

Liberating the NHS:

Greater Choice and Control

Your response to the consultation questions

Your details (optional)	
Name *	Philip Satherley
Organisation	Compassion in Dying
Organisation type ⁺ : e.g. Public, patient, PCT etc	Charity or Voluntary organisation Other (if applicable):
Email *	Philip.Satherley@compassionindying.org.uk
Telephone *	020 7479 7736

Greater Choice and Control	
1. How should people have greater choice and control over their care? How can we make this as personalised as possible?	
2. Which healthcare services should be our priorities for introducing choice of any willing provider?	
3. How can we offer greater choice of provider in unplanned care?	
4. What would help more people to have more choice over where they are referred?	
5. Which choices would you like to see in maternity services and which are the most important?	
6. Are these the right choices for users of mental health services, and if not why not?	
7. When people are referred for healthcare, there are a number of stages when they might be offered a choice of where they want to go to have their diagnostic tests, measurements or samples taken. At the following stages, and provided it is clinically appropriate, should people be given a choice about where to go to have their tests or their measurements and samples taken: - At their initial appointment - for	

<p>example, with a GP, dentist, optometrist or practice nurse?</p> <ul style="list-style-type: none"> - Following an outpatient appointment with a hospital consultant? - Whilst in hospital receiving treatment? - After being discharged from hospital but whilst still under the care of a hospital consultant? 	
<p>8. Are there any circumstances where choice of where to go for diagnostic testing would not be appropriate, and if so what are they?</p>	
<p>9. Would you like the opportunity to choose your healthcare provider and named consultant-led team after you have been diagnosed with an illness or other condition?</p>	
<p>10. What information and/or support would help you to make your choice in this situation and are there any barriers or obstacles that would need to be overcome to make this happen?</p>	
<p>11. Is there anything that might discourage you from changing your healthcare provider or named consultant-led team - for example, if you had to repeat tests, wait longer or travel further?</p>	
<p>12. What else needs to happen so that personalised care planning can best help people living with long term conditions have more choice and control over their healthcare?</p>	<p>Compassion in Dying is a charity that focuses on research, education and advice on all aspects of the end-of-life process (for adults). Our charitable objectives are to conduct research and to provide advice, information and guidance to all those affected by the end of life; including patients, carers and health professionals.</p> <p>Compassion in Dying's expertise is in end-of-life care, therefore we will not comment on the issues raised in this consultation in general terms, but focus on those which impact on end-of-life care.</p> <p>Compassion in Dying agrees with point 2.30 which states: "We want everyone who lives with a long term</p>

	<p>condition to be able to make informed choices about their care and managing their condition. They should have an opportunity to discuss and ultimately agree a plan of how their care will be managed, expressing their preferences and making choices."</p> <p>The case study used in the consultation of Lorna who has diabetes, skin cancer, arthritis and mild heart failure reflects the lives of many people who have multiple conditions. It highlights how, in theory, personalised budgets can improve the day-to-day quality of life of individuals. The proposed plans to roll out a programme of support for all Primary Care Trusts (PCTs) must take into account any changes to the PCT system and money must be ring-fenced to ensure that plans to promote and embed choice have longevity.</p> <p>Furthermore, beyond personal budgets and planning day-to-day care support, people with long term conditions must be able to explore the options for current and future medical treatment with their healthcare team, be supported to record any decisions they make and be assured that the decisions they make will be respected.</p> <p>Important lessons can be learnt from the USA. Research by Schamp and Tenkku (2006) details the recording of Present Directives (such as levels of comfort care) and Advance Directives (such as Do Not Attempt Resuscitation (DNAR)) (1). In other words, the formal recording of care for now and care for the future. Their research found that, when these tools were used, the patients' wishes were respected in most cases.</p> <p>(1) Schamp R, Tenkku L (2006) Managed death in a PACE: Pathways in present and advance directives, American medical Directors Association7: 339-344</p>
<p>13. What choices are most important to people as they approach the end of their lives? What would best help to meet these?</p>	<p>At the heart of Compassion in Dying's work is the concern is that we should all have choice and control at the end of life. There are three key points at which the planning of end-of-life care should be formally discussed and recorded: 1) when an individual is healthy, but wants to record their preferences 2) when an individual is diagnosed with a terminal illness or long-term condition 3) when a person enters an end-of-life</p>

	<p>phase and decisions around issues such as place of death and the use of life-prolonging medical interventions become paramount.</p> <p>The consultation focuses on people being given a choice of where to die, with homes (including care homes) being the preferred option for most people. Dying at home can be achieved by ensuring that patients are not transported out of their home to the acute setting when they have recorded that they do not want to have particular life-prolonging medical interventions if they have lost capacity (or at any point).</p> <p>Patients can document treatment preferences such as DNAR and the refusal of artificial nutrition and hydration in Advance Decisions which are supplied, free of charge by Compassion in Dying (1). Advance Decisions are legally binding, in England and Wales, under the Mental Capacity Act 2005. Following the wishes detailed on an Advance Decisions means that the patient's treatment wishes are respected.</p> <p>Tools such as Advance Decisions or Lasting Power of Attorneys (LPA) need to be written into the detail of any plan to promote choice at the end of life. Place of care and death is an important choice, but existing work to develop this should not overshadow the fundamental and legal importance of decisions around refusal or consent to life prolonging treatment.</p> <p>As long as a person has capacity, refusal of life prolonging treatment – in person or in advance (in the event of a loss of capacity) – is already a right. Plans to evaluate how effective these tools such as Advance Decisions are, i.e. numbers of patients whose preferences were respected, needs to be conducted to ensure the choice is being implemented and acted upon effectively. This needs to be written into the proposals for establishing choice and control.</p> <p>(1) http://www.compassionindying.org.uk/</p>
<p>14. We need to strengthen and widen the range of end of life care services from. Which patients and carers can choose how can we best enable this?</p>	<p>Plans to establish a 'national choice offer' should be executed at a faster pace than suggested in the consultation. A review undertaken in 2013 would potentially mean that any new way of working would not be implemented until 2015. In</p>

the meantime thousands of people would continue to die in hospitals against their wishes. The Preferred Priorities for Care (PPC) tool goes some way to ensure that patients at the end-of-life in hospital choose where they are cared for and die (1) (2). However, this is for patients at the very end-of-life and not for those with long-term conditions living in the community.

Advanced Care Plans (ACP) are targeted at those already in end-of-life care, those with long term conditions or those in care homes (many of whom suffer from dementia). Treatment decisions made in an Advance Care Plan are only legally binding if expressed in an Advance Decision.

Conversations about end-of-life choices should become part of more social and healthcare practice, from diagnosis situations where there has been a diagnosis of a long-term/terminal condition, or as part of general care. This would ensure that real choice is embedded in general care, not just palliative care.

The End of Life care Strategy (3) highlights the need for locality registers, which could be used to coordinate care and record patient preferences onto official electronic systems: “For those approaching the end of life and for their carers, friends and families, it is important to access reliable sources of information as quickly as possible. Gaining access to information that is understandable and appropriate to the individual situation can reduce anxiety and enable and empower people to cope more effectively. Often, it is when people do not understand and have little information that they feel the most powerless and vulnerable.” (pg 74) (3)

End-of-life care can be daunting for anyone to think about (from those in palliative care, to those with life-limiting conditions who want to plan their end-of-life care, to the general public who want to document their treatment preferences but have no current health issues). Having consistent, accurate, up-to-date and clearly set out information available from a variety of sources would clearly help to lessen stress and anxiety.

Standardisation of systems for recording and acting-on patient wishes need to be initiated. This would ensure that patients' treatment preferences could be accessed at any time by healthcare professionals. There is the potential to include Advance Decision-type information on Summary Care Records (SCR), but this has not yet been realised. Pilot work has found that, where there is good integration of services and a strong IT infrastructure, there is the potential to upload patient information such as end-of-life wishes (4). However, the future of SCRs appears to be unstable. In the absence of Advance Decisions and LPAs being recorded on SCRs, there should be clear signposting to organisations (such as Medic Alert) which record patient treatment preferences and allows healthcare professionals 24 hour access to important information.

On a positive note, locality registers for recording patient end-of-life preferences and care plans are being developed across England (5) and ACP is becoming more common as a means for ensuring patients have a good end-of-life experience. However, only information detailed on an Advance Decisions which is incorporated into an ACP is legally binding.

Research into the promotion, uptake and impact of Advance Decisions and LPAs needs to be conducted to ensure they can impact positively on people's lives.

General awareness of end-of-life issues is lacking in many of those healthcare professionals who do not deal directly with palliative patients and those with long-term conditions. Education and on-going training needs to be implemented effectively across the board if good care planning etc. by healthcare professionals is to become a reality.

(1) Wood J (2007) Preferred place of care: an analysis of the 'first 100' patient assessments (Letter to the editor), *Palliative Medicine* 21: 449-450

(2) Newton J, Clark R, Ahlquist P (2009) Evaluation of the introduction of an advanced care plan into multiple palliative care settings, *International Journal of Palliative Nursing* 15(11): 554-561

	<p>(3) Department of Health (2008) End of Life Care Strategy</p> <p>(4) Tait C, Braunold G, Jeeves R, Hopwood L, Thick M (2009) Summary Care Record - the Bury experience European Journal of Palliative Care 16(3): 124-126</p> <p>(5) Department of Health (2010) End of Life Care Strategy: Second Annual Report</p>
<p>15. Carers may sometimes feel that they themselves have no choice when the person they care for chooses to die at home.</p> <p>How should the respective needs and wishes of patients and carers be balanced?</p>	<p>Carers need to be involved in conversations and decisions about their loved ones so that their input can inform the delivery of care. In relation to a carer's loved one wanting to die at home, carers need to have good information about home care services available and the support available to them. Carers and patients need realistic information about the choices, benefits and challenges of dying at home with a particular condition. Health care professionals need to be able to assess and balance the best interest of both patient and carer when a patient is thinking about being cared for and dying at home.</p>
<p>16. What sort of choices would you like to see about the NHS treatment that you have? Treatment could mean therapy, support for self-management, medication or a procedure like surgery.</p>	
<p>17. How can we encourage people to take more responsibility for their health and treatment choices?</p>	

Shared Healthcare Decisions	
<p>18. How do we make sure that everyone can have a say in their healthcare?</p>	
<p>19. How can we make sure that people's choices can reflect their different backgrounds - whether ethnic, religious or any other background that could affect their healthcare preferences?</p>	
<p>20. How can we make sure that carers and the families of patients and service users can have a say in decisions about the healthcare of the people they support, where appropriate?</p>	<p>Patients and carers need access to clear information as to what their respective rights are. Changes made as a result of the Department of Health consultation 'An Information Revolution' need to be thought through and implemented alongside this 'Greater Choice and Control'</p>

consultation.

Patients need to be aware of the different roles carers can play in decision making, especially if they (the patient) lose capacity. In this instance the carer will have no formal decision making powers unless they have been appointed as the patient's LPA. Many people do not realise that this is the case and then are shocked that their role in decision making on behalf of a loved one is, at best, advisory to health care professionals. A poll found that 39% of people were not aware that relatives did not have an automatic legal right to ensure that their loved ones' medical treatment wishes are respected at the end of life (1). Both patients and carers need more information about the tools available to them to ensure that their loved ones can make decisions on their behalf.

Those carers that are appointed as an LPA for the patient will need information on how best to discuss care and treatment preferences with their loved one when they still have capacity. Once the LPA is active (when the patient has lost capacity) the carer will need support from health care professionals to understand the different treatment and care options they are asked to decide upon. They will also need health care professionals to respect the legal force of attorney status, i.e. to respect their decision making, unless they are not acting in the best interest of the patient.

As detailed in our response to Q13, Advance Decisions can ensure that a patient's treatment preferences are respected, which can lessen the anxiety and burden on carers who might otherwise have to make decisions on behalf of the patient.

The impact of healthcare professionals is profound on conversations about dying and the recording of patient wishes. A recent survey conducted by Nursing Times found that more than one in four nurses did not feel competent to discuss end-of-life issues with patients (2), even though two thirds of respondents said they had been involved in nursing a dying patient on the Liverpool Care Pathway (LCP) (designed to manage the last days in a patients life).

	<p>Research demonstrates that information and formal processes for initiating end-of-life discussions are often lacking. A study of palliative care services for those with chronic lung disease found that 87.9% of respiratory physicians had no formal process for initiating end-of-life discussions with those with terminal respiratory illness (3). Recent research by the NHS National End of Life Care Programme reported that while most health and social care staff have some involvement in end-of-life care, the majority have not received communications skills training beyond a very basic level (4).</p> <p>(1) ICM Poll for Dignity in Dying 2006 (2) http://www.nursingtimes.net/nursing-practice/clinical-specialisms/end-of-life-and-palliative-care/nurses-lack-skills-in-end-of-life-care/5022455.article (3) Partridge MR, Khatri A, Sutton L, Welham S, Ahmedzai SH (2009) Palliative services for those with chronic lung disease Chronic Respiratory Disease 6: 13-17 (4) http://www.endoflifecareforadults.nhs.uk/publications/talking-needs-action</p>
<p>21. How can we support the changing relationship between healthcare professionals and patients, service users, their families and carers?</p>	
<p>22. What needs to be done to ensure that shared decision making becomes the norm? What should we do first?</p>	
<p>23. Should healthcare professionals support the choices their patients make, even if they disagree with them?</p>	<p>Looking at end-of-life choices, the responsibilities of doctors in this area are set out in the General Medical Council's (GMC) guidance Treatment and Care towards the End of Life: Good Practice in Decision Making (2010) (1). Doctors must respect the law which allows patients with capacity to make their own health care and treatment decisions. If a doctor has a conscientious objection to the choice a patient makes they may withdraw from the patient's care, but not without first ensuring that arrangements have been made for another</p>

	<p>doctor to take over their role. It is not acceptable to withdraw from a patient's care if this would leave the patient with nowhere to turn. The GMC gives further guidance on these sorts of issues in Personal Beliefs and Medical Practice (2008) (2).</p> <p>Similar guidance is needed for nurses and allied health professionals. A recent survey conducted by Nursing Times found that more than one in four nurses did not feel competent to discuss end-of-life issues with patients (3).</p> <p>(1) General Medical Council (2010) Treatment and care towards the end of life: good practice in decision making GMC (2) General Medical Council (2008) Personal Beliefs and Medical Practice GMC (3) http://www.nursingtimes.net/nursing-practice/clinical-specialisms/end-of-life-and-palliative-care/nurses-lack-skills-in-end-of-life-care/5022455.article</p>
<p>24. What sort of advice and information would help healthcare professionals to make sure that everyone can make choices about their healthcare?</p>	<p>Healthcare professionals need clear information and training on their own legal and professional responsibilities around patient choice. For example, they should understand how the Mental Capacity Act interacts with their practice. Healthcare professionals also need clear training on how to communicate with patients and carers to ensure that they understand the choices available to them and the relative benefits and risks associated with each of them.</p> <p>Healthcare professionals also need to be supplied with good sources of information that they can give to patients and carers to take away and think about before making decisions.</p>
<p>25. How can we encourage more people to engage in advance care planning about their preferences for the care and support they receive - for example, when they are approaching the end of their life?</p>	<p>ACP is fairly well embedded in long-term care. Research into the use of ACPs in England found that 89% of managers of care homes recommended the use of an ACP within their care home (1). The process used to record and discuss end-of-life issues varied: 63% of care homes used ACPs, 77% used a 'statement of wishes and preferences', 55% used Advance Decisions and 61% used a Lasting Power of Attorney. These were used alongside tools such as the LCP and Gold Standards Framework (a pathway designed for end-of-life patients). This reflects the flexible approach taken by care</p>

homes. However, with so many decision and choice aids available, questions about the knowledge levels of practitioners need to be directed at policy makers.

Training and clear information for practitioners and the general public at all stages of care (from those with no illness to those at the point of diagnosis and onwards) is needed. With carefully thought through planning and appropriate training of healthcare professionals, important conversations and the recording and respecting of patient wishes can happen.

Healthcare providers in La Crosse, Wisconsin in the USA have implemented a successful system for talking to patients and families early on in diagnosis. This has positively impacted on end-of-life experiences and ensures that treatment preferences are adhered to (2) (3). There are many other examples of good practice from the USA. If you would like further details please contact Compassion in Dying. We have also just finished a systematic review which examines whether the preferences detailed in treatment preference tools are adhered to. A copy will be sent to the Department of Health.

The success of ACPs and Advance Decisions is dependent on the right cultural and professional circumstances being present. There needs to be buy-in from healthcare professionals, patients and the wider general public, appropriate IT support and continued monitoring and evaluation of effectiveness.

(1) Froggatt K, Vaughan S, Bernard C, Wild D (2008) Advance Care Plans for older people: a survey of current practices, International Observatory on End of Life Care
http://www.eolc-observatory.net/pdf/ACP_240408.pdf

(2) http://www.newyorker.com/reporting/2010/08/02/100802fa_fact_gawande

(3) Hammes B, Rooney B, Gundrun J (2010) A comparative, retrospective, observational study of the prevalence, availability and specificity of advance care plans in a country that implemented an advance care planning microsystem, The American Geriatrics Society 58: 1249-1255

<p>26. Would you welcome a chance to engage in advance care planning before you become ill – for example, when you go for your mid-life Health Check – rather than after a diagnosis of a life-threatening condition?</p>	
<p>27. How could training and education make choice and shared decision-making a part of healthcare professionals' working practices?</p>	
<p>28. How can we help people to learn more about how to manage their health?</p>	
<p>29. What help should be available to make sure that everyone is able to have a say in their healthcare?</p>	
<p>30. Who would you like to go to for help with understanding information and making decisions and choices about your healthcare, or that of someone you support?</p>	
<p>31. How can we make sure that carers' views are taken into account when the person they support makes a healthcare choice?</p>	
<p>32. What information and support do carers, parents, guardians and those with powers of attorney or deputyship need to help others to make choices or to make choices on others' behalf?</p>	<p>Carers, parents, guardians, and those with powers of attorney or deputyship will need support from health care professionals to understand the different treatment and care options available and the relative benefits and risks of each. They need to feel that they can have open and honest conversations with healthcare professionals, and there should be clear, accessible information available to them in formats that they can take away and discuss with the patient.</p> <p>Some carers might also appreciate advice on how to talk to patients with capacity about the choices available to them.</p>

<p>33. What information and support do voluntary sector and patient-led support groups need so that they can continue to help people to make choices about their healthcare?</p>	
<p>34. How can people be encouraged to be more involved in decisions about their healthcare?</p>	
<p>35. Would decision aids be a useful tool for healthcare professionals and their patients and service users? Are there any barriers to their use?</p>	

Making it Happen	
<p>36. How should people be told about relevant research and how should their preferences be recorded?</p>	
<p>37. How can we encourage more healthcare professionals to use Choose and Book when they make a referral?</p>	
<p>38. How can we encourage more healthcare providers to list their services on Choose and Book?</p>	
<p>39. How else can we make sure that Choose and Book supports the choice commitments in chapter 2?</p>	
<p>40. Do you agree with the proposed approach to implementing choice of named consultant-led team? What else would you suggest needs to be done?</p>	
<p>41. Do you agree with the proposed approach to establishing a provider's fitness to provide NHS services? What other criteria would you suggest?</p>	

<p>42. Should this approach apply uniformly to all providers, no matter what size, sector and healthcare services that they provide? For example, should a small charity providing only one healthcare service to a very localised group of patients be subject to the same degree of rigour as a large acute hospital that delivers a range of services to a regional catchment of patients?</p>	
<p>43. Do you agree that an “any willing provider” directory should be established to make it easier for commissioners to identify providers that are licensed and have agreed to the NHS standard contract terms and conditions?</p>	
<p>44. The White Paper indicates that the Government will explore the potential for introducing a right to a personal health budget in discrete areas. Which conditions or services should be included in this right?</p>	

Safe and Sustainable Choices

<p>45. How can we make sure that any limits on choice are fair, and do not have an unequal effect on some groups or communities?</p>	
<p>46. What do you consider to be the main challenges to ensuring that people receive joined-up services whatever choices they make, and how should we tackle these challenges?</p>	<p>The End of Life Care Strategy (1), whilst not setting concrete objectives, suggests good practice for PCTs. These include ensuring out-of-hours care is properly coordinated, the creation of locality registers for recording patient preferences and that SCRs are implemented nationally.</p> <p>Reports on the strategy are being produced annually and demonstrate that, while key work to promote choice and control at the end-of-life is being conducted, it is down to the discretion of PCTs to choose what activities they engage in (this is often dependend on capacity). Dedicated money to pay for these services is an on-going</p>

	<p>concern.</p> <p>A wider change in culture is needed to ensure that preferences are discussed, recorded and respected across care settings. This must include raising awareness amongst all health and social care professionals and policy makers to ensure that end-of-life care is on the agenda in care other than just the palliative setting.</p> <p>(1) Department of Health (2008) End of Life Care Strategy</p>
<p>47. What do you consider to be the main risks to the affordability of choice and how should we mitigate these risks?</p>	
<p>48. How far should we extend entitlements to choice in legislation and hold organisations to account against these?</p>	
<p>49. Where no specific right to choice applies, how can the Board best encourage GP consortia to maintain and extend the choice offer?</p>	
<p>50. What is the right mix of measures to encourage GP consortia to offer appropriate choices to their populations?</p>	
<p>51. What is the best way to gather patient feedback about the extent to which commissioners have put in place choices?</p>	
<p>52. Are the responsibilities of organisations as outlined enough to:</p> <ul style="list-style-type: none"> - ensure that choices are offered to all patients and service users where choices are safe, appropriate and affordable? - ensure that no-one is disadvantaged by the way choice is offered or by the choices they make? 	
<p>53. If you do not get a choice you are entitled to, what should you be able to do about it?</p>	<p>Firstly, patients and carers must be informed about what rights and choices they have. Patients, carers and health care professionals must all be encouraged to discuss decisions where there is disagreement in the first instance. If a choice is denied there should be a clear</p>

	<p>procedure so that the decision can be reviewed quickly.</p> <p>Current complaints systems are complicated and too bureaucratic for carers to deal with on top of the challenges of supporting a loved one who is dying. However, it is crucial that patients and carers do understand their legal rights at the end of life.</p>
<p>54. What are the main risks associated with choice and how should we best mitigate these risks?</p>	

Please send your responses via email to:

ChoiceConsultation@dh.gsi.gov.uk

or via post to:

**Consultation Responses
Choice Policy Team
Department of Health,
11th Floor, New Kings Beam House
London
SE1 9BW**

Comments should be received by 14 January 2011.

A summary of the response to this consultation will be made available before or alongside any further action, such as laying legislation before Parliament, and will be placed on the Department of Health consultations website at:

<http://www.dh.gov.uk/en/Consultations/Responsestoconsultations/index.htm>

+ Options for Organisation type

- GP
- Nurses
- Health Visitors
- Clinicians
- Managers
- Commissioners
- SHA
- PCT
- Regulatory Body
- Academic/Professional Institution
- Employer representative
- Employee representative
- Trade Union
- Local Authority
- Social Care Provider
- General Public
- Patients
- Carers
- Service Users