

A Guide to Involving patients, carers and the public in palliative care and end of life care services

THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE

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				For further information about palliative and end of life care, see the National Council for Palliative Care (NCPC) website www.ncpc.org.uk .

Over the last few years, we have seen a real push towards improving palliative care services for all people with life-threatening and life-limiting conditions and their carers. Good palliative care is essential in ensuring the highest of standards of care and dignity at the end of life, in death and beyond into bereavement. There is also increasing recognition of the need for greater consistency of services and greater choice for those at the end of their life, through better commissioning and co-ordination of care. The need for good quality end of life care is at the heart of the first 'End of Life Care Strategy' (Department of Health, 2008).

Alongside these service changes in palliative care, a parallel set of reforms have been taking place, giving patients, carers and the public a more direct say in shaping the organisation and delivery of health and social care services. This has particular challenges for palliative care. Patients, carers and professionals can be uncomfortable discussing palliative and end of life

issues. People in general shy away from talking about death and dying. Patients are likely to be experiencing poor health and may be approaching end of life, making the task of involvement appear inappropriate and daunting.

In the summer of 2008, shortly after the publication of the 'End of Life Care Strategy', the chief executives and senior staff from the National Council for Palliative Care (NCPC) and the NHS Centre for Involvement (NCI) held an exploratory meeting to identify how the two organisations might collaborate to support their mutually inclusive agendas. The idea of this guide, which explicitly looks at practical aspects of involving people in palliative and end of life issues, came about. Further meetings took place and the NCPC service user advisory group led the development of this document. The aim was to improve the patient and carer experience of palliative and end of life care through maximising their involvement in the planning and provision of services. This document

represents the outcomes of that work. It is supplemented by a Practical Educational Tool (PET) (details on page 51) to facilitate delivery of this material in an educational context. Further guidance on PPI in palliative and end of life care will be produced by NCPC in spring 2010 and will be available from www.ncpc.org.uk/publications

As part of the implementation of the End of Life Care Strategy NCPC is also leading a new coalition to raise public awareness about death, dying and bereavement and there will be a planned programme of activities promoting this during 2009/10.

At the present time there few examples of public involvement but this new coalition will be **the first significant national public involvement programme** in this area, and learning from this will be shared in later editions of the guide.

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About this document

In the summer of 2008, the 'End of Life Care Strategy' was published and the National Council for Palliative Care (NCPC) was given a clear remit to 'develop a national coalition to raise the profile of end of life care and to change attitudes to death and dying in society'.

A meeting between NCPC and the NHS Centre for Involvement (NCI) resulted in a programme of collaborative work, part of which was the development of a guide to involvement in palliative and end of life care services. NCPC's service user advisory group and professionals with experience of Patient and Public Involvement (PPI) were approached for their guidance and input.

NCPC are in the process of running a three year project to develop user involvement and to share learning. *Details available at www.ncpc.org.uk/users/project.html* They had the remit of developing a guide on best practice in the involvement of patients, carers and

the public in all aspects of palliative care and end of life care services.

This guide is designed as a starting point for involving patients, carers and the public in palliative and end of life care. At the present time there are few examples of public involvement and so far, NCPC's work has focussed mainly on involving patients and carers. The new coalition to raise public awareness about death, dying and bereavement and will be the first ever national public involvement program in this area, and learning from this will be shared in later editions of the guide. In addition, NCI's remit is both patient and public involvement and many of the principles in this guide apply to patients, carers and the public.

It was recognised that palliative and end of life care provision is very different from other parts of the care services. This is partly because there is a discomfort around discussing dying and death.

Patient, carer and public involvement appear in the title but, so far, NCPC's

work has focussed mainly on involving patients and carers. The National Coalition for public awareness will increase public involvement. NCI's remit is both patient and public involvement and many of the principles in this guide apply to patients, carers and the public. Therefore, "the public" remains in the title.

This document is one of a series of NCPC publications exploring patient, carer and public involvement in palliative and end of life care. Details are listed on page 38. It is complemented by a Practical Educational Tool (PET) designed to facilitate teaching this material. Further information is found on page 51. NCPC will develop further guidance in spring 2010.

Key points

1. The guide was organised around a wheel of involvement made up of eight spokes which together make up the end-to-end process of Patient and Public Involvement. Examples from the field of palliative and end of life care are provided to illustrate each part of the process.
2. The process starts by getting organisations to undertake an audit of existing PPI activity. Good PPI should comprise a balance of individual and group activity; proactive and reactive activity; retrospective and real-time activity; and direct and indirect activity. A simple map enables organisations to get a feel for the extent of activity and to identify gaps in involvement activity.
3. When undertaking any PPI, it is important to ask why you are involving people and what you are seeking to do through involvement and then set clear aims and goals that can be monitored and measured.
4. Before embarking on any specific PPI activity, organisations should make sure that they identify what information they already have about that activity. In this way, activity can be planned sensibly and appropriately.
5. PPI does involve the use of resources both in terms of money and people-time. Costs should be identified when planning activity so that PPI does not 'fail' because of a lack of resources.
6. Identifying who needs to be involved in PPI activity is dependent on the aims and goals. It might be appropriate to segment the target population into smaller groups by age, gender, location or other characteristics.
7. The methods chosen for the PPI activity should match the nature of the activity, the people you want to involve, the resources available and the aims and goals. A list of possible PPI methods is provided as an appendix to this guide.
8. Evaluation is a key phase in the palliative and end of life care PPI wheel, but is also the most challenging phase. Identifying the impact of involvement requires the use of a range of different outcome measures, including measures of patient and carer experience, which are not always simple to capture.
9. Providing feedback to those who have been involved is the final phase of the wheel. The way in which organisations do this will influence how much trust and confidence patients, carers and the public have and will also influence how prepared people are to continue to be involved in the future.

Why a guide for palliative and end of life care?

The quality of palliative and end of life care within health and social care services is variable and the profile of these services is relatively low ('End of Life Care Strategy', Department of Health, 2008). The 'End of Life Care Strategy' aspires to ensure that high quality care should be available to all regardless of who they are or where they are. A great deal of evidence and experience informed the Strategy and there is a sense that we are at the cusp of being able to make real and sustainable change for patients and carers.

While Patient and Public Involvement (PPI) has become increasingly common in many parts of NHS organisations, it has played a less consistent role in palliative and end of life care. This is partly because of the special challenges that involvement presents in this context. Care for people with life-threatening and life-limiting conditions crosses organisational boundaries of health and social care, care homes, housing, independent and voluntary sectors, and is relevant to almost every branch

of medicine that exists. Whilst a recognised model of palliative care exists for cancer and in hospices, models are still being developed in other conditions, for example chronic respiratory, heart failure, neurological and dementia, as well as in other places of care, such as at home or in care homes. *For more information, visit www.ncpc.org.uk*

As a society, we are less familiar with death and dying than our ancestors were a century ago. Death and dying are often 'medicalised' and people do not generally have direct experience of being with, talking about or observing death and dying. Discussion of death and dying does not generally take place openly. So why do organisations need to be concerned about involving patients and carers in the provision, commissioning and evaluation of palliative and end of life care? We suggest the ten top benefits for you and your organisation below – and there are many more. Examples of how these benefits can be realised can be found throughout this guide.

Ten benefits of Involvement

1. Everyone deserves the best quality of care when they face life-threatening and life-limiting conditions and when they die. Patients, carers and the public can help to achieve this by identifying ways to improve care. This can have a knock-on effect of improving staff morale by enabling them to meet the needs of patients and carers and provide more dignified care.
2. Involving patients and carers in the development of end of life care services upholds and reflects the fundamental principles of palliative and end of life care, which are person-centred. As Cicely Saunders, the founder of the modern hospice movement said: "You matter because you are you, and you matter to the very last day of your life".
3. The lack of public awareness and open discussion around death, dying and bereavement contribute to the lack of appropriate and responsive services ('End of Life Care Strategy', Department of Health, 2008). Involving patients, carers and the public in planning, developing and evaluating services can help to raise awareness of, and promote discussion around, end of life care issues.
4. Patient and Public Involvement (PPI) will help to demonstrate that organisations providing palliative and end of life care services are actively responding to the challenges set out in the 'End of Life Care Strategy' (Department of Health, 2008) and particularly chapter 21, and the 'Healthcare Standards' (Healthcare Commission, 2005), Core Standard 17, as well as other vital signs, targets, standards and outcomes.
5. The Healthcare Commission report, 'Spotlight on Complaints', (2007) reported that 54% of complaints in acute hospitals related to care of the dying and bereavement care. Many of these related to poor communication around end of life issues. Improving end of life care in partnership with patients and carers will help to address this.
6. Involving staff in decisions about the planning, delivery and evaluation of services is a way of gaining an expert public view, as well as enhancing motivation and morale. It is worth noting that public opinion about services is significantly influenced by staff views.
7. In the NHS and social care settings in which organisations are in competition, demonstrating good PPI can give an organisation a competitive edge when bidding for contracts or when undergoing contract reviews.

Ten benefits of Involvement

8. There is now a legal imperative for all organisations providing NHS-funded services to demonstrate that they have involved patients, carers and the public in planning, evaluating and developing their services (through Section 242 of the National Health Service Act 2006 and Section 233 of the Local Government and Public Involvement in Health Act 2007).
9. World Class Commissioners need to ensure that they involve patients, carers and the public throughout the commissioning cycle and this includes commissioning palliative and end of life care services as outlined in 'World Class Commissioning: competencies' (Department of Health, 2007).
10. Involving people in decision-making is a good way of demonstrating to the public that the service provides value for money. Remember that these services are funded through public money – people will support organisations better if you tell them how you are spending their money and why.

Who the Guide is for

The short answer to 'who the guide is for' is that it is for any organisation that provides or commissions palliative and end of life care services, the staff within those organisations and interested members of the public, including:

- senior leaders including the chair, chief executive and directors/senior managers within organisations that provide or commission palliative and end of life care services;
- clinicians and non-clinical staff working in health and social care, especially those who provide end of life care, such as staff from hospitals, care homes, supported and sheltered housing, hospices and in the community;
- those who manage and organise palliative and end of life care provision, whether based in an NHS, for profit, non-profit, independent or social enterprise organisation;
- directors with responsibility for service reconfiguration;
- commissioners;
- patients, carers and members of the public who have an interest in this area;
- PPI professionals i.e. those people who have a significant role in PPI across an organisation providing palliative care and end of life care services, such as people working for the NHS in the Patient Advice and Liaison (PALS) service;
- service improvement leads;
- PPI leads in Primary Care Trusts (PCTs) or Strategic Health Authorities (SHAs), in their role to quality assure community engagement;
- PPI leads in voluntary organisations and community groups; and
- Local Authority Health Overview and Scrutiny Committees (OSCs) and Local Authority involvement/engagement leads.

What the Guide is for

This guide aims to help you to strengthen involvement in palliative and end of life care and meet the national and local imperatives around Patient and Public Involvement in order to:

- help the NHS, health and social care to make better, more responsive decisions about palliative and end of life services that have taken account of the views and preferences of local people, groups and communities – including the commissioning of services;
- clarify the existing involvement and consultation requirements within the palliative and end of life care system;
- identify ways to make involvement and engagement processes more efficient and effective in palliative and end of life care;
- embed involvement within the mainstream of palliative and end of life care provision and commissioning rather than it being an activity only undertaken when there is a proposed major change or a problem that needs solving; and
- show how the NHS, health and social care should approach involvement and consultation work in palliative and end of life care.

How to use the Guide

To get the most from this guide, each organisation that provides or commissions palliative and end of life care services should make an honest and robust assessment of where it stands, in relation to:

- public understanding of the organisation and the services it provides, the need for change, the planned way forward and any emerging options for change;
- the effectiveness of recent and current involvement and consultation activity around palliative and end of life care – including work with staff;
- the ways in which they engage with their local community and, particularly, the Local Involvement Network (LINK); and
- plans for ongoing work to build a system of involvement and consultation that is integrated throughout each organisation that makes up the palliative care and end of life care system.

In Part 2 of this guide, we suggest ways to help organisations get started on this assessment. It is the **right** time for you and your organisation to take stock of what you are doing in terms of involvement activity so that you can plan and prioritise effectively and reap the key benefits of good involvement. After undertaking a baseline assessment, each organisation and the palliative and end of life care system as a whole (including those who commission services) should identify themselves as one of the following:

- well-prepared and in a climate of positive public confidence. (For those in this category this guide will act as an advisory checklist);
- that good community and staff involvement is ongoing, but there is still a perceived lack of public confidence. (In this case the guide will help you plan further work); or

- that public confidence is low and community and staff involvement has not been effective. (This guide will provide comprehensive and up to date advice based on evidence and practice. It will also provide links to relevant statutory guidance and some tools to help plan and undertake robust engagement and consultation processes).

Before we go on we have included a few 'myth busters' about PPI – things that you might have heard, and might even identify with!

Myth Busters

Talking about end of life care is too upsetting.”

Whilst there are some people who find end of life care difficult to face, others accept it as a natural part of life and would like to have some say in how they are cared for. Others are keen to talk about end of life care issues, but simply haven't had the chance to do so. Opportunities should be offered with appropriate, sensitive wording and support.

People with a life-limiting condition will be too ill to get involved.

Firstly, not everyone is too ill to talk. Secondly – someone nearing the end of life might not be well enough to attend a meeting, but may be able to have a telephone conversation, a face-to-face conversation or send an email. There are no real barriers if you're prepared to be creative and flexible.

Patients and carers will have more important things to do if they have a life-limiting condition. It's not right to ask them to get involved.

Granted – people are likely to have pressing priorities and less resources with which to address them. However, many people are very keen to 'give something back', leave a legacy for others or have some control at a time when they may feel powerless.

Involving former carers will be sufficient.

Former carers can provide extremely useful insights into palliative and end of life care services. However, this is not an adequate substitute for involvement from people who have direct and current experience i.e. the patients themselves.

PPI is difficult to do.

Yes it can be, but if you think of involvement as a lot of varied small and simple activities on their own they are not difficult.

We might open a 'Pandora's box' and not be able to please the public because there are too many differing views.

You are never going to please everyone but people, on the whole, are reasonable as long as they are given sufficient information to enable them to understand the realities within which the service functions.

It will all just be tokenistic.

Good involvement means asking people for their views early so they can genuinely influence your plans. Make sure that people have really good information and evidence about available choices.

PPI is expensive.

It can certainly be expensive if you do not do it. Some organisations have been involved in lengthy acrimonious consultations and legal challenges when they got it wrong! PPI does not cost the earth and it can save resources if you get your service improvements right.

Myth Busters

We might have to change our plans if we ask the public.

Correct.

You only need to consult people if you are making big changes to services.

Wrong. Under the new legislation, you must involve people in decision-making on an ongoing basis – not just where there is a significant variation to a service.

There is no money for PPI.

Find it. Given the benefits set out on page 7, PPI can help you to save money, win contracts, uphold standards and improve services.

There is no point doing any PPI because our previous attempts at establishing user groups have failed – we just attract the same old suspects.

Try a different approach or, better still, a range of different approaches. There are lots of examples of where PPI in palliative and end of life care has worked, both in this document and in the Practical Educational Tool (PET), so look at these and adapt them for your organisation and community context. You might not get it right every time but you will not always get it wrong either.

We already know what the public want so this is all a waste of time and money.

Your assumptions may be wrong. You may be surprised at what the public really want when they are asked. You never know what innovation patients and carers may bring to the table that might even save you money. In addition, whilst you may have general understanding of what is needed, you may be surprised by simple, inexpensive and straightforward changes that can significantly improve patient and carer satisfaction with services.

Related NCPC guidance about patient and carer involvement in palliative and end of life care

Practical Educational Tool (PET)

A training tool for delivering the material from this guide in an educational setting. It contains lesson plans, handouts and much more. Further details on page 51.

of best practice; and advise how these might be further developed and sustained.

*All available from
www.ncpc.org.uk/publications*

Listening to users – helping professionals address user involvement in palliative care

Helps professionals address user involvement in palliative care by placing ideas about user involvement into the context of palliative care, making them of practical use to professionals working in the field.

Listening to the experts: A summary of 'User involvement in palliative care - a scoping study'

Reviews research, policy and practice literature to identify what is known about user involvement in palliative care; to identify methods of accessing user views which are suitable for use in palliative care; to elicit the views of key informants (users, advocacy groups, researchers, practitioners and policy makers) on user involvement in palliative care; and to offer examples

User involvement in palliative/end of life care: How involved can patients/carers be?

End of life care; 2 4 64-69

Aims to demystify the concept of user involvement, examining its place in end of life care, exploring practicalities and offering guidance about how to make it a beneficial and effective process.

*Available from
www.library.nhs.uk/palliative/ViewResource.aspx?resID=304326&tabID=290*

Coming soon:

10 questions to ask if you're scrutinising end of life care.

NCPC and the Office for Public Scrutiny.

Designed to help health Overview and Scrutiny Committees (OSC) develop a range of high-level questions around the provision of end of life care services.

How to involve patients, carers and the public in palliative and end of life care

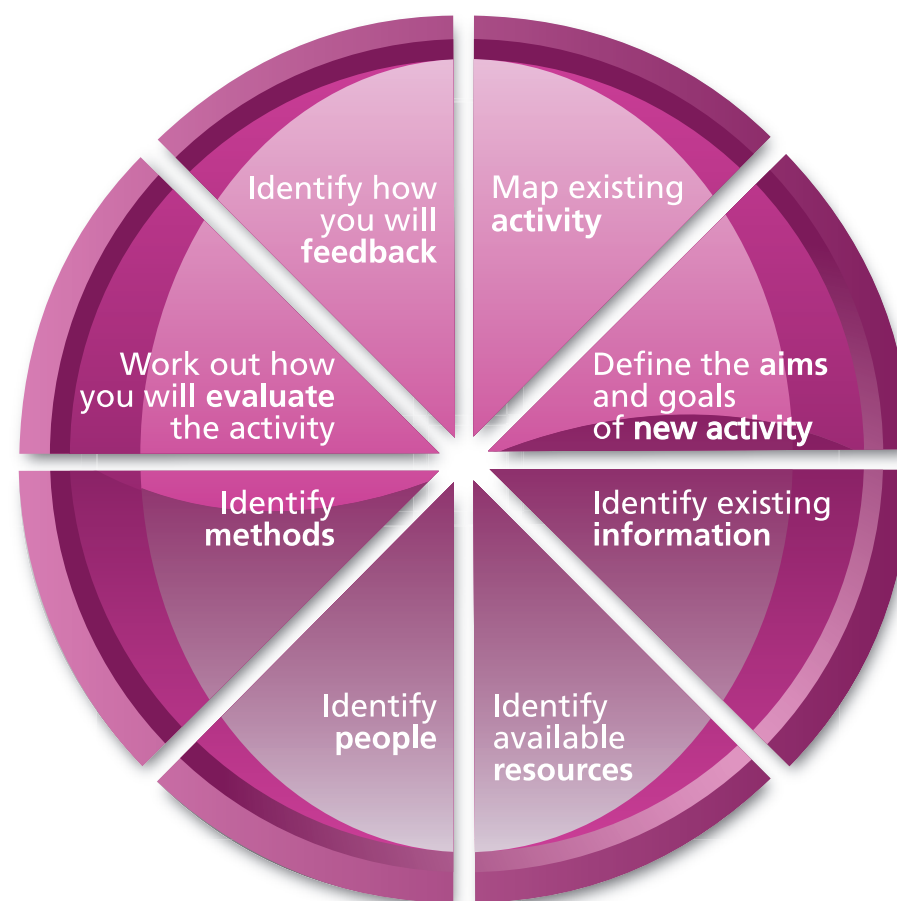
Patient and Public Involvement – driving forwards

Building any involvement system for developing, monitoring and evaluating health and social care services is complicated and takes time. In palliative and end of life care, involvement is even more challenging due to:

- difficulties in defining palliative care;
- physical and time limitations; and
- discomfort around discussing end of life issues.

In this section we present patient, carer and public involvement as a set of different phases and processes illustrated with examples from palliative and end of life care. We have called this the Patient and Public Involvement 'wheel'. It is based on the Patient and Public Involvement Cycle developed by Tritter et al (2003) and adapted from work we did in the field of urgent care. Carrying out the activities depicted in the wheel will drive forward improvements in palliative and end of life care, by enabling organisations to provide more responsive and appropriate services.

The Patient and Public Involvement Wheel



How to involve patients, carers and the public in palliative and end of life care

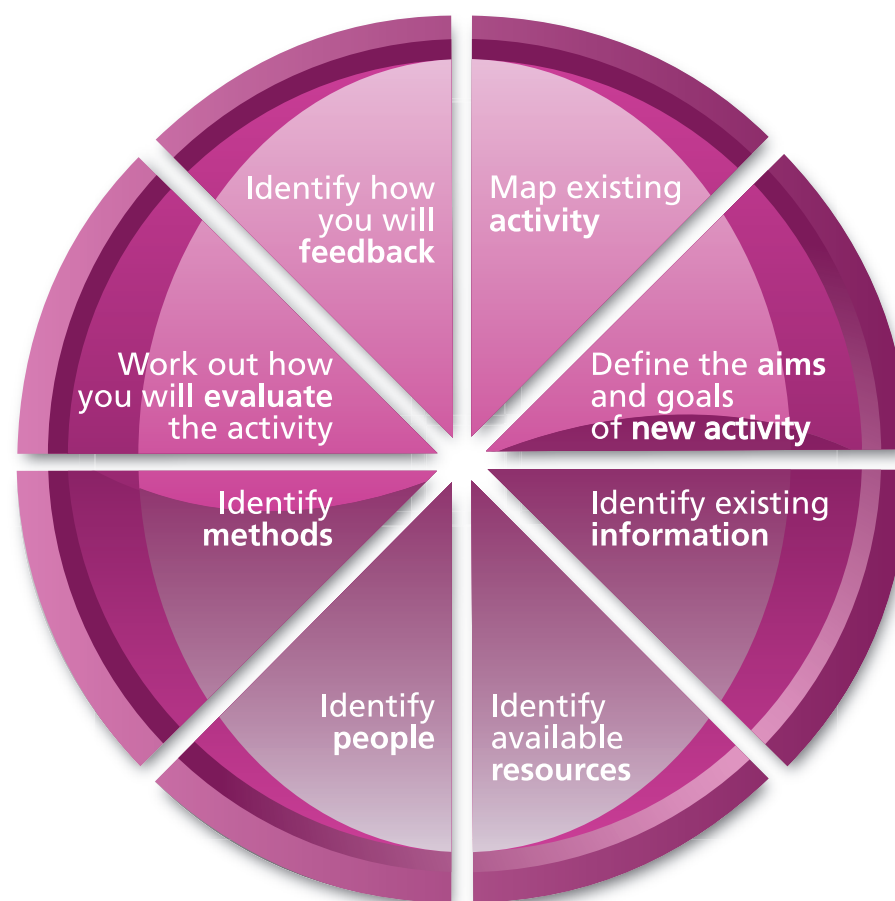
Maintaining momentum

In reality, there are likely to be many PPI wheels turning in your organisation at any one time. For example, at a macro level, you may be involving patients and carers in developing a PPI strategy for your entire organisation, and at a micro level you may be looking at patient and carer experiences in one particular ward or care home. The wheel is designed to be applied to each activity rather like a set of interrelated cogs. Some activities will be smaller than others and some will take place over a longer period of time. Progress in one area may help drive another forward, especially if lessons learned are documented and shared.

Documenting examples of the impact of PPI is important in breaking down myths about its irrelevance. After all, patients, carers and professionals generally share the same aim, which is to provide the best possible care for people who are nearing the end of life. Providing evidence of PPI's effectiveness in achieving this may fuel ongoing momentum. Having a 'champion' in each department and publicising successes is one way of doing this.

It is important to build accountability into your PPI processes. Without this, it may fall by the wayside. For example, in some organisations, PPI is an essential activity in all job descriptions and is assessed in appraisals.

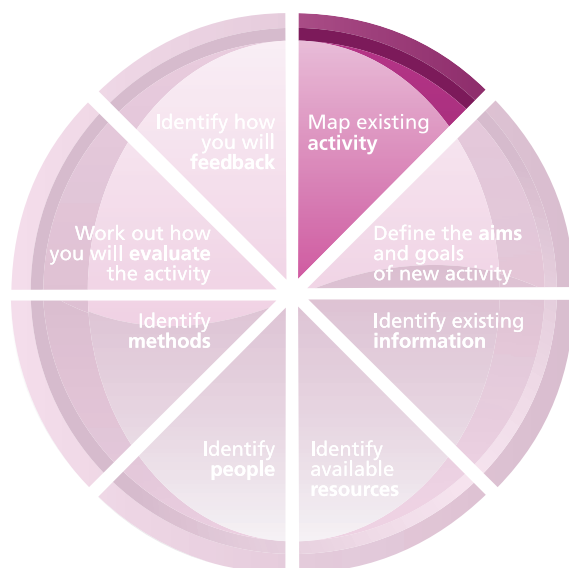
The Patient and Public Involvement Wheel



How to involve patients, carers and the public in palliative and end of life care

Phase 1

Mapping existing activity



All organisations need to know what Patient and Public Involvement (PPI) activity is going on within the services they provide or commission.

Undertaking a brief audit of involvement activity – say, over the last six months – will give you a good starting point for moving forwards

with new activity, will help to embed existing good practice and to identify existing capacity within your organisation. Auditing activity does not need to be complex, although using a short standardised form fed back to a co-ordinator can help generate a coherent database systematically and will make it easier to sort and share evidence and examples. It is important to note that PPI does not have to be on a large, formalised scale to 'count'.

Any attempt to learn what patients, carers and the public want from services is valid.

As a starting point, a simple grid, like the one in Figure 2.1, will suffice. There are also a range of available tools that can be utilised such as the checklist from 'Patient Insight: harnessing the power of public opinion'

www.drfoosterintelligence.co.uk/newsPublications/localDocuments/Patient_Insight.pdf

Figure 2.1%

Which service area?	What were the aims?	Which organisations did you work with (statutory, voluntary etc)?	What was the approach?	How was the work evaluated?	What was the outcome/ impact?	Lessons learned (what worked, and didn't work, how you would change this activity in future)?
Clinic	To improve information provision	Cancer Network, Patient Advice and Liaison Services (PALS), user forums.	Setting up a design panel of patients, carers and the public	Patient satisfaction survey	Improved information provision. Patients and carers more empowered.	Ensure that all involved are clearly briefed about what is being asked of them.

How to involve patients, carers and the public in palliative and end of life care

When auditing activity, it is useful to remember that PPI covers a spectrum of activity, including:

- participation in decisions about treatment and care;
- involvement in service development e.g. planning and design of services, commissioning;
- evaluation and audit of services;
- involvement in teaching;
- involvement in policy and strategy development;
- involvement in recruitment;
- involvement in research; and
- involvement in defining and shaping organisational priorities, direction and activities.

Therefore when you undertake your mapping, you should include activity from the whole spectrum of involvement activities. Below we have identified some sources of information that should be readily available to support your mapping and ongoing audit:

- Patient and staff survey data

- Data from complaints, concerns and compliments
- Feedback from commissioners and other key stakeholder groups
- Inspection data from e.g. Care Quality Commission, Internal Audit
- Clinical audit data
- Committee membership i.e. patient, carer or public representation
- Feedback through website
- Patient satisfaction/patient experience data (locally gathered – paper versions and electronic handsets)
- Comment cards (from patients and staff)
- Recent consultations
- Expert patients and carers involved in staff training
- Patients and carers involved in any research activity

Once you have completed your mapping, you should be in a strong position to identify where the gaps in your PPI activity are and this will

enable you to take steps to plug the gaps. You should be looking for a **balance** of activities in your map.

In Figure 2.2 we have included some of the essential **elements** of a good system and provided a couple of examples to help you with this idea. For example, you should have activity that is aimed at involving individuals as well as groups; you should be supporting involvement that is both direct as well as indirect and so on. We expand on these elements in the following sections of the guide.

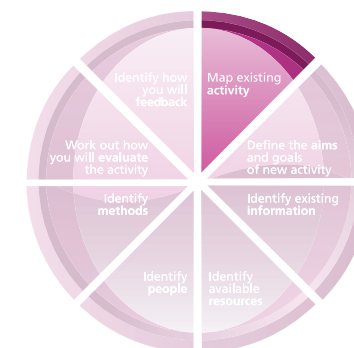
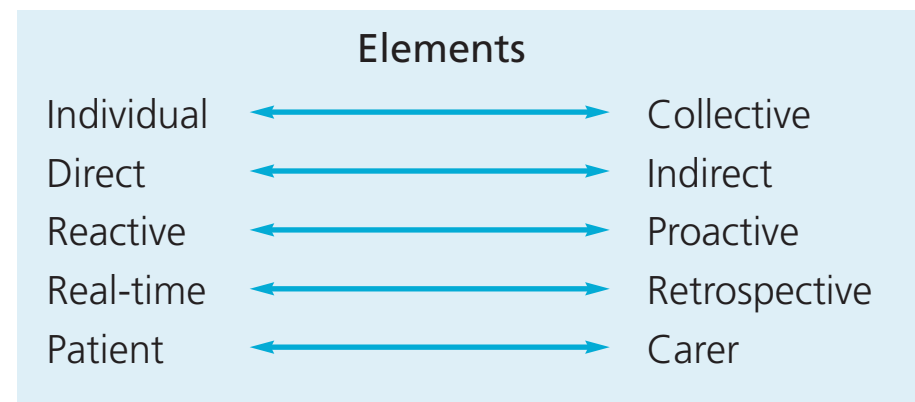


Figure 2.2



How to involve patients, carers and the public in palliative and end of life care

Examples

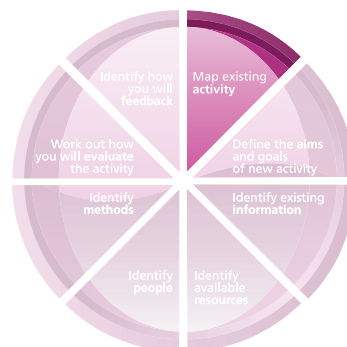
Involving a patient on a performance monitoring committee would be:

- individual;
- direct;
- proactive;
- real-time.

Using trends from carer survey data to plan service changes would be:

- collective;
- indirect;
- reactive;
- retrospective; and
- would capture carers' perspectives.

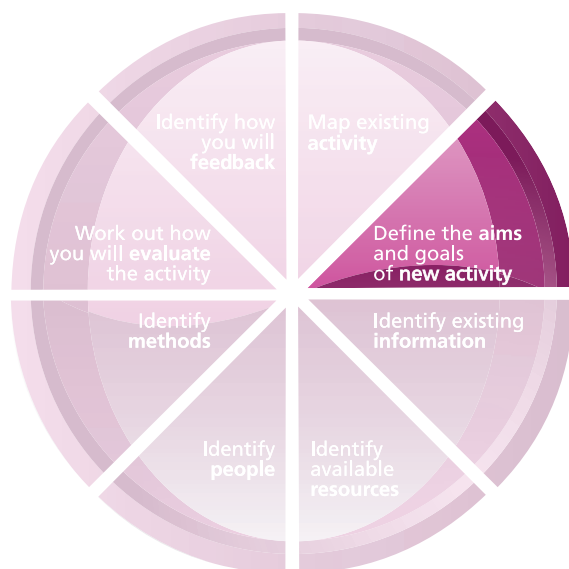
One final point – it really is worth keeping the map 'live' and adding to it on an ongoing basis. It is much easier to update your lists of activities regularly than to have to keep starting from fresh and you will find these lists enormously useful for all sorts of purposes (see page 7: 'Ten Benefits of Involvement').



How to involve patients, carers and the public in palliative and end of life care

Phase 2

Aims and goals



The next spoke of the Patient and Public Involvement (PPI) wheel focuses on clearly identifying the aims and goals of each involvement activity.

Key questions you need to consider in this phase are:

- Why are you involving people?; and
- What do you want to change, evaluate or develop?

Identifying why you are involving people is absolutely fundamental to becoming a good involvement organisation. We have seen examples in our work across the country where people have been motivated to volunteer to be part of a PPI group or system, but they are not then approached to 'do' or 'be' anything, and so, not surprisingly, become disengaged. We have also heard of situations where people have taken part in a consultation but found out later that the decision had already been made and so their input was worthless. In both cases, the emphasis has been upon recruiting people to be involved without giving thought to why. If, for example, government policy or financial constraints mean that there is only one choice, then do not involve

people on the pretext that there are different options for proceeding. It may be appropriate to consider a minimal change as one possible option. People will be cynical of involvement processes if they do not have a real say in outcomes. Having said this, they will respond more positively if they are fully-informed and understand why options are limited.

Equally, patients, carers and the public will be able to more meaningfully contribute to an activity which has clear aims or tangible outcomes. What is required of them should be clearly explained. For example, if involved in higher level activities such as developing policy or strategy will be easier to achieve if specific questions are asked. Without this, it can be difficult to know how to respond and feedback may be more general and less constructive.

How to involve patients, carers and the public in palliative and end of life care

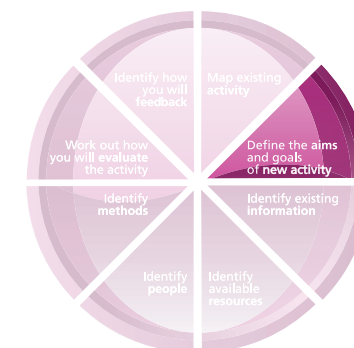
You should then be able clearly to answer the key question about **why you are involving people** e.g. 'we want to know what the experience of patients has been in x'; 'we want to know what people's expectations are about y'; 'we want to make sure that we have members of the public involved in prioritising our clinical audit programme so want representation on z committee'.

The next question to answer is **what do you want to change, evaluate or develop?** We mentioned in Phase 1 that there is a broad range, or spectrum, of reasons as to why you involve people from individual participation in treatment decisions to involvement in research. When answering this second question, think about where the involvement fits into the spectrum of activity (see page 18) and consider two further distinctions to help define your aims and goals:

Is this a continuous and proactive involvement activity, such as including members of the public on key decision-making groups within your

organisation or setting up a reference panel to support ongoing decisions about service redesign?; and

Is this an activity which is responding to a particular issue identified through audit or raised for example by the Local Involvement Network (LINK) (see Appendix I)?



How to involve patients, carers and the public in palliative and end of life care

Example:

NHS Bath and North East Somerset (BANES) PCT: 'Improving palliative and end of life care for people living with long term neurological conditions'.

The PCT's aim is to help individuals achieve their potential and improve healthcare, health and well-being, and to reduce inequalities. Within the area of palliative and end of life care they have three stated ambitions:

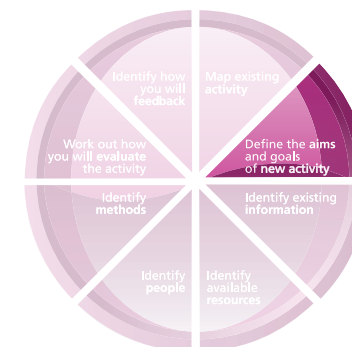
- *all those who need palliative care will have access to appropriate services regardless of diagnosis by 2009;*
- *the Gold Standard Framework and the Liverpool Care Pathway (listed in references) for the dying (or an equivalent) will be adopted in primary/community and secondary care settings respectively; and*
- *the number of people who die in hospital who had previously expressed a preference to die at home will be reduced.*

The PCT was approached by the Commissioning Support Service (CSS) to be one of its three national pilot sites. The CSS was established by the MS (Multiple Sclerosis) Society, the Motor Neurone Disease (MND) Association and the Parkinson's Disease (PD) Society to provide a wide range of management services to PCTs, Strategic Health Authorities (SHAs) and Adult Social Care Departments across England. The aim of the CSS is to work alongside commissioners so that people living with long-term neurological conditions are at the heart of analysing need, implementing strategy and monitoring the result.

To support these aims, a consultancy project was commissioned by NHS BANES and BANES council to undertake qualitative research into the end of life experiences of people with long-term neurological conditions. The report produced focuses on individuals' accounts of living with a long-term neurological condition and what their preferences

would be in facing end of life issues. It identifies a number of themes that arose and makes recommendations to enable Commissioners to use resources in the most effective way and improve care pathways for individuals.

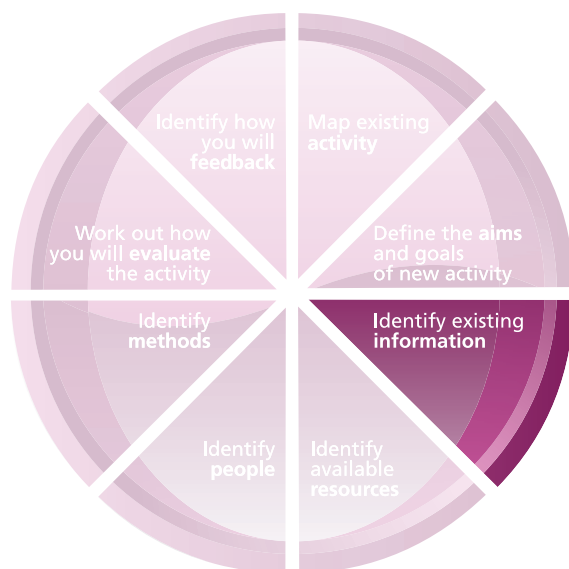
This is a good example of an involvement activity which had clear aims and goals, agreed collaboratively between statutory and voluntary sector organisations.



How to involve patients, carers and the public in palliative and end of life care

Phase 3

Identifying existing information



The third spoke of the PPI wheel is about identifying existing information relating to the activity in which you are seeking to involve people. This is an essential part of the involvement process in order to:

- avoid undertaking activities that are already taking place elsewhere;
- enter into an activity or process with the best available evidence to hand;
- identify what sorts of activities have been successful in the past;
- identify the types of activities which have been less successful; and
- identify the members of staff who have experience and expertise in involvement.

A good starting point is to make sure you are aware of legal and policy information that relates to the activity, large scale relevant research and any relevant public health or demographic data. You will find information about National Council for Palliative Care (NCPC) publications that relate to palliative and end of life care on page 14 and in the references section.

We refer again to the spectrum of involvement on page 18. If your involvement activity is about, for

example, the evaluation of services, then you would want to ensure that you have all the information available about that service such as:

- complaints, concerns and compliments data concerning that service;
- any incidents relating to that service;
- any central or local policy drivers relating to that area;
- any audit data relating to that area;
- any public health data relating to that area; and
- research about patient and carer experiences.

You will then be in a position to build an evidence-based evaluation process designed around what you now know are the issues you need to concentrate on.

The following brief example highlights the need to identify existing information.

How to involve patients, carers and the public in palliative and end of life care

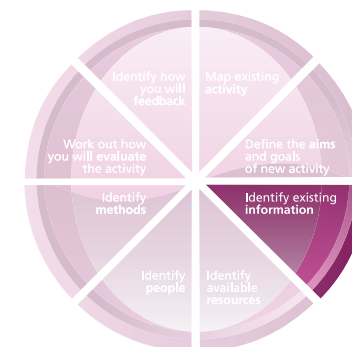
Example 1

West Hertfordshire Hospitals NHS Trust has three main sites: in Watford, Hemel Hempstead and St Albans. Although Hertfordshire is generally an affluent area, there are pockets of deprivation and areas such as Watford have a rich ethnic mix.

The Trust has been faced with a number of challenges as a result of its population base. One of the first things that triggered the community-based work around bereavement in this area was the number of complaints made about releasing bodies out-of-hours for burial. Islamic rules, for example, state that Muslims should be buried as soon as possible, and yet constraints around registering death were causing delay. As a result, a meeting was set up between the Trust, all religious leaders in West Hertfordshire and the coroner. The sharing of information, mapping existing pathways and barriers led to the development of a series of bereavement flowcharts which

provide clear information for staff in the Trust about what actions they must take when there is involvement from the coroner, a post mortem, a death in Accident & Emergency, releasing a deceased patient out of hours or cadaveric donation of organ, tissue or body.

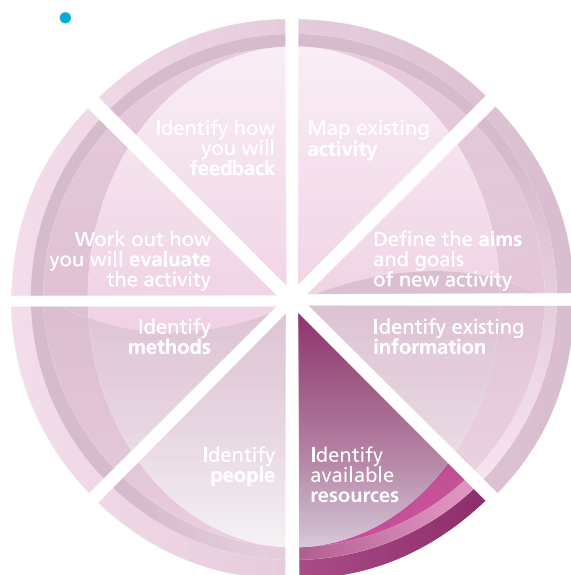
The stakeholder group continued to meet for several months after the development of the flowcharts to address a range of other issues around bereavement and has established an End of Life Care & Bereavement Steering Group, comprising modern matrons, macmillan nursing staff, senior sisters, spiritual & pastoral care, patient affairs staff, bereavement staff and the coroner. The aim of the group is to identify gaps in the community around bereavement and plan actions to address these.



How to involve patients, carers and the public in palliative and end of life care

Phase 4

Identify available resources



Involvement costs money. A dedicated and realistic budget is crucial to support involvement activities across an organisation. The last thing you want is to run out of funds part way through an activity. The fourth spoke of the PPI in palliative and end of life care wheel relates to identifying

resource requirements and you need to consider including:

- Staff time.
- Fitting the methods to the resources.
- Reimbursement of people's expenses/reward and recognition for their time.
- Support for staff and the people that you involve.

Staff time

Involvement activities do not have to be excessively expensive, especially if you plan consultations creatively. You may find that a significant resource requirement is staff time. It is fairly obvious that when you are planning your activity you need to make sure that all staff involved are clear about what they must do and deliver, by when and in what form. However, it is easy to forget about staff when you are focusing your efforts on getting patients involved. It is vital, for example, that you build into your activity things like staff annual leave. If you have a consultation closing on

a particular date, you also need to make sure the person or people who are going to analyse the feedback are available and have the capacity to complete the work.

It is also important to acknowledge colleagues' concerns about the validity of Patient and Public Involvement and work collaboratively to plan an approach that all 'believe in'. If user involvement does not have credibility for staff, they are less likely to be committed to associated activities, particularly if they are concerned about the sensitivities surrounding palliative and end of life care. You may, therefore, need to allow more time in order to carry out activities at a pace that is comfortable for all involved.

In this challenging area, patients, carers and staff need support and mentoring. It is important to allow time for planning this and carrying it out.

In addition, patient and carer attendance at meetings may be

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difficult or unpredictable. Therefore, extra time may be needed for one-to-one involvement or for rescheduled meetings.

In summary, PPI in palliative and end of life care may demand more staff time than in some other areas.

Fitting the method to the resource

We discuss more on methods of involvement on page 31. In an ideal world, the method would be chosen because it is the best and most sensitive way of involving people. However, most organisations have limited resources, and methods should be chosen that are consistent with the available budget and expertise. We have already outlined additional costs that may be incurred in this area of involvement, for example in providing staff, patient and carer support. One solution might be to consider exploring one or two areas in some depth rather than attempting large scale investigations, and support findings with qualitative data drawn from larger scale research.

It is also always worth considering if you can collaborate with other organisations or combine activities with other projects.

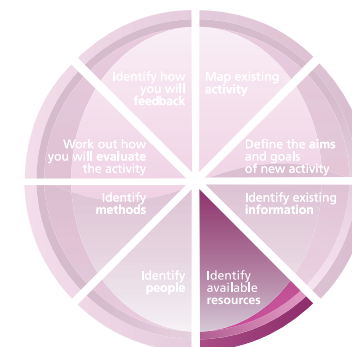
Example 1

NCPC worked with the British Lung Foundation (BLF) to explore the palliative and end of life care needs of people with Chronic Respiratory Diseases.

They circulated a questionnaire to patient and carer delegates at BLF 'Breatheasy' conferences throughout the UK. This was beneficial to both NCPC and BLF, allowing them to draw on each other's specialist skills to plan a sensitive approach in order to understand people's needs. There were limitations in that the sample of respondents was not predictable or controlled, and therefore representativeness could not be guaranteed. However, it is something that could be built upon, for example by carrying out focus groups or individual interviews.

Reimbursement of expenses/ payment

Organisations must make sure that people who get involved in your activities, and those who support them, for example, unpaid/informal carers, are not disadvantaged financially and should make provision to at least pay out-of-pocket expenses at the event; expecting a patient on income support to wait weeks to be reimbursed for a train or taxi fare is not acceptable. An organisational policy on reimbursement for PPI helps to demonstrate that participants are valued for the time they give to involvement work (see 'Reward and Recognition', Department of Health, 2006). The Volunteering England website contains excellent information about volunteer expenses on <http://volunteering.org.uk/Resources/information/on-lineinformationsheets/>



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Organisations should also consider whether it may be appropriate to pay people for their time. This may be particularly appropriate for ongoing forms of involvement, like membership of decision-making boards, in addition to cases where you want to attract people for specific purposes but are struggling to get people involved without an incentive. For example, in *Tower Hamlets* they have been very successful in attracting young people (typically a hard-to-reach group) by offering gift tokens.

Having said this, it is important to bear in mind that payment may affect benefits or tax. The User Involvement in Voluntary Organisations Shared Learning Group has produced a discussion document about the issues related to payment in user involvement www.user-involvement.org.uk/resource-centre.php?cat=1 'Impact of paying patients and carers for involvement'.

Support

Resources are about more than money and time. The staff, patients, carers and the public, undertaking or affected by involvement work, need to be supported and may need training. This is particularly the case where patients, carers or members of the public are engaged in ongoing activity within a palliative and end of life care organisation. At the NHS Centre for Involvement, we are encouraging members of the public undertaking formal PPI roles within organisations to use our 'Passport to Involvement' which highlights the need for patients, carers and members of the public to receive training and support for their roles.

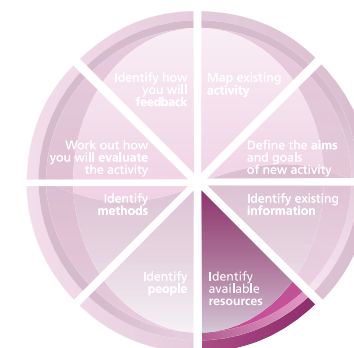
Organisations need to ensure that training needs (for staff, patients, carers and the public) are regularly reviewed as staff training is imperative to the success of PPI. It should be noted that patients and carers can be valuable and valued teachers of staff just as staff can be valuable and valued teachers of patients, carers

and the public. We have provided an exemplar below as well as a far reaching training initiative aimed at training trainers to support patients and carers make decisions about where to go for palliative and end of life care.

Example 2

The University of Sheffield: Development of a peer education programme for advanced end-of-life care planning.

This project aimed to develop an appropriate and effective method of informing older people about treatment and care options around the end of life. The purpose was to enable more informed decision-making about care. Older people from the local community were involved in the entire process, including research project meetings, commenting on and contributing to reports, facilitating discussions about end of life issues and taking part in pilot educational projects. They followed 'Involve' guidelines about



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payment www.invo.org.uk/pdfs/guidanceonpaymentstothepublicjuly%202008.pdf

for those involved, and paid an hourly rate via university payroll and transport costs. They let participants know that payments could affect tax/benefits.

Example 3

NCPC has a systematic process for supporting and training patients and carers. This includes providing contact details for a dedicated staff member to whom they can address any queries or concerns. Information about what they can expect of the organisation and what the organisation would value from them is outlined in documentation given to every new patient or carer. A training program provides further information about the organisation and how personal experiences can make a difference to national policy and strategy. Regular one-to-one meetings with patients and carers are held to ensure that they are happy with how things are going.

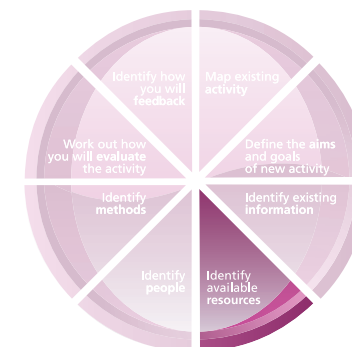
Example 4

'Trust me I'm a patient'

The 'Trust me I'm a patient' workshop is a powerful method of learning, and feedback from participants has been excellent. As of May 2009, 1708 employees in the NHS have attended 51 workshops. The delegates have ranged from the chair and chief executive of a PCT, NHS Trusts and Mental Health Trusts, through to frontline staff and patients.

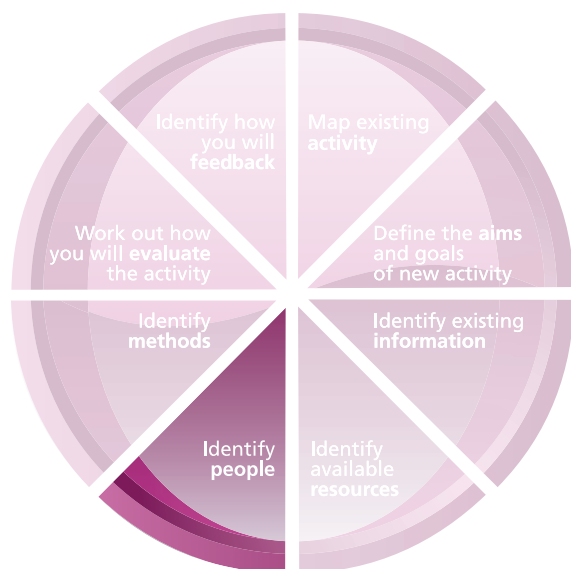
'Trust me I'm a patient' is an interactive workshop to help healthcare staff, managers and leaders in the exciting challenge of involving patients, their carers and the public. The sessions use drama and expert facilitation and run for approximately two to three hours. The workshop simulates real issues that managers grapple with every day about how to effectively involve patients and the public in local decisions and healthcare issues.

For further information on the workshops, see www.simplicityisthekey.com or contact trevor.simplicity@gmail.com



How to involve patients, carers and the public in palliative and end of life care

Phase 5 Identifying people



Once you have identified why you are involving people and what your budget is, decisions about the appropriate people to involve becomes a much easier question to answer. This is covered in the fifth spoke of the PPI wheel.

In the first instance those you wish to involve are likely to be in one or more of the following categories:

- patients, carers and former carers;
- potential patient or carers;
- the general public;
- members of local voluntary and community organisations;
- commissioners of services; and
- service providers and planners.

You can then segment these groups into smaller subsets by characteristics such as age, gender, known illness, occupation and so on. You will then need to decide on 'how many' of each category or groups you will involve. It is useful to consider phases 5 and 6 of the PPI palliative and end of life care wheel together, as the involvement method(s) selected need to be appropriate for the people you are intending to involve. The methods will also determine the number of people you will need to involve. For example, a questionnaire can reach a far larger number of participants than one-to-one interviews, but may not

be appropriate in the area of end of life and palliative care due to potential sensitivities of the subject area.

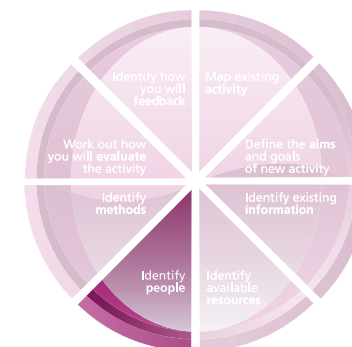
It is also important to ensure that those involved are clearly briefed and receive support and, where needed, training in order to effectively carry out tasks.

How to involve patients, carers and the public in palliative and end of life care

Example 1

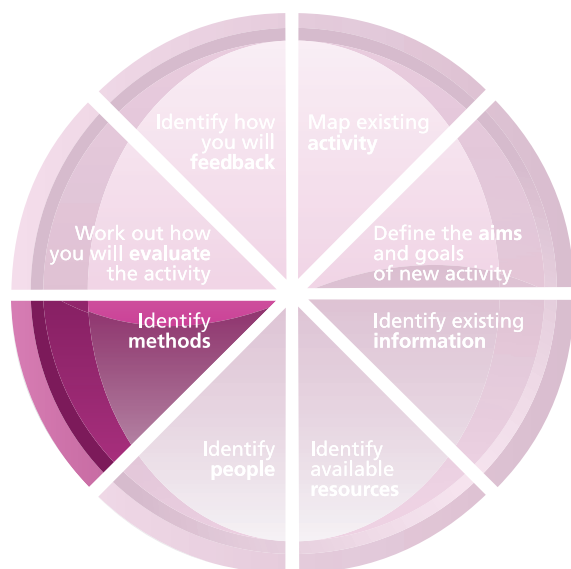
BANES PCT: Improving palliative and end of life care for people living with long-term neurological conditions

To carry out qualitative research into the end of life experience of people living with long-term neurological conditions to support the commissioning of excellent end of life care, the Multiple Sclerosis (MS) Society, Motor Neurone Disease (MND) Association and Parkinson's Disease (PD) Association identified and contacted individuals to take part. This resulted in 21 individuals being interviewed. Seven individuals with MS were seen in two Focus Groups. A further 13 individuals were seen in their own homes and one person was interviewed by telephone. The latter group comprised three people with MND, six people with PD and five carers. The project identified and involved a rich mix of people with a depth and range of experience who could meet the aims of the project.



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Phase 6 Identifying methods



Methods of involvement

In Appendix 2, we have included a summary of over 30 methods of involvement. You can find further information about how to use these methods at www.nhscentreforinvolvement.nhs.uk

As we have stressed before, the involvement process involves an integrated series of phases that build upon each other. Spoke six of the PPI wheel relates to your choice of method or methods. You will need to consider all of those questions identified in earlier phases:

- Why are you involving people?
- What are your aims and goals?
- What have you done before in this area?
- What has worked and what has not worked?
- What resources (money, people, time) do you have at your disposal?
- Which segments of the community do you need to involve?
- What are the characteristics of the people that you would like to involve?

What we are trying to stress is that the method or methods must match the qualities, preferences and attributes of the people you're trying to involve and the aims of your involvement. Most methods will need to be adapted so that they are accessible and to facilitate the most valid feedback. Combinations of methods will also be needed to ensure that a broad range of people's views are gathered. For example, methods that involve meetings should be complemented with methods that reach out to people in their own environment. Not everyone wishes, or is able, to attend meetings.

In all cases, prompt feedback should be given due to the time limited nature of end of life and palliative care. We have listed some common methods below along with issues that should be taken into consideration in palliative and end of life care.

How to involve patients, carers and the public in palliative and end of life care

Method	Benefits	Considerations
Questionnaires	Are good for gathering input from a wide range of people.	Careful consideration about wording is needed due to the potential sensitivity of the subject area. One-to-one interviews may be more appropriate.
Workshops	Are useful in bringing people from different backgrounds together for problem-solving, and can be used at various stages of service development.	Patients may have physical limitations and carers may have demands on time which affect their ability to travel or inclination to attend meetings.
Partnership Forums	A more formal, longer-term involvement method. Flexible e.g. can be made up of mixed groups, including professionals, patients and carers, and can include other stakeholders such as members of the public. They generally raise the profile of user perspectives within organisations and can have formal links with health and social care structures as well as acting informally in an advisory capacity.	People with life-limiting conditions may not be able to contribute on a long-term basis.
Technology-based e.g. email, web-based. SMS-based feedback, real-time tracking devices.	Enables people to provide anonymous feedback about their experience of services. Instant opportunities to give input from comfort of home. May provide a way for people with verbal communication difficulties to have a say.	May be a barrier to those who are not comfortable with technology. If anonymous, harder to provide feedback.

It can be tempting to stick with tried and tested methods of involvement. Don't be afraid to 'think outside the box' and try something new.

How to involve patients, carers and the public in palliative and end of life care

Example 1 National Council for Palliative Care (NCPC) 'Share your story' facility.

NCPC have developed an online facility to allow people who have experience of life-limiting conditions to share their stories. This information is then used to inform the direction of NCPC's work and good practice guides that are produced. It allows people to share their experiences any time of day or night from the comfort of their home
www.ncpc.org.uk/users/share_your_story.html

Example 2 Dove House Hospice

Dove House Hospice in Hull involves patients and carers in many activities. One patient was keen to attend the service user forum but was confined to her bed. Staff made arrangements for her to be transported to the meeting in her bed. Despite concerns that this may have been embarrassing for her and other group members, it was not a barrier, did not cause

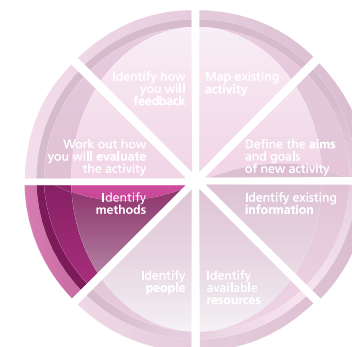
awkwardness and she was able to contribute actively. She was able to get involved in a meaningful way despite her physical limitations.

There are, of course, many times when a single method of involvement will not be sufficient and the nature of activity requires a mix of methods in order to maximise involvement. This is more likely to be the case when a system-wide engagement activity is planned. We provide a further example below where the NCPC investigated the palliative and end of life care needs of people with dementia.

Example 3 The palliative and end of life care needs of people with dementia

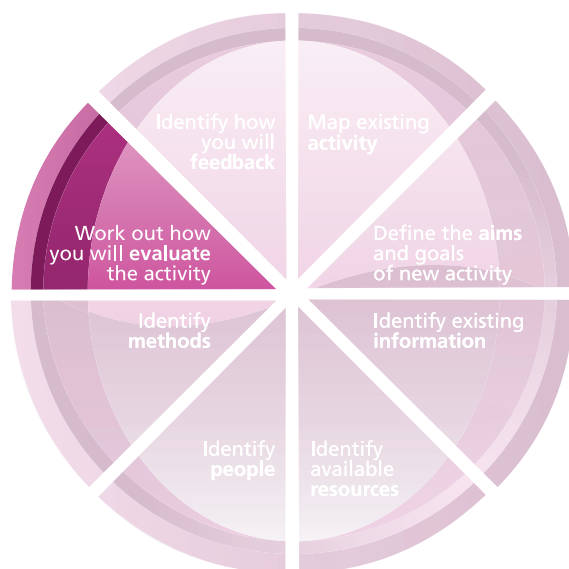
NCPC is carrying out a three-year project investigating the palliative and end of life care needs of people with dementia and their carers
www.ncpc.org.uk/policy/dementia
Workshops were carried out, in collaboration with The Alzheimer's Society, in order to explore concepts

of palliative care and what is important in end of life for people with dementia, from the perspective of people with dementia and their carers. To investigate the views of a wider sample of people, a questionnaire was developed and circulated to carers through For Dementia's 'Uniting Carers for Dementia' initiative and made available on NCPC's website. Over two hundred people responded, enabling NCPC to understand the views of a wide range of individuals. This example demonstrates how different user involvement methods can complement each other and allow more comprehensive exploration of patient and carer views.



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Phase 7 Evaluation



The seventh spoke of the PPI wheel concerns working out how you will evaluate PPI within your organisation. Illustrating the different PPI phases within a wheel emphasises very clearly that user involvement is a continuous process rather than a one-off activity. Evaluation is a crucial

aspect of PPI, although PPI involves complex processes, some of which are only apparent long after the actual involvement activity is finished and is not simple to measure.

A strategy for evaluation must reflect the previous phases of the wheel. Just as you choose a method of involvement that is fit for purpose, so you must choose an evaluation process that reflects why you are involving people (who), what the focus is (what) and using which methods (how).

Evaluation is absolutely fundamental to the other phases within the wheel. After you have planned your activity and implemented it, you **must** evaluate it to see if it has had an impact and whether that impact is an improvement. This not only helps you in your current work but will inform future activity. It also ensures that PPI remains credible to patients, carers and staff. The User Involvement in Voluntary Organisations Shared Learning Group has produced a

shared practice paper about evaluation of user involvement, available from www.user-involvement.org.uk/resource-centre.php

Logging lessons learned i.e. what worked and what didn't, as you go along will help with this process, allowing easy identification of trends and enabling you to continually improve on your involvement processes. See page 17 for an example of how this can be logged as part of the mapping exercise in phase 1. NCPC provides a facility in which you can share your experience of user involvement palliative and end of life care, in order that lessons can be shared www.ncpc.org.uk/users/share.html They plan to publish case studies to help others to develop their own user involvement in this area.

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Example 1 NHS Norfolk: 'Hearing patient and carer views on palliative and end of life care. An evaluation of successful and unsuccessful approaches'

Several NHS Trusts have worked with external research organisations to explore the palliative and end of life care needs of patients, carers and the public. NHS Norfolk worked with Ipsos Mori to identify learning points from both successful and unsuccessful activity. Some of the points raised were:

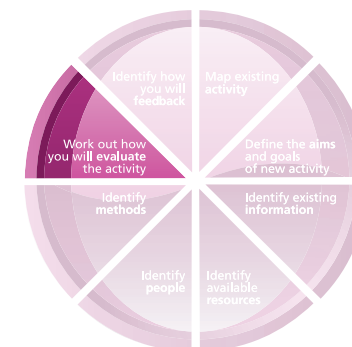
Recruitment

- The complexity of defining 'end of life'. When does this begin?
- Traditional recruitment methods, such as on street and door to door, are inappropriate and largely ineffective.

- Recruitment via health professionals will exclude those who are less engaged with services
- Suggestions:
 - The methodology must be flexible and sensitive to the needs of the patients and carers. For example, in-depth interviews may be more appropriate than discussion groups.
 - Recruitment via agencies and organisations with established relationships is likely to be useful.
 - Unconventional methods of research, e.g. the training of caring professionals as researchers, should be considered.

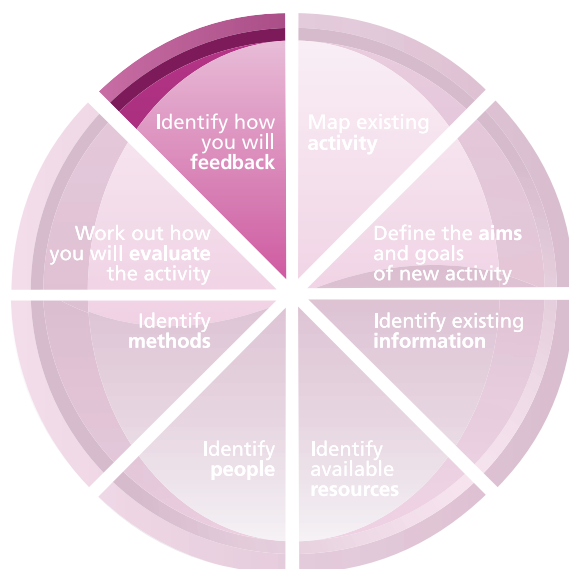
This, and other, learning points will be used to shape future PPI activity. You will note that this evaluation focuses largely on the methodology. As appropriate methodological approaches are developed, the impact of this engagement on services will also be evaluated.

In this case, one of the impacts of PPI was to enable both the Trust and research organisation learn from their approaches. This is a valid and worthwhile outcome in itself. PPI in this area is not impossible but does have its challenges. It is realistic and valuable for PPI activities to provide opportunities to learn about appropriate methodology. Measurable impact on services should not feel like the only beneficial outcome.



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Phase 8 Providing Feedback



The final spoke in the PPI wheel focuses on developing appropriate ways of providing feedback about involvement activity to patients, carers and staff. It is of fundamental importance when planning effective PPI and should be considered early on in the planning process. Effectiveness

of feedback processes should also be evaluated on a regular basis.

It is similar to evaluation in that providing feedback will help to maintain credibility for PPI activity by showing that the views of patient and carers are listened to, and that it is not tokenistic.

This should take place at two levels:

- targeted feedback; and
- generic, routine and regular reporting.

Targeted feedback

All who participate in PPI activities, i.e. patients, carers, members of the public and staff, should routinely receive feedback about initiatives in which they involved, explaining the outcome and impact of their involvement and, where necessary, explaining why it was not possible to implement their suggestions.

Feedback that is specific to participants who have, for example, contributed to a consultation or who have participated in a focus group

about a service redesign proposal needs to fit the purpose of the consultation or activity. Ideally, you should make sure that, if individuals have made the effort to write to you with their views on a personal level, you make the effort to reciprocate and respond personally. It is also important to provide prompt feedback in view of the unpredictable nature of life-limiting conditions.

General and routine feedback.

Where involvement has been on a more generic or anonymous basis, it is still important to report the impact of involvement. In this case, standard methods of reporting, for example board papers, websites or notices could be used.

We mentioned in the first part of the guide that there are benefits of doing PPI which relate to meeting quality requirements, standards, targets and so on. Developing a system of regular reporting about PPI to your organisation's Board (or equivalent body) provides evidence of the types

How to involve patients, carers and the public in palliative and end of life care

and intensity of activity and can help provide a basis for informed decision-making. This demonstrates that PPI is being considered at the highest levels within the organisation. Board papers of health and social care organisations and most equivalent papers from independent sector organisations will often be made public via websites, and this permits members of the public to get feedback about their own and others' involvement in the organisation, if they know where to look. It is good practice for senior managers to take time to thank those who have made valued contributions to the organisation, for example publicly at Board meetings, or personally and periodically in writing.

Other forms of routine feedback can be linked to how information is gathered and whether it is anonymous. For example, in a clinic you can have a comment box and then regularly review comments and respond to them by placing the organisation's response above or near to the comment box. It may be appropriate to complement this by

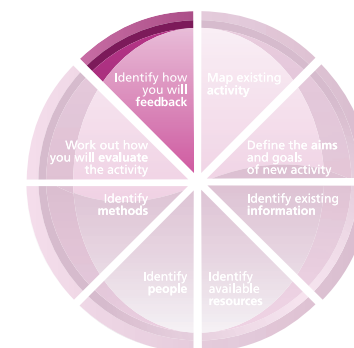
providing information on a website to allow access for those who cannot physically visit the clinic.

Example 1 St Christopher's Hospice

In view of the changing nature of patients' conditions, St Christopher's Hospice endeavours to feed back on suggestions and questions as soon as possible. For example, following the User Forum, they write up proceedings in detail, including themes, concrete suggestions and quotations. This is presented to heads of department. A letter is then written to each of the patients/carers who attended the Forum on action being taken and verbal feedback is provided at the next Forum meeting.

Example 2 NHS Hull

NHS Hull has introduced a simple leaflet which is called 'You say...we hear'. It provides feedback on comments received by the Primary Care Trust and how these have influenced services. Feedback is received via comment cards (postal and online), subscription to Patient Opinion, PALS, and surveys, as well as through consultation. This leaflet enables the PCT to share the changes they are making as a result of feedback with the individual as well as a wider audience. In other words, it provides a two-way feedback process.
See www.hullpct.nhs.uk



References, further reading and resources

Anderson, E., Tritter, J. and Wilson, R. (eds.)
Healthy Democracy: The future of involvement in health and social care.

Involve and the NHS Centre for Involvement November 2006.

Black, J (2009)
User involvement in EOLC: How involved can patients/carers be?
End of Life Care; 2:4. 64-69. London

Department of Health (2006)
A stronger local voice: a framework for creating a stronger local voice in the development of health and social care services.
London, Department of Health.

Department of Health (2005)
Commissioning a patient-led NHS.
London, Department of Health.

Department of Health (2007/08)
WCC Assurance Framework.
London, Department of Health.

Department of Health (2005)
Creating a Patient-led NHS: Delivering the NHS Improvement Plan.

London, Department of Health.

Department of Health (2008)
The End of Life Care Strategy.
London, Department of Health.

Department of Health (2006)
Health reform in England: update and commissioning framework.
London, Department of Health.

Department of Health (2005)
Health Reform in England: Update and next steps.
London, Department of Health.

Department of Health (2006)
Our health, our care, our say, a new direction for community services.
London, Department of Health.

Department of Health (2006)
Our health, our care, our community: investing in the future of community hospitals.

London, Department of Health.

Department of Health (2007)
World Class Commissioning: competencies.
London, Department of Health.

Department of Health (2007)
The Operating Framework for 2008/09.
London, Department of Health.

Gay, T (2007)
Ten Great Myths of Patient and Public Involvement, 2007
available from:
www.simplicityisthekey.com

Gold Standards Framework.
www.goldstandardsframework.nhs.uk/background_to_gsf.php.

Healthcare Commission (2008)
Spotlight on complaints.
London, Healthcare Commission.

Home Office (2004)
What works in community involvement in area-based initiatives: a systematic review of the literature.
London, HMO

Liverpool Care Pathway.
www.mcpcil.org.uk/liverpool_care_pathway.

Local Government and Public Involvement in Health Act, 2007
(particularly Section 233).

National Assembly for Wales and OPM (2001)
Signposts One A practical guide to involving the public and patients in Wales.
www.wales.nhs.uk/publications/signposts-e.pdf

National Assembly for Wales and OPM (2001)
Signposts Two. Putting public and patient involvement into practice in Wales.
www.wales.gov.uk/subihealth/content/nhs/signposts/signposts2-e.pdf

National Audit Office (2006)
National Audit Office report on the provision of out-of-hours care in England.
London, NAO.

National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (2003)
User involvement in change management: a review of the literature.

National Health Services Act, 2006
(particularly Section 242).

National Institute for Clinical Excellence (2004)
Guidance on cancer services. Improving supportive and palliative care for adults with cancer: The manual.
London, NICE.

National Standards, Local Action: health and social care standards and planning framework, 2005/06-2007/08.
Health Care Commission.

NCPC (2004)
Listening to Users: Helping professionals address user involvement in palliative care.
London, NCPC.

NCPC (2008)
Listening to the Experts: A summary of 'user involvement in palliative care: A scoping study'.
London, NCPC.

Patient Insight (2008) Harnessing the power of public opinion.

www.drfoosterintelligence.co.uk/newsPublications/localDocuments/Patient_Insight.pdf

Sanders C, Seymour J, Clarke A, Gott M, Welton M (2006)

Development of a peer education programme for advance end-of-life care planning.

International Journal of Palliative Nursing 12(5): 214–23

The National Leadership Network (2006)

Strengthening Local Services

Trent Strategic Health Authority (2005) Principles for Practice

Involving service users and carers in healthcare education and training.

Tritter, J, Daykin, N, Evans, S and Sanidas, M (2003)

Improving Cancer Services Through Patient Involvement.

Radcliffe Medical Press.

Resources

www.ncpc.org.uk/users/resources

This website contains links to websites and documents which may help when approaching PPI in this area.

The work to develop this guide was undertaken by Dr Jayne Taylor and Professor Jonathan Tritter from the NHS Centre for Involvement and Jo Black from the National Council for Palliative Care.

We would like to thank the Urgent Care team at the Department of Health who funded the work around the development of a user guide and who gave permission for NCI to use the design work from that project. We would also like to express our sincere thanks to the members of the NCPC service user advisory group and NCPC staff for their contribution to this document and the organisations that allowed us to use examples of their work.

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Local Involvement Networks (LINKs)

Information contained within this appendix is based on a series of fact sheets and guidance which can be found at

www.nhscentreforinvolvement.nhs.uk

Local Involvement Networks will be set up in all Local Authority areas with social service responsibility by 1st October 2008. Once the LINK has been set up, it (the LINK), will need to work in different ways with local Primary Care Trust commissioners, and with health and social care providers of services.

The relationship between LINKs and commissioners needs to include the following functions:

1. Using the LINK as a vehicle to consult with local people about their experiences of health and social care.
2. Using the LINK to consult with local people about proposed changes to the commissioning of health and social care.
3. Responding to the LINK formally when they request information

about a particular health [and social] care issue that has been generated by local people and adopted as a LINK issue.

4. Responding to the LINK formally when they raise a particular health or social care issue.

The LINK and organisations that provide services will need to develop a relationship to include the following functions:

1. Providing information to the LINK about, for example, complaints and incidents and other data when they are requested, to help inform the LINK about an emerging issue (an issue raised by a member of the public or an organisation).
2. Complying with requests to enter and view premises (this might be when a LINK is exploring an issue to take to the commissioners and they are seeking additional observational data). Trained LINK members will be able to make unannounced visits, as long as the visit does not disrupt services. There are also provisions

about not using enter and view powers to go into any premises that constitute a patient or individual's home (e.g. a LINK can go into communal areas of a nursing home but not into private rooms; a LINK cannot go to the home of a Looked After Child).

3. Using the LINK as a vehicle to demonstrate to commissioners that they have consulted on substantial proposed variations to service change. Good practice would indicate that Provider Services might want to consult routinely on any proposed variation (substantial or otherwise) that will have an impact on patients or the public.
4. Using the LINK to involve local people in monitoring services.
5. Using the LINK as a means to demonstrate to Care Quality Commission (the watchdog that has replaced the Healthcare Commission) that it has consulted and involved local people in monitoring and developing services.

Local Involvement Networks (LINKs)

The host organisation is responsible for establishing the LINK and will look at how these functions will work in practice in consultation with commissioners and providers. Other things that the LINK must consider are:

1. how it will decide if it should take on an issue that is brought to its attention;
2. how it will log issues that are brought to its attention; and
3. how it will raise these issues with providers and commissioners.

LINKs are expected to produce an annual report outlining their activity throughout the year, and the host will need to provide accounts of how it has allocated resources.

There is a great deal of further information about LINKs available on the following websites:

www.nhscentreforinvolvement.nhs.uk

[www.dh.gov.uk/
patientpublicinvolvement](http://www.dh.gov.uk/patientpublicinvolvement)

Methods of Involving People and Groups

The methods below are taken from many areas of Patient and Public Involvement (PPI). We would like to hear about how you have used them in palliative and end of life care environments. If you would like to tell us about your experience of PPI in palliative and end of life care, please go to www.ncpc.org.uk/users/share.html

Strategy	Key Attributes
Publications, media releases and displays	Written with no requirement for dialogue, but can provide information on how consumers can participate.
Patient charters/constitutions	Written statements setting out what patients and customers should expect. These should specify service conditions and provide pathways for complaint and possibly redress for consumers.
Use of art in involvement	Anything from large scale public art projects to small events. Can be used in conjunction with other methods and aims. Useful way of engaging with people who are reluctant to express views.
Use of theatre in involvement	Anything from large scale to small events. Useful way of triggering views through the use of scenarios and story telling.
Consumer friendly administrative procedures	Reviewing and reforming administrative communication with consumers to encourage Patient and Public involvement and partnerships for health.
Project groups	Instigated by organisations to advise on specific issues and / or to guide a project. Time limited. May be used to demonstrate the value of Patient and Public Involvement to key players.
Surveys (questionnaires)	Means of gathering information. Agenda set by organisations. Scope of information limited. Quantifiable, but you need to know what you want to ask and have an appropriate array of respondents.

Methods of Involving People and Groups

Strategy	Key Attributes
In-depth patient interviews	Extended, semi-structured (usually) face to face interviews. Provides rich information from selected consumers. Useful as a follow up to surveys to explore particular issues and / or for specific population groups, but time consuming.
Focus groups	A facilitated discussion with usually about 6-8 people for 30 minutes to 2 hours. People can be invited on basis of who they are and what they can contribute to discussion. Interactions among participants can help explore issues rapidly and in depth. Used for information collection focused on a specific issue (not for decision making) and can include various examples and props. Provides rich information, but may not be representative of all consumers.
Submissions	Oral and written presentation of views. Dialogue limited. Can attract consumers who are organised and in a position to put in a submission. Less articulate / literate, non-English speaking background and / or socially disadvantaged consumers may be excluded.
Delphi technique	Formal process using a series of mailed surveys to selected individuals. Used for building consensus across consumers with conflicting views. May be useful for particular groups of stakeholders on specific contentious issues, but relies on good literacy skills.
Nominal group techniques	Small group process for clarifying priorities. May be useful for consumer involvement in identifying priority issues, allocating scarce resources etc. However, does not allow for much in depth exploration of the issues.
Suggestion boxes	Easy to implement, but may be limited in obtaining useful feedback. May attract negative and unhelpful comment. Only for use in conjunction with other strategies. Responses limited to those with time and literacy skills.

Methods of Involving People and Groups

Strategy	Key Attributes
Hotlines and phone-ins	Information gathering. Relies on publicity and the phone being attended. Works best with skilled staff or volunteers to answer. Attracts respondents fairly indiscriminately.
Text (SMS) messaging	Information gathering. Useful for getting feedback from young people.
Complaints handling	Response to consumer feedback and complaints. Valuable resource because restricted to consumers who have identified possible area for service improvement. Requires staff understanding of the value of complaints. Not representative of patient experience or necessarily the worst service experience.
Responding to users initiatives	How your organisation/team responds to inquiries or requests initiated by consumers. Developing clear policies, processes and skills to be 'response-able'.
Workshops	Working meeting usually of 8-12 consumers, possibly with providers, to share information and to develop a shared approach to a specified issue. Participants usually have been selected on the basis of particular skills, knowledge or experience. Requires informed participants.
Patient advocates / consultants	Health care organisation employs person to consult with consumers and advocate on their behalf for service improvement.
Promotions and campaigns	Ways to get information out. Can be innovative and creative and can involve consumers, possibly through consultation in planning and partnerships in implementation.
Search conferences	Meeting of 30-50 invited people. Investigates a subject / issue in a planned manner. May use discussion paper as starter. Asks specific search question. Wide range of views canvassed. Answer(s) expected as outcome.

Methods of Involving People and Groups

Strategy	Key Attributes
Public inquiries and hearings	Instigated by organisations. Formally set terms of reference. Receives public submissions, oral and written. Formal and possibly intimidating. Likely to exclude views of socially disadvantaged consumers.
Distributing discussion papers	Written presentation of information for discussion. No dialogue involved unless structured. May, however, be used as precursor to public meetings or other discussion.
Public meetings and forums	Audiences usually over 20 people. Meeting structured to canvass views and / or debate an issue. Representatives, nominated by consumer groups / associations. Open to public.
Seminars and conferences	Instigated by organisations to explore ideas / issues. May cost and, therefore, be restricted to those who can pay. Audiences over 20 people. Format structured. Informal or spontaneous input may be restricted, tending to give providers / professionals more 'air time' than consumers / community.
User councils, panels and reference groups	Structure and role prescribed by organisation but should be negotiated and written down. Input to whole organisation based on advice from consumers. Need to ensure and support user representative links with appropriate constituency. Representatives need to have tenure long enough to learn to be useful, but not so long that they become part of organisation.
Policy round tables	Invitations to discuss policy items. Structured. Convened to advise on the development of specific policy and implications.

Methods of Involving People and Groups

Strategy	Key Attributes
Stakeholder representatives on your committees	Informing, training and supporting, stakeholder representatives. Ensuring they have a relationship with their constituency. Negotiated and recorded roles and terms of reference for all members of the committees that they sit on. A medium to long term investment.
Advisory committees	Usually up to about 15 members. Role is to provide input on an issue / subject on the basis of expertise about an issue / experience. Members can be appointed or elected. Usually limited terms.
Patient panels	Patients invited to focus on an area / issue. Usually structured.
Facilitating mutual support groups	Support to assist people, on their terms, about their issues. Groups can be consulted about service improvement. Clinicians can enter into partnership with groups as expert advisers.
Negotiation partnership	Patients, members of the public and providers work together to develop a written agreement as a basis for future process. May be part of consumer initiated participation. Requires clarity of objectives and good communication skills.
Networking	Informal relationship building with people who have common interests on goals. Will include building links to consumer organisations, advocacy groups etc.
Partnership of consumers and providers	Structured cyclical planning process with specified role for consumers in shared decision making with providers. Process and outcomes are a shared responsibility. Usually the result of years of development of Patient and Public Involvement and a strong consumer focus and culture in the organisation.

Methods of Involving People and Groups

Strategy

Key Attributes

Electronic logs (Blogging)

Patients and members of the public provide on-going continuous dialogue through web-site. May be consumer initiated. Informal relationship building with people with common interests or goals.

My Space

Patients and members of the public can provide feedback in an anonymous form. Useful to receive feedback about sensitive areas of service provision or where patients do not want to be identified because of the nature of their attendance e.g. sexual health and pregnancy conditions.

Terminology and definitions

Terminology

The following terms are used throughout this document:

Patients, carers and the public

there are many terms that describe those with personal experience of palliative and end of life care. For example, 'service user', 'user', 'patient' and 'carer'. In this guide, the National Council for Palliative Care (NCPC)'s service user advisory group opted to use the terms 'patient', 'carer' and 'public'.

Carers

'carer' refers to people who provide unpaid or informal care for someone who has a life-limiting condition, or who is drawing near the end of life.

Patient and Public Involvement (PPI)

this is still the prevailing term of choice in other areas of health and social care, describing the involvement of patients and the public in the development of services. The PPI wheel was developed outside the area of palliative and end of life care. For consistency with other

guides, the title is retained. In this document, the term 'PPI' is used interchangeably with 'patient, carer and public' involvement.

Definitions

Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments (National Institute for Clinical Excellence [NICE], 2004).

Palliative care incorporates end of life care, but, as these terms are sometimes used interchangeably, the following definition is provided:

End of life care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and

palliative care needs of both patients and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support ('End of Life Care Strategy', Department of Health 2008, p47).

For further information about PPI, please see the NHS Centre for Involvement (NCI) website:
www.nhscentreforinvolvement.nhs.uk

For further information about palliative and end of life care, see the National Council for Palliative Care (NCPC) website:
www.ncpc.org.uk

Glossary of terms and acronyms

Term	Description
BANES	Bath and North East Somerset
BLF	The British Lung Foundation
CSS	Commissioning Support Service
DH	Department of Health
LiNK	Local Involvement Network
MND	Motor Neurone Disease
MS	Multiple Sclerosis
NAO	National Audit Office
NCI	The National Centre for Involvement
NCPC	The National Council for Palliative Care
NHS	National Health Service
NICE	National Institute for Clinical Excellence
OSC	Overview and Scrutiny Committee
PCT	Primary Care Trust
PD	Parkinson's Disease
PPI	Patient and Public Involvement
SHA	Strategic Health Authority
SMS	Short Message Service. Also known as text message.

User Involvement in palliative and end of life care - Practical Educational Tool (PET)

This PET is a Practical Educational Tool developed to support better Patient and Public Involvement (PPI) and engagement in palliative and end of life care.

*It is available from
www.ncpc.org.uk/publications*

It is designed for:

- Higher and Further Educational Institutions to support teaching about involvement in pre- and post-qualifying curricula;
- NHS and Social Care Organisations to support their in-service education programmes;
- Voluntary and Community organisations to provide training in PPI;
- Schools to support the Personal and Social Education (PSE) curriculum; and
- Local Involvement Networks (LiNKs) to support their members.

What does it look like?

Material from this guide has been used to produce the following educational materials:

- a lesson plan, including the aims and objectives of the lesson;
- a teacher guide;
- handout(s);
- a reading list;
- a PowerPoint presentation (available in hard copy and on a CD rom);
- an evaluation form;
- a Knowledge and Skills Framework (KSF) mapping grid; and
- a version control grid.

PETs might additionally include:

- case study material;
- model documents;
- practical exercises; and
- video and/or audio material.

User involvement in palliative and end of life care guide feedback form

We'd like your feedback!

I found this guide useful because:

I would have liked more of:

I would be interested in receiving information about the following:

- ☐ Study days about user involvement in palliative and end of life care
- ☐ Future NCPC publications/toolkits on this topic
- ☐ NCPC publications about palliative and end of life care

Subscribing to NCPC

If you would like a copy of the Practical Educational Tool, please go to www.ncpc.org.uk/publications

Please return this form to:

NCPC,
The Fitzpatrick Building,
188-194 York Way,
London N7 9AS

Email: enquiries@ncpc.org.uk
Telephone: 020 7697 1520

This guide has been written with providers of end of life care services as its prime audience. Commissioners will however find the guide useful in enabling them to understand the types of PPI that service providers could and should be providing.

We are aware that not all staff are yet familiar with Local Involvement Networks (LINKs) and so have included a brief review in Appendix I of this Guide.

All PETs are available on NCPC's and the NHS Centre for Involvement's websites:
www.ncpc.org.uk/publications
www.nhscentreforinvolvement.nhs.uk

Teachers are advised to check that they have the most up-to-date version of the tool so that learners receive the most up-to-date information.

CARE TO LEARN

The NCPC End of Life Care Training Programme

Many people feel scared and overwhelmed when caring for people at the end of their lives. By providing staff with fundamental skills as an integral part of good care and support, we can improve people's quality of life at the end of life.

Care to Learn is a module-based training programme which:

- Delivers introductory end of life care training for staff in all settings
- Follows the End of Life Care Pathway, from *Starting the Conversation* through to *Care after Death*, including support for carers and the Mental Capacity Act
- Is written by NCPC's acknowledged experts in the field: Lucy Sutton (Director of Policy Development) and Simon Chapman (Ethics Advisor)
- Offers eight modules that staff can complete in their own time and at their own pace, in groups or individually
- Contains a training book, work book and mentor's guidance book within a durable folder
- Can be expanded with future supplementary modules on specialist topics to create a comprehensive end of life care resource



CARE TO LEARN



Care to Learn is relevant to all staff caring for people at the end of life: in particular those working in care homes, housing organisations, other community settings and hospitals. It will also benefit hospice staff who deliver support and education to other services.

Care to Learn can be purchased singly or in the following multiples, with a further 10% discount on all orders for NCPC subscribers:

- 1-2 packs - £75 each
- 3-4 packs - £65 each
- 5-9 packs - £60 each
- 10 packs - £50 each
- 10+ packs - P.O.A.

For more details visit
www.ncpc.org.uk/training
 or contact Jenny Thurston
 on 020 7697 1520 or email
j.thurston@ncpc.org.uk



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Supporting quality of life at the end of life