



Department
of Health

One Year On:

The Government Response to the Review of Choice in End of Life Care

August 2017

DH ID box
Title: One Year on: The Government Response to the Review of Choice in End of Life Care
Author: Community Care/Technology Digital and Data/Dental, Optical, voluntary Sector, End of life Care and Long-Term Conditions/CC-TDD-DOVLE/13920
Document Purpose: Government Report
Publication date: 21 September 2017
Target audience: Public Clinicians and other health and care staff Commissioners Providers
Contact details: Primary Care Department of Health Richmond House 79 Whitehall London SW1A 2NS

You may re-use the text of this document (not including logos) free of charge in any format or medium, under the terms of the Open Government Licence. To view this licence, visit

www.nationalarchives.gov.uk/doc/open-government-licence/

© Crown copyright 2017

Published to gov.uk, in PDF format only.

www.gov.uk/dh

Contents

Contents	3
Foreword.....	4
Foreword.....	4
Introduction	6
1. Personalised care for people approaching the end of life	8
2. Measures to improve care quality for all across different settings	10
3. Innovation in the delivery of high quality care	12
4. National and local leadership to prioritise and improve end of life care	14
5. The right knowledge and skills to deliver high quality personalised care	15
6. Working together with system partners and the voluntary sector.....	16
7. Strengthening accountability and transparency to drive improvements.....	18
8. Palliative and end of life care for children and young people	19
9. Closing remarks.....	20
10. Ambitions Partnership commentary.....	21
Annex 1 - National End of Life Care Programme Board.....	23
Annex 2 - Ambitions Partnership.....	24

Foreword

By the Parliamentary Under-Secretary of State for Care and Mental Health

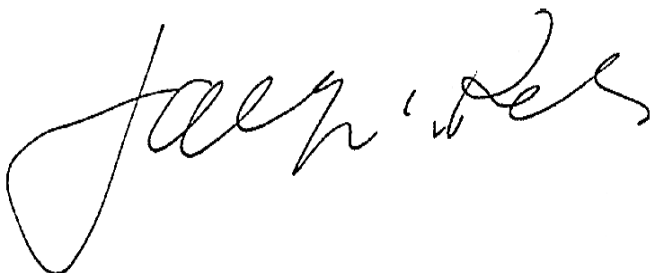
Good palliative and end of life care, focused on the perspective of the dying person and those important to them, is at the heart of our commitment to everyone at the end of life.

As we look to the challenges of improving end of life care, I want to recognise the excellent job that many health and social care professionals, commissioners, and charities are already doing to look after people at the end of life. It is easy to forget that in many cases people receive excellent, personalised and compassionate care from the NHS, however pockets of poor care still exist, and that is unacceptable. Our commitment to everyone at the end of life is to make high-quality personalised care a reality for all, and in our manifesto we made clear our intention to deliver this.

In February 2015 the *Independent Review of Choice in End of Life Care* was published. In our response we set out a commitment to everyone at the end of life and our ambition for everyone to receive high quality care that reflects their individual needs, choices and preferences. The Government is fully committed to improving standards across all end of life care and palliative care services, and we were delighted by the positive reception that this commitment received across the end of life care community. This *One Year On* report sets out all the hard work we have undertaken since the publication of the commitment, in partnership with system partners and other stakeholders, to ensure everyone has access to the support they need and deserve.

The National End of Life Care Programme Board, set up to oversee this work, has made excellent progress delivering the commitment in its first year and I have faith in the Board to implement the remaining deliverables by 2020. I would like to thank the Board's Chair, Bruce Keogh, and its members for all their hard work since the publication of the commitment.

The *One Year On* report demonstrates the dedication to improving end of life care across Government, system partners, commissioners and the voluntary sector, and the hard work going on across the sector to make high quality personalised end of life care a reality for all.



Jackie Doyle-Price MP

The Parliamentary Under-Secretary of State for Care and Mental Health

Foreword

By the National Medical Director for NHS England

The quality of end of life care will affect all our families. As chair of the National Programme Board for End of Life Care, I am immensely proud of how so many people have come together to develop and deliver a national programme for such an inevitable event in everyone's' lives.

Whilst much progress has been made, there is more to do to ensure that everyone receives high quality end of life care that enables those who wish to do so, to spend as much quality time at home as possible throughout the last years of life, and for that experience to be as good as possible for them and their families. We know that certain groups in society are still more disadvantaged than others, not only in terms of access to services and health outcomes, but also in the quality of care they receive, including end of life care. We remain determined to reduce this unfair variation, particularly for people with learning disabilities, dementia, the homeless and those in secure and detained settings, so that high quality end of life care becomes a reality for everyone, regardless of diagnosis or circumstance.

Our efforts remain focussed on improving care co-ordination. We will continue building and sharing evidence and exemplar models such as bereavement care pathways and innovative hospice-led interventions, as well as improving the availability of data, intelligence and metrics to help drive improvement and inform decision-making. We will tackle workforce planning to provide staff with the necessary skills to improve end of life care, and we will drive personalisation and increase patient empowerment through the expansion of personal health budgets.

In helping deliver improved care for patients nearing the end of their lives, I find myself overwhelmed by the commitment and passion of so many people for driving end of life care improvements across all parts of the country. I am acutely aware that without such dedication, much of the progress made would not have been possible. I would like to give a heartfelt thanks to everyone involved.

A handwritten signature in black ink that reads "Bruce Keogh". The signature is written in a cursive style and is positioned above a horizontal line that extends to the right.

Sir Bruce Keogh
National Medical Director, NHS England

Introduction

The Government's commitment to everyone at the end of life was published on 5 July 2016 in response to the [Independent Review of Choice in End of Life care](#) (the Choice Review).

The Choice Review was the product of extensive public consultation and engagement with charities, patients, clinicians and key health and social care partners by the Choice in End of Life Care Programme Board. The Board was asked to provide advice to the Government on improving the quality of end of life care in England, and set out the elements of end of life care that people most cared about and where people felt choice should play the greatest role.

The Government's response to the Choice Review, [Our Commitment to you for end of life care](#) set out our ambition for everyone to receive high quality care that reflects their individual needs, choices and preferences. This response set a clear expectation of the standard of care that everyone should be offered as they approach the end of life, and the policy changes necessary to make that standard a reality for all.

Our commitment to you for end of life care

The Government response states that as you approach the end of life you should be given the opportunity and support to:

- have honest discussions about your needs and preferences for your physical, mental and spiritual wellbeing, so that you can live well until you die
- make informed choices about your care, supported by clear and accessible published information on quality and choice in end of life care; this includes listening to the voices of children and young people about their own needs in end of life care, and not just the voices of their carers, parents and families
- develop and document a personalised care plan, based on what matters to you and your needs and preferences, including any advance decisions and your views about where you want to be cared for and where you want to die, and to review and revise this plan throughout the duration of your illness
- share your personalised care plan with your care professionals, enabling them to take account of your wishes and choices in the care and support they provide, and be able to provide feedback to improve care
- involve, to the extent that you wish, your family, carers and those important to you in discussions about, and the delivery of, your care, and to give them the opportunity to provide feedback about your care
- know who to contact if you need help and advice at any time, helping to ensure that your personalised care is delivered in a seamless way

The Department of Health, its system partners and the voluntary sector all committed to take actions to improve end of life care in line with this commitment across all settings. These are organised under themes that characterise our vision of high quality care:

1. We will develop more personalised care for people approaching the end of life
2. We will put in place measures to improve care quality for all across different settings
3. We will identify and spread innovation in the delivery of high quality care
4. We will lead on end of life care nationally and provide support for local leadership, including commissioners, to prioritise and improve end of life care
5. We will ensure we have the right people with the right knowledge and skills to deliver high quality personalised care
6. We will work together with system partners and the voluntary sector to deliver this commitment
7. We will strengthen accountability and transparency to drive improvements.

Additionally, the Government Commitment included a note on children's palliative and end of life care and we have also provided an update of progress in this area,

We know that joint working between the Department of Health, system partners and the voluntary sector is at the core of the success of the Government's commitment to everyone at the end of life. The [*Ambitions for Palliative and End of Life Care*](#), published in 2015 by a partnership (the Ambitions Partnership) of over 20 organisations, whose work the Department supports, embodies the collaborative nature of the approach. After the publication of the response to the Choice Review, a National End of Life Care Programme Board, chaired by NHS England Medical Director Sir Bruce Keogh, was established to oversee implementation. System partners, local commissioners, representatives of the voluntary sector from the Ambitions Partnership, and people with lived experiences of end of life care are members of the Board to scrutinise and hold each other to account for progress against the commitment.

This report sets out the overall progress the National End of Life Care Programme Board has made on delivering the Government End of life Care Commitment since July 2016.

1. Personalised care for people approaching the end of life

In our commitment, we made it clear that personalised care, built around individualised care planning, is central to delivering improvements to end of life care services. We acknowledged that to make meaningful choices a reality, all services involved in the care of the people approaching the end of life need to play their part in supporting informed, sensitive, two-way conversations with dying people and their relatives and carers about what is important to them. This means staff must be able to have difficult conversations about death and dying and recognise that choice and preference are not static but can be subject to changes of circumstance, preference and belief. Finally, it is essential that professionals and organisations work together, record and share information and focus on individual needs.

To support greater personalisation of end of life care, the following progress has been made

- One of the key aspects of our commitment is the roll out of shared digital palliative and end of life care records, such as Electronic Palliative Care Coordination Systems (EPaCCS), to the majority of areas by 2018 and all areas by 2020. These enable the recording and sharing of people's care preferences and key details about their care at the end of life. Some areas have made more progress than others on rolling out records, including MyRightCare in Lincolnshire, Blackpear in Worcestershire, Co-ordinate My Care in London and the Medical Interoperability Gateway in the North West. The full roll out of EPaCCS remains one of the key objectives of NHS England's regional palliative and end of life care leads, working in conjunction with colleagues from NHS Digital.
- To promote choice and personalisation at the end of life, NHS England has led a social media campaign to raise the profile of the Government End of life Care Commitment. The campaign included twitter chats focused on each element of the commitment and worked closely with Dying Matters' #KnowAboutMe campaign.
- NHS England also continued their work with five local areas to consider how personal health budgets could work within end of life care to personalise services and improve choice and control for individuals at the end of life. The work involves community health and social care teams, general practices, hospices, acute hospital departments and volunteer organisations, and includes looking at the training and development needs of practitioners to engage early in sensitive care and support planning conversations around end of life. One of the aims of the exploring the use of personal health budgets in end of life care is to develop best practice for a smooth, effective and efficient Fast Track Continuing Healthcare Pathway, for patients patient nearing the end of life, in line with the commitment to ensure people who receive Fast Track Continuing Healthcare have more choice and control over the services they receive.
- To ensure spiritual needs are met and well-coordinated at the end of life, in line with Public Health England's [Faith at the End of Life](#) report, the Care Quality Commission (CQC) continues to inspect whether people's spiritual needs at the end of life are met, and are well co-ordinated with bereavement support, as part of inspections of end of life care services (in hospitals and the community, including hospices).
- The Serious Illness Conversations pilot being tested by the New Care Model sites in Airedale and Southend has successfully led to extensive system change across the three pilot sites, including: the development of a screening tool to identify patients; a questionnaire

to enable conversations; and an agreed clinical workflow. A formal three month extension to the programme has been agreed with NHS England. Post-training coaching support (individual, group and telephone) has commenced across the pilot sites, with additional sessions also being offered to General Practitioners in Airedale and Southend over the project extension period. All pilot sites are now considering sustainability plans to continue to implement the programme going forward.

- To support patients to have better end of life care conversations, the National Council for Palliative Care (NCPC) and NHS England produced a patient empowerment film providing advice and guidance for people with advanced diseases and long term conditions to prepare for consultations with clinicians. The [film is available online](#) and features Lucy Watts MBE, a campaigner for palliative care.
- Designated care coordinators also have the potential to help people express their preferences, make informed choices and navigate their way through the complex health and care system. The NCPC undertook research into 66 potential care coordinator models, presenting the findings to stakeholders in November 2016 and publishing the guidance [Best Practice in care coordination for palliative and end of life care services: information for commissioners](#) in June 2017.

2. Measures to improve care quality for all across different settings

Supporting informed and sensitive conversations about death and preferences that are truly meaningful means we must deliver services that can provide the care, treatment and support that patients require in the setting of their choice and at the time they need it. However, in setting out our commitment we recognised that changes in the way services and support are provided need to happen in order to make this a reality for everyone, whether their preference is to die at home, in a hospice or in hospital. Furthermore, we recognised that there is significant variation in end of life care, in terms of access and experience, as well as geographically, societally and between people with different health conditions. Therefore, in seeking to improve the way we deliver services in end of life care to deliver our commitment, we must also go further in reducing unwarranted variation.

To Improve quality of end of life care the following progress has been made

- This year, the CQC has completed inspections of all hospital and community health services, and reported on and rated end of life care as a core service. In addition, the CQC has inspected all hospices. Hospital ratings have already been published in March 2017 as part of [The state of care in NHS acute hospitals 2014 to 2016](#) report, and reports covering hospices and community services will follow. For future inspections, the CQC has developed two new overarching assessment frameworks, one for healthcare services and one for adult social care services. Both frameworks prompt inspectors to consider whether people are supported to make informed choices about their end of life care.
- Over half of hospitals inspected were rated good or outstanding for end of life care. However, in recognition of the need to do more to ensure all hospitals deliver high quality care, NHS Improvement has visited 20 Trusts rated as 'Inadequate' or 'Requires improvement' in end of life care to give them bespoke support with their end of life care strategic planning and practice. NHS Improvement has now launched a formal improvement collaborative for 16 of these Trusts to help them to learn about quality improvement methodology and enhancing care and experience for patients and carers. The collaborative, which includes a study session over four days, will enable Trusts to work on an improvement project in end of life care, using improvement methodology and sharing best practice. They will be supported by visits from national and regional teams to monitor progress. NHS Improvement will also work with the remaining Trusts with 'Requires improvement' CQC ratings and support them with visits, bespoke advice and through sharing best practice.
- Since the publication of the Government's End of Life Care Commitment, NHS England has worked to embed end of life care across all relevant programmes in the NHS. The National End of Life Care Programme Board brings together lead directors from across NHS England to ensure opportunities for joint working and alignment are maximised. Joint working has taken place across several national programmes, including the production of an end of life care and learning disability ['top tips' guide](#), published in August 2017 and new [care planning guidance](#) for people diagnosed with dementia, published in May 2017.
- To improve end of life care in hospitals, NHS England and NHS Improvement established an oversight board for the Transforming End of Life Care in Acute Hospitals Programme. This supports statutory and voluntary sector partners to extend the use of quality improvement

initiatives such as Macmillan Cancer Support and the NCP's [Building on the best programme](#), funded by Macmillan, Guy's and St Thomas's Hospital's [AMBER care bundle](#) and the Point of Care Foundation's [Patient and Family Centred Care programme](#). The board supported this important work during the transitional period when NHS Improvement was taking on the improvement functions previously managed by NHS England.

- To improve end of life care in care homes and spread lessons from existing Vanguard sites that include care homes, an [Enhanced Health in Care Homes framework](#) was published in September 2016. A benchmarking tool was created to allow organisations to assess themselves against the framework and identify areas that they wish to prioritise. Additionally, Public Health England is publishing a series of products in summer 2017 looking at end of life care in care homes to identify best practice. PHE has also hosted a webinar on end of life care and published a number of new indicators on care homes in their [End of Life Care Profiles](#).

3. Innovation in the delivery of high quality care

The implementation of our commitment is taking place at an exciting time in health and social care. Local organisations are coming together with their communities and the voluntary sector to develop Sustainability and Transformation Plans (STPs) to design and deliver services in a way that best reflect the needs of local populations. At the same time a range of new care models have been deployed in England that are working across the traditional boundaries between care settings with a keen focus on strengthening out of hospital care. As we set out in our report last year, the changes currently underway offer a real opportunity to ensure innovative ideas on the design and delivery of end of life care services are realised.

To embed innovation in end of life care the following progress has been made

- The National End of Life Care Programme Board is developing a collaborative support offer to engage with STP leads. The Board is conducting an in-depth review of STP plans considered to have good end of life care content and will use this to develop an optimum plan to support STP discussions at both a strategic and operational level. The Board is also developing a public-friendly narrative based on the in-depth review to help STP areas and Health and Wellbeing Boards see the benefits of improving end of life care and to enable local populations to understand the opportunity STPs can bring to an issue that affects everybody. The Board is analysing key priorities and themes that recur in STPs, such as 'Urgent and Emergency Care', 'Financial Sustainability' and 'Transformation' and then using the themes identified to develop a support offer that sets out how end of life care can support the delivery of these key priorities, what this looks like, and what support and resources are available to help achieve this from a strategic, operational and delivery perspective.
- Over the last year, NHS England worked collaboratively with regional partners to successfully host nine End of Life Care Roadshow events across the country to showcase best practice and promote person centred care and patient empowerment. NHS England also updated regional colleagues on its national programme of work to deliver [The Government's Mandate to NHS England](#), the *Ambitions for Palliative and End of Life Care* and the Government's End of life Care Commitment.
- Working with NCPC, NHS England expanded the Ambitions for Palliative and End of Life Care website to create a [Knowledge Hub](#) which brings together end of life care tools and resources in one place. A cross-sector stakeholder group was established to oversee the transition of national documents, leaflets, booklets, policies and educational resources. The hub provides those involved in the commissioning and provision of palliative and end of life care with a quick and easy way to source information, including helpful tools and resources to drive delivery of the *Ambitions for Palliative and End of Life Care*.
- In February 2017 Public Health England published [Cost effective Commissioning of End of Life Care](#), which included new research looking at cost effective, evidence based benefits for specific groups at the end of life. Public Health England is also planning a webinar for later in the year to share the research with stakeholders.

- To support commissioners, NCPC [published seven evaluations](#) of different approaches to 24/7 models of care that have been made available on the Knowledge Hub to guide commissioning of round the clock access to specialist palliative care.
- In addition, in the past year the National Institute for Health Research has funded three research projects into improving end of life care, investing a total of £1,288,475. The three projects were:
 - The Namaste Care intervention to improve the quality of dying for people with advanced dementia living in care homes: a realist review and feasibility study for a cluster randomised controlled trial
 - ImproveCare: The management of clinical uncertainty in end of life care - a feasibility cluster
 - CARer-ADministration of as-needed sub-cutaneous medication for breakthrough symptoms in home-based dying patients: a UK study
- Other end of life care research projects, totalling an investment of £3,935,242, include:
 - Supporting Excellence in End of life care in Dementia (SEED programme)
 - C-CHANGE: Delivering high quality and cost-effective care across the range of complexity for those with advanced conditions in the last year of life

4. National and local leadership to prioritise and improve end of life care

The delivery of our commitment on end of life care requires action nationally and locally. After the publication of the commitment, a National End of Life Care Programme Board was established to oversee its implementation. Represented on the board are key health and social care system partners, local commissioners, the voluntary sector and people with lived experiences of end of life care. This ensures that those actions that are instrumental in delivering the commitment receive the right levels of support, monitoring and scrutiny and that those responsible for their delivery are held to account. National leadership also plays an important role in supporting and engaging with commissioners and providers on how end of life care can be improved and offering advice on service models that work well in different areas and sharing best practice.

In providing national and local leadership, the following progress has been made

- Together with NHS England, we have emphasised the importance we place on end of life care at both a national and local level by promoting the End of Life Care Commitment to commissioners, health and social care staff and other important stakeholders. In December 2017, the then Parliamentary Under-Secretary of State, David Mowat MP wrote to all Health and Wellbeing Boards to highlight the value of the Government commitment as they worked on local strategies, including STPs. In January 2017 he also spoke at an End of Life Care Roadshow in Crawley to set out the Government's ambition for everyone at the end of life.
- To support commissioners, NHS England and Public Health England published an [individual-level clinical dataset for adult specialist palliative care](#) in December 2016. NHS England also published a definitive set of [palliative care currencies](#) in April 2017 to help in quantifying palliative care complexity locally. Alongside the previously published *Specialist Level Palliative Care: Information for commissioners* and revised *End of Life Care Commissioning Toolkit*, which are both available as part of NHS England's [suite of resources](#) for clinical commissioning groups, these represent important developments supporting commissioners to deliver high quality care for local populations.
- The Chief Social Worker's priorities for developing the social care workforce over 2016/17 included making progress on developing a clearer role and capabilities for social workers in end of life and palliative care. Work is currently underway to develop capabilities and a continuous professional development pathway for social work with older people, led by the British Association of Social Workers, which will include the skills and knowledge required for end of life care. They are currently out for consultation with the sector and will be published later in 2017.

5. The right knowledge and skills to deliver high quality personalised care

High quality, personalised and compassionate end of life care cannot be delivered without the staff having the training support and expertise to deliver it. We know there are many clinicians and care staff in the NHS who deliver care in this way on a daily basis, supporting patients, their families and carers, but our commitment also recognises that effecting real change means ensuring training in end of life care extends beyond those clinical specialities and care settings focused on its delivery to being a more fundamental part of training for all health and care professionals.

In delivering end of life care education and training the following progress has been made

- It is planned that the importance of excellent education and training to deliver end of life care will continue to be reflected in the forthcoming 2017/18 Health Education England Mandate, with progress reported to its Board. At the Board, strategic risks and issues are discussed collectively to support the delivery of the [Five Year Forward View](#).
- Working with key members of its Medical and Nursing Advisory Groups, Health Education England is strengthening the undergraduate and postgraduate curricula to support patient choice and improve quality in end of life care. To ensure staff are appropriately trained in end of life care, Health Education England, in partnership with Skills for Care and Skills for Health, published a refreshed [End of Life Care Core Skills Education and Training Framework](#). This aims to standardise end of life care training and education. Within its organisation, Health Education England has also developed a strategic approach for end of life care that links national and local work streams as well as related programmes such as person centred care and dementia.
- Health Education England has produced materials with NHS Employers to promote best practice on employer-led training to demonstrate the benefits to employers to incentivise further investment in end of life care training. They promoted new webpages, interviews and good practice examples, an online guide for employers and a webinar. Materials have been made available on the [NHS Employers website](#).
- The NCPC has also been working with Health Education England to produce a report into asset based education and training which will be published in summer 2017. Asset based approaches are those that encompass and involve the whole community including the public, volunteers and voluntary sector, patients and carers. The *End of Life Care Core Skills Education and Training Framework* also supports asset based approaches. It is also important to note that end of life care is also an integral part of workforce planning within the overall support for STPs.

6. Working together with system partners and the voluntary sector

The voluntary sector has long played an important role in the delivery of high quality end of life care across communities, in homes and in hospital and hospice settings, working in partnership with local service providers and national system leaders. Some of our voluntary sector partners made specific commitments in the Government response to the Choice Review to improve end of life care. As we set out in our commitment, the expertise and insight the voluntary sector can bring is invaluable, and we will continue to learn from the best the voluntary sector has to offer and work with our voluntary sector partners.

In working with, and learning from, voluntary sector, the following progress has been made

- The Department of Health and system partners work closely with the voluntary sector through the Ambitions Partnership to promote the implementation of the *Ambitions for Palliative and End of Life Care*. The Department also supports the Dying Matters Coalition to promote issues around death and dying and the importance of individuals making end of life care plans in advance. NHS England contributed funding to the Dying Matters campaign in 2016/17, and promoted Dying Matters Week at the National End of Life Care Programme Board.
- The Cabinet Office, in partnership with NHS England, NHS Confederation and the Department of Health ran a pilot End of Life Social Action project on end of life care volunteer networks, which ended in November 2016. The findings of the report will support the new national volunteering programme (Q-Volunteering) the Department of Culture Media and Sport is developing. Public Health England and NCPC [published reports into their community resilience](#), including on bereavement, based on the [Dying Well Community Charter](#) in eight local pathfinders.
- NCPC and the Dying Matters group led [#KnowAboutMe](#), a social media campaign to raise public understanding and expectations about record sharing in end of life care during March and April 2017, in partnership with NHS England. National Voices also supported the project alongside their work on NHS England's People and Communities Board. Dying Matters Week 2017 aimed to encourage people to not only talk and plan ahead for the end of life but to support each other through, building on a public health approach to palliative care. Over 300 events were held by Dying Matters members across England to raise awareness and change behaviour.
- NCPC has also published guidance on public health approaches to palliative care in [Every Community Prepared to Help](#), together with an [evaluation](#) of their *Dying Well Community Charter* project.
- NCPC promoted the voice of people with lived experiences to inform palliative and end of life care through their People in Partnership Group, including working with the General Medical Council on educational films and 'Speaking Out' training, which focusses on developing public speaking skills and confidence in talking about dying, death and bereavement

- Through their membership of the Strategic Partner Programme hosted by the Department of Health, NHS England and Public Health England, Hospice UK and NCPC published the guidance [No Painful Compromise](#) on pain management for people at home, alongside public facing advice in May 2017.
- Similarly, Age UK is working to produce a booklet and animation, *Let's talk about death and Dying*, that provides information about conversations, care and choices at the end of life. It will be promoted through their media channels including radio and trade press.
- Age UK has also helped to identify five priorities at a roundtable event, hosted by the Malnutrition Task force, with input from NHS England, to implement the guidance [Commissioning Excellent Nutrition and Hydration 2015 – 2018](#).

7. Strengthening accountability and transparency to drive improvements

In order to make our end of life care commitment a reality we need to ensure there is clear accountability for delivery; an understanding of what is required; and transparency on progress. Publishing this report and setting out the progress that has been made is part of that. We and our system partners are also taking further steps to ensure the objectives are clearly defined for system partners and local commissioners.

In strengthening accountability and transparency, the following progress has been made

- End of life care is reflected in the NHS England Mandate and is planned for inclusion in the forthcoming Health Education England Mandate, and both system partners will report to the Department on their progress delivering the Mandates next year.
- NHS England has developed metrics in conjunction with Public Health England for potential inclusion in the Clinical Commissioning Group Improvement and Assessment Framework as part of their work to develop an Atlas of Variation in end of life care. NHS England is also considering new ways of capturing the experience of people approaching the end of life. Funding has been secured to continue the National Audit of Care of the Dying Adult for the next five years, and Ipsos MORI has completed an options appraisal on the best ways to capture feedback on the quality of end of life care. The options appraisal has been informed by a number of stakeholders from across the health and social care system, and NHS England is now considering the Ipsos MORI recommendations.
- NHS England has also worked with Integrated Personal Commissioning sites to develop a Personalised Care and Support Planning Framework, which explicitly refers to end of life care. It will be published as part of the wider delivery framework.
- Importantly, the new system-wide Governance Board, the National End of Life Care Board includes representatives from across the relevant system partners, people with lived experience of end of life care, and representatives from the voluntary sector through the Ambitions Partnership.

8. Palliative and end of life care for children and young people

It remains true that our commitment to end of life care is for people of all ages, including children and young people. Most of the actions we have set out to deliver the commitment apply equally to everyone needing end of life care. However, there has been some specific progress made in work to improve palliative and bereavement services in children's palliative care.

In improving care for children and young people at the end of life, and enhancing support to families, friends and carers who look after them, the following progress has been made

- The Department is working works closely with the Paediatric Bereavement Network as they develop standards for bereavement services in paediatric tertiary centres and guidelines for children bereavement. The Department is also engaging with a consortium of baby loss charities including SANDS (the stillbirth and neonatal death charity) on the definition of a standard bereavement pathway for families who have experienced baby loss. The Government will also ensure all families who lose a baby are given the bereavement support they need, including a new entitlement to child bereavement leave, in line with its manifesto commitment.
- NHS England is also working with Together for Short Lives to promote the implementation of the National Institute for Health and Care Excellence Clinical Guidance [End of Life Care for Infants, Children and Young People](#), published in December 2016. This new guidance was welcomed by clinicians and charities working in end of life care. It sets out important recommendations about end of life care planning and engagement that emphasises the importance of putting families at the heart of care. This includes around bereavement support, highlighting the need to discuss and plan in advance the arrangements that may be needed and ensuring parents and carers can access that support both before and after the death of a child and young person. The guidance was developed with the help of children at the end of their lives, as well as families in order to reflect what they felt mattered most.

9. Closing remarks

In the year since the publication of the Government's response to the *Independent Review of Choice in End of Life Care*, good progress has been made on making high quality personalised end of life care a reality for all.

The National End of Life Care Programme Board is now responsible for overseeing the delivery of the report until 2020. Going forward, we expect to see more patients having informed honest discussions about their needs and preferences with clinicians, developing personalised care plans, involving their family and carers as much as they wish in their care, and having the confidence to know who to contact to get help and advice day or night.

The Programme Board will keep stakeholders and the public up to date with future progress through the Ambitions Partnership's Knowledge Hub. [Papers from every meeting of the Programme Board](#), including detailed project plans, have been made publically available.

10. Ambitions Partnership commentary

The Ambitions Partnership is a broad coalition of national organisations working in England to improve palliative and end of life care. Our organisations came together as a partnership approach to refreshing the [End of Life Care Strategy](#), first published in 2008. We took into account a number of independent reviews and reports from the Health Committee and the Health Ombudsman, as well as the work of national charities, regulators and Royal Colleges, which drew attention to the variation in quality of end of life care across England.

How care is personalised to our individual needs and preferences, especially towards the end of our lives, is absolutely central to the work of the Ambitions Partnership. After all, if the quality of care available to people is variable, and access to that care patchy, people are less likely to have their choices and preferences respected. This leads to poorer outcomes both for people at the end of life, and their families and friends.

To that end we published the *Ambitions for Palliative and End of Life Care* in 2015. This document is a framework, developed at a national level, but intended to support local commissioners and providers deliver better palliative and end of life care. The framework provides six ambitions that commissioners and providers should aspire to as well as building blocks to help them make the ambitions a reality. The ambitions are all expressed as statements of what good looks like from the perspective of someone at the end of life, and designed to give people as much control as possible over where and how they receive their care.

Six ambitions to bring that vision about:

- Each person is seen as an individual
- Each person gets fair access to care
- Maximising comfort and wellbeing
- Care is coordinated
- All staff are prepared to care
- Each community is prepared to help

Now, each of our individual organisations is committed to aligning its own work to the Ambitions framework. Collectively, we are working to use our influence to ensure that the framework is adopted and used to guide commissioning and service delivery throughout England. For example, in the last year we have held a deep-dive session on communities who are less likely to have access to palliative care, including Black and Minority Ethnic communities and the Lesbian, Gay, Bisexual and Transgender (LGBT) community. The CQC has examined these issues in their report on inequalities in end of life care, [A Different Ending](#), published in May 2016. Marie Curie has also published the report [Hiding Who I Am](#) on access to palliative care for the LGBT community in June 2016, as well as funding research by King's College London that has led to ten recommendations to help providers of palliative and end of life care better support LGBT people and their families. NHS England is also leading on work relating to end of life care for people with learning disabilities and people who are homeless and Macmillan Cancer Support is supporting a community of practice on end of life care for people in secure and detained settings.

One Year On:

The Ambitions Partnership is pleased to be represented on the National End of Life Care Programme Board and will continue to contribute its collective efforts to this work, recognising the power of collaborative working.

Annex 1 - National End of Life Care Programme Board

Membership

NHS England

NHS Digital

Health Education England

National Council for Palliative Care

Macmillan Cancer Support – Ambitions Partnership

Department of Health

NHS Improvement

Royal College for General Practitioners – Ambitions Partnership

ADASS

Public Health England

Care Quality Commission

The national End of Life Care Programme aims to deliver a number of objectives:

- Embed the *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*
- Deliver the government's response to the Choice Review including the six point End of Life Care Commitment
- Deliver the NHS England Mandate objective that by 2020 we should “significantly improve patient choice, including in maternity, end of life care and for people with long-term conditions, including ensuring an increase in the number of people able to die in the place of their choice, including at home”.

The purpose of the End of Life Care Programme Board is to ensure and support progress against the three end of life care work streams. This includes to:

- Provide accountability, challenge and assurance of programme delivery
- Ensure coherence and a common sense of direction across the three work streams
- Identify where further work, within or across individual work streams might be needed to achieve the government's response to the Choice Review, *The Government's Mandate to NHS England* and *Ambitions for Palliative and End of Life Care: A national framework local action 2015-2020*, and to commission work accordingly
- Identify synergies between individual projects and recommend changed or additional deliverables to help exploit these with programme board members and other Arm's Length Bodies, individual project groups, voluntary sector organisations
- Identify and manage high-level risks to delivery
- Be accountable for the project's expenditure

Annex 2 - Ambitions Partnership

The Ambitions Partnership is a crucial component of the implementation of the Choice commitment. Members have set out their plans for 2017-18 and mapped work which is directly aligned to the work of the Programme Board to its work streams and objectives.

Membership

Association for Palliative Medicine

Association of Ambulance Chief Executives

Association of Directors of Adult Social Services

Association of Palliative Care Social Workers

Care Quality Commission

College of Health Care Chaplains

General Medical Council

Health Education England

Hospice UK

Macmillan Cancer Support

Marie Curie

Motor Neurone Disease Association

National Bereavement Alliance

National Care Forum

National Council for Palliative Care

National Palliative Care Nurse Consultants Group

National Voices

NHS England

NHS Improving Quality

Patients Association

Public Health England

Royal College of General Practitioners

Royal College of Nursing

Royal College of Physicians

Social Care Institute for Excellence

Sue Ryder

Together for Short Lives