

End of Life Care

Creating and communicating an End of Life Care Register that works for the medical and legal professions

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The International Longevity Centre - UK (ILC-UK) is an independent, non-partisan think-tank dedicated to addressing issues of longevity, ageing and population change. It develops ideas, undertakes research and creates a forum for debate.

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This report is accompanied by '*Creating and communicating an End of Life Care Register that works for the medical and legal professions: progress and insights*' which contains the presentations of the speakers.

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Introduction and overview

As population ageing continues to increase, and the repercussions of the higher numbers of people living with chronic disease, and eventually needing End of Life Care (EoLC). At the moment, the majority of people are dying in hospitals, with around a fifth dying in care homes and their own homes respectively¹. With only 1% of patients stating that their choice would be to die in a hospital, with far higher numbers preferring to die at home², the argument for change is clear. The argument is bolstered by the extremely costly nature of providing EoLC in hospital and the drive to avoid unnecessary costly processes in the National Health Service along with the need to focus on quality, and support choice.

In recent years, the quality of EoLC has come under review, with provision historically lacking in organisation and integration coming under renewed interest from practitioners, policymakers, patients and the public. With the publication of the End of Life Care Strategy by the Department of Health in 2008,³ a number of key areas of EoLC were explored, including (though not limited to):

- Identifying people approaching the end of life and ensuring that staff have appropriate training to communicate and deliver care to these individuals.
- Care planning to be crucial, with all people approaching the end of life having an assessment of their needs, and a discussion of their wishes and preferences with agreed actions.
- Coordination of care across sectors, which should be able to continue regardless of the time of day or night Strategic commissioning, such as having an 'integrated approach to planning, contracting and monitoring of service delivery'.

Recent progress on this topic includes the introduction of a Quality Standard from the National Institute of Health and Care Excellence (NICE) (formerly the National Institute of Health and Clinical Excellence) on 'End of life care for adults'. The quality standard covers 'all settings and services in which care is provided by health and social care staff to all adults approaching the end of life', helping to move towards a more integrated model as prioritised in the EoLC strategy.

In July 2012, a number of key stakeholders met at an ILC-UK-organised discussion on the key debates in EoLC. These included representatives from Government departments, practising clinicians, lawyers and academics. This meeting discussed the development of improvements in EoLC, particularly around recording people's desires, setting up registers to record and communicate to medical professionals the details of these wishes, and to explore the identification of good practice regarding EoLC.

With discussion of further legislation on assisted dying currently taking place, alongside plans for an alternative to the Liverpool Care Pathway, the future shape of end of life care is somewhat uncertain. However, the appetite for new Bills on this topic demonstrates the need for improvement in processes around end of life. Developments such as the introduction of electronic care

¹ NHS End of Life Care Programme (2012) *What do we know now that we didn't know a year ago? New intelligence on end of life care in England*. Leicester: NHS End of Life Care Programme (Figures: 53% die in hospital, 18% die in care homes, 21% die in own home).

² Ibid.

³ Department of Health (2008) *End of Life Care Strategy*. <https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life>

coordination systems (such as EPaCCS, see below) form part of a broader programme of planned and potential change and improvement in this area. Ensuring excellent quality for patients and professionals using these systems is a vital step in the continued transformation of End of Life Care. As the demand for support at the end of life increases with the older population, there is a need to ensure that high quality will be facing these people when they reach the end of life.

Overview

This report is a representation of the meeting 'Creating and communicating a National End of Life Care Register that works for the medical and legal professions'. The meeting was intended to update key stakeholders on progress on the Electronic Palliative Care Coordination System (EPaCCS) as well as considering the challenges facing the delivery of excellent End of Life Care. EPaCCS is designed to work across care settings, as a single source of information of an individual's desires and preferences for their care, including advance care planning and information sharing.

The presentations from the meeting are summarised, followed by a report of the discussions held at the meeting, arranged by theme. Finally, the report ends with a review of the goals established at the July 2012 meeting, progress made on these, and future plans.

Presentations

NB. All speaker presentations are shown in full in the document 'Creating and communicating an End of Life Care Register that works for the medical and legal professions – progress and insights', which accompanies this report.

Anita Hayes, on behalf of the NHS EoLC programme, thanked Baroness Greengross and ILC-UK for the opportunity to address the latest roundtable discussion. She said that she intended to build on the previous meeting, to share the progress and emergent developments in ongoing work since 2008 (when the EoLC strategy was published), and talk about next challenges.

Anita set the background for the presentations and stated the meeting would focus on two main areas: the end of life care pathway route to success and the national roll out of Electronic Palliative Care Co-ordination systems (EPaCCS). Firstly, she commented that the starting point for EoLC needs to be with the individual and their carer. A 'route map' diagram and 'steps of the end of life pathway' diagram were presented in order to show all the components of the End of life care framework.

She discussed the three main ambitions of the NEdLCP. These are improving access to high quality, person centered, EoLC for all who need it; sharing and embedding innovation to ensure good practice is 'the norm'; and focusing attention of equipping the workforce and general public to meet future challenges. For the latter point, the Dying Matters Coalition had done some work on this already.

Anita then introduced the panel speakers:

- Professor Julian Hughes, Consultant in Old Age Psychiatry and Honorary Professor of Philosophy of Ageing, Newcastle University
- Professor Rob George, Professor Palliative Care, Cicely Saunders Institute, KCL; Clinical Lead Palliative and End of Life Care, NHS London Consultant Palliative Care Guy's and St. Thomas' Hospitals NHS Foundation Trust
- Dr Catherine Millington-Sanders, RCGP lead for EPaCCS and Practising GP
- Kate Mansell, 'Coordinate My Care' – General Manager, The Royal Marsden NHS Foundation Trust.

Professor Julian Hughes highlighted the four conceptual points about end of life decision making. The first point was that end of life care is *fundamental*, that people should retain the right to make decisions about what happens to them for as long as they could, even in the face of dementia or other degenerative conditions. This was what drove the desire to encourage advance care planning, but he noted that in a systematic review of advance care planning in dementia only four studies had been undertaken, all in nursing homes, with only 36% people judged to have the capacity to engage with advance care planning. Professor Hughes cited the *Nuffield Council on Bioethics* 2009 dementia report which suggested that advance care planning should be an ongoing process and not a one-off event. The report also stated that welfare powers of attorney should be made accessible to anyone who wishes to make one.

His second point looked at what it is to be a *person*. In his article about dementia in the *Journal of Medical Ethics* (2001) and in his book on the same subject in 2011 he characterised people as being *situated, embodied agents*. The key notion being that people are situated in all manners of ways: in personal narratives, in families, in communities, in traditions and in morals. That lives are complex and dynamic – things change all the time. Julian added that both preferences and capacity change so reviewing care regularly is essential.

Thirdly, people are *interconnected and interdependent*. That people should be able to depend on others, whether that be a spouse or doctor, to take decisions for them, with or without care plans, as a manifestation of respect for autonomy. Also that multiple dependencies make implementation of advance care planning problematic. Professor Hughes drew upon the research from Newcastle University which demonstrated confusion and uncertainty over roles and responsibilities when it came to advance care planning in dementia and palliative care. The research emphasized the need for documentation.

His final point was *communication*. People have a language to engage with others but communication requires interpretation. Word meanings and gestures are not always set in stone, language is dynamic and the meaning is fluid. Documentation has to be secondary to conversation as it can be misleading if the understanding from the dialogue has not been captured accurately. The important matter is that dialogue must come first and last.

Professor Rob George commented that there are two aspects that should be addressed in training and development in clinical practice around end of life. Firstly, that professionals need to ensure that what is meant is what's understood in decision making. Secondly, it should be noted that as the inevitability of death increases the ability to make decisions decreases (Professor George referred to the Deciding Right diagram which can be found in Appendix III), and as a result the urgency to make decisions increases as the time decreases towards end of life. While expected time before end of life can fluctuate (with prognoses moving between years to months and vice versa, and weeks and days, or vice versa), there is unlikely to be a significant change which will result in a further additional period of time (that is, from days before end of life to years before end of life), and consequently time is often of the essence in these discussions.

Professor George also spoke of a need to examine morality and ethics around involving families and carers in planning. While it is vital to ensure patient protection, it is also important to address the need to involve families in these decisions. He noted that the GMC Good Practice guide in particular takes shared decision-making as a central aspect of good EoLC.

There are great opportunities from technology; video advance care planning work is about to start by embedding video documentation in documents, including nonverbal cues, providing the texture of communications. There is a need to exploit the technology available for documentation to capture information about people in a different way, but also to ensure the legal robustness of video documentation. Professor George provided a case study of non-verbal cues from a patient who was minimally conscious and for whom several clinicians had ruled a lack of capacity and had recommended withdrawing support. However, during the period of a morning spent by the patient's bedside he (Professor George) noted non-verbal signals of hostility and anxiety towards him sitting alongside her as a stranger and other occurrences at her bedside. It struck him that this lady was

interested enough on what was going on around her that there was conflicting evidence to support her fluid and food being stopped.

Dr Catherine Millington-Sanders worked on one of the first sites of Coordinate my Care. She provided an overview of the Electronic Palliative Care Coordination systems (EPaCCS) progress (see Appendix I).

Dr Millington-Sanders explained that the EPaCCs supports individuals approaching the end of life and their families by allowing advance care plans to be recorded, by facilitating instant access to crucial information about patients, and by providing a shared local electronic record for health and social care professionals. Eight pilot programmes ran between October 2009 and March 2011 and nationally, EPaCCs enabled an additional 46,000 people die at home (Q3 2003/10 and Q2 2010/11). There has now been a fourfold increase in pilot sites. The pilots have seen some technology challenges though including synchronization between systems, consistency of information between localities and links with other care planning solutions.

The former National QIPP lead for End of Life Care, Sophia Christie, was quoted saying “1% of each GP practice list should be identified as end of life, through the course of a year with particular emphasis on nursing and residential homes”. This small, but important, cohort of patients should be known to healthcare professionals and equates to approximately 20 patients per year; 25% of these will die from cancer and around 40% are frail and/ or have dementia. However, the National Death Audit revealed that only 27% who died have been identified and only 42% had an advance care plan recorded with patients on registered receiving better coordinated care.

In order to ensure the success of EPaCCS, Dr Millington-Sanders, stated that multi professional workforce training was required to help identify patients, have conversations with their families and carers and record their plans on the EPaCCS in order to co-ordinate between professionals.

Kate Mansell presented on the progress of Coordinate My Care (see Appendix I). Kate explained that Coordinate My Care (CMC) was originally a pilot within Sutton and Merton which subsequently merged with Camden and Islington with the need for one centralised record across London. Kate provided diagrams showing coordination of patient information across all providers and how information in CMC is captured. In total there are over 4,000 patients across London on the CMC and nearly 80% of patients that have died on the CMC have reached their preferred place of death.

Summary of points

This section covers topics discussed during the meeting ‘Creating and communicating a National End of Life Care Register that works for the medical and legal professions’.

Service delivery and roll out

Patient confidentiality and data access

EPaCCS has an information governance framework, covering who should be accessing the information. These need to be signed up to before access to the system granted, in addition to training for professionals. While accessing a patient’s file, health and social care professionals must declare a legitimate patient care relationship when, and these are all audited.

Patient confidentiality must be ensured throughout the register and a need to ensure that the system is as strong as it can be. Alongside the electronic record, at any stage patients are able to access a paper copy of their own records, and the ability to do so must be well-communicated.

Discussions around video footage being used as documentary evidence for decision-making are in their infancy, and this is an area where there are many issues. There are great benefits to be found in providing more evidence, particularly in the form of non-verbal and contextual evidence (see Professor George’s presentation comments for further details). However, there are serious concerns for the privacy of the patient and security issues around the possibility that footage might be altered or edited to support a particular outcome. Additionally, it seems unlikely that there will be a speedy response from a legal perspective for footage to become recognised as respected supplementary evidence.

National roll out of EPaCCS

The issue of improving EoLC will have a strong position in the new NHS structures, as both at an individual GP perspective and at commissioning level, EoLC is high on the list of areas to improve. Further options for rolling out the scheme include increasing the number of patients reached through each GP surgery from 1 to 2%; to include not just those who aren’t just in their last year of life; to expand geographically by region; and to include further key people from different health and social care professions.

There is a potential mismatch between the desire for standardisation of EoLC and the new move towards localism, and how these fit together. One of the outcomes from the eight pilots was recognition of this challenge. One recommendation from the pilot projects is working with the Information Standards Board. The ISB have a National Information Standard published in February 2012 which includes a process of compliance, to ensure consistency throughout different areas. This provides standardised definitions (and these have been consulted on with professional bodies).

While there is a national mandate on standards for IT solutions, ‘one size fits all’ will not work for the whole country. There are different IT solutions in different areas but there is only a single core dataset. Pilots have made differing decisions on the IT solutions put in place to fit their local needs for EPaCCS. The NHS are working on interoperability standards to be shared between different IT systems. For example, in London the ambulance service need access to the dataset

from different pilot areas as the service covers a wider geographical location, so there is a need to work alongside the varied IT solutions used by the different trusts within London.

As of yet, it is unclear what the total national cost of the scheme has been, as the costs have been borne locally within their budgets. Economic evaluations of the projects have taken place, and initial figures demonstrate. Stakeholders commented that in economic evaluations of these systems the biggest unaccountable cost is the cost of the time spent by professionals undertaking additional tasks and evaluations. It is important that these figures are included in economic evaluations to gain a true picture of the financial impact of the scheme.

It is vital that as the scheme expands there is a consistency that confidentiality for patients must continue to be a top priority. With regard to an electronic record, there is a need to ensure that the system is as strong as it can be. This is a particular concern for videos and the possibility of manipulation or editing of footage. The system has an information governance framework, covering who should be accessing the information. Before access to the system is granted, professionals must have signed up to this framework, in addition to receiving training. While accessing a patient's file, health and social care professionals must declare a legitimate patient care relationship when, and these are all audited. When a patient dies, their data is kept anonymously after death for research purposes, a process included in the patient consent form. Alongside potential concerns, it is important to note that NHS Improving Quality continues to support the care coordination programme including implementation of EPaCCS across England.

Differing health pathways

Increasingly, people are dying of chronic diseases – for example: diabetes complications, long term Chronic Obstructive Pulmonary Disease. The trajectories for these diseases go gently downhill and the EoLC system needs to respond to this. We should be able to find triggers to mandate discussions around EoLC in these trajectories. Lawyers often ask doctors for capacity assessments and experience doctors' reluctance to conduct these. A particular issue identified has been with GPs passing on the responsibility for making an assessment. Anecdotal evidence suggests that situations have arisen where assessments might have been made earlier, and subsequently windows where a patient was had capacity (during a period of fluctuation) have been missed. How we create incentives for professionals to have these discussions, and how a mandated system would be accepted by health and social care professionals should be fitted around medical knowledge of patients' journeys towards the end of life.

It has been noted that GP Practice end of life registers often contain disproportionate numbers of people with cancer, perhaps because it is easier (in terms of more assured prognoses) for GPs to identify cancer patients who are dying. While much of the work around EoLC is driven by people with cancer, there is a need to recognise that those with frailty and dementia are different; for example the certainty around prognoses differs and is often more uncertain. Additionally, we already have big problems around providing adequate community care for those with frailty and dementia. In this area there are ties with the Care and Support Bill and EoLC.

End of life care in different settings

There are a number of challenges around the delivery of EoLC in care home settings. Within one of the pilots concerns were raised that there were difficulties accessing and communicating with individuals in care homes and their families.

It was suggested that care homes have big problems appreciating the law and the rights of the individual and potentially overrule some of these because they haven't communicated with the family about their and the individual's wishes. There have been worrying reports of care homes having a standardised sign-off for Do Not Attempt CPR orders. For people who perhaps do not have the ability or confidence to challenge and question practices like this there is a need to ensure dialogue starts at a much earlier stage. These conversations should also include families where appropriate.

Training and education

Medical professionals

Discussion around EoLC with patients should be occurring much earlier than at present. We should be able to find triggers to mandate these discussions, as well as how incentives can be created for professionals to have these discussions, and how a mandated system would be accepted. There is discussion to be had around whether the medical professional alone should be the only ones to discuss and whether guidance is needed for legal profession and others.

It has been noted that many GPs find this conversation incredibly difficult, with some referring to old age psychiatrists on matters of testing capacity. Communications training needs to be expanded to support professionals in these discussions and to ensure that they are taking up the subject of EoLC at an earlier stage, for example at undergraduate level.

Communication around EoLC is about competency to have the discussion, not just about a particular professional label. Some people would say that the best professionals to have these conversations are nursing staff, rather than doctors. Additionally, organisations such as the Mental Health Trust have a role in e.g. dementia care and should be borne in mind to have access to the scheme. There is a great deal of concern around mandating advance care discussions; and nurses and care staff will do this very well as they more commonly have a personal relationship with the patient. We need to empower nursing clinicians and in doing so can work towards a greater continuity of care at end of life. There are ongoing discussions on making EoLC discussions a key competency for the professions with the representative bodies. This would mean that, like life support, professionals have to repeat training every year to maintain competencies.

Behind the work of the EPaCCS register there is a need to change the culture towards EoLC. Having a patient record is a good idea but there is a further need to address the actions behind the low levels of identification of patients nearing the end of life (for example, after a recent audit was conducted, the numbers of people identified trebled.) and low uptake of discussions around the end of life.

Patients and families

There is a need to enhance the ability to have dialogue with individuals and families. There is a need to do ensuring good communication around the register or run the risk that it will be branded in same negative light as the Liverpool Care Pathway has been portrayed recently.

Concerns were expressed around the fears experienced by both patients and families around dying in different places. There are conflicting arguments around patients' fears both of dying at home and of dying in hospital. The role of the register must be to resist taking a policy direction (that is, the need to reduce hospital beds) and instead to have a sole focus on people's wants. Additionally, families' concerns that their next of kin might not have access to treatment, nutrition, hydration or adequate care can be included. In measuring effectiveness of this scheme, all outcomes need to be taken into account – rather than hospital admissions only – there is a need to include qualitative outcomes too.

Medical and legal liaisons

There is a need to raise awareness and encourage people to use the current systems available. At the moment 80% of Power of Attorneys (POAs) made are through solicitors and of these, only small percentages are about healthcare decisions. Health and welfare POA can be a more flexible tool and applicable to wider range of issues than advance decisions. The Office of the Public Guardian (OPG) – the body responsible for registering Powers Of Attorney (POA) – is currently going through a transformation programme. Technology can make thinking ahead and planning easier. There is a need to make POA less bureaucratic and understandable has been identified and OPG are trying to achieve this by making the system smoother and easier to navigate.

Concerns have been raised around tensions of proxy decision making, and proxy views also raise concerns around lasting POA. There is a need to raise a question around which voices are heard; care staff may have a clear perspective of a patient's desires but do not currently have a voice.

The register of POA needs to be made accessible and able to interact with other systems it needs to work alongside (such as EPaCCS). No matter how good the technology is the need to encourage people to have early conversations remains, and those people having these conversations need access to the right information.

While dying is not a big issue of discussion for lawyers it is perhaps an easier conversation to have for them, and will naturally lead into conversations on lasting POA. Health and welfare POA have not had as good a take-up as finance and property POAs, and raising awareness in public is an issue we need to address. Lawyers often ask doctors for capacity assessments and experience doctors' reluctance to conduct these, a particular issue being GPs passing on this responsibility. In the past situations have arisen where assessments might have been made earlier, and subsequently windows where a patient was had capacity (during a period of fluctuation) have been missed.

While acknowledging that non-verbal communication is very important, it will take a long time to persuade powers that be that you can have a legally-binding video. There is already a struggle with getting paper documents into electronic form, and wishes and guidance through video are another level on top of this. There are advantages of using video such as being able to see a conversation and the establishment of capacity as part of that communication. However, a particular issue will be protecting against the ability to edit and doctor video footage. The proposed way forward for video footage would be that it would sit alongside other documentation.

Further recommendations

Expert stakeholders who attended the meeting were asked to prioritise their top recommendations for action in this area. This list is a summary of these recommendations.

- Create a national register, through supporting the implementation of the electronic palliative care coordinating system (EPaCCS) in each locality – which requires IT systems that are interoperable and organisations willing to sign up to processes that enable key information (with patient's consent) to be shared. This process should include further research on EoLC registries that already exist locally, to support better understanding of benefit and impact on quality of care, and to avoid duplication.
- Once this step is in place, to raise awareness of the ability to share such records amongst the public so that the request to create and share such records come from the patients as much as from professionals. This to be part of a major public relations programme to make more in the population at large (not only those in their last year of life) of the ways in which they can make things easier for themselves and their loved ones by planning ahead.
- To use the NHS guidance on advance care planning as core to any changes to EoLC systems.
- Similarly, advance care planning is locked into the Mental Capacity Act in England and Wales and the Adults with Incapacity Act in Scotland (Northern Ireland does not currently have capacity legislation). This legislation must be central to any register containing decisions made in advance.
- Using resources which already exist (such as e-ELCA, the e-learning programme for end of life care) to support professional education and training on the skills required to initiate conversations about care planning and the communication and clinical skills to ensure that choices are informed, supported and properly communicated.
- The links between the medical and legal professions are key. Lawyers are often blamed for causing medics to continue care unnecessarily, for fear of negligence actions. Some of that criticism is no doubt justified. But some may also be the result of genuine attempts of dedicated, caring, legal professionals to ensure that the law is complied with. So in addition to changing the attitude of some lawyers, there may also be a need to change the law itself. And there are equivalents in the medical professions, where a change in behaviour, and in professional guidelines, would help achieve more positive objectives.
- Improve the training of doctors and lawyers, including of each other's perspectives on this issue. This could be done both top down (by establishing links at a senior level between the Law Society and the GMC to encourage them to take steps to improve mutual understanding between the legal and medical professions on EoLC issues) and bottom-up, with individual doctors and lawyers sharing their experiences and helping develop training materials for their respective colleagues.
- Alongside this, lawyers and doctors could work in a more co-ordinated fashion in discussing end of life issues with members of the public, for example, partnerships between them to offer advice on wills, advance decisions, and care options (and potentially also financial planning, perhaps including Independent Financial Advisers) in a more holistic fashion.

Appendix I – Useful resources

Resources on EPACCS implementation

A list of useful resources for EPaCCS implementation provided by the NHS National End of Life Care Programme.

Section A: Key Guidance Documents

1a. End of Life Care Locality Registers evaluation: Final Report (Ipsos MORI, 2011)

This report presents the findings from an evaluation of eight locality register pilot sites across England. The report includes details of the approaches used by the pilots, the learning and a detailed case study report.

www.endoflifecare.nhs.uk/search-resources/resources-search/publications/end-of-life-locality-registers-evaluation-final.aspx

1b. EPaCCS Implementation Audit: EPaCCS - Mid 2012 survey report

www.endoflifecare.nhs.uk/search-resources/resources-search/publications/epaccs-mid-2012-survey-report.aspx

1c. EPaCCS Making the case for change

www.endoflifecare.nhs.uk/search-resources/resources-search/publications/epaccs-making-the-case-for-change.aspx

2. End of Life Care Co-ordination: national information standard

Full details about the information standard, the requirement and access to the specification is available from the Programme's website:

www.endoflifecare.nhs.uk/care-pathway/step-3-co-ordination-of-care/national-information-standard.aspx

Includes the following resources:

- End of Life Care Co-ordination Implementation Guidance (to support organisations implementing EPaCCS)
- End of Life Care Co-ordination Record Keeping Guidance (to support health and social care professionals using EPaCCS)
- End of Life Care Coordination Summary of Record Keeping Guidance
- Data Items Content
- Glossary of terms used in the standard

3. Information Standards Board website

Information standard ISB 1580 approved by the Information Standards Board for Health and Social Care. Includes:

- Specification for the standard with full details and codes for data items
- Information Standard Notice
- Clinical Safety Report

www.isb.nhs.uk/library/standard/236

Section B: Additional Resources

4. Record Keeping Guidance

- Guidance on shared records: Shared Professional Guidance Project Informing shared clinical care: Final report of the Shared Record Professional Guidance Project. RCGP and NHS Connecting for Health www.rcgp.org.uk/health_informatics_group/srpg.aspx
- Good Medical Practice. General Medical Council. (2006) www.gmc-uk.org/guidance/good_medical_practice.asp
- Record Keeping Guidance for nurses and midwives (2010) www.nmc-uk.org/Publications/Guidance
- A clinician's guide to medical record standards Part 1. (2008) Academy of Royal Medical Colleges www.ifhima.org/docs/Clinicians-Guide-Part-1-Context.pdf
- A clinician's guide to medical record standards. Part 2 (2008) <http://www.rcoa.ac.uk/sites/default/files/FPM-clinicians-guide2.pdf>
- Nursing Content of eHealth records (2010). Royal College of Nursing eHealth Publications www.rcn.org.uk/data/assets/pdf_file/0005/328928/003596.pdf

5. Organisational Guidance and Resources

- National Voices Principles for Integrated Care (2011) provides useful guidance for policy makers and practitioners and includes users' views and suggested measures for success. www.nationalvoices.org.uk/principles-integrated-care
- The NHS Institute for Innovation and Improvement (2010) Sustainability Model and Guide provides guidance to support sustainable and effective improvement. www.institute.nhs.uk/sustainability_model/general/welcome_to_sustainability.html
- Local commissioners, providers and clinicians may want to consider the development of CQUIN schemes linked to provider payment to support implementation of registers and sustainability www.institute.nhs.uk/world_class_commissioning/pct_portal/cquin.html

6. Information Governance

- NHS and legal requirements for information governance www.connectingforhealth.nhs.uk/systemsandservices/infogov/igap/igaf
- Connecting for Health's Principles of Information Security www.connectingforhealth.nhs.uk/systemsandservices/infogov/security#
- Information governance toolkit version 8, Connecting for Health <https://www.igt.connectingforhealth.nhs.uk>
- Role Based Access Controls www.london.nhs.uk/lpfit/service-management/registration-authority/frequently-asked-questions/frequently-asked-questions--rbac-pbac
- NHS code of practice on confidentiality: www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/DH_4100550
- Guidance on informing next of kin: www.nigb.nhs.uk/advice/faqs/fair-processing-guidance-for-next-of-kin-information/
- Informing Shared Clinical Care. Final Report of the Shared Record Professional Guidance Project. RCGP Health Informatics Group (June 2009) <http://www.rcgp.org.uk/clinical-and-research/practice-management-resources/health-informatics-group.aspx>
- Consent model for London's Co-ordinate my Care Programme. www.royalmarsden.nhs.uk/diagnosis-treatment/patient-care/palliative/pages/coordinate-my-care.aspx

7. Advance Care Planning Guidance

- Mental Capacity Act 2005 www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act
- Mental Capacity Act Code of Practice 2005 www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf
- The General Medical Council. Treatment and care towards the end of life: good practice in decision making. (2010) www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp
- The King's Fund. Making Shared Decision-Making a reality: No decision about me, without me. Angela Coulter, Alf Collins (2011) www.kingsfund.org.uk/publications/nhs_decisionmaking.html
- Decisions relating to cardiopulmonary resuscitation. A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing. November 2007 www.bma.org.uk/ethics/cardiopulmonary_resuscitation/index.jsp
- Deciding right: an integrated approach to making care decisions in advance with children, young people and adults. Newcastle upon Tyne: NHS North East., January 2012. Available: www.theclinicalnetwork.org/end-of-life-care---the-clinical-network/decidingright
- Advance Decisions to Refuse Treatment: A Guide for Health and Social Care Professionals. NEOF, September 2008. www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/advance-decisions-to-refuse-treatment.aspx
- ADRT NHS website with downloads of important documentation, training modules, advice and further links www.adrt.nhs.uk/
- Preferred Priorities for Care www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/preferred-priorities-for-care.aspx
- Capacity, care planning and advance care planning in life limiting illness. A Guide for Health and Social Care Staff (2011) www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/capacity,-care-planning-and-advance-care-planning-in-life-limiting-illness.aspx
- A wide selection of examples of DNACPR forms are available from www.endoflifecare.nhs.uk/search-resources/dnacpr-web-resource.aspx
- The differences between general care planning and decisions made in advance (NEoLCP, May 2010) www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/the-differences-between-general-care-planning-and-decisions-made-in-advance.aspx
- Advance Care Planning: It all ADSE up www.endoflifecare.nhs.uk/search-resources/resources-search/publications/acp-guide.aspx
- DNACPR Decisions: Who decides and how? www.endoflifecare.nhs.uk/search-resources/dnacpr-web-resource.aspx

8. Technical Guidance

- Information on interoperability and the NHS interoperability toolkit: www.connectingforhealth.nhs.uk/systemsandservices/interop
- NHS Common User Interface: design guidance developed by the Connecting for Health to provide components for a common interface. www.cui.nhs.uk/
- Privacy Impact Assessment (PIA) to ensure that appropriate information governance controls are in place. www.connectingforhealth.nhs.uk/systemsandservices/infogov/igap
- Details about the Summary Care Record and extension with additional information: www.connectingforhealth.nhs.uk/systemsandservices/scr/staff and www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/impguidpm/createscrs/additional
- A reference source of information about general practice IT systems- The Good Practice Guidelines for GP electronic patient records. Department of Health /Royal College of General

9. Training

- Common core competences and principles for health and social care workers working with adults at the end of life. www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/common-core-competences-and-principles.aspx
- National End of Life Care Programme: Communication skills webpages www.endoflifecare.nhs.uk/education-training/communication-skills.aspx
- Resources and information on raising awareness and promoting conversations about death, dying and bereavement on the Dying Matters website www.dyingmatters.org/overview/resources
- e-Learning for Healthcare (e-LFH) contains a range of online self-learning programmes, including several relating to end of life care (e-ELCA). Registration is required but is free. www.e-lfh.org.uk/projects/e-elca/index.html
- Help the Hospices www.helpthehospices.org.uk/clip
- Finding the Words is a training DVD and workbook to support staff in end of life conversations www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/finding-the-words.aspx
- Conversations for Dementia. (NCPC, July 2011) www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/difficult-conversations.aspx
- The NICE Quality Standard for End of Life Care for Adults published by the National Institute for Health and Clinical Excellence (NICE) in November 2011 www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp

10. Economics

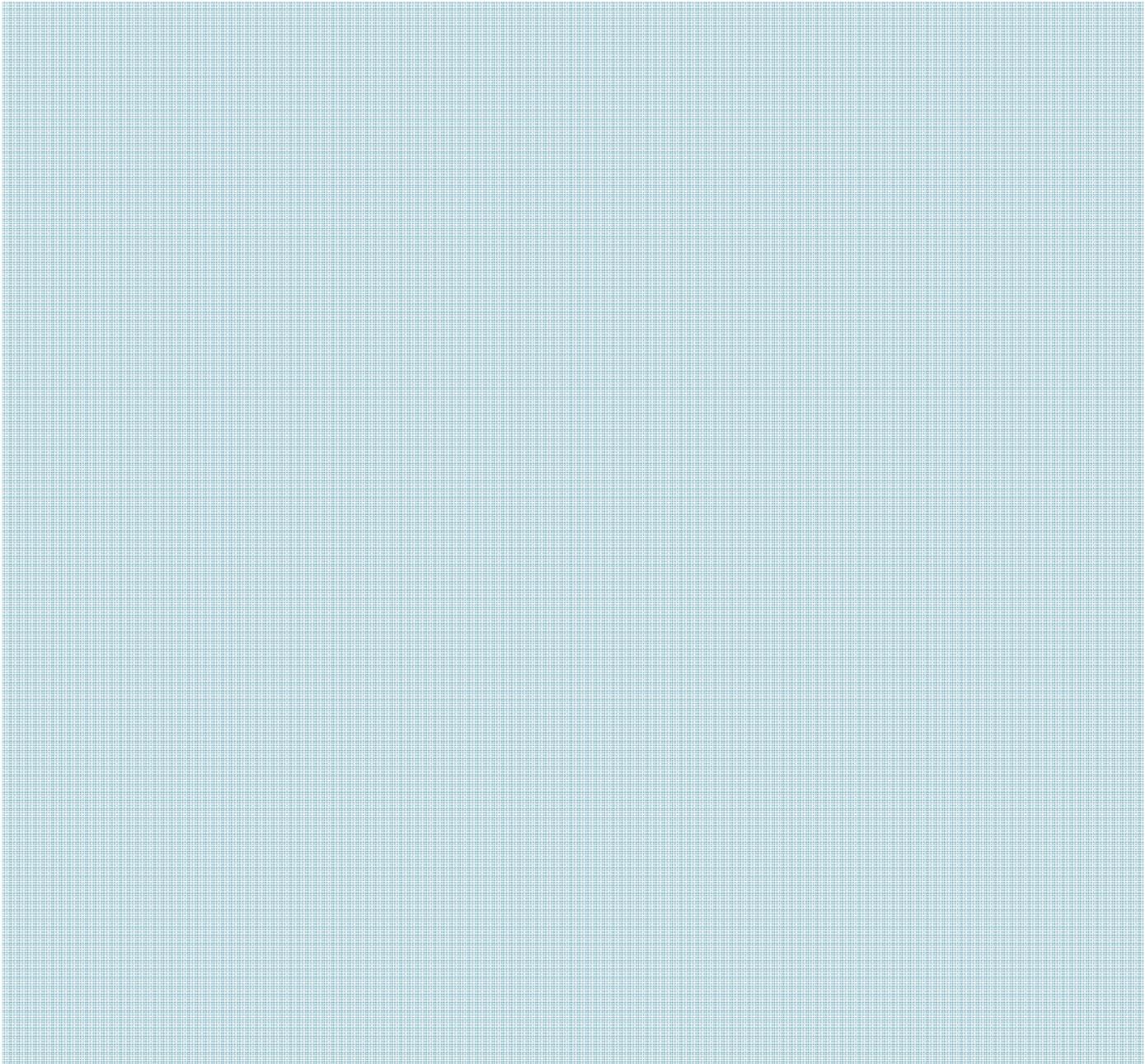
- EPaCCS Economic Evaluation Report due to be published April 2013 www.endoflifecare.nhs.uk
- QIPP costings report www.endoflifecare.nhs.uk/search-resources/resources-search/publications/qipp-costings-report.aspx

Additional resources

The Gold Standards Framework <http://www.goldstandardsframework.org.uk/>

Appendix II – Meeting attendees

First Name	Surname	Organisation
Elaine	Bayliss	Department of Health
Dr Carl	Brookes	Consultant Physician and Cardiologist, The Hampshire Clinic
Professor Dame Hazel	Genn	Dean, Faculty of Laws, University College London
Professor Rob	George	Consultant in Palliative Medicine / Snr. Lecturer, Biomedical Ethics, University College London
Baroness Sally	Greengross	Chief Executive, ILC-UK
Anita	Hayes	Department of Health
Professor Julian C	Hughes	Consultant in Old Age Psychiatry and Honorary Professor of Philosophy of Ageing
Nigel	Jones	Partner, Linklaters Llp
Professor Paul	Knight	President , BGS
Kate	Mansell	Royal Marsden & Royal Brompton Palliative Care Service
Matt	Loveridge	NHS
Dr Catherine	Millington- Sanders	RCGP National Clinical Lead / Richmond CCG GP, EPaCCS
Olwen	Minford	Royal College of Nursing
Dr Jackie	Morris	Consultant Physician and ILC-UK Advisor
Professor Graham	Mulley	Retired Consultant Geriatrician (Emeritus Professor) and ILC-UK Trustee
Dr Liz	Sampson	
Noreen	Siba	Managing Director, ILC-UK
Maggie	Stobbart- Rowlands	GSF Centre CIC
Dr Martin	Vernon	Consultant Physician & Geriatrician /Clinical Director/ British Geriatrics Society
Patricia	Wass	Consultant at Foot Anstey LLP, Representing STEP
Jessica	Watson	Research and Public Affairs Officer, ILC- UK
Dr Bee	Wee	President, The Association of Palliative Care Physicians



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