remains very small and forms part of predominantly professional books (Beresford et al 2000, Monroe and Oliviere 2003).

Sitzia et al (2004) provides a good overview of user involvement within the UK cancer network partnership groups, a critique of the identified problems and a set of recommendations. This is an important contribution, although the critique focuses on service delivery models of user involvement. The report identifies models and practises of user involvement as well as the barriers to maintaining future development within the current political framework.

The problem of definition

There is very little in the literature addressing the definitional and conceptual issues surrounding user involvement. Tritter et al (2004) breaks user involvement down into direct and indirect involvement, whereas Gott et al (2000) reveal the lack of consensus between professionals and service users about what user involvement means. On the whole the literature is based upon assumptions about what user involvement is, and who can be considered a 'user'. This lack of definition is also compounded by the use of multiple terminologies, in which the words 'consumer', 'patient', 'carer', 'service users' are used in conjunction with 'involvement', 'participation' 'partnership' and derivatives of these. Little attempt is made by authors to make explicit their own conceptual framework within the analysed texts.

Consultation

Consultation is the method of user involvement written about most often by service managers and health professionals. The initiatives are described in varying levels of detail, occasionally with comment about the success of the event. There is little detail provided about the questions asked of service users (other than that a consultation took place about a particular issue.) (Lamont and Levenson 2001; Wilson 1992). Two papers provide a critical perspective on consultation, one focused on a managerial approach in mental health services (Rutter et al 2003; Lammers and Happell 2003) and another on older people's care within Canada (Aronson 1993). Bureaucratic language and fixed agendas appeared to exclude or stifle service users' voices, although more active engagement with people who have learning difficulties was described (Last 2003). The latter paper not only described details of consultation with service users but offered a list of the questions agreed upon by service users and health professionals to ask potential candidates seeking posts in health service management. The service user's voice is predominantly missing in discussions about user involvement methods apart from the report by (Beresford et al 2000) in which user's voices and wishes were included.

Detailed user involvement processes

Several reports are written about user involvement projects and studies including: action research (Cornwall et al 2003, Pilgrim and Waldron 1998) and community initiatives (Crowley et al 2002, Allen 2000a, 2000b; O'Keefe 1999, Barnes and Bennet 1998, Raynes 1998). These professionally written papers were published in peer reviewed journals and offered clear descriptions of the process of setting up and managing user involvement initiatives. They are analytical and reflective. They highlight outcomes which demonstrate that user involvement can achieve change, including with older people or social groups who are hard to reach.

Creating and developing partnerships

'Creating Partnership' was a theme that developed out of the action research and community participation literature and from the personal narratives of service users. Partnership between service users and health and social care professionals is central to developing and sustaining user involvement in a variety of settings. Partnership requires breaking through social and professional barriers to develop trust and respect. Barriers to partnership such as lack of partnership working, funding issues

and perceptions of users by professionals are discussed in the mental health service user papers (Connor 1999; Small and Sudar 1995; Cornwall et al 2003).

Facilitation

Facilitation was an important theme identified across a wide range of literature, which not only included action research, community development and personal narrative writing, but also evaluation studies (Stizia et al 2004, Cornwall et al 2003, Pilgrim and Waldron 1998; Crowley et al 2002; O'Keefe 1999; Barnes and Bennet 1998; Small and Sudar 1995). Effective facilitation is acknowledged as central to developing and maintaining user involvement initiatives and for motivating staff to value developing creative approaches to user involvement in areas such as dementia care (Allen 2000a, 2000b). It was observed that service users can ask other service users the questions that health professionals are not always able to (Truman and Raine 2002; Rose 2001; Dixon 1994).

Motivation

Motivation to engage in user involvement from the service user's accounts reveals a drive to make a difference. For example mental health service users developed long term user involvement initiatives, and for them changing public and professional perceptions through education has been the motivating force (Small and Sudar 1995). For some, there was a drive to stand up and be counted (Connor 1999). While for others, the motivation was to improve services and give something back to the community (Sitzia et al 2004; Rose 2001; Raynes 1998; Berger et al 1996). In some areas such as in cancer and palliative care, health policy developments have driven user involvement and the initiatives have started with professionals rather than patients.

Contested Identities

Some of the literature raised the issue of contested identities. Both Connor (1999) and Faulkner (2003) discuss the tension between being both mental health services users and health professionals. This is also discussed in relation to service users crossing the boundary between being a service user to a service provider and the challenges this raises for managing identify. There was some evidence that where users held dual roles (as patient and service provider) they experienced difficulties.

Representation

The issue of representation was raised in a number of papers. Questions are raised by health professionals as to how representative service users are of the wider population from which they are drawn (Rutter et al 2004; Pilgrim and Waldron 1998; Bowl 1996; Barnes and Wistow 1994). Service users also acknowledged that they are criticised for not being representative enough (Faulkner 2003, Gray et al 1995).

Power

Observation of user involvement processes has revealed a lack of motivation to devolve power to service users or to adapt organisational structures (Bowl 1996; Rutter et al 2004). There have been different degrees of devolution of power (Sitzia et al 2004) and changes to organisational processes (O'Keefe 1999; Patmore 2001),

such as community engagement and action projects. It appears from the evidence in the literature that there is increased consultation with service users but often without providing sufficient training to service users, or with unrealistic expectations that service users can turn their experiences into practical suggestions without assistance.

Education

Participation of users in the education of health professionals about palliative care has been positively evaluated by Turner et al (2000) and developed through service user partnerships (Berger et al 1996; Small and Sudar 1995). O'Sullivan and Donovan (2003) described an educational initiative for service users. However, apart from Turner et al (2000) there appeared to be little evaluation of service users as peer educators within the selected literature.

User involvement with hard to reach groups

There is limited literature on user involvement in hard to reach groups such as services for older people, and those using palliative care services. The literature that exists offers examples of user involvement with people with long term conditions (Small and Rhodes 2000). The remainder of selected palliative care texts, discuss contextual and practical problems of undertaking user involvement with patients with advanced disease (Oliviere et al 2001; Monroe and Oliviere 2003) and identify approaches that are currently used by palliative care services (Kraus et al 2003; NCPC 2004; Beresford et al 2000). Generally user involvement is still required to fit into a conventional organisational frameworks instead of developing community approaches in which a range of techniques may be developed for capturing the views of hard to reach people such as those who are house bound people (Patmore 2001; O'Keefe 1999; Barnes and Bennett 1998) or those with cognitive impairment (Woolrych 2004; Last 2003; Allen 2000a, 2000b).

Conclusions

It would appear that from this analysis of the selected literature that user involvement is predominantly written by a few professionals and that there is little critique of the benefits of user involvement. However, there are areas from which insight can be drawn; the work on hard to reach service users and community development projects offer some alternative approaches for palliative care to consider. Sitzia et al (2004) provided the most up to date review of user involvement within the UK in relation to Cancer network partnership groups. The problems and the recommendations made are pertinent to palliative care within the current socio-political climate of health reform. Analysis of the selected literature indicates that most authors report descriptive accounts of initiatives, projects, conferences or other practical activities. Few of these activities have been evaluated in any way except for simple 'satisfaction' measures. There is remarkably little evidence of the efficacy of user involvement for participating patients and carers, or professionals, or for their organisations, apart from anecdotal accounts. The literature review sheds little light on what motivates the minority of patients to become involved in these initiatives and what sustains their involvement despite well recognised barriers. None of the literature we located examines why the majority of patients and carers decline to participate in user involvement opportunities. These represent important areas for future research.

4.2 Phase 2 Findings

In Phase 2, we aimed to obtain the views of key informants using telephone or face-to-face interviews and at site visits, from a sample of people who have expertise about user involvement in palliative care (**Aim 3**). Semi structured interviews were undertaken using an interview protocol to elicit information about user involvement in palliative care (see Appendix C: health professional’s version; Appendix D: patient’s and carer’s version). The questions included:

- How do people understand the term user involvement?
- How do people become involved in user involvement initiatives?
- What different user involvement models are being used?
- Examples of good policies and practices
- Perceived and actual barriers to user involvement in palliative care.
- How can user involvement be assessed?

Site visits and observation of user forums were undertaken to elicit how each meeting was organised and facilitated and who attended. Table 7 reports that in total 51 people participated in interviews and two people declined (96% response rate).

Participants	Total number agreeing to interviews	Total number of individuals declining interviews
Service users who are patients	19	1
Service users who are carers	6	0
Health and social care professionals	22	1
‘Experts’	4	0
Total	51	2

Table 7 Description of People Participating in Interviews

The findings are presented in relation to major themes reflecting the questions above.

- **Who is seen as a service user?**

Participants had different perceptions about what the term user involvement implied and who could be considered a service user. For most participants service users were patients and carers who are involved in making suggestions and contributing to developing current services. Only occasionally were health professionals and the public mentioned as service users.

“My understanding of user involvement, well anything to do with patients or carers as they’re becoming involved in either the planning or development of cancer services, and

basically getting involved in having their voice heard regarding the experience that they've had of receiving those services... And that might be through making comments about the existing services and whether they're working well or not, and also making suggestions for new services that they'd like to see provided here.” (Professional no 1 who is also a current service user)

“User involvement means to me that patients, users, carers are given the opportunity to voice their experience and to have some input into the way services are provided”. (Service user who was a patient no.1)

For some health professionals user involvement has been an evolving concept

“My understanding is I suppose it's influenced by a lot of things, but I think any patient care is best when you're involving the patient in it, so I've got it at that level. But I suppose as time has gone on it's been to do with recognising the importance of users being involved in development of services, and that the patients are the people who actually know best what they require. And so I see it as part of getting the best for people and I can see it's doing all sorts of things I suppose. I see it as demystifying the whole issue about healthcare, and empowering patients so that they understand what's happening around them, and ultimately I see it as, so I see it as empowering patients but about making better services”.(Professional no. 9)

- **A problem of language**

The term 'user' was problematic for some participants because of its close connection and association with the term 'drug user'. Alternatives such as consumer involvement were also problematic because of the connotations of consumerism.

“User is probably about as good as you can get, because consumer has other overtones which we don't altogether like; client doesn't seem to, well maybe that's not too bad. There are services which we use and wish to be able to say whether they are being given to us in the way that we want to use them or not. So, of all the words I would guess user is less harmful than any of the others”.(Service user who is a patient no. 7)

However, most participants felt that the term is not problematic and describes what they do, although some participants have been involved in trying to find another term that fits their understanding of what they are trying to achieve. Nevertheless, there was recognition that there is little consensus about which term to use, and that for some this was the best available.

“I think a lot of it's semantic isn't it. It's like whether we call them patients, clients, consumers. There isn't really a right word is there, and I don't think service users is, but I think it's an attempt to address that. It's a little less passive than some of the others. I think maybe service user involvement is encouraging, veering towards that activity as opposed to passivity, which is invaluable, particularly in end of life care. I think people on the receiving end of everything can be made to feel that their receptors have to be grateful; the receptors and that's all. That's not a good situation.”(Professional no. 11)

- **Policy driven user involvement**

A clear difference was identified between how service users and health professionals become involved with user involvement. There is a drive from government for increased user involvement within health services; therefore user involvement in certain areas of health care are a politically driven phenomenon. Several health professional participants commented that their services had developed user involvement as a response to clinical governance guidelines and the recent Guidance for Supportive and Palliative Care (NICE 2004). Responding to clinical governance requirements was a commonly reported driver for user involvement.

“When I first came into post, which was just over a year ago, it was one of my first sort of aims was to look at ways of involving service users. And that was because the NICE guidelines were about to be published and there was a big emphasis on service user involvement there. And so when I came to the hospice it was very much presented to me as something that the hospice wanted to get into, it fitted in nicely with the hospice’s philosophy anyway because there’s a great sense even without all the guidelines that patients should be involved in decision-making.”(Professional no.9)

“I only did it because it was part of my job description and I think for us at the hospice, Clinical Governance was very timely, and we thought it fitted in with our philosophy quite well, so that was my initial involvement with user involvement, obviously it is part of the Clinical Governance Framework, and then it developed further from there really”.(Professional no. 2)

- **Service evolution and charismatic staff**

For other services there appeared to be a gradual evolution in user involvement which was seen to be related to members of staff developing initiatives, rather than it being attributed to responses by services to policy developments.

“Yes, I think that would be fair, since I’ve been at B Hospice, and I would say that it’s probably been evolving. I’ve been at B Hospice for seven and a half years, I think this has probably been evolving for us over the last five years. I think one of the key people that started it off for us was when we appointed a new day care leader, which must be about three and a half years ago now. Whose attitude was very much about involving the day care patients in what they wanted to do, so rather than say this is what we’re going to do, we’re going to do this today, that tomorrow, the way that she worked with people was that she was very much about talking with them and saying, right, what would you like.” (Professional no.4)

Staff members were also perceived to be important for motivating and generating interest in user involvement within a service. Their presence motivates others, but the loss of such a person can slow the development of user involvement.

“I think the difference has been the enthusiasm of pr9 who’s wanted to get it going. Previously when we tried to do it, it never really got off the ground, we never got as far as actually holding a user forum and a user meeting. The education department and Pr9’s predecessor did a lot of talking, a lot of theorising about it and we never actually got to the stage of moulding anything. Whereas pr9’s picked up on it and got into it and implemented it and got it going and it’s starting to pay dividends” (Professional no. 12)

- **User involvement by invitation from professionals**

Many service users become involved through an invitation. Initial invitation often comes from a member of the health team in contact with service users attending palliative care and cancer care services or a support group. Professionals appear to identify people for their skills and abilities.

“after I had received my treatment I was approached to be part of a gynae review at the hospital; so as a patient witness if you like. So after I had done that the hospital stated that they were thinking of starting a cancer user group, and they had just had a couple of meetings and I joined them, and after a year they elected me as their chair” (service user who was a carer and is a patient 5)

“It’s, after my own cancer I decided I wanted to put something back into it and I retrained as a counsellor and I decided that I needed to get some experience, which I did, then I went to, not my local support group because that was foundering at the time but the one that was nearest and very active, which is at W, and started working as a counsellor there. And was asked out of the blue to attend a meeting over in X one Saturday and where there was a discussion I was told taking place concerning user involvement, which didn’t mean anything to me. And quite honestly I went over there without any idea as to what I was going too; I thought I was just going to support the support group. And got quite involved, I mean my background is in the oil industry, I’ve got a lot of management training, university training behind me. And it became fairly clear to me then that what wasn’t available there was clear thinking about processes and management structures, so I volunteered to get involved as part of a prototype for this network. I didn’t realise, I didn’t know even then that this was one of 34 networks. I knew nothing about that at all” (Service user who is a patient no. 4).

Observations of two user forums identified invitation as the main process by which service users were informed and attended meetings. Posters and flyers inviting attendance were also distributed with one hospice.

- **Self initiated user involvement**

For other service users, seeking information about a disease or listening to speakers and making contact with them initiated an invitation to attend a user involvement event.

“Yes, well, initially what happened was my husband was diagnosed with bowel cancer, I went onto the internet to find out as much information as I could, and I went onto one particular website, and don’t ask me which one it is because I can’t remember now, it’s like four years ago. And they said if there is anything you want to know or if you want to have a hand in the services or when to find out what’s on offer please contact this person, and they gave a lead nurse’s name from R, which is where I’m from, so I actually wrote to them or phoned them up and they gave me the details for the UE NETWORK.” (Service user who is a carer no. 6)

“I got involved when I listened to You and Yours on Radio 4 and I heard Jane Bradburn from Cancer Voices just doing an item about patient views and I wrote to her with my own experience and how I felt that it was important to approach it in two ways; a positive way, sharing good practice and also highlighting the things that go wrong so they could be put right. She wrote back and I didn’t hear any more until suddenly I got an invitation to attend the very first meeting of the Cancer Network” (Service user who was a patient no.1)

- **Support groups and user involvement**

Some service users become involved by attending a support group, and developing their degree of user involvement over time with the group.

“I got involved here as a service user to begin with because I’m a cancer patient myself, and I basically came here for welfare benefits advice because at the time I’d had to give up my job and needed some financial advice, and that’s when I found XX Cancer Support and I was assigned a Welfare Benefits Adviser. From there, I had a couple of chats with a few people here at centre and they must have sounded me out as a good person to get involved. I mean I expressed, I mean first of all I found that it was very useful coming to a centre where you could meet with other people who were going through a similar experience to you, and I quite sort of fancied the idea of becoming a volunteer here so I expressed an interest, and at that time the centre had just set on a Community Development Worker who was particularly looking at user involvement and the setting up of a patient forum, a patient carer forum, and so I got involved with that and began to help to set up the patient forum that we have here”.(Professional no 1)

For other participants their first involvement was through a study undertaken to research user involvement of people in palliative care. Their initial involvement leads to repeated requests to join other initiatives looking at user involvement from different perspectives.

- **Reliance on accessible voices: a service user career pathway**

Some service user participants, who have been or are currently patients and carers are involved in several different user involvement initiatives. Involvement in one group often leads to involvement in regional and national user involvement initiatives for those who are judged (typically by professionals) to be articulate and confident, and are able to attend day time meetings.

“Well, they formed the network group, I think it’s sort of two years ago, and I was asked if I’d like to come along to discuss how it would all be set up. So I was in as a founder member, and then we decided that we were too small a group, so we then invited it to be three members from each hospital ... Two of us sit on the X hospital Cancer Board. So that’s a big step forward, and we’ve got two members on the breast site specific. And we’ve got others coming along, and I’ve joined the U hospital Clinical Modernisation Group for Specialist Palliative Care”(Service user who is was carer and a patient no. 5)

“I was a palliative care patient at the Day Unit, and I attended that she asked if there was any patients that would be prepared to go down to St Christopher’s and there was four of us... we went down and we were so forward and forthcoming at this conference we actually got our photograph put on the front of the report, and as I say we were so outspoken that David and Susie and Peter got in touch with us after to ask us if we would do the Involve project; and then from there the Co-ordinator the Cancer Services Advisory Group, came asking for patients who might be interested in coming along to that group and I was the only one that ... So I am a member of the Patients Council and through the Cancer Services Advisory Group I joined a group that looks at new trials and user involvement projects that are being looked at to be set up, you know up and running and we started to vet them.”(Service user who is a patient no. 2)

- **Representation**

Meetings are often held during office hours and require service users to be on email and be able to read copious amounts of literature before attending a meeting and being able to travel. Service users who are involved to this degree are very well informed of local and regional policy changes. However, as one participant comments

“The National Health one’s fit into National Health Service structure, they’re sort of in London at a hotel, 9 to 4, they’re part of the away day structure. This concerns me because I’m recently retired, what happens to people who are working? I feel this is a big weakness. Then they turn round and say they’re getting middle class, middle aged people, but one problem we have in the Network, we cannot get primary care people to come on Saturdays.”(Service user who was a patient no. 1)

Service user forums observed at two hospices and at one cancer support centre, also timetabled meetings during the day. For the hospices this was aligned to day centre timetables and the availability of volunteer drivers. The majority of people attending hospice user forums were receiving palliative care services at home or attending the day centre. One hospice did hold a small meeting for people on the wards who were able and willing to attend to discuss their views of the service and to discuss what could be done differently. The cancer support centre user forum met over lunch enabling local people to attend where possible.

- **User involvement training**

Training for a service user representative has been provided by Macmillan Cancer Voices. It is clear that the participants who have undergone this training have found it invaluable in developing their skills and confidence. However, there appears to be little training available for health professionals and service users who are not linked into a cancer network partnership group.

“So we did some, a few of the people here, the service users, did some training around sort of meeting health professionals and learning about the structure of the NHS so that we’d all have a better understanding, and also so that we’d sort of be less fearful about going and meeting with the health professionals, because that can be quite scary for both sides; that’s for the health professionals as well. So we did this thing that is called Cancer Voices Training”(Professional no. 1).

- **Models of user involvement**

Several different models of user involvement were discussed and at times described by participants during the interviews (see Table 8).

Table 8 Examples of methods of obtaining user involvement

<ul style="list-style-type: none">➤ Regular service user forum groups<ul style="list-style-type: none">○ Led by service users○ Led by health professionals○ Led by volunteers➤ Partnership/Network groups<ul style="list-style-type: none">○ Chaired by Health professional○ Chaired by service users➤ Management/feedback meetings➤ Occasional focus groups➤ Service users membership of other local, regional and national groups➤ Satisfaction surveys➤ Face to face interview➤ Comment boxes➤ Development of videos telling personal stories➤ Internet Web page feedback➤ Attendance and presentations at conferences and educational meetings➤ One to one involvement➤ Market research➤ Volunteering and supporting➤ Community/ Day events➤ None

Group meetings, be they led by service users, by health professionals or in one case by a volunteer, are the most common approach for active and direct user involvement. *Ad hoc* focus group meetings were used as consultative exercises to develop services. The palliative care service users attending regular and *ad hoc* groups are often drawn from day care. Carers appear to be more often invited to bereavement listening days or to be part of education groups.

Observation of the professionally led user group revealed an agenda largely set and pursued by the professionals. With the volunteer led user group, the agenda was set during the meeting focusing on one issue which was discussed at length. In comparison the user led user group combined both approaches some previously tabled issues and issue brought to the table.

- **Satisfaction surveys**

Satisfaction surveys are the most common method of service user feedback, but return rates can be low, and there is a tendency for services to be only positively appraised. There is a statutory requirement for satisfaction questionnaires to be sent out each year. However completion of questionnaires requires literacy skills, time and concentration from the service users.

“We tried again more recently with another questionnaire, which is what we need to do anyway and we’ve used the Help the Hospices questionnaire with ones that were in the care of day hospice and we’re trialling that at the moment and we’re asking our users their opinion of the questionnaire itself. The other problem we find, particularly with in-care

ones, is when you give them a questionnaire, I think it's crucial, if you get them to fill it in whilst they're still with you, we feel that, they feel not pressured as such, but we feel that they want to say the right thing, so they always give us a very positive report. And I don't know whether that's true or not, but it evens out I think. We're doing it at the moment on the point, at the point of discharge, you're going home today can you do this, can you fill it in with us, or if you want to take it home and send it back. We do it that way to try and increase the return". (Professional no. 15)

- **One to one interviews**

Interviews are undertaken by some palliative care service in addition to satisfaction questionnaires or as a method in its own right. Interviews have advantages for in-patient service users who tend to be much less well and less able to attend meetings.

"what I find works better is the Senior Nurse on each Ward as the team leaders who you probably know as Junior Sisters, they do what we call an Individualised Care Audit and they actually, they do that in two ways really, part of it is through what they read in the documentation, but the rest of it is through interviewing the patient and you know, unless patients are extremely close to death, as long as their able to communicate with us we don't exclude patients in anyway, and we find out really valuable, mainly for things that I guess that, well I know to some people within the organisation, may not sound like very much but to the patient they mean an awful lot and they are things we can easily rectify, and things that have come out of that are things like, like a few of the patients complained that the nurses were a bit noisy first thing in the morning and they always knew when they'd arrived on duty, because they were woken by all this noise. And that is such a thing that we don't really think about". (Professional No. 2),

"the problem we've found with the telephone interviewing, I think because it was someone from in the hospice, and although she was a nurse manager there attached from clinical care, it was a one to one albeit over the phone. Patients, I felt were responding positively because they didn't want to upset the person or they didn't want to cause trouble. So those were the kind of ways we have approached it and I don't think anything's been particularly satisfactory but we've got to kind of do something"(Professional no.15).

- **Anonymous comment boxes**

Comment boxes, as methods of gaining a range of different comments and suggestions, were discussed and observed to be in use at two hospices,. Comment boxes were opened by a dedicated person and the comments collated and then presented at the management or clinical governance meeting for consideration.

"we have a comment scheme, which basically is an anonymous system where anybody, and that includes patients, carers, staff, visitors, etc, can post a comment, and that might be a suggestion, a compliment, a concern, absolutely anything, in our strategically placed boxes within our three sites. The boxes were placed in positions that were suggested by patients because we felt that we needed to go by what they felt as to where we'd put it, because there was lots of – I mean it's quite interesting actually because there was a lot of feedback that if you put them where they're seen, you might inhibit people posting them. So we originally put one in the reception area, this was a long time ago before we was very much into user views and user involvement, so that one in a way was a no-no because it was under the eye of the receptionist. But, ironically, that's the one that has the most comments posted."(Professional no.11)

- **Courses**

One hospice service responded to issues raised by carers during visits by community palliative care nurses. A carer's course was developed and modified in response to feedback.

“So I think from our point of view, had that nurse specialist not picked up the clue and taken it back and got her colleagues to check out with other carers, because it might have been something that one carer thought was a good idea, and a lot of others didn't. And I think, for me, that's an example of where we've listened”. (Professional no. 14).

One day community events developed in conjunction with local PCTs were also effective methods of getting new membership to user groups. Other methods have been tried by some services, such as internet feedback web pages, but these were rarely used. Attendance at educational forums occurred at one hospice and service users talked directly to health professionals about their experiences at another hospice. This enabled service users to be involved in the education of health professionals.

- **Changes to organisational culture**

Organisational culture appeared to play a significant role in the extent to which user involvement was valued and integrated into the service. It appeared clear that the support of managers is required for user involvement to make a difference.

“Being the chief officer, from my perspective, it gives me an additional insight of what's happening. And I value it very much because it enables me to see whether or not things that we're doing are appropriate. It gives us an opportunity of simple things which people may think are difficult to implement, are not always difficult to implement. On the other side of the fence is things that people might think are easy to implement, are not always that easy to implement because of legislation and other things that you've got to get around. So I see as a very valuable way of being able to give people what they need if it's possible without having to go through a mass of bureaucracy to get there because once it comes to the chairman and myself, if we make a decision, it happens, so we don't have to go up the management tree, resolving all the issues that involves, going back down the management tree to get back to where we need to be”. (Professional no. 12)

However there was evidence that in some palliative care services, user involvement initiatives were marginalised and in these circumstances it was difficult to maintain its momentum and to value its contribution to service development.

“I don't think there is any ownership of it throughout the organisation, and I think that's a culture we have at the moment unfortunately. I think we're just going through that kind of phase of development at the moment where lots of things are happening and there doesn't seem to be a collective ownership. I think we've got a fairly new management team of which I'm one, I mean we're feeling our way to some extent with this. And I have found that there is some resistance but if we try and introduce something, change something, that there is an element, a kick back sometimes”. (Professional no. 15)

- **Outcomes of user involvement initiatives**

Different user involvement initiatives have achieved a range of outcomes, which are locally specific. The following represent some examples. Increasing car parking has been a success for several user groups. Another example is changing name badges to ones which are credit card size with staff names printed in large font which is readable for those with poorer eye sight. The creation of information leaflets, undertaking a breaking bad news audit and the writing of a carer's guide are also achievements attributable to service users working together. One participant described his participation in an expert carer's group working with Macmillan, who have written a guide for carers called 'hello, how are you?'. He explained this had arisen because people rarely ask how the family carers were feeling, and that carers experience considerable distress and their distress continues after the death of their family member.

"The first task we undertook was the bad news audit. We sent out two of the specialist cancer nurses in all the Trusts questionnaires, which they gave the patients to know, to have a detailed response of how they were told they had cancer. And they were, the rate of return was good, it was about 30%. Most were positive and spoke most highly of the way the news was broken to them and the support they received, but I would say the ones that weren't positive were most valuable because we discovered some very poor practice going on... So when we got all this in, we analysed them and looked at them in detail and they're being fed back to the Trusts. If there was a glaring practice that we felt should be tackled straightaway then the Trust was contacted straightaway or that clinic to, because one or two were so dreadful that we want to be, you know, training, if there's a training need, we go and what's to be looked at." (Service user who was a patient no. 1)

- **Barriers and challenges**

There are many barriers to successful user involvement in palliative care, principally because many people are nearing the end of their lives and being able to concentrate, participate or attend user forums or complete questionnaires can be difficult. However, protectionism by staff can also be problematic.

"Just the very short nature of the people we look after, that the turnover, the huge number of patients against the small number who, at the end of the day, are interested, willing to actually come to an event. The challenge of having to find very creative and imaginative and find, still work in a big range of ways the people feeding back. For example, I'm very keen to sort of investigate in the future making much more email access and telephone line if somebody's well enough one day and just wants to feedback that day one idea, one experience for future people without having to come to the meeting and fill out a satisfaction survey. I think one needs to go on finding more kinds of facilities, channels and media to get their comments, criticisms, ideas, because the traditional set ways only meet the needs of some people, are only suitable for some people, like user forums or survey forms, we have one off consultations and that kind of thing. I think the challenge of other staff being protective, or other staff being threatened when user involvement has become an important aspect of healthcare and part of care standard requirements, clinical governance, and I think there is an element of attitude from the staff, the challenge is staff training, preparation and staff support, because user involvement can potentially be threatening to professional staff. But I do think there is an element, one of the barriers to good user involvement is a degree of protection. In practice, a lot of the, the invitation process in my experience has to involve other staff, and to be done through other staff, because cold letters, invitations, are of very limited value, you know what I'm saying" (Expert no. 4).

- **Professional dominance**

Some service users who attend strategic level meetings, such as the Palliative Care Coordination Service Working Group discussed by the respondent below, have found these meetings driven by policy and strategic agendas incorporating professional technical language which is difficult to contribute to. Groups such as the cancer support group run by the respondent below have sought other ways to enable users to contribute more effectively.

“I mean what I basically said to them, I thought that it was a good idea to have a service user on there but they needed to be having service users who had a fair amount of experience of using more than, you know, if somebody who’d just sort of come into user involvement went to those meetings they’d find it quite sort of mind blowing and a bit boring as well... I’ve had a couple of meetings with some of the palliative care team and we’ve been discussing other ways that we can have an input, perhaps into groups, other groups that meet who are not at such a strategic level” of peripheral groups.” (Professional no.1)

- **Tokenism**

Tokenism was very frustrating for service users. Service users reported attending local and regional meetings where they perceived that they are not being listened to which resulted in loss of motivation. There was a tension between user’s wishes to voice their opinions and achieve small gains, and the recognition that professional agendas dominated meetings.

“I’m not sure that our voice was ever listened to in reality. I think we were there to say that we were there. I’m not really sure that, that we said will carry much weight. I’m not saying that it should carry an enormous amount of weight but I’m not sure it was actually heard a lot of the time. But I think that equally if we hadn’t been there we would probably have never had what little influence that users, patients and carers would never had any influence on what’s come out of that, and that would have been to the detriment of users and patients. So whilst it’s been frustrating I think it’s been very necessary and hopefully in the future we can build on this. And certainly with the carers, and the user and patient and carer reference group, we’ve been extremely frustrated, as a group we’ve had two people who have resigned from the group because of this frustration” (Service user who is a patient no 4.).

- **Assessing the success of user involvement**

Assessing the success of user involvement was felt to encompass more than just measuring the changes that had occurred, although there was little clarity as to how best to capture the complexity of user involvement. From the professional and expert perspectives success was not just related to improvements in services but also to potential benefits inherent within the process of user involvement such as empowerment. There are difficulties due to the changes in user group membership in establishing agreed outcomes.

“I don’t really know. We need to find somewhere ... how we’ve done. I don’t think we’ve cracked that one yet. What is right for one group of people is not always right for another group of people. And because of the transient nature of the membership of the group because it being palliative care, things could change the more, the longer we have this, what we’ve just put things into place now, later down the line people might say we don’t

like that and we may end up going round in a circle, I don't know, so I'm not really sure as yet, how we can measure the success. From a gut feeling perspective, what I see happening is a lot more commitment from both staff and volunteers and patients to actually sitting down and talking about things. And that to me is a major success." (Professional no. 12)

Establishing a baseline point from which to evaluate success was regarded as important. This would record the impact of user involvement on service development. Measuring changes within service users themselves such as feelings of empowerment, were regarded as more difficult to capture.

"I suppose the ultimate test is whether services improve. And yes, so I mean there are ways that you could look at, take a baseline and see if services have improved. Because I think there's a lot of user involvement that goes on which doesn't really have any impact, it might improve little bits but not systems... I suppose it's leading on from the last question, is that in terms of what benefit it brings, it's not only about improving services but actually can kind of empower people and make them feel more in control. And so certainly we've seen some quite spectacular things happen with individuals who've been involved in user involvement at the end of their lives. And I think that's very important about them gaining control".(Expert no1)

From the service user perspective, assessing the success of user involvement took a slightly different focus, although it was clearly acknowledged that a baseline evaluation was important, and that outcomes should be audited. However a personal and reflective perspective was also important for service users, as well as a preparedness to keep trying different approaches.

"So assessing the success I think that it will be, I think it must be done because there's no good putting something in place if you don't audit it at the end of the day, because you don't want to waste people's time, either professional or the user. No user wants to feel they're a token or a tick in a box. They want to be able to say, "I've done this. This group has done that. It's been a success. Now we can go onto bigger things," but if something fails, and sometimes you can't win every battle, you have to sort of say, "Right, well we tried that one. We tried it the wrong way, or we can't win that one. So now let's see what we can do," because the more successes you have, the richer the group, and the satisfaction comes then. So they've got to assess this. And I think that's a two-way problem. I think the user members have got to say, "Was that a worthwhile experience? Did it work? If it didn't, why didn't it work? Do we want to try again in a different way? Was it something we did, we didn't get right, or we weren't trained to get it right?" And in the same way the team, the palliative care team has got to be able to say, "Was it better? Was it beneficial having the user involvement, or did it slow things down? Did it make it difficult?" So that's got to happen, and I think that's got to be done independently and collectively, and I think people have got to be frank with one another, because in that way we'll make it work. You know, even if it doesn't work to begin with, as long as we're prepared to accept that not everything, everything has gone so well, but I'm prepared to accept the fact that that might not always. So we'll take it from there". (Service user who has been a carer no 5)

4.3 Phase 3 Findings

In Phase 3, a consensus building meeting was arranged in which service users, carers, professionals and 'experts' who were identified during Phase 2, were offered preliminary

findings and were invited to comment on them to help shape the findings of this scoping study (**Aim 4**). In total 54 people attended the meeting, while four people who expressed a wish to attend, failing to attend on the day generally due to poor health. Table 9 identifies the different participant groups that attended the meeting.

Table 9 Participants attending the consensus building meeting

Service users (patients)	17
Service users (carers)	12
Volunteers	2
Professionals	13
Experts	4
UI project team	8
Total present on the day	54

The themes emerging from the meeting are presented below.

- **User involvement groups/forums**

Participants felt that their experience of attending and contributing to groups was a good method of putting their views across and contributing to service development

- **‘No one size fits all’**

Participants commented that different user involvement approaches were needed for different people and different services. There was a need for local services to develop different types of user involvement. As one participant commented *‘One size does not fit all’*. Suggestions were made to try new and different methods, such as contact via the telephone or internet, and not relying on written questionnaires and surveys. Participants expressed a desire to develop imaginative ways to reach those who are ill.

- **Inequity of palliative care service provision**

Not everyone had the option of participating in user involvement in palliative care, because they could not access specialist palliative care services (this was especially highlighted by those with diseases other than cancer). It was suggested that there was a need to draw upon views about palliative care from those with a wide range of illnesses.

- **Education and training**

Education and training was seen as important for both service users and health and social care professionals. It was felt that people took for granted that everybody understood what user involvement meant. User involvement training was recommended to be included during induction programmes for all staff throughout an organisation. A post-it note read:

'Need appropriate funding for activities, posts, expenses and time. Training for service users and also for professionals from cleaners to medical directors throughout a service.'

- **Organisational and attitude change**

Tokenism and lack of valuing of user involvement remained a problem experienced by participants. It was recommended that there needed to be a change in organisational attitudes towards more support for user involvement. One participant wrote on their post-it note:

'User involvement is not about meetings, it's about a living process of valuing empowering people – it needs a real cultural change.'

- **Resources**

Adequate funding was identified in discussions to maintain user involvement groups, fund administration, rent space for groups to meet and to employ a facilitator. It was also suggested that one member of staff be identified and funded to co-ordinate user involvement initiatives.

- **Payment of service users**

Paying service users for their time was debated. Issues around being valued were highlighted but it was also recognised that there were individual benefits such as feeling valued and being able to contribute to others.

- **User involvement is developmental and evolutionary**

User involvement was a developmental process, groups and methods used change over time.

- **Positive experiences**

Participants talked about how they have seen changes happen because of their involvement and suggestions, for example, increased parking and redesign of buildings.

- **Negative experiences**

People get frustrated when they do not see change happening, or their views are not listened to. People believed that some managers have little insight into user involvement.

- **Language**

The term palliative care remained not well understood and put some people off attending meetings. There was discussion about the use of alternative terms to describe end of life care which reflected everyday language and could indicate its importance without frightening people.

- **Who are service users?**

The issue was raised about how people were identified as a 'user'. Multiple identities were highlighted such as a health professional that was also a family carer or had been treated as a patient. A written comment on a post-it note read:

'Who am I? My badge says 'Health Professional' but I was close to my mother-in-law through her cancer journey so I feel like I'm a carer too.'

- **Telling one's story and gaining support**

It was clear some people found telling their story helpful, and enabled them to identify issues that needed changing to improve care for others. It appeared to be necessary for there

to be a supportive element to palliative care user involvement to enable people to gain confidence to have their voice and experience heard.

5.0 Discussion

This scoping study has identified an increasing level of activity in relation to user involvement in palliative care. The review of the research, policy and practice literature undertaken during Phase 1 indicates that professional accounts of user involvement dominate what is known in palliative care. Moreover, these published sources are largely descriptive accounts of local initiatives rather than evaluations employing more rigorous research methods, which confirms the methodological problems highlighted in a previous systematic review (Crawford et al 2002). The scope of Phase 1 necessitated excluding some sorts of activity – most notably user involvement in research - and limiting the extent to which examples were sought from other countries, in particular non-English speaking ones. However some trends do emerge. There remains a need to clarify what user involvement is and who its beneficiaries are. There have been some attempts at critically examining the concept of user involvement as it relates to palliative care but more needs to be done here. While there are things that can be learned from user involvement in relation to other areas of activity the specific circumstances of palliative care – particularly problems in supporting long-term involvement – require more consideration at the conceptual level and at the level of thinking about models of best practice. While we do identify examples of good practice – projects where a link can be made between user involvement and enhanced service - there is little by way of rigorous evaluative research. This is a gap and a challenge that our scoping study reveals. It is therefore not possible to demonstrate from the existing literature any clear evidence of the effectiveness of user involvement in palliative care in increasing access to services, improvements in satisfaction or on quality of life for patients or carers. These shortcomings in the evidence base also were founded by Crawford et al (2002). On the basis of our review it is difficult to judge which research designs should be employed in further work, although we found no comparative or experimental designs have been reported. We acknowledge there are considerable challenges both methodological and ethical in employing these designs in palliative care contexts (Davies and Higginson, 2004). Accounts of user involvement are often written by project workers who may wish to present their projects favourably. Future research should explore a range of participatory methods such as co-operative inquiry and action research, where evaluation and analysis are jointly produced by project workers and patients. Moreover these approaches are compatible with the philosophical basis of user involvement. Alternatively, there is a place for hypothesis derived experiments or quasi-experimental designs that test assumptions about the impact of involving patients and carers in service planning and delivery.

In Phase 2, we sought to obtain evidence based on the accounts given by current patients and carers who were participating in user involvement, health and social care professionals actively involved as co-ordinators and managers, and the views of a few recognised ‘experts’. We endeavoured to speak with organisations from the statutory and non-statutory sectors, those predominantly concerned with people affected by cancer and a few of those servicing other disease groups. We specifically sought the experiences of user involvement initiatives with black and ethnic minority groups. Finally we collected data from services that had formerly undertaken user involvement activities but then abandoned them. We do not claim these data are representative in a statistical sense but in our view they capture the range of activities that were being undertaken in Britain during 2004. We were overwhelmed by the willingness of people to contribute to our project – we exceed the anticipated recruitment of 25-30 people by over 20 people – resulting in a wealth of rich data. Likewise, we had anticipated problems in a poor response to our invitation to a consensus meeting at St Christopher’s Hospice (Phase 3), but once again we were pleased to welcome 54 people to that day. Therefore we can conclude that user involvement as a topic is highly salient and one in which people from many backgrounds and sectors wish to engage. However, we were

unsuccessful in recruiting people from black and ethnic minority backgrounds to the consensus meeting despite offers of interpreting services. Further attention needs to be directed to the needs of these groups of people as language problems alone may not account for their unwillingness to engage in what may be perceived as largely 'white' cultural events.

Challenges that arise from the history of user involvement in palliative care

User involvement in palliative care has arisen, and been driven, in a 'top down' rather than a 'bottom up' way (unlike users commenting on mental health services, childbirth services and some cancer groups). There are two main drivers of this top-down process, each have inherent areas of vulnerability associated with them.

1. Much user involvement has been initiated by 'interested' pioneer staff and key leaders. We suggest that user involvement has been initiated by a number of social care professionals who were trained in models of client empowerment. Some professional organisations are vulnerable to the loss of these key 'pioneer' individuals. Other organisations have not been as affected because they have not had this high level commitment
2. User involvement in palliative care has expanded in response to central government policy directives since 2000 and NICE (2004). A change in emphasis at the centre could undermine this policy emphasis.

Characteristics of service users in user involvement projects

The findings suggest we need to consider three groups when reviewing the effects of patient involvement in palliative care services: patients participating in the development of services, subsequent patients using the services and healthcare providers and managers. It is assumed that involving patients enhances their self esteem (by being consulted, being given an opportunity to express choices and participating in democratic decisions) and we found some evidence of this from patients and carers who were currently involved. Involvement may also have a negative effect for some people, such as those with chronic and life threatening conditions. It may be difficult for these people to contemplate the types of services needed in advanced stages of their condition (Small and Rhodes, 2000). This leads to concerns about how participants are selected and the 'representativeness' of people who participate in groups and committees. Because of the top-down nature of user involvement, service users that are involved were often contacted and 'selected' by professionals. It is important that further work is undertaken on the implicit/explicit criteria used? Is there a 'right type' of patient? – for example well rather than very ill, educated, mobile, English speaking, with access to Information Technology (email), available in the daytime, have own transport, articulate, knowledgeable and socially skilled, with experience of committee processes. Currently there are no criteria for when patients and carers stop being regarded as 'service users' – for example, what length of time since their initial treatment episodes are their views regarded as reflecting current practice? This is particularly important for emerging groups such as cancer 'survivors'. Involvement may appeal to certain types of people, such as those that are fitter, those who 'recover' (the views of the dead can only be accessed through proxies) and people who are more assertive, more articulate and more familiar with committee structures and processes. The views of these people may not reflect those of people less likely to participate. Moreover, patients may become disillusioned by the process of consultation if they feel that their views are neglected or over-ridden. Our scoping study found evidence that there are a few users who have become 'professionalised' and have developed 'careers' in user involvement. Their motivation and experiences are worthy of further investigation. To this end, we are currently conducting a small study (in the context of a Master's degree supervised by Sheila Payne), to explore in greater depth this subgroup of influential service users. We are also aware of another influential subgroup of patients, those who were formerly (or still are) health professionals. These people are often motivated by their poor experiences when they made the transition from professional to patient or carer, Finegan, W.C. 2004, "Trust Me I'm a Doctor *Cancer Patient*" Radcliffe Medical Press. . Further investigation of their contributions and difficulties are warranted.

Challenges

This scoping study has identified progress but also challenges for user involvement in palliative care:

- It has underlined the complexity of establishing and maintaining autonomous user voices – able to develop expertise over time and set agendas for organisations.
- It has reminded us of the barriers that can prevent people who are very ill and tired from taking part and reinforced the importance of developing ways to accessing their opinions. We can not assume either that the dying or the very weak cannot talk or will not participate. Service users may also be excluded from participating because of language, social class, ethnic background, financial cost, and other factors which again requires us to think about the specifics of user involvement in this area, about the need to offer a variety of models and about the importance of evaluating new initiatives to see what works, when and why.

Our interviews with service users and our consensus meeting reinforce the value of drawing on personal experiences. But they also remind us about the need to be clear as to:

- questions of representation,
- how to turn experience into action
- how to reconcile user empowerment with professional expertise
- how to reconcile the often length timetables of policy practice change with the wishes and needs for those users who are involved or who might become involved to have a sense of the impact of their contributions.

Further work is needed to examine the efficacy of different methods for different groups of people. Committees are commonly used to increase patient involvement in cancer services but these may not be suitable for people with advanced disease or communication difficulties (Gott et al 2000, Gott et al 2002, Gott 2004). Paper and pencil ‘satisfaction’ questionnaires, which are often used to gather user views, exclude people who have literacy problems and do not offer the possibility of ongoing dialogue, something that users have identified as important (Gott et al 2000). Newer modes of involvement such as citizen’s juries may not be appropriate for people who do not wish to meet others or who are unwilling to commit their time (Wakefield 2002). Innovative use of new information and communication technologies may enable wider involvement, such as telephone conferencing for those unable to leave their homes. These should be investigated for their acceptability and effectiveness.

6.0 Recommendations

This scoping study is a step along the way to thinking more critically about what, why and when to involve patients in palliative care services. We offer a number of recommendations:

- User involvement should be part of a new notion of citizenship. There should be recognition that we may all be service users at some time. People may occupy multiple roles and that over the lifespan, roles and identities in respect to health care services may vary.
- Creative and novel ways need to be explored to involve those who are too ill, too tired or unable to attend meetings. There is a need to build relationships between community groups and services, for local voices to contribute (Cancer Networks may offer one way forward here).
- Developing practical initiatives which capture service user’s stories and experiences, especially those people who are frail and very ill, using novel information technology, can contribute to widening participation.

- The development of greater participation by current carers and bereaved carers who appear to be under represented (for example, only they can comment on the death experience) using outreach schemes, should be considered.
- We need to help people express themselves in different ways and consider how to incorporate these into service planning. Currently there is a dominance of views elicited in writing such as those obtained from satisfaction surveys.
- The availability of dedicated resources, leadership and openness to change are key factors in sustainability.
- Organisational cultures in hospices and specialist palliative care providers need to be supportive of user involvement and show a willingness to respond to suggestions.
- Further consideration of how to develop organisational cultures that are respectful and open to service users feedback are required, and mechanisms to track the outcomes of their suggestions.
- There needs to be clear lines of accountability in the managerial structure of organisations to implement changes otherwise user involvement initiatives may appear to be tokenistic.
- A programme of information and education for professionals engaging with services users needs to be developed.
- Some training courses are already available for service users to help them understand health services and committee procedures and these have advantages but there are concerns about potentially ‘professionalising’ patients and carers.
- Consideration should be given to the problems associated with the current heavily reliance on relatively few highly motivated individuals. This places heavily demands on a few patients and carers. The reliance on a few key professionals makes organisations very vulnerable to their loss and jeopardises the sustainability of user involvement.
- Criteria should be developed to indicate when patients and carers can no longer be regarded as current service users.
- Further research is needed to investigate the efficacy, and costs and benefits of user involvement from the perspectives of: 1) patients and carers, 2) professionals, and 3) organisations.

7.0 Dissemination Activities

Publications

Sargeant, A., Payne, S. (2004) User involvement in Palliative Care a Scoping Exercise *Read Issue 2*: 4-5 Sheffield: University of Sheffield.

Sargeant, A., Gott, M., Oliviere, D., Payne, S. and Young, E. (2005) User Involvement in Palliative Care a Scoping Study. *Palliative Care Research Society Newsletter* Spring 2005

Conference Presentations

Sargeant, A., Payne, S., Small, N., Gott, M., Oliviere, D. and Young, E. (2004) User Involvement in Palliative Care a Scoping Study. National Council for Palliative Care, London. 30th November 2004 – **oral paper**

Payne, S., Sargeant, A., Small, N., Gott, M., Oliviere, D. and Young, E. (2005) User in Palliative Care Learning from Research, Oxford Brookes University 9th March 2005, - **oral paper**.

Sargeant, A., Payne, S., Small, N., Gott, M., Oliviere, D. and Young, E. (2005) ‘Being Heard’: Engaging patients and families in designing, developing and evaluating palliative care in the UK. **Poster** Presentation European Association of Palliative Care, Aachen, Germany, April 8th 2005

Sargeant, A., Payne, S., Small, N., Gott, M., Oliviere, D. and Young, E. (2005) User Involvement in Palliative Care a Scoping Study. Joint British Psycho-oncology Society and Palliative Care Research Society meeting 28th April 2005 - **oral paper**.

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Appendix A – Flow chart of literature review process
Accepted

Stage 1.

Initial search identified **n = 2046** 'hits'

Stage 2.

Abstracts and literature obtained from databases and experts.

Abstracts included where: user involvement was mentioned; methods or outcomes of user involvement initiatives were mentioned; the context of user involvement was mentioned. Personal perceptions of health professionals and service users were discussed.

References were accepted where titles contained key words but no abstract was available
n = 507

Stage 3.

Literature was included where: methods, processes and outcomes of user involvement were presented; where the perceptions of service users and health professionals about user involvement initiatives were recorded. Further refinement of inclusion criteria was made, and literature which considered user involvement in research or research methodology was excluded.

n = 53

Rejected

Reasons for exclusion:

- duplicate references
- satisfaction measures,
- patient-health professional decision making,
- clinical treatment decisions, medication,
- no reference to user involvement

n = 1539

Reasons for exclusion:

- no information about user involvement methods and processes
- methodology of research involvement
- discussion of sociological and other academic perspectives user involvement
- not received or available by 31st December 2004

Literature excluded **n = 1848**

Papers that did not arrive in time to be reviewed **n = 145**

Appendix B

Assessment Form

Reject / Accept

Author (s):

Date of publication:

Abbr. Title:

Reviewer:

Relevance to research questions:

- Is UI defined?
- Is the context of UI discussed?
- Is the context addressed?
- Are existing UI methods described?
- Are the formal and informal strategies for UI involvement addressed?
- Is the effectiveness of the methods of UI discussed?
- Are outcomes of UI discussed?
- Are perceptions of UI participants discussed?

User involvement domain:

- Palliative care
- Cancer care
- HIV
- Older peoples care
- Learning disabilities
- Mental health
- Midwifery
- Other

Source of data

- Professionals
- Patients / clients
- Carers / family
- Other

Study Type (circle)

- [1.] Empirical study – peer reviewed
- [2.] Theoretical paper – peer reviewed
- [3.] Research paper – non-peer reviewed
- [4.] Theoretical paper – non-peer reviewed
- [5.] Professional document
- [6.] Case Study
- [7.] Other

Comment:

User Involvement In Palliative Care: A Scoping Study

Semi-structure interview for experts, health and social care professionals

Introduction: Hello, My name is Anita. Thank you for taking part in this interview.

As you may recall this study is looking at user involvement in palliative care. By carrying out interviews, this allows us to hear what different peoples experiences of user involvement are and to ask questions about what they think are important aspects of user involvement in palliative care.

Can I just reconfirm whether you are happy for me to record this interview?

Thank you.

I would like to begin by asking:

1. What do you understand by user involvement?

Terminology –there is debate about which terminology to use.

2. Do you prefer a particular phrase or name for this ? Eg. ‘user’, ‘consumer’, ‘patient’, or something else?
 - a. If so why?
3. How did you become involved with user involvement?
4. Are you involved in any user involvement initiatives within palliative care?
 - a. If so what does that involve? (explore who, what, when where and how)
5. Are you involved with any user involvement initiations outside of palliative care?
 - a. If so what?
 - b. Does it/do they have anything to offer palliative care?
6. How does the process work with the user initiatives you have been involved with ? (explore leadership, focus, how decisions taken etc)
7. Do you think it is a good idea to involve palliative care service users in research / service development?
 - a. If so why?
 - b. Can you give any examples?
8. What do you think are the best ways to involve palliative care service users in research / service development? (explore those described and not described, perhaps give examples of methods used e.g. steering group, phone conferencing, citizen’s juries, via e:mail)

9. Do you see any of these as examples of good practice?
10. if so why? Or why not?
11. What do you see as the challenges of involving palliative care service users in research / service development?
12. How do you think these barriers can be over come?
13. How do you think the 'success' of involving palliative care service users in research and service development should be assessed?

User Involvement In Palliative Care: A Scoping Study

Provisional semi structured interview schedule for service users who are patients and carers

Introduction: Hello, My name is Anita. Thank you for taking part in this interview.

As you may recall this study is looking at user involvement in palliative care. By carrying out interviews, this allows us to hear what different peoples experiences of user involvement are and to ask questions about what they think are important aspects of user involvement in palliative care.

Can I just reconfirm whether you are happy for me to record this interview?

Thank you.

I would like to begin by asking:

1. What do you understand by UI?

Terminology – explain there is debate about which terminology to use.

2. How would you prefer to be known or described? As a ‘user’, ‘consumer’, ‘patient’, or something else?

- a. If so why?

3. Have you been involved with user involvement initiatives/projects?

- a. How did you become involved with user involvement?
- b. What were your reasons for becoming involved?

4. Can you tell me about your experience of being involved as a service user?

- a. prompt - How does your user group/initiative work?
- b. How is it organised?
- c. Who leads it?
- d. How are changes achieved?

5. Do you think it is a good idea to involve palliative care service users in research / service development? (may have to give some examples)

- a. Why is that?

6. What do you think may be the problems of involving palliative care service users?

- a. Why is that?

7. What do you think are the best ways to involve palliative care service users in research / service development? (may give examples of methods used e.g. steering group, phone conferencing, citizen's juries, via e:mail)
 - a. Why is that?
8. How do you think the 'success' of involving palliative care service users in research and service development should be assessed?
9. Is there anything else you would like to add?



User involvement in palliative care: a scoping study Information sheet for the consensus meeting

Would you like to take part in a meeting to find ways of helping hospices and palliative care services listen to people's wishes better?



This letter tells you about the research and the meeting. It is important for you to understand what you will be doing in the meeting so that you only take part if you are happy about it.

What is the research about?

- We have been finding out about how different hospices and palliative care services are asking people to take part in making hospice and palliative care services better
- Service users can be people who are being looked after by nurses, doctors and social workers. Service users can also be the person's family and their friends or the people helping to look after them.
- User involvement is the name used when service user's thoughts and wishes are asked for by hospices and palliative care services to make the care better.
- We want to make a list of the best ways of getting people to take part in making hospice and palliative care services better.

What have we done?

- We have read lots of books by other people about user involvement.
- This has helped us find out how different hospice and palliative care services have asked people to take part in telling them how to make their service better.
- We have also talked to people who have been patients or bereaved family carers, nurses, doctors and researchers about how they have taken part.



Why have you been asked to help us?

- We were told that you have been a hospice and palliative care service user.

Or

- That you might like to tell us what you think are the best ways of getting people to take part in making hospice and palliative care services better.

Do you have to take part?

- No one will force you to take part.
- You take part only if you want to.
- If you come to the meeting and you don't feel happy with it, you can leave.
- If you stop taking part it won't change how you are supported.
- We will pay for your train or car journeys.

What will the meeting be like?

- People who are patients, family members or carers, nurses, doctors and researchers will join you at the meeting.
- There will be a lot of people. All the people will be asked to sit together in small groups. This makes it easier to talk to each other and listen to each other.
- We will ask you what you think the best way is to get people to take part in making hospice and palliative care services better.
- We will also ask you how this helps in finding the best ways for asking other services users about how they might want to take part.
- We will have drinks when you arrive, at lunchtime and in the afternoon. There will be food for you to eat at lunchtime.

What happens to what I say?

- Everything you say will be listened to.
- It may be written down by someone from our research team.
- Your name will not be used when what you say is written down.
- You do not have to worry about what you say, no one will know.
- When we write the report about the meeting we may use your words, but we will never use your name.



What are the good things about taking part?

- The good thing about taking part is that you may help to make the way hospices and palliative care services ask people about the care they give better.
- You will help us make a list of the best ways of getting people to take part in making hospice and palliative care services better.
- You will meet other people and share your experience.
- You will be valued and listened to.

What are the bad things about taking part?

- You may get tired.
- It might be a long day for you.
- But if you need to rest or feel poorly we have a nurse to help you and a quiet room to rest in.
- You might not understand everything. But tell us and we will explain what has been said in a way that is easier to understand.

What will happen afterwards?

- After you go home, we will read all of the written notes that have been made and talk about what has been said.
- We will then write a report about the meeting.
- We will also write a report about the whole research study on user involvement.
- In the report we will use what people have told us about user involvement and what we have read about user involvement.

- When the report is finished we will send it to St Christopher's Hospice and the National Council for Palliative Care. We will also write about it in research magazines.

Who are we?

The study is being paid for by St Christopher's Hospice. The research is being done by the Palliative and End of Life Care Research Group at The University of Sheffield.

What if I am not happy?

If you are not happy with the meeting and you want to tell us you can telephone Professor Sheila Payne on 0114 222 8303 or email s.a.payne@sheffield.ac.uk



Who do I talk to if I don't understand? Who do I talk to if I want to know more?

If you do not understand something or you want to ask more questions you can telephone me on 0114 222 8308 or email me on a.r.sargeant@sheffield.ac.uk My name is Anita Sargeant.



User Involvement in Palliative Care: A Scoping Study

Consensus Meeting Consent Form

Principle Investigator: Professor Sheila Payne

Researcher : Dr Anita Sargeant

Initial or
mark box

1. I have read and understood the information sheet.
2. I have been able to ask questions.
3. No one has forced me to take part.
4. I can stop taking part when I want to
5. I don't have to tell any one why I want to stop
6. If I stop taking part it wont change how I am being supported
7. I am happy for my photograph to be taken

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