End of Life Care Strategy
Equality Impact Assessment
Action plan template: progress report

Category	Actions	Target date	Person responsible and their Directorate
Para 5.1, Age, Issue: "...older people in particular will need information and support to help them make choices and be fully involved in planning their care...this needs to be provided at an early enough stage to ensure that the individual has the best chance of being able to participate in planning their care before their condition deteriorates" **Para 5.2, Age, Action: "**Advance care planning is a useful way of ensuring that individuals can be involved in planning their care before their condition worsens to the extent that they are no longer able to communicate their wishes"	The National EOLC Programme has published a summary guide to care planning and advance care planning for patients ('Planning your future care') and guides for health and social care staff ('Advance care planning: a guide for H&SC staff' and 'Advance decisions to refuse treatment: a guide'). Work we are doing on QIPP (where EOLC is one of the 12 workstreams), aims to accelerate work on the first two stages of the EOLC pathway, one of which is effective care planning, putting people at the centre of decision making of their own care and care planning. The work of the national Dying Matters Coalition – set up under the strategy and funded by DH – seeks to increase public and professional awareness of EOLC issues, including encouraging planning for EOLC. One of the core competences for EOLC training for health & social care staff is around advance care planning	Completed Ongoing Ongoing June 2009	Tessa Ing, End of Life Care Team

	Offering a care plan to those approaching the end of life is one of the top 10 Quality Markers for EOLC The draft second annual report includes several local examples where effective care planning and advance care planning are being implemented	June 2009 August 2010	
Para 5.3, Age, Issue: "There is a need for increased awareness of dementia. Carers can play a crucial role in the care of people with dementia and medical professionals will benefit from their expertise in identifying when the person is in pain, distress or discomfort." **Para 5.4, Dementia, Action:** "The strong messages about the role of carers and the value they have in supporting patients to live in a place of their choice must not be ignored. The EoLC Strategy incorporates the needs of carers and devotes a chapter to this."	The EOLC Strategy includes a chapter on support for carers and families. The National EOLC Programme, in collaboration with NICE, has developed a commissioning guide for EOLC for people with dementia. This stresses the importance of care planning and advance care planning. The National EOLC Programme has been working with the DH dementia team to develop a good practice guide for the NHS. This will be published in August 2010. DH published 'Living well with dementia: A National Dementia Strategy' in February 2009; this includes consideration of the specific needs of dementia patients as they approach the end of life. Ensuring the needs of carers are assessed is one of the top 10 Quality Markers for EOLC Also, see response to paras 5.32 and 5.34.	Completed ongoing August 2010 February 2009 June 2009	Tessa Ing, End of Life Care Team

Para 5.5, Disability and long-term conditions, Issue: "...there is potential for inequality to occur in respect of people with a learning disability or severe mental illness. These people will require skilled professional care from people who understand the complexities of LD and MI...should also recognise the importance of the role the family or carer..." **Para 5.6, Disability and LTC, Action:** "More training is needed for those who work with people with a learning disability"	The draft second annual report on the strategy states that, for workforce, some of the work we anticipate to take forward next year includes to work with the National EOLC Programme, Skills for Care and Skills for Health to test how well the materials developed to date support the workforce delivering EOLC in learning disabilities, mental health and people with sensory impairment. The Dying Matters coalition (funded by DH) is planning to meet the team who produce 'Books Beyond Words' for people with learning disabilities to gain feedback and explore opportunities for joint working. Feedback from this will inform ongoing Dying Matters work.	Ongoing Ongoing	Glenis Freeman, Cancer & End of Life Care Workforce Lead Tessa Ing, End of Life Care Team
Para 5.7, Disability and LTC, Issue: "To have any chance of closing the inequalities gap between the EOLC that cancer patients receive and that which those living with other LTC receive, it will be necessary to raise the profile of other LTC. The workforce will need to be equipped with the right skills..." **Para 5.8, Disability and LTC, Action:** "EOLC Strategy will address workforce issues."	The EOLC Strategy includes a chapter on workforce. The second annual report on the strategy reports: DH's LTC QIPP workstream will adopt the 'surprise question' into its own plans to be sure that people with conditions such as heart failure and COPD are identified as in need of EOLC at the right point. DH has consulted on a COPD strategy, which includes a chapter on EOLC, including specific recommendations aimed at improving access to EOLC services and ensuring appropriate information to carers and those who are bereaved. It also recommended that further work should be undertaken to pilot markers of a prognostic indicator to identify the EOLC phase for people with COPD, to develop an EOLC pathway and evaluate different models of support for carers. This work is supported by the National EOLC Programme.	July 2008 August 2010 Ongoing February 2010 and ongoing	Glenis Freeman, Cancer & End of Life Care Workforce Lead Tessa Ing, End of Life Care Team

	The National EOLC Programme is developing a pathway for neurological conditions working in collaboration with clinical champions, an expert clinical reference group and the Neurological Alliance. This will be published later this year.	Ongoing	
	The National Institute for Health Research Service Delivery and Organisation programme has funded new research projects on generalist services for people at the end of life, including one on the factors that influence the place of death for patients with non-cancer conditions.	Ongoing	
	DH published 'Supporting People with Long Term Conditions: Commissioning Personalised Care Planning – A guide for commissioners', which includes the needs of people approaching the end of life.	January 2009	
	DH published 'End of Life Care in Advanced Kidney Disease: A Framework for Implementation'.	June 2009	
	For all workforce issues, note that DH launched e-learning for end of life care (ELCA) in January 2010, which includes over 100 training modules with free access to H&SC staff.	January 2010	
	Future work for workforce set out in the draft second annual report includes:	August 2010	
	Continue to prioritise work related to e-learning access issues for all health and social care staff and employers;	Ongoing	
	Establish, with the Association for Palliative Medicine and e-Learning for Healthcare, an Editorial and Review Board for ELCA which will periodically review content and commission additional modules or sessions;	Ongoing	
	Continue to raise awareness with Medical Royal Colleges of	Ongoing	

	our work on e-learning and competences and influence other professional bodies and standards to include end of life care.		
Para 5.9, Race, Issue: "... staff education in multi-cultural health could play a large role in helping EOLC to embrace society's diversity and changing needs. Language has the potential to be a barrier to good quality EOLC" **Para 5.10, Race, Action:** "The use of formal interpreters could be encouraged to prevent a large burden being placed on children and younger generations who often have to act as interpreters. This will help to create a more standard quality of service for people across the country and across difference ethnicities."	This has yet to be addressed We are mindful of the need to address this issue. However, the End of Life Care Strategy is a strategy for the long-term and it will necessarily take a number of years to implement. This issue is one which will be addressed in due course, but progress will depend on the availability of resources nationally and locally for either the continuation or the uptake of this area of work.		Glenis Freeman, Cancer & End of Life Care Workforce Lead
Para 5.11, Race, Issue: "Communication skills are important and it will be essential that all professionals providing EOLC are trained in effective communication." **Para 5.12, Race, Action:** "Communication skills need to be part of all under and post graduate training."	12 pilot projects are underway across England led by the National EOLC Programme, to review the needs and provision of communication skills training for the health & social care staff delivering EOLC. The sites are building on existing good practice and knowledge and using a whole system approach to consider the training needs and the coordination, planning and delivery of communication skills training. The second annual report on the strategy states that, for workforce, some of the work we anticipate to take forward includes to review the published competences for communication skills following feedback that they were not detailed enough and to review the evaluation and reports from the above communication skills pilot sites and identifying appropriate next steps.	Ongoing Ongoing	Glenis Freeman, Cancer & End of Life Care Workforce Lead

	The Dying Matters coalition (funded by DH), is planning a collaborative workshop with the Policy Research Institute for Ageing and Ethnicity, to explore the views of BME people, which will complement work already carried out with South Asian Elders. Feedback from this will inform ongoing Dying Matters work. Good communication skills covering the whole range that may arise in EOLC, is one of the core competences for EOLC training for health & social care staff (see above)	Ongoing June 2009	Tessa Ing, End of Life Care Team
Para 5.13, Race, Issue: "It should be recognised that some patients, particularly those of recent migration, will either wish to return to their 'home' country to die or will wish to be buried in their country of origin after they have died. Where possible these wishes should be elicited by the professional responsible for the individual's care at the time of care planning and while the patient is still well enough to travel." **Para 5.14, Race, Action:** "Assessment and care planning should include a prompt by the healthcare professional about the option of returning to another country to die. Having a discussion about EOLC and drawing up a care plan at early stage within a person's illness could also help family /friends living abroad to have sufficient time to make arrangements to travel to England to visit the individual or for the person to return to their country of origin."	More needs to be done on this, but one of the core competences for EOLC training for health & social care staff for assessment and care planning includes to ensure that all assessments are holistic, including culture and lifestyle aspirations, goals and priorities. Two of the Quality Markers for EOLC are to ensure that people approaching the end of life are offered a care plan and to ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals. We are mindful of the need to address this issue further. However, the End of Life Care Strategy is a strategy for the long-term and it will necessarily take a number of years to implement. This issue is one which will be addressed in due course, but progress will depend on the availability of resources nationally and locally for either the continuation or the uptake of this area of work.	June 2009 June 2009	Glenis Freeman, Cancer & End of Life Care Workforce Lead

Para 5.15, Race, Issue: "Formal statistical collection by care homes, hospices, extra care housing etc about the ethnicities of residents would be a useful way of monitoring whether uptake to these services increases over time." **Para 5.16, Race, Action:** "PCTs and LAs should make information widely available… care homes, hospices, extra care housing etc should consider collecting information about a resident's ethnicity, religion, language & culture."	We hope that the early products from the newly established National EOLC Intelligence Network could include an analysis of quality data on place of death by age, gender, ethnicity, social deprivation and geographical location and cause of death registered on the death certificate. We are piloting a survey of carers (based on the VOICES questionnaire), which will provide valuable information on carers' views of the EOLC their relatives have received and help guide future developments. This includes developing a strategy to encourage engagement from ethnic minority populations, which in prior VOICES studies have had very poor response rates. We are mindful of the need to address this issue further. However, the End of Life Care Strategy is a strategy for the long-term and it will necessarily take a number of years to implement. This issue is one which will be addressed in due course, but progress will depend on the availability of resources nationally and locally for either the continuation or the uptake of this area of work.	Ongoing Ongoing	Tessa Ing, Head, End of Life Care
Para 5.17 Religion & Belief, Issue: "…It will be important for healthcare professionals to have a basic knowledge of the differences between different religions & be aware of the limits to their knowledge." **Para 5.18, Religion and Belief, Action:** "Spiritual care should be coordinated across the care pathway and those caring for the dying and bereaved should have a reasonable knowledge of various faiths and practices."	The first Annual Report on the strategy recognised that meeting the spiritual needs of those approaching the end of life, their carers and families is an important, although very complicated, area which needs to be addressed. During the past year, our work on this has concentrated on identifying and obtaining all the available evidence and information and gathering the preliminary views of experts in the field. To do this, the National Programme has commissioned a literature review, due to report in July 2010, and the Department has provided funding support for two conferences, one organised by the National Council for	July 2009 Ongoing	Tessa Ing, Head, End of Life Care

Para 5.19 Religion & Belief, Issue: "... Religious practice is an area where discrimination could occur, even if this is indirect." **Para 5.20, Religion and Belief, Action: "**PCTs and LAs should ensure that there is space and time for religious practices to be carried out by both the individual and their visitors, family or carers regardless of the setting." **Para 5.21 Religion & Belief, Issue: "**Respect and forethought needs to be given to whether certain medical practices are acceptable to certain religions." **Para 5.22 Religion & Belief, Action: "**Assumptions should not be made about the treatment or care an individual may wish to receive. Health care professionals should seek individuals' views about whether any aspect of their religion would make certain medical practices inappropriate."	Palliative Care and the other by the British Association for the Study of Spirituality. The findings of the literature review and feedback from the conferences will provide pointers on next steps for this important work. This includes addressing the spiritual needs of all patients, whatever they may be. The core competences for EOLC training for health & social care staff for assessment and care planning includes to ensure that all assessments are holistic, including religion and/or spiritual well-being, where appropriate. We intend that the work described above will contribute to future work to develop Quality Markers for spiritual care which we hope to do within the next year.	June 2009 June 2011	

End of Life Care Strategy

Equality Impact Assessment

Action plan template: progress report (continued)

Category	Actions	Target date	Person responsible and their Directorate
Para 5.23 Sexual orientation and gender identity, Issue: "health care professionals should be careful not to make assumptions that people are heterosexual and if an individual reveals they are lesbian or gay, stereotypical assumptions should not be made about what type of person they are. The language that health care professionals use should be selected carefully so as not to inadvertently make someone feel that they have to reveal their sexual orientation or transgender identity." **Para 5.24 Sexual orientation and gender identity, Action:** "Care homes, hospices and extra care housing should be encouraged to positively market themselves as being gay friendly places…Staff need to be trained to understand LGBT issues and policies should be developed to require staff to report any incidences of discrimination by staff or other residents."	Little progress has been made in this area. However, DH has allocated funding to the national Dying Matters Coalition to work with the consortium of lesbian, gay, bisexual and transgendered VCS organisations to map the research, projects and services known to exist on EOLC for LGBT people, with a view to highlighting these issues and promoting the aims of the Dying Matters within those communities. We are mindful that more needs to be done to address this issue further. However, the End of Life Care Strategy is a strategy for the long-term and it will necessarily take a number of years to implement. This issue is one which will be addressed in due course, but progress will depend on the availability of resources nationally and locally for either the continuation or the uptake of this area of work.	Ongoing	Tessa Ing, Head, End of Life Care

"**5.25** ...it should be a requirement, as part of continuing professional development, that staff attend relevant courses on LGBT issues, equality and diversity and keep themselves up-to-date on current equality legislation." "**5.26** Healthcare providers also need to have in place a clear policy on confidentiality..."			
Para 5.27 Homeless people, Issue: "... for many, it will be important to have advocates to help in the care planning process...health care professionals [should] ask the individual if there is anyone else they would like to be involved in their care and to refrain from making assumptions about the individual's relationship with family members." **5.28 "...** it will be important for hospital discharge teams to understand the history of the homeless person... and to work with organisations supporting homeless people to plan the discharge and produce an appropriate care plan." **Para 5.29 Homeless people, Action:** "The care planning process should help to ensure that hospital discharge teams identify when a homeless person might be at the end of their life and work with other organisations to put in place an appropriate package of care." **Para 5.30** "...Further work may be needed in the UK to ascertain whether the same benefits (both for the residents and in respect of cost savings) [from studies in Canada] could be realised here."	DH has allocated funding to the national Dying Matters Coalition for a project for public engagement of marginalised groups. The Dying Matters coalition project, jointly with the National Council for Palliative Care, held two workshops with homeless projects in March and early April 2010, to complement feedback from project workers. Feedback from this will inform ongoing Dying Matters work. More needs to be done on this. However, the End of Life Care Strategy is a strategy for the long-term and it will necessarily take a number of years to implement. This issue is one which will be addressed in due course, but progress will depend on the availability of resources nationally and locally for either the continuation or the uptake of this area of work.	Ongoing Ongoing	Tessa Ing, Head, End of Life Care

Para 5.31 Carers, Issue: "...regular support should be provided...breaks from care should also be considered as a means to support people to continue living at home and to support carers to enable this to happen" **Para 5.32 Carers, Action:** "The service should recognise the vital role carers play in enabling someone to die in the place of their choice and acknowledge that they are central to the caring team. Carers have a right to an assessment of their own needs and systems should be in place to ensure that in addition to supporting carers in a planned way, they are also able to provide support to carers who, because of a crisis or emergency, are temporarily unable to care." **Para 5.33 Carers, Issue: "...**visiting hours (in hospitals, care homes and hospices) could be more flexible." **Para 5.34 Carers, Action:** "Visiting times for patients at the end of their lives should be flexible where possible and dedicated family rooms for relatives and friends to sleep the night when a loved one is very close to death should be made available."	The EOLC Startegy includes a chapter specifically on carers and families, which is reported on each year in the annual report on the strategy Progress since 2009 includes: the Standing Commission on Carers recognised the need to encourage closer links between the implementation plans for the Carers Strategy and other strategies relevant to carers, including the EOLC Strategy. A number of activities were launched under the auspices of the Carers Strategy, including Carers Direct, a website and helpline to provide accessible information and advice to all carers. DH set up 25 Carers Demonstrator sites to gather evidence of different ways of providing breaks, health checks and better NHS support for carers. A number of the sites have a particular focus on EOLC – for example, Northumberland Trust is offering health checks to carers who have recently stopped caring for someone with complex needs and Halton and St Helens is focusing on identifying and supporting 'hidden' carers within a range of services, including palliative care. One of the top ten Quality Markers for EOLC is to ensure that the needs of carers are appropriately assessed and recorded through a carer's assessment. A high proportion of the Enhancing the Healing Environment projects highlighted in the second annual report involved	June 2008 Ongoing Ongoing Ongoing June 2009	Tessa Ing, Head, End of Life Care

	areas such as mortuaries and viewing rooms which allowed services to offer properly respectful, discreet and sensitive services to bereaved relatives. A number of the projects funded through the DH's £40m capital fund for hospices will enhance facilities for carers and families in hospices. However, we are not aware that the issue of visiting times (5.34) has yet been specifically addressed and are mindful of the need to address this. The End of Life Care Strategy is a strategy for the long-term and it will necessarily take a number of years to implement. This issue is one which will be addressed in due course, but progress will depend on the availability of resources nationally and locally for either the continuation or the uptake of this area of work.	Ongoing April 2010 to March 2011	
Para 6.1 Monitoring: "NHS & social care bodies will wish to ensure that, when implementing this strategy they bear in mind their responsibilities towards ensuring that EOLC is available equitably, and with due regard to the differing needs and wishes of different members of society. To this end they will wish to put in place suitable ways of monitoring EOLC to provide assurance."	One of the top ten Quality Markers is, for PCTs, to monitor the quality and outputs of EOLC and submit relevant information for local and national audits. The work on the locality register pilots, the VOICES survey of bereaved relatives and the National EOLC Intelligence Network will contribute to monitoring how effective implementation of the EOLC Strategy is and services are improved.	Ongoing Ongoing	Tessa Ing, Head, End of Life Care

Name of person who carried out the EqIA Progress Report:	Robert Freeman, End of Life Care Team, Clinical Policy and Strategy
Date EqIA completed:	15 July 2010
Name of Director/Director General who signed the EqIA Progress Report:	Gerard Hetherington, Director of Clinical Programmes, Clinical Policy and Strategy 
Date EqIA Progress Report was signed:	19 August 2010