

Liberating the NHS:

An Information Revolution

Your response to the consultation questions

| Your details (optional) | |
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| Name * | Philip Satherley |
| Organisation | <p>Compassion in Dying</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> |
| Organisation type ⁺ : e.g. Public, patient, PCT etc | <p>Charity or Voluntary organisation</p> <p>Other (if applicable):</p> |
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| CHAPTER 1: An Information Revolution | |
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| <p><i>1. What currently works well in terms of information for health and adult social care and what needs to change?</i></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>The End of Life Care Strategy (1) and the General Medical Council's Treatment and Care Towards the End of Life (2) have helped to raise the profile of end-of-life care and provide some guidance for practitioners and policy makers.</p> <p>Overall though, this is an area that needs further developing if the principle of “no decision about me without me” as outlined in the foreword of the consultation is to be realised. Concrete outcomes are needed to measure the impact of information and access to choice.</p> <p>One of Compassion in Dying's key activities is the production and promotion of Advance Decisions. These record the medical treatment preferences, such as Do Not Attempt Resuscitation (DNAR) and no artificial hydration or nutrition, of patients should they lose capacity. Alongside this we produce an Advance Decision toolkit for healthcare professionals. Both documents are free of charge. In 2007, in England and Wales, Advance Decisions were given statutory force under the Mental Capacity Act 2005. We believe that access to Advance Decisions (and other preference tools) is essential to ensure patients' wishes at the end-of-life can be respected. As yet, there is no formal system for recording whether a person has an Advance Decision, and what it says, on a patient's medical record. Compassion in Dying is currently the only charity that provides information and campaigns on patient end-of-life rights and choices in the UK (although other organisations provide information to their specific patient group, e.g. Marie Curie Cancer</p> |

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| | <p>Care).</p> <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, discovered 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>This type of service and the means for informing and discussing options with patients is often lacking.</p> <p>However, examples of good information sharing in end-of-life care are becoming more common. The End of Life Care Strategy Second Annual Report (5) details the work of the NHS South Central Strategic Health Authority (SHA) which implemented a unified DNAR policy and documentation which would work across its services. There was buy-in from all stakeholders and a patient information leaflet was produced. This is a new initiative and is currently being audited and discussed with other SHAs.</p> <p>(1) Department of Health (2008) End of Life Care Strategy (2) General Medical Council (2010) Treatment and care towards the end of life: good practice in decision making (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 (5) Department of Health (2010) End of Life Care Strategy: Second Annual Report</p> |
| <p>2. <i>What do you think are the most important uses of information, and who are the most important users of it?</i></p> | <p>Compassion in Dying believes that information which is accurate, clear and consistent is needed to inform every decision made by patients, carers and healthcare professionals. Information should be available which spans the the end-of-life journey, from appropriate and realistic discussions around prognosis (predicted time until death), to what community and out-of-hours services are available, to what patients can and can't refuse at the end of life in advance should they lose capacity, and at any point when they have capacity.</p> |
| <p>3. <i>Does the description of the information revolution capture all the important elements of the information</i></p> | <p>Diagram 1.13 is very confusing and not user-friendly. This needs to be simplified for the purpose of explaining key concepts.</p> |

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| <i>system?</i> | |
| <p>4. <i>Given the current financial climate, how can the ambitions set out in this consultation - to make better use of information and technology to help drive better care and better outcomes - be delivered in the most effective and efficient way?</i></p> | <p>In general there is a paucity of financial information for end-of-life care. This needs to change in order to assess what is and isn't working financially with information giving.</p> <p>In terms of end-of-life care, if better information about patient rights and choices were delivered and had an impact on care there could be money-saving implications. For example, if a patient dying at home or in a hospice requests that they should not be transported to a hospital in specific circumstances there are potential savings in both financial (for the hospital) and emotional (for the patient and family) terms. This can be realised through detailed information sharing.</p> <p>In order for this to happen, Advance Decisions need to be formally registered and embedded in electronic systems so they can be acted upon across care settings. Lasting Powers of Attorney (LPA) have to be registered with the Office of Public Guardian, but they should be also recorded on a patient's medical record, including whether the LPA is authorised to make decisions on life-prolonging treatment.</p> |
| <p>5. <i>Where should the centre be focusing its limited financial resources and role to achieve the greatest positive effect?</i></p> | |

CHAPTER 2: Information for patients, service users, carers and the public

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| <p>6. <i>As a patient or service user, would you be interested in having easy access to and control over your care records? What benefits do you think this would bring?</i></p> | <p>Compassion in Dying provides information and represents service users rather than direct provision of health or social care.</p> <p>The principle of “no decision about me without me” as outlined in the foreword of the consultation is one which Compassion in Dying endorses and has at the heart of its charitable objectives.</p> <p>In principle, we agree with the notion of access and control over care records. This is further explored in the consultation document in points 6.13-6.17 which set out plans for the standardising of patient and care records.</p> <p>Advance Care Plans (ACP) document a patient's planned last months and weeks of life. This is done by the patient, healthcare professional and family. They can contain both Advance Decisions (which are legally binding) and advance statements such as Preferred Priorities for care (PPC) (which can be used to document</p> |
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| | <p>what the patient wants to happen - but are not legally binding). The sharing of information contained in an ACP is critical to ensure that health care professionals and carers are aware of the individual's care preferences and, if appropriate, their wishes regarding resuscitation etc.</p> <p>Currently Advance Decisions can be recorded with GPs and it is up to them to enter this information into the medical care records system appropriately. However this practice is not compulsory and patients may be setting out treatment preferences that do not get officially recorded. There are additional difficulties in accessing medical records during out of hours care and ensuring that all healthcare providers are aware of patients' needs.</p> <p>There is the potential to include Advance Decision-type information on Summary Care Records, 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 (1).</p> <p>The section of the consultation titled 'Standardising patient and care records' (6.13-6.17) fits with question six. We agree, in principle, with the plan to achieve efficiency, consistency and comparability of records of care through standardisation. Alongside the key elements listed under 6.17 we would recommend that standardised information which details end-of-life treatment and preference wishes is included. Whether these wishes were acted upon could also be recorded and this data used to improve service provision.</p> <p>In relation to the wording in the consultation, 'access' and 'control' are loose concepts and need to be treated with caution.</p> <p>(1) Tait C, Braunold G, Jeeves R, Hopwood L, Thick M (2009) Summary Care Record - the Bury experience, <i>European Journal of Palliative Care</i> 16(3): 124-126</p> |
| <p>7. <i>As a patient or service user, in what ways would it be useful for you to be able to communicate with your GP and other health and care professionals on-line, or would you prefer face-to-face contact?</i></p> | <p>We believe that end-of-life conversations and decision-making processes should take a variety of formats according to the situation at hand.</p> <p>For people who choose to fill in an Advance Decision 'at home' (i.e. not in the presence of a healthcare professional) this document ideally still needs to be discussed with a GP/healthcare team and then embedded in the medical records system. Other methods of discussing preferences, such as face-to-face contact, still need to ensure that decisions are recorded accurately and embedded in care systems appropriately. For all forms of communication and recording of patient preferences, the patient must be fully aware of what their current rights are, and how and when they can be exercised.</p> |

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| <p>8. <i>Please indicate any particular issues, including any risks and safeguards, which may need to be taken into account in sharing records in the ways identified in this consultation document.</i></p> | |
| <p>9. <i>What kinds of information and help would ensure that patients and service users are adequately supported when stressed and anxious?</i></p> | <p>The End of Life Care Strategy states that:</p> <p>“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) (1)</p> <p>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 help to lessen stress and anxiety.</p> <p>Systems for recording and acting-on patient wishes need to be standardised. The PPC tool documents where patients would like to be taken care of during their final weeks/days and is often used in conjunction with the Liverpool Care Pathway (designed for patients during the very end of the end-of-life stage). Whilst research and audit indicates that the PPC tool has been successful in ensuring that patients' wishes are respected, research into the effectiveness of the promotion and uptake of the PPC tool has only just begun (2). Research into the promotion, uptake and impact of Advance Decisions needs to be conducted to ensure they can impact positively on people's lives.</p> <p>(1) Department of Health (2008) End of Life Care Strategy (2) Department of Health (2010) End of Life Care Strategy: Second Annual Report</p> |
| <p>10. <i>As a patient or service user, what types of information do you consider important to help you make informed</i></p> | <p>Having clear information on your rights and options for care is important, regardless of condition or user group. Those involved in end-of-life care (patients, carers and healthcare professionals) have the additional issue of it being a highly emotional time for all concerned. Lack of clear guidance can lead to the wrong decisions being made. Guidance needs to detail how and when healthcare</p> |

choices? Is it easy to find? Where do you look?

professionals should have difficult conversations and what patients and carers need to know about their rights. Unless patients are told what their rights and choices are by healthcare professionals it is very difficult for them to find out. This needs to be addressed at a national level. We are aware of the work being conducted by the Dying Matters coalition (of which Compassion in Dying is a member) to engage the general public with dying, but cannot comment on the success of the coalition at this stage as evaluations have not yet not been published.

The recent GMC guidance (1) helps doctors to work alongside patients to come up with the best course of action. 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 (2), even though two-thirds of respondents said they had been involved in nursing a dying patient on the Liverpool Care Pathway.

Compassion in Dying produces Advance Decisions and campaigns for their use. We believe a central register containing patients' wishes and treatment decisions would benefit all stakeholders in end-of-life care and would ensure access to important patient data across care settings. Locality registers to record preferences are essential to realise this:

"...it is recommended that PCTs create locality-wide registers for people approaching the end of life, so that they can receive priority care" (3)

There has been investment in the development of locality registers (1% of total end-of-life care spend in PCT across England) (4). Continued investment and promotion, and an evaluation of their impact is needed.

In the absence of Advance Decisions and Lasting Power of Attorneys being recorded on a patients Summary Care Records, there should be clear signposting to organisations (such as Medic Alert) which record patient treatment preferences and allows healthcare professionals 24-hour access to such information.

- (1) General Medical Council (2010) Treatment and care towards the end of life: good practice in decision making
- (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) Department of Health (2008) End of Life Care Strategy
- (4) Department of Health (2010) End of Life Care Strategy: Second Annual Report

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| <p>11. <i>What additional information would be helpful for specific groups – eg</i></p> <ul style="list-style-type: none"> - <i>users of maternity and children’s health services;</i> - <i>disabled people;</i> - <i>people using mental health or learning disabilities services;</i> - <i>the elderly;</i> - <i>others?</i> | <p>See more detailed comments in reponse to question 10.</p> <p>However, in summary, people approaching end-of-life and their loved ones would benefit from:</p> <ul style="list-style-type: none"> i. Clear information on their rights ii. Clear information about recording treatment decisions iii. Clear information about support services |
| <p>12. <i>What specific information needs do carers have, and how do they differ from the information needs of those they are caring for?</i></p> | <p>Carers are often the ones who have to make difficult decisions about loved ones. Clear guidance for carers (e.g. patients' rights, what to expect during different stages of end-of-life care and how to ensure the carer receives appropriate support) is essential. This can be used to inform decision making and put them at ease as much as possible.</p> |
| <p>13. <i>What are the information needs of people seeking to self-care or live successfully with long-term physical and mental health conditions and what support do they need to use that information?</i></p> | |

CHAPTER 3: Information for improved outcomes

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| <p>14. <i>What information about the outcomes from care services do you (as patient, carer, service user or care</i></p> | <p>See question 15.</p> |
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| <p><i>professional) already use?</i></p> | |
| <p><i>15. What additional information about outcomes would be helpful for you?</i></p> | <p>Research evidence about the extent to which patient preferences are respected when they have lost capacity at the end of life is in short supply in the UK. Evidence from the use of the PPC has been generated by small-scale audit and indicates the tool is effective and patients are being cared for or dying in their preferred place (1) (2). However, evidence about whether patients' medical treatment preferences (as documented in Advance Decisions or living wills) are being respected does not, to the best of our knowledge, exist.</p> <p>Evidence from the USA indicates that treatment preference tools such as the Physician Orders for Life-Sustaining Treatment (POLST) (3) and more generic advance directives (the equivalent of Advance Decisions) have been successfully implemented and are proving successful at ensuring that documented treatment wishes are respected (4) (5).</p> <p>To ensure that lessons are learnt from the USA, Compassion in Dying believes that:</p> <ul style="list-style-type: none"> i) Advance Decisions, or their equivalent, need to be implemented in general healthcare at the national level. This would involve ensuring that patients and healthcare professionals are educated in the purpose and application of Advance Decisions. Compassion in Dying already does this work, but with limited resources and buy-in from formal structures. ii) Evaluation (either clinical audit or academic research) is urgently needed to examine the effectiveness of such tools, e.g. if are treatment wishes are adhered to. <p>Useful information on end-of-life issues such as place of death and underlying cause of death is being gathered and disseminated by the National End of Life Care Intelligence Network (6). It is vital that this information is fed into the wider research, practice and policy community.</p> <p>(1) Wood J (2007) Preferred place of care: an analysis of the 'first 100' patient assessments (Letter to the editor), <i>Palliative Medicine</i> 21: 449-450</p> <p>(2) Newton J, Clark R, Ahlquist P (2009) Evaluation of the introduction of an advanced care plan into multiple palliative care settings, <i>International Journal of Palliative Nursing</i> 15(11): 554-561</p> <p>(3) Hickman SE, Nelson CA, Perrin NA et al (2010) A comparison of methods to communicate treatment preferences in nursing facilities: traditional practices versus the Physician Orders for Life-Sustaining Treatment Program <i>The American Geriatrics Society</i></p> |

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| | <p>58: 1241-1248</p> <p>(4) Pekmezaris R, Breuer L, Zaballero A et al (2004) Predictors of site of death of end-of-life patients: the importance of specificity in advance directives, <i>Journal of Palliative Medicine</i> 7(1): 9-17</p> <p>(5) Molloy DW, Guyatt GH, Russo R et al (2000) Systematic implementation of an advance directive programme in nursing homes: a randomized controlled trial, <i>Journal of the American Medical Association</i> 283(11): 1437-1444</p> <p>(6)http://www.endoflifecare-intelligence.org.uk/home.aspx</p> |
| <p>16. <i>How can the benefits of seamless and joined up information be realised across the many different organisations (NHS and non-NHS) a service user may encounter?</i></p> | <p>There are examples of joined-up working across different NHS (and other) agencies, for example see question 1: NHS South Central Strategic Health Authority (SHA) implementing a unified Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policy and documentation across all services.</p> |
| <p>17. <i>For which particular groups of service users or care organisations is the use of information across organisational boundaries particularly important?</i></p> | <p>For all stakeholders involved in end-of-life care the sharing of information across boundaries is important.</p> <p>Out-of-hours care, ambulance services, acute care, discharge planning, allied health professionals and community care are just some of the types of services and professionals involved in the care of patients at, or during the planning stages, of end-of-life care.</p> <p>Information needs to be shared between these services to ensure patient-centred care can be delivered. Examples of information needed include: i) a patient's treatment wishes ii) the capability of other services to deliver care if a patient is to be transported between settings iii) the supportive needs of patients and their carers who are living at home.</p> |
| <p>18. <i>What are your views on the approach being taken, and the criteria to be used to review central data collections?</i></p> | <p>We agree in principle.</p> |
| <p>19. <i>How could feedback from you be used to improve services?</i></p> | <p>See question 15. Compassion in Dying will be publishing a systematic review of research on adherence to wishes documented in patient preference tools in Spring 2011. A copy will be sent to the Department of Health.</p> |

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| <p>20. <i>What would be the best ways to encourage more widespread feedback from patients, service users, their families and carers?</i></p> | |
| <p>21. <i>What are the key changes in behaviour, systems and incentives required to make the NHS and adult social care services genuinely responsive to feedback and how can these be achieved?</i></p> | |
| <p>22. <i>Which questions, if asked consistently, would provide useful information to help you compare and choose services?</i></p> | |
| <p>23. <i>What will help ensure that information systems - and the data they collect - are appropriate to support good commissioning at different levels, including decisions by individual patients, GP practices, GP consortia, service providers, local authorities and the NHS Commissioning Board?</i></p> | |

CHAPTER 4: Information for professionals

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| <p>24. <i>How can health and care organisations develop an information culture and capabilities so that staff at all levels and of all disciplines recognise their personal responsibility for data?</i></p> | |
| <p>25. <i>As a clinician or care professional, how easy is it for you to find the evidence you need to offer the best possible care and advice? What could be done better?</i></p> | |
| <p>26. <i>Clinicians, practitioners, care professionals, managers and other service provider staff will be expected to record more data and evidence electronically. How can this be facilitated and encouraged? What will be the benefits for staff and what would encourage staff to reap these benefits?</i></p> | <p>Compassion in Dying's research finds that for Advance Decisions and other patient preference tools to work there must be commitment to ascertaining and recording patient decisions among the healthcare team. This demands cultural change. This started with the Mental Capacity Act 2005, but more could be done through education and training programmes.</p> <p>Please see question 15 for more detail. Benefits should be seeing patients have better end-of-life experiences and better relationships between patient and healthcare professional.</p> |
| <p>27. <i>What are the key priorities for the development of professional information management capacity and capability to enable the information</i></p> | |

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CHAPTER 5: Information for autonomy, accountability and democratic legitimacy

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| <p>28. <i>The ‘presumption of openness’ in support of shared decision-making will bring opportunities – but may also generate challenges. What are the greatest opportunities and issues for you a) as a care professional? or b) as a services user?</i></p> | |
| <p>29. <i>What benefits and issues do you think will arise as a greater range of information providers offer information? How could issues be addressed?</i></p> | |
| <p>30. <i>Would there be benefits from central accreditation or other quality assurance systems for information providers and ‘intermediaries’? Would factors such as cost and bureaucracy outweigh any benefits?</i></p> | |
| <p>31. <i>How can a health and social care information revolution benefit everyone, including those who need care most but may not have</i></p> | <p>There must be a recognition that information does not necessarily mean information technology. For patients at/approaching end-of-life, the ability to use IT may be highly limited. Furthermore, it is important that patients and carers are empowered to have conversations with healthcare professionals.</p> |

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| <p><i>direct access to or know how to use information technology? This might include those who do not have access to a computer or are remote and can not access the internet, people using mental health or learning disabilities services, older or disabled people or their carers who may need support in using technology, and those requiring information in other ways or other languages.</i></p> | <p>Patients need accessible and clear information, available in a variety of formats, that can they can take away and think about, and they need to know that they can talk to healthcare professionals about care and choices.</p> |
| <p><i>32. Are there other datasets that you think could be released as an early priority, without compromising individuals' confidentiality? Would there be any risks associated with their release – if so, how could these be managed?</i></p> | |

CHAPTER 6: Setting the direction – the Information Strategy

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| <p><i>33. The information revolution can deliver many improvements. What are particular benefits or other challenges – including sustainability, business, rural or equality issues – that need to be considered in developing the associated impact assessment?</i></p> | <p>Sustained financial investment with ring-fenced monies are essential if any change to the generation and distribution of information is to be successful long-term. The consultation document does not detail money or how spending will be targetted. We believe that end-of-life care and the planning of such care needs to be embedded across services and that this should be reflected in a whole-systems approach to information. However, attention needs to be paid to specialist areas, such as end-of-life care, so that monies reach their intended audience.</p> <p>Coordinated and consistent graduate education and on-going training for healthcare professionals around the information needs of patients and good communication skills is needed.</p> <p>It has been recognised that there are differing services based on diagnosis and location, with care being poorly coordinated and difficult to access (1). It is vital that access to information does not</p> |
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| | <p>follow a similar path.</p> <p>(1) Palliative Care Funding Review (2010) Interim Report</p> |
| <p><i>34. Are there any critical issues for the future of information in the health and adult social care sectors that this consultation has not identified?</i></p> | |

Please send your responses via email to:

InformationRevolution@dh.gsi.gov.uk

or via post to:

**Consultation Responses
Information Strategy Team
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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

- Patient / Service user / Carer
- Public
- Healthcare provider
- Social Care provider
- Charity or Voluntary organisation
- Advocacy or support organisation
- SHA
- PCT
- Local Authority
- Health professional
- Social care professional
- Clinician
- Commissioner
- Management and staff
- Regulatory body
- Academic / Professional Institution
- Employer representative
- Employee representative
- Trade union
- Supplier
- Information provider
- Information professional
- Informatics professional
- Other – please specify