Getting it right

End of life care and user involvement in palliative care social work

Suzy Croft, Gillian Chowns, Peter Beresford
About the authors

Suzy Croft is User Involvement Officer and past Chair of the Association of Palliative Care Social Workers. She is Social Work and Bereavement Team Leader at St John’s Hospice, the Hospice for Central London. She is a Board Member of The College of Social Work and co-author of Supporting People: Towards person centred support (Policy Press, 2011).

Dr Gillian Chowns was a local authority social worker for many years, establishing an innovative post within the East Berks Macmillan Team, to support children with parents facing a life-threatening illness. Formerly Senior Lecturer in Palliative Care At Oxford Brookes University, she is the founder of Palliative Care Works, a not-for-profit consultancy focused primarily on resource-poor countries, has a part-time post as a Visiting Fellow at the University of Southampton and is a freelance trainer and researcher.

Peter Beresford OBE is Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University. He is Chair of Shaping Our Lives, the national user controlled organization and network and a Trustee of the National Skills Academy for Social Care. He is co-author of Service Users, User Involvement and Social Care (Jessica Kingsley Publishers, 2012).
Acknowledgements

We have many people to thank for making this report possible. First and our special thanks must go to all the social workers who took part in the national survey whose findings it reports. Thank you for finding time to do this when we know how much else you already have to do. Thanks also to the Committee of the Association of Palliative Care Social Workers for supporting the survey and making a grant to cover its cost. We’d also like to thank Kathy of St John’s Hospice, London for her help in laying out the survey schedule and Dame Barbara Monroe, Chief Executive of St Christopher’s Hospice for developing the idea that led to this report. Thanks also to Joanna Black, Involvement Manager of the National Council for Palliative Care.

For a wonderful friend, Sue Kirkham 1949 – 2012, from Suzy
The survey offers a platform to begin the work of building a partnership with patients and families to create the wider and more complex spectrum of services we will all wish for in the future.

Contents

Forewords 6
Summary 9
Introduction 11
What social workers say 15
Exploring user involvement 23
Analysis of responses 27
Recommendations 37
References 39
Appendix 1: Survey schedule 41
Appendix 2: The survey method 46
Foreword
Developing an evidence base for all aspects of palliative care has been neglected for too long. In an increasingly resource poor environment against a background of ever growing need as a result of changing demographics and patterns of disease, we need to understand clearly what matters to patients, their families and networks. We need to know what helps, and why, where the gaps are and what the costs are. We must move beyond the easy rhetoric about the importance of user involvement, to challenge ourselves about the reality and extent to which users are involved across the whole breadth of possibilities, including less utilised areas such as audit, governance, planning, policy development, evaluation and research.

This thoughtful survey provides a useful policy and practice context and establishes a baseline detailing what user involvement currently looks like in palliative care social work; identifying what practitioners consider to be the benefits and barriers and their ideas for improvement. Significant changes in the shape of our population mean that we need to rethink our assumptions about care preferences and needs and how most effectively to meet them. This will demand new and active ways of involving users. The survey offers a platform to begin the work of building a partnership with patients and families to create the wider and more complex spectrum of services we will all wish for in the future.

Dame Barbara Monroe
Chief Executive, St Christopher’s Hospice
Foreword

In end of life care there is only one chance to get it right. Social care for people who are nearing the end of life is vital, as is the communication and collaboration between health and social care. Whilst we hear many stories of wonderful, compassionate, kind and skilled care we do, sadly, hear of avoidable and unnecessary suffering at an already difficult time. There are many reasons for this, the most obvious being the extreme pressure on resources: time, funding and people-power.

It is logical, and perhaps more important than ever, to ask (and keep asking) service users ‘Are we getting it right?’, ‘Did we get it right?’ and ‘How could we get things right another time?’. Simple but not easy. We need courage to hear the answer and time to ask, listen and respond.

‘Getting it right’ is a ray of hope. It reveals how palliative care social workers desire to ‘get it right’ and do so by asking precisely these questions in a variety of different ways. We see the impact of asking these questions and acting on what they hear. Yet they are reassuringly honest about how difficult this can be.

We hope that this report will inspire palliative care social workers, especially those who feel daunted and immobilised by the enormity of the task, to ‘start small’. Create informal networks and learn from each other and reflect on the difference that involving people has made. Once we can demonstrate the impact, however small, we are likely to inspire the support and investment that it deserves.

We don’t always get it right at the end of life or in the way that we involve service users, but we can always learn from experiences and make things better for the future. Remember that for the person who is dying we only have one chance to get it right and also for loved ones who are left behind.

Eve Richardson
Chief Executive, National Council for Palliative Care
Summary
Summary

This report sets out the findings from a national survey of palliative care social workers carried out in 2012. Its aim was to provide evidence on the state of user involvement in palliative care social work and to explore barriers in the way of such policy and practice and how the two could be improved. The survey drew on responses from social workers in a wide range of end of life care settings in the UK. While the survey reports a generally positive situation, there is still much to be done and many social workers feel that the current climate of reduced budgets in end of life care mean that what has been achieved may be at risk of being undermined.

Most social workers taking part in the survey see the importance of service user involvement and are active in supporting it and responding to it in their workplace.

They give a wide range of examples of user involvement but there is a lack of consistency in what is meant by user involvement and a disparate range of activities are included under its heading.

Most participants think that service user involvement is of crucial importance for their work, the work of the hospice movement and for service users themselves. They are readily able to see the benefits of user involvement.

Following on from the gains that user involvement is seen to bring to the workplace, social workers clearly feel that user involvement had had a positive impact on their workplace.

However, there seem to be some noticeable gaps in user involvement in services. In particular, very little user involvement is reported in audit and education, planning, evaluation and research.

Social workers are very clear about the drivers needed to take forward user involvement, particularly the importance of there being commitment at a senior level, as well as among practitioners.

However, generally social workers report a lot of pressure on staff from heavy workloads and cutbacks.

In this climate they feel it can be difficult to make time for developing user involvement and the gains that have been achieved may be put at risk despite their acknowledged benefits.

A series of recommendations are offered to ensure the sustainability of user involvement in palliative care and to support social workers to play their part in taking it forward.
Introduction
This is a time of major change and also external difficulties for palliative care/end of life care social work. Major changes are proposed in end of life care funding and it has been affected directly and indirectly by the large scale public spending cuts now being made. At the same time, the government has emphasised the importance of putting the patient at the heart of policy and provision and introduced the slogan ‘No Decision About Me Without Me’. There are also increasing pressures on services and workers to develop user involvement in their practice and organisations in order to take this forward.

At the Association of Palliative Care Social Workers’ (APCSW) Annual Conference in Winchester, 2010, Dame Barbara Monroe, Chief Executive of St. Christopher’s Hospice, London and a qualified social worker, highlighted the importance of palliative care social work strengthening its evidence base to better secure its future. It was in response to this challenge that the survey reported here was commissioned by the Association.

Aims

- Produce a clearer picture of service user involvement in palliative care social work.

- Provide up to date evidence of user involvement.

- Identify both the drivers and the constraints in contemporary palliative care policy and practice.

It is hoped that the findings will contribute to support the efforts of palliative care social workers to deliver improved care and involvement for patients and their families as part of a multi-disciplinary team, through strengthening the evidence base for their work.

Background

The history of specialist palliative care social work, like that of modern specialist palliative care, is a relatively short one. A small group of hospice social workers first met together at St Christopher’s Hospice in Sydenham in 1982. In 1986 the Association of Hospice Social Workers (Now the Association of Palliative Care Social Workers) was founded. (Franklin, 1996).

The Association defines palliative care social work as:

an integral part of the multi-disciplinary team within palliative care, offering an holistic service to patients and families. Unlike many fields of social work, specialist palliative care social work is potentially a universal service and we are used to working with a diverse range of people in terms of age, diagnosis, class, ethnicity,
sexual orientation, religion and culture. Palliative care social work involves working with two groups of people – direct service users with life threatening or terminal conditions and those who are bereaved. Social workers are skilled at balancing the different and sometimes competing needs of the two groups. Specialist palliative care social work is provided in a range of settings, including independent hospices, day hospices, NHS specialist palliative care units, oncology wards and in home care teams. …Specialist palliative care social workers are used to working across the fields of health and social care and often provide a link between the two. They are also used to working with both children and adults and in working with people in their own homes.

Specialist palliative care social workers offer a wide range of support to patients and families from practical help and advice around income maintenance, debt counselling, help with housing and accessing other services, through to advocacy, individual counselling and group support. This will include bereavement work with adults and children both as individuals and in group settings. Key to specialist palliative care social work is the desire and ability to see people as whole people and not as a set of problems, to understand the connections of their lives and to seek to act on, rather than ignore the constraints and discrimination they experience in society …Social work places ideas about crisis, loss, grief and bereavement within an appreciation of people’s diverse and unequal social circumstances. (APCSW, 2006).

Considerable change has been taking place in social work generally which affects specialist palliative care social work. It is now regulated by the Health and Care Professions Council (HCPC) which has replaced the General Social Care Council (GSCC). Social workers now work to a Professional Capabilities Framework (PCF), established by the Social Work Reform Board.

Palliative/end of life care and user involvement

Public, patient and user involvement have become formal requirements for good policy and practice in health and social care. The Calman Hine Report in 1995 paved the way for user involvement in palliative care by recommending that cancer services should be patient centred (Department of Health, 1995). Subsequent developments have taken place within a wider context of government emphasis on user involvement and service users being at ‘the centre’ of health and social care services.

There are, however, some significant contradictions about user involvement in palliative care. Palliative/end of life care, particularly as reflected in the hospice movement, has always emphasised the centrality of the patient or service user and its own ‘holistic’ approach to provision and practice. It has highlighted its concern with the individual’s physical, social, psychological and spiritual needs. It has traditionally placed an emphasis on ‘voice and choice’, ideas which have subsequently gained a key place in health and care more generally. As Dame Cicely Saunders said, one of its key and explicit aims was to provide a ‘voice for the voiceless’ (Oliviere, 2000).
Yet it can be argued that palliative/end of life care has been slow to address service user involvement. One explanation for this and perhaps the most likely is that palliative care services work with two groups of people who are seen as particularly vulnerable in our society; people with life limiting illnesses who may be facing death and people who are either facing bereavement or have been bereaved. Thus palliative care service users are at very difficult times in their lives, having to cope with massive change, fears for the future and possibly financial uncertainty. For some it may mean having little time and feeling weak and very ill; for others coping with loss and perhaps the prospect of loneliness and isolation.

It would not be surprising, therefore, if workers and services were reluctant to place additional burdens on service users who can already be seen to have other difficulties and preoccupations. (Small and Rhodes, 2000; Payne, 2002; Gott, 2004). Nonetheless, user involvement has become an article of policy and practice under successive governments and there is some evidence that it is valued by many service users. That’s why it seems important to check out progress in this area as carefully as possible in changing times.

The Survey

This study to explore the state of user involvement among palliative care social workers in the UK was carried out by questionnaire survey between September 2011 and April 2012. The aims of the survey were to:

- produce a clear picture of service user involvement in palliative care social work
- provide up to date evidence of the state of user involvement
- identify both the drivers and the constraints in contemporary palliative/end of life care policy and practice.

It secured a 20 per cent response rate and included social workers in the diverse range of specialist palliative/end of life care settings, both within the NHS and the voluntary sector in the UK. This included 42 different organisations and settings. A more detailed account of the method used in the survey is provided in Appendix Two.

We have structured the report to offer an overview discussion of the findings from the survey, a more detailed examination of people’s responses to the different issues the survey explored and a broader discussion of user involvement. and the analysis of the responses to each individual question is set out in the next section with a more detailed discussion of the findings to follow.
What social workers say
What social workers say

The importance attached to user involvement

The most notable theme to emerge from the survey is that the overwhelming majority of palliative care social workers understand the importance of service user involvement and are active in supporting it and responding to it in their workplace. Thus they say:

“It must be the only way we can move forward with the service, as it’s pointless developing something that does not meet the expressed needs of the service users. It gives validity to what we do.”

“It helps develop and improve services. It can be a positive experience for service users.”

“A large gain is the sense of not being at the end of a paternalistic service but rather one that tries to get alongside service users and understand their perspective and the development of services.”

Issues emerging

Social workers offer a wide range of examples around user involvement, but there does seem to be a lack of consistency or agreement about what is meant by ‘user involvement’. Examples given varied widely. This ranges from:

“Dedicated service user involvement officer post – leading to time spent encouraging service users to give their views.”

“Appointment of an independent service user facilitator.”

“Satisfaction surveys within all departments.”

“Evaluation forms.”

“User forum meetings every two months on a different day of the week to get feedback on the quality of services received. At our other site, a forum that meets twice a year and is facilitated by and external person.”

“Advisory group of users proposes, approves and evaluates training courses delivered through the education department.”

To:

“Former patients/bereaved family becoming volunteers.”

“Service user speaking at a conference.”

“Free attendance at education events for users and carers.”

Much service user involvement seems to centre on contributing to leaflets and publicity and to offering feedback, through questionnaires, interviews and informal discussion. Thus most involvement appears to operate still at a consultative level. It was also not possible from the survey to assess how seriously, consistently or effectively the organisations involved responded to such feedback.

The survey highlighted some noticeable gaps in user involvement in services. In particular very little user involvement was reported in audit and education, planning, evaluation and research. These are some key areas where progress seemed to be slow,
although much has been achieved in health and social care more generally. About a third of respondents identify ways in which service users are involved in governance, and just under half cite the existence of service user groups as evidence of the development of service provision for user involvement.

‘Feedback’ is the most frequently cited ‘evidence’ for both practice and service planning development. Detailed, concrete and clear examples, however, are frequently lacking. Almost half of respondents could not identify any service user involvement in education planning and delivery, and where there was some involvement, this ranged from free attendance at educational events, to service users acting as presenters and, in two instances, service users being members of the programme planning group. Overall, participants’ responses suggest that audit is either not well understood or not seen as a priority. However, although almost half the respondents did not or could not identify any user involvement in evaluation and research, 20 per cent were able to offer evidence of active involvement, including examples of service users contributing to research design and small scale studies. So, for instance:

**The benefits of involvement**

“Day care focus group which led to a young person’s group being developed.”

“Focus groups and surveys involving service users in evaluating a service.”

“Parents involved in a research project.”

Most participants see user involvement as of crucial importance for their work, the work of the hospice and palliative care movement and for service users themselves. Thus they see it as useful and helpful both for service users themselves and for their organisations and work. They are readily able to identify the gains of user involvement. This is reflected in comments like:

“User involvement can be empowering for users. It means real working in partnership and not just professionals being the experts. It encourages them to have influence.”

“It keeps the organisation grounded.”

“Can help users to feel valued.”

“Contributes to a good atmosphere.”

“A greater ‘in-touchness’ for the organisation with the needs of the community it serves. The service users feel listened to.”

Participants refer to the part user involvement has to play in identifying gaps in services, in prioritising, in keeping users central to the service and in both challenging and valuing staff. Service user benefits included enhanced self-esteem, being empowered and feeling valued. Examples of impact offered include:

- Noise levels reduced, improved environment as result of user input.
- Relatives no longer asked to leave bedside when patient at end of life is being turned.
• Family members have option to help give bath.

• Young person’s essay on dying father has changed staff attitudes and practice for the better.

• Bereavement day attracts more fathers, as result of user input.

• Bereavement leaflet and death notification now given together.

• More funds raised.

Social workers taking part in the survey demonstrate a commitment to ensuring the maintenance of person centred support in their work. They see user involvement as being really important for their practice as part of this.

“Service user feedback is a good indicator in checking that we are providing the correct information at the right level of understanding and this confirms that we have got it right.”

“It allows us to hear the views of users and to make changes to improve our service, even if sometimes only in small ways.”

“User involvement is crucial in keeping the hospice firmly rooted in reality and in relation to [its] local community. I believe it is the biggest gain. It provides an insight from people dealing with life threatening illness and their carers and lets us see how the service actually fits into their lifestyle.”

“I believe that it can ensure that services are appropriate and timely and that a partnership model ensures a better experience for patients, carers and families.”

“As a practitioner involved in focus groups with patients and carers I have found that such an approach enables all those involved to participate and to feel empowered.”

Challenging the limits of existing involvement

Just two respondents seemed to think that the impact of user involvement could be negative rather than positive. In their assessment of their own particular situation in relation to service user involvement, respondents were divided, with a relatively even split between positive and negative comments. Interestingly, for some respondents, the survey had challenged them to give service user involvement greater priority in future. Thus, for example:

“We are currently revamping our day care and I feel I have been remiss in not suggesting that we involve users in this.”

“This has made me think maybe I should bring it to the agenda at a Heads of Department meeting to raise the profile and see if there are other things going on that I’m not aware of or things I could help colleagues with.”

“Doing this survey makes me realise how woefully absent user involvement is in my work but if I am honest I feel rather paralyzed about it.”
Gains from user involvement
Following on from the gains that they feel service user involvement can bring to the workplace, participants clearly believe that user involvement can have a positive impact on services and beyond:

“Holding a focus group before [our] first ‘family day’, gave a much better understanding of what parents, their children and extended family wanted from the day.”

“Day care focus group [were helpful] which led to a young person’s group being developed.”

“[Getting] positive feedback from service users about some service provision.”

“One service user has blossomed as a result of her involvement.

“User involvement adds additional knowledge to our Clinical Governance meetings.”

There was clear evidence that service user involvement provision was holding its own or improving, with only one respondent considering that provision for service user involvement was deteriorating.

Ways of improving user involvement
Respondents were very clear about the drivers needed in taking forward user involvement, particularly the importance of commitment from senior managers, front-line workers (and users). Some of the examples social workers give are:

“Grants!!”

“Guidance documents such as that of NCPC [National Council for Palliative Care], expectation from peer review that Cancer Networks engage in active user involvement. An enthusiastic and committed management lead for user involvement (which we do not have at present).”

“Support from senior managers and trustees, enthusiasm of front line practitioners, some service users who are committed to this and proactively come forward to advocate on their own behalf and on behalf of current and future users of palliative care and end of life services.”

“Being dedicated to wanting services to be developed round true service user need and acknowledging service user expertise.”

“I feel it is very much dependent upon the organisational culture and attitudes and values of staff. The authority of the lead of any service user involvement needs to be recognised and good support from management.”

“A genuine community focussed approach that consistently has representation from the policy makers so that issues are fed back.”

“Management needs to be supportive and be actively involved in the process. They don’t necessarily need to understand everything but be supportive and let people plan and arrange user involvement.”
“Constructive evaluation and feedback are essential for promoting development within the organisation, however the involvement on a regular basis of forums, meetings etc that enable service users to regularly have the opportunity to actively voice their ideas, struggles, needs is essential.”

“Good chair of the [service user] group and recognition [from services].”

**Barriers in the way of user involvement**

Generally respondents report that there is considerable pressure on staff from heavy workloads and cutbacks. This is not surprising given current government austerity politics and represents the context of the work of practitioners and services. The situation is reflected in comments like:

“Workload increases all the time.”

“[It’s] becoming difficult to discharge patients when applying for fast track NHS continuing care. People [are] being penalised for dying at a time of cuts.”

“General economic climate of doom and gloom.”

“Staffing pressures.”

“More and more mandatory training leaving less time for anything not seen as mandatory including User Involvement.”

“Palliative care social work is seen as an optional extra, not a routine necessity.”

“Strategically [there is] little support for my role.”

“We have a ‘cuts-watch’ campaign.”

Of particular significance are the effects identified of current restrictions and cuts on user involvement. Social workers seem to be evenly divided in their opinion with similar numbers stating that there had been no effect from the cuts and identifying a variety of factors that had impinged negatively on service user involvement, including budget cuts, time constraints, and increased workloads. Overall, the responses indicate a significant degree of frustration and concern.

In this climate it can be difficult for social workers to make time for maintaining and developing user involvement. Service user involvement is seen by social workers as a priority, but this can be difficult to achieve under the present circumstances. Thus for example:

“There just isn’t enough time in the day to tackle things in a wider way than we are at the moment.”

“Difficult to create the time needed to properly focus on user involvement.”

“Pressure of targets including seven day working.”

“High staff turnover; people do not carry through long term projects.”

“Reduction in staff has slowed down pace of development.”
“Time [is] required to promote effective user involvement not allowed for in our workplace.”

“Staff cuts/restrictions on filling posts, means there is less time for staff to do their jobs – so don’t have as much time for user involvement.”

“I think it [user involvement] has moved down [the] workplace agenda.”

Discussion
A number of the questions included in the survey were concerned with involvement of service users in activities that could alter the balance of power in organisations and services, for example, in governance, research and policy-making. In this respect, the development of service user groups that directly influence services, through pressing for change, contributing to policy and service development, having a seat on the board, and so forth, clearly meet the more developed definitions of user involvement which are concerned with the capacity to have an effective influence make change.

On the other hand, much of the evidence that was submitted under the category of ‘feedback’ would not fit this bill. A substantial amount of the service user activity cited by participants in the survey was at much more of a consultative level. At the same time, as we have seen, there were some significant examples of service user involvement that were located on the higher rungs of the ‘participation ladder’ and demonstrated genuine involvement and shared decision-making. It is arguable whether any of these examples would be seen to operate at the highest level of involvement, associated with service users having control and making decisions.

There are other distinctions to draw too. Some participants considered that user involvement was well supported in their organisations because they had user groups that were primarily social and therapeutic. Others, however, saw service user involvement as primarily being about representation on committees, influencing policy, and/or participating in interview panels, research and presentations.

None of this though devalues the specific activities highlighted by participants; user groups in which participation was an end in itself are undoubtedly valuable. It is simply to make the point that in terms of driving organisational change and fulfilling the government’s stated desire to put service users at the centre of services, involvement as a means to that end is more challenging and less well-evidenced.

Conclusions
So what can we conclude from these findings? There is a real interest in and commitment to user involvement among palliative care social workers. The majority of palliative care social workers who responded to this survey regard service user involvement – in principle – as central to good palliative care provision. They see it as a priority.

“If we don’t ask and involve users in the service we provide, we are fundamentally failing them.”
It is recognised as part of the key move to person-centred support and personalisation in end of life care, to which most hospice social workers are already strongly committed.

There are a number of encouraging examples of higher-level service user involvement (representation at Board level, on governance and quality and education groups) as well as examples of specific changes to practice and provision in response to service user feedback. However, there continues to be a need for more rigorous, hard evidence of the impact and effectiveness of service user involvement at all levels. Detailed examples of organisational changes in practice are more likely to convince politicians, policymakers and senior management than generalised and unspecific feedback.

However, service user involvement can be difficult to achieve and sustain in the current climate affecting such services. There are serious barriers in the way, including lack of resources, overstretched staff and competing responsibilities and priorities. There can be no question that this is taking its toll on this crucial development.

There is also an urgent need to debate the contemporary understanding of the term ‘service user involvement’. It was evident from the responses received that individuals interpreted this concept very widely indeed. Palliative care social workers need to be both clear and confident in their understanding, definition and practice of service user involvement, if they are to be able to advocate effectively for its centrality within palliative care, at a time of uncertainty, recession and political pressure.
Exploring user involvement
Social work and social care have long been leaders in the development and implementation of user involvement (Braye and Preston-Shoot, 1995). This interest has extended to specialist palliative care social work. It has been suggested in some quarters, for example, that the founding work of Dame Cicely Saunders, who was herself a qualified social worker, can be seen as a more radical call for engagement, dialogue and co-production with those facing death and with their families. This would involve the giving up of professional authority to both ‘enabling alternative views and voices to emerge and to question and improve existing practices and care relationships’ (Cotterell et al 2011 p159).

Although traditional social work values – such as respect for the individual’s autonomy, support for the poor and marginalised, a commitment to fight oppression in all its forms, and therefore a willingness to challenge society – all lend themselves to embracing empowerment, participation and involvement, the practice is more problematic. For some practitioners, user involvement may be focussed on the therapeutic – how it benefits the individual client, whereas for others the emancipatory and strategic purpose is key. These different goals as we have seen were reflected in this project.

Different approaches to involvement
Whatever the level of user involvement that is achieved in practice, philosophical doubts are still raised. Three main criticisms have been levelled at what has been characterised as the conventional and prevailing ‘consumerist’ approach to involvement. First, no matter how strongly the consumer (user) voice is articulated, it may do little to alter the balance of power in terms of the provision of services – which are likely still to be delivered, controlled and owned by agencies or professionals. Second, as Barker and Peck (1987, p1) once memorably remarked, any analogy with commercial life may be false. They used an example from psychiatry, saying that, ‘survivors of the mental health system are no more consumers of services than cockroaches are consumers of Rentokil’. Third, the consumerist approach is fundamentally individualistic, based on the notion of meeting individual needs rather than on making collective provision or enabling increased collective control. Open to the charge of tokenism, this approach also tends not to involve service users in the conceptualisation of support, which may thus further disempower patients and carers. Palliative care service users’ groups and forums, cited by a number of participants to this survey, which are primarily therapeutic in
purpose, are open to this criticism. Disabled people’s and service user organisations, have tended to develop an alternative ‘democratic’ model of user involvement, based on a more liberatory or democratising set of values, where the aim is to redistribute power and support people’s empowerment (Beresford and Croft, 1992).

The history of service user involvement in health and social care is highlighted by Barnes and Cotterell (2012) who say it can be traced back to at least the early 1970s with the creation of community health councils that were intended to represent the public interest. They point out that by the early 21st century, patient and public involvement in planning services, proposals for changes to services and decisions that affect how services operate “had become a duty” (Barnes and Cotterell 2012 pxviii) through implementation of The Health and Social Care Act 2001 (Department of Health 2001). It is not only through official initiatives however that patients, service users and citizens can be given a say. Other service user and carer groups, including the disabled people’s movement where there were differences between service users and professionals about the ability of disabled people to live independent lives (Campbell and Oliver, 1996), have organised separately to try and influence policy and practice. They have also developed their own understandings of and practices for getting involved.

The terminology of involvement
As we have seen, ‘user involvement’ is a contested term. Frequently the terms participation, user involvement and empowerment are used almost interchangeably. Two further terms – partnership and consultation – are also often invoked. Empowerment, nevertheless, is usually seen as the ultimate goal.

In considering the multiple understandings of service user involvement it may be helpful to consider briefly the typologies of Arnstein (1969), Hoyes (1993), and Hart (1992) all of whom argue for empowerment as the top rung of the ladder.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Citizen control</td>
<td>User authority to make decisions</td>
<td>User initiated and directed</td>
</tr>
<tr>
<td>Delegated power</td>
<td>User authority for selected decisions</td>
<td>Shared decisions</td>
</tr>
<tr>
<td>Partnership</td>
<td>Consultation</td>
<td>Consultation</td>
</tr>
<tr>
<td>Consultation</td>
<td>Assigned/informed</td>
<td>Assigned/informed</td>
</tr>
<tr>
<td>Placation</td>
<td>User initiative to influence decisions</td>
<td>Tokenism</td>
</tr>
<tr>
<td>Informing</td>
<td>Dissemination/explanation of decisions before implementation</td>
<td>Decoration</td>
</tr>
<tr>
<td>Manipulation</td>
<td>Information</td>
<td>Manipulation</td>
</tr>
</tbody>
</table>
Treseder (2004), in contrast, however, challenges the very notion of a hierarchy, arguing that full participation is not necessarily appropriate in every situation and developing a different schematic for involvement.

Involvement is not only affected by the language, theory and ideology associated with it. The process of implementing it creates complexities which can draw it away from whatever principles may underpin it. That is why conventional hierarchies and ‘ladders’ of participation may be of only limited usefulness. While tokenism and manipulation may be inherently unacceptable aspects of consultation, in reality such consultation can sometimes be as involving and empowering as approaches which are meant to have more decisive effects. Perhaps the litmus test of different approaches, techniques and terminology rests on what the actual outcome is. Does the individual, or group, feel more involved and empowered than before? What actual change has been achieved?

Monroe and Oliviere (2003) have defined user involvement as “concerned with the means of achieving a person-centred service and the meaningful participation and consultation of service users.” Perhaps the adjective ‘meaningful’ is the key word here for both theorists and practitioners. Without that, arguments about the term are irrelevant.

This is very much in line with Freire’s work (1972) which sought to engage, and support the empowerment of people to change their own situation. From reflection, awareness and understanding would come action for change. Ruegger (1999) offers a simpler definition; empowerment is ‘concerned with altering the balance of power between groups or individuals in favour of those who are traditionally in a weaker position’ (p 75). Many social work theorists would argue that this has implicitly or explicitly been a key commitment of social work since its creation.
Analysis of responses
Analysis of responses

PART ONE

1. Can you let me know what provisions for user involvement exist in your service/agency/workplace, in the following:

<table>
<thead>
<tr>
<th>GOVERNANCE</th>
<th>SERVICE PROVISION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Left blank/unanswered 6</td>
<td>Response not relevant 5</td>
</tr>
<tr>
<td>Unsure of provision 3</td>
<td>User group provision 19</td>
</tr>
<tr>
<td>No provision 7</td>
<td>Feedback 14</td>
</tr>
<tr>
<td>Involvement 16</td>
<td>Unsure of provision 1</td>
</tr>
<tr>
<td>Feedback from users 14</td>
<td>No provision 4</td>
</tr>
<tr>
<td></td>
<td>Left blank/unanswered 4</td>
</tr>
</tbody>
</table>

Of the 45 replies, 16 could not or did not identify any user involvement in governance.

‘Feedback’ (14) included ‘complaints system’, ‘user group feedback’ ‘satisfaction surveys’ and other less relevant responses. None of these replies offered concrete evidence of direct involvement in governance. Sixteen replies highlighted such things as users as trustees; carers or ex-carers, service users chairing or sitting on the clinical governance group; attendance at cancer network, clinical quality and effectiveness groups and strategy groups.

It is not possible to judge the effectiveness of such involvement or indeed whether the choice of the word ‘attend’ rather than ‘participate in’ has any significance. Similarly, respondents clearly interpreted ‘governance’ quite broadly to include a range of committees and groups carrying different titles –but which arguably would have some governance remit.

Nine replies could not or did not identify any user involvement in service provision.

‘Feedback’ – the range of replies included such things as using suggestion boxes, questionnaires, evaluations, and informal feedback.

Nineteen replies referred to the existence of formal service user groups as evidence of user involvement in service provision.

Frequency of meetings ranged from monthly to yearly. Some groups appeared to be primarily therapeutic (for example, art and bereavement groups) while others were more strategic. However, it is not possible to draw firm conclusions from the titles alone.
The Feedback group of replies included several one word responses – ‘feedback’ – and generalised comments such as ‘feedback helps inform best practice development’. Also included were service users’ experiences used in teaching sessions; service user on a practice development accreditation steering group and involving families in staff and volunteer induction programmes.

Detailed, concrete and clear examples were somewhat lacking.

Seven respondents could not or did not identify any user involvement in service planning and development.

The great majority of replies (28) cited feedback of some sort as evidence of involvement, with over 20 replies consisting solely of the word ‘feedback’, Nine replies offered more concrete detail; a bereavement service user group had led to new bereavement services; service users had given input to plans for new builds/extensions/redesigns; service users’ advocacy for a duty consultant for in-patient unit; service user ideas for bereavement groups; involvement in carers skills programme.

It is unwise to make judgements about the efficacy and commitment underlying the ‘evidence’. A response such as ‘we may respond to suggestions’ did not necessarily suggest wholehearted commitment to user involvement, but that may not have been the intended message. On the other hand, the encouraging reply about the existence of a ‘user consultation group on service planning and development’, suggested a more committed and concerted approach - but ended with the comment ‘has ceased to meet because of poor attendance’.
PART ONE

1. Can you let me know what provisions for user involvement exist in your service/agency/workplace, in the following:

**EDUCATION AND TRAINING**

- Involved in planning group 3
- Contribute to education events/conferences 13
- Featured in video/DVD 2
- Free attendance at events 3
- No provision 12
- Left blank/unanswered 9

**AUDIT**

- Response not relevant 5
- Involvement in audit 5
- Feedback 13
- Unsure/Don't know 2
- No provision 11
- Left blank/unanswered 9

A substantial number (21) of replies could not or did not identify any user involvement in education.

Three respondents mentioned that service users could attend education and training events for free, but whether this justifies a designation of ‘involvement’ is debatable.

Two replies highlighted training or publicity videos that featured users and which presumably would have either a general or broadly educational purpose.

In 13 organisations, services users participated in education programmes, although it was not always clear at what level. A few responses identified service users as speakers or as conference presenters.

In two instances, service users were part of the group tasked with planning education and training programmes.

Twenty two respondents could not or did not identify any user involvement in audit.

There were 13 responses grouped under the section ‘feedback’. Typically these replies mentioned such things as complaints/compliments, (satisfaction) surveys or ‘feedback noted.’

Five answers referred to service users’ involvement in audit, but it appeared that this was more likely to be in terms of bereavement or other user groups being audited by the organisation, rather than any users being actively involved in planning or conducting audits.

Overall, the responses suggest that audit is either not well understood or not seen as a priority.
Slightly less than half of respondents (19 of 45) did not or could not identify any user involvement in evaluation and research.

Twelve replies indicated service user ‘participation’ in one of two ways – either through professionals taking note of general user feedback as they planned audits, or through service users being the ‘subject’ of audits, completing surveys etc.

Nine replies, however, suggested a more active involvement. In one organisation, a service user is involved wherever possible, in the research planning group, and research has been carried out to identify what types of research service users themselves consider important. Elsewhere a service user has been a user representative on the research programme; service users have been actively involved in designing questionnaires for patients and carers, and user groups have worked with a research nurse to carry out small scale studies.

These figures are not particularly useful on their own since what is identified as an ‘other area’ in this question may have been given, by other respondents, as an identified area in an earlier section (for example, user groups/feedback). The number of blank replies may be more indicative of comprehensive responses to earlier sections than of lack of interest or ignorance.

Three respondents highlighted the ‘career’ trajectory of service users into becoming volunteers.
A range of different examples of good practice were offered by participants. These tended less to reflect common practice as particular initiatives in specific service settings. Again they highlight the range of activities currently undertaken and included in the category of user involvement.

Replies fell broadly into two categories – benefits to the service/organisation, and benefits to service users themselves. A number of replies identified and included both these categories.

Participants mentioned user involvement in identifying gaps in services, in prioritising, in keeping users central to the service and in both challenging and valuing staff. Service user benefits included enhanced self-esteem, being empowered and feeling valued.

Overall, this question elicited a strong endorsement of service user involvement.
Ten respondents did not or could not provide any direct evidence of impact. Twelve responses were either very generalised or referred to unspecific feedback. While these participants presumably believed that there was a positive impact, their responses would be unlikely to be seen as providing robust evidence for policy makers or managers.

Seventeen respondents gave specific details, some of which had already been given in replies to earlier questions. Such evidence included:
- noise levels reduced, improved environment as result of user input
- relatives no longer asked to leave bedside when patient at end of life is being turned
- family members have option to help give bath
- young person’s essay on dying father has changed staff attitudes and practice for the better
- bereavement day attracts more fathers, as result of user input
- bereavement leaflet and death notification now given together
- more funds raised.

Clearly, user involvement can impact on a wide range of activities and issues.

However, it is important to take note of two comments offered, concerning ‘negative’ aspects of user involvement. One respondent made the point, well attested to in the literature on user involvement, that where service users are consulted but see no positive change, or see valued services closed, they may then feel alienated. Another reply also highlighted the often raised issue of service users who get involved being ‘unrepresentative’. This offered the example of meeting a service user’s request for a dedicated space for families of no faith – and this space was then never used.
Of the 16 responses which indicated that provision for user involvement was staying much the same, three indicated that this provision was remaining poor, two that it was remaining good and one that such provision was essentially non-existent!

These figures do not tell us that improved provision is good provision – simply that it is better than it was, regardless of whether it was originally poor, average or very good.

Examples cited by participants included:

• user involvement in new build
• development of an anniversary centre
• debate on best time to run a group – ‘then the manager suggested that instead of debating among staff, we ask service users’
• patients invited to attend clinical sub-group.

(Negative) changes to day services caused widespread concern among service users.

Fourteen respondents considered that current restrictions and cuts had no effect on user involvement. A further seven did not or could not offer an answer. Ten responses were not directly relevant – although they tended to reveal feelings of frustration and dissatisfaction and a view that palliative care services generally were being affected.

Twelve replies indicated that user involvement was being affected. Respondents cited increased workloads, main focus on management rather than relationships, user involvement budget cuts, time constraints, posts frozen, unpopular changes due to cuts (not specified).

Overall, the responses indicated a significant degree of frustration and concern, although many of the points made were not strictly relevant to the question.
Positive commitment was a key issue raised in these responses, with 13 responses highlighting the importance of senior management support, and five (not necessarily different) replies noting the significance of individual worker commitment to taking forward user involvement effectively. Finance – encompassing dedicated budgets, grants, funders’ commitment to user involvement and fundraising in terms of user involvement impacting beneficially on fund raising efforts – was commented on in five responses.

Eight replies cited commitment from service users themselves and/or community involvement.

Two organisations had dedicated posts for user involvement which had clearly driven this forward.

Responses were relatively evenly divided between positive and negative comments. Positive comments centred on feeling encouraged and supported around user involvement, not facing any restrictions, having reasonable resources and having opportunities to develop work in this area. Some of these responses also contained a note of caution (for example, ‘no restrictions – as yet’; ‘needs more management support’), which points to concerns that things may not necessarily remain positive.

Negative comments focused on workload/time pressures (9) and management attitude (3), as well as uncertainties about posts, the low priority given user involvement, the existence of a tick box cultures and the difficulty of doing anything on one’s own

There were also two negative comments related to service users. One was framed in terms of the limits of what they could be expected to do because of the nature of their illness or condition – framed in terms of their unreliability – and the other relating to service users’ negative perceptions of services and the discouraging and difficult impact this could have on the worker.
Although it was not its aim, an unexpected consequence of the survey was to raise awareness among participants of the issue of user involvement. Four participants indicated that the survey was galvanising them to make user involvement more of a priority.

An additional four respondents commented that they were either unable to find out the information the survey sought, or they could not devote time to doing so.

Miscellaneous comments included an offer to take part in further discussions, a call for a debate in palliative care as to what is meant by ‘service user’ and an observation that mention of user involvement usually meets with a cool response, as well as a concern that much user involvement is tokenistic.
Recommendations
Recommendations

The findings from this project indicate that palliative care social workers have a commitment to user involvement in policy and practice but this needs more support to be fully effective. Without such support, it is unlikely to maintain the momentum that has so far been achieved and which is required by government in all areas of health and social care, including palliative and end of life care.

With the continuing prospect of cuts in funding for public services, including social work and end of life care, these are particularly difficult times for ensuring that the momentum for user involvement is not undermined in palliative care. There are signs that this is happening. Because there will be growing pressure to prioritise and focus resources most cost effectively, user involvement will assume a greater not lesser importance.

As people survive life limiting illnesses and conditions longer and longer, their involvement is likely to become both more important and more readily achieved. These are additional reasons for developing knowledge and skills in this area.

User involvement must be ensured continued priority in palliative care social work education, policy, services and practice.

It is important for there to be more informed and rigorous debate about the meaning of ‘user involvement’. Very different understandings of what it might mean and what should be included in it, continue to operate and this is unhelpful in taking it forward.

There is need for more education and training about user involvement both in general qualifying social work courses, in post-qualifying courses and in specific courses for palliative care social workers. It is important to develop a more systematic approach to advancing and sustaining user involvement. This includes clarifying:

- the meanings of user involvement
- the objectives being sought
- the areas in which user involvement is being undertaken.

Palliative care relies heavily on multi- and inter-disciplinary working. User involvement is likely to be enhanced by developing joint training, policy and practice for user involvement across disciplines.

A range of practical steps can be identified which are likely to encourage and enhance user involvement in palliative care social work. These include:

- identifying and establishing champions for user involvement in palliative care social work at national level and in specific local services
- setting up of service user groups linked with local services and supporting the maintenance and development of such groups in national bodies and organisations
- building links and alliances more broadly with service users and their user led organisations (ULOs), as well as palliative care service users specifically.

The Association of Palliative Care Social Workers, alongside other end of life care and professional associations, has its own key and expanding role to play in supporting and advancing service user involvement at both national and local levels.
References


Freire, P. (1972) Pedagogy Of The Oppressed, Harmondsworth, Penguin


Appendix 1: Survey schedule
End of life care: Strengthening the case for social work

There are requirements for user involvement in end of life/palliative care and an increasing pressure to make provision for it. Government highlights the importance of putting the service user at the centre. At the same time, these are difficult times for end of life care services because of public spending cuts and also times of major change.

The aim of this survey is to get a clearer situation report from palliative care social workers to provide up to date evidence about user involvement, so that we can use such evidence helpfully to support the work of palliative care social workers, end of life care more generally and service users and their families who need our support.

We hope you find time to complete this simple but important survey. It should not take you long.

All data will be treated as anonymous and in strict confidence.
No individual or specific service will be mentioned by name

PART 1

The state of service user involvement (including both people with life limiting illnesses/conditions/bereaved people).

1. Can you let me know what provisions for user involvement exist in your service/agency/ workplace in any of the following:

GOVERNANCE

SERVICE PROVISION
2. Does user involvement operate in any other areas?

PLEASE SPECIFY AND DETAIL
3. What gains do you think such user involvement can bring?

4. Do you have any evidence of the impact of such involvement? (e.g. the positive difference it makes for service users, policy, practice and provision on service quality and/or outcomes).

PART TWO

5. Do you think provisions for user involvement in your service/agency/workplace are improving/getting worse/staying much the same?

PLEASE GIVE ANY EXAMPLES YOU CAN IN SUPPORT OF YOUR VIEWS
PART THREE

6. What effects, if any, do you think current restrictions and cuts in public expenditure are having on user involvement in your service/agency/workplace?

7. What drivers, from your experience, are helpful in taking forward effective user involvement?

8. More generally how would you describe the general current situation facing you as a palliative care/end of life social worker in taking forward user involvement?

YOUR DETAILS:

Name
Address

Thank you very much for taking the time to complete this survey.
Appendix 2: The survey method
The survey method

This survey of all 225 members of the Association of Palliative Care Social Workers was sent out initially in September 2011. Further reminders were sent out later that year and then again in January 2012. The survey achieved a 20% response by April 2012. It was then agreed to close the survey.

All surveys, however well designed, are limited by the fact that what the author of the survey understands by a word, phrase or complete question is not necessarily the same as the understanding of the reader of the question who responds according to their own particular interpretation. While face-to-face interviews offer the opportunity to check, explore and expand meanings, the survey analyst has no such opportunity and must at times make their own judgement as to how to categorise a response. In this survey some questions were very straightforward, eliciting ‘yes/no/don’t know’ responses that were easily tabulated; others inevitably required some interpretation.

Figures quoted are numerical, with percentages given in the tables. However, since there were only 45 responses, any one response represents over 2% of the survey total. Percentages therefore have required rounding up or down, and numbers will not always add up to 45 if, for example, respondents have ticked more than one box, or not all respondents completed a particular section.

Forty five replies were received from 42 organisations. Two hospices sent in two reports from two different people, with no indication of whether each was aware of the other. In another cases, the report was signed by two workers, indicating a joint agreement to the responses. The survey included respondents from England, Scotland, Northern Ireland and Wales.

Their distribution by country and kind of service broke down as follows:

- 22 voluntary hospices in England
- 9 NHS hospitals/community teams in England
- 1 community team in England working with people with Motor Neurone Disease (MND)
- 3 voluntary hospices in Wales
- 2 voluntary hospices in Northern Ireland
- 2 voluntary hospices in Scotland (one was a children’s hospice)
- 3 respondents did not state where they were from.

Most respondents clearly made a serious effort to give time and attention to the survey, but there were one or two examples of a misreading of the focus of the survey and while valuable information was contained in some answers, it was necessarily disregarded if it did not relate to the question in hand. It was also apparent that the central focus of the survey – namely user involvement – tended to be overlooked by some respondents as they worked through the questions, so that later answers were broader and less specific to user involvement per se. This however may help us gain some appreciation and understanding of their concerns and preoccupations. The understanding and definition of user involvement was also variable. This was a significant issue and is discussed in more detail in this report.
A number of respondents drew a distinction between patients as services users and carers or family members as service users, but for the purposes of this study the term ‘users’ includes all these categories.

There was some evidence that respondents found the survey quite lengthy and that they tackled it question by question; as a consequence specific examples of activities/user involvement were discussed in response to more general questions and then the question asking for examples was left blank. Thus information was provided, but not necessarily in the order requested.

Not all respondents understood or made the same distinctions between practice development, service provision or governance, for example, and as a consequence what one person offered as evidence under one heading would be given as evidence for a different heading in another reply.

Despite these difficulties, inherent in survey methodology, the questionnaire has shed valuable light on the current situation in palliative care social work. We have sought to provide the information from the survey in both tabular and descriptive forms.
Getting it right
End of life care and user involvement in palliative care

Suzy Croft, Gillian Howns, Peter Beresford

www.apscw.org.uk