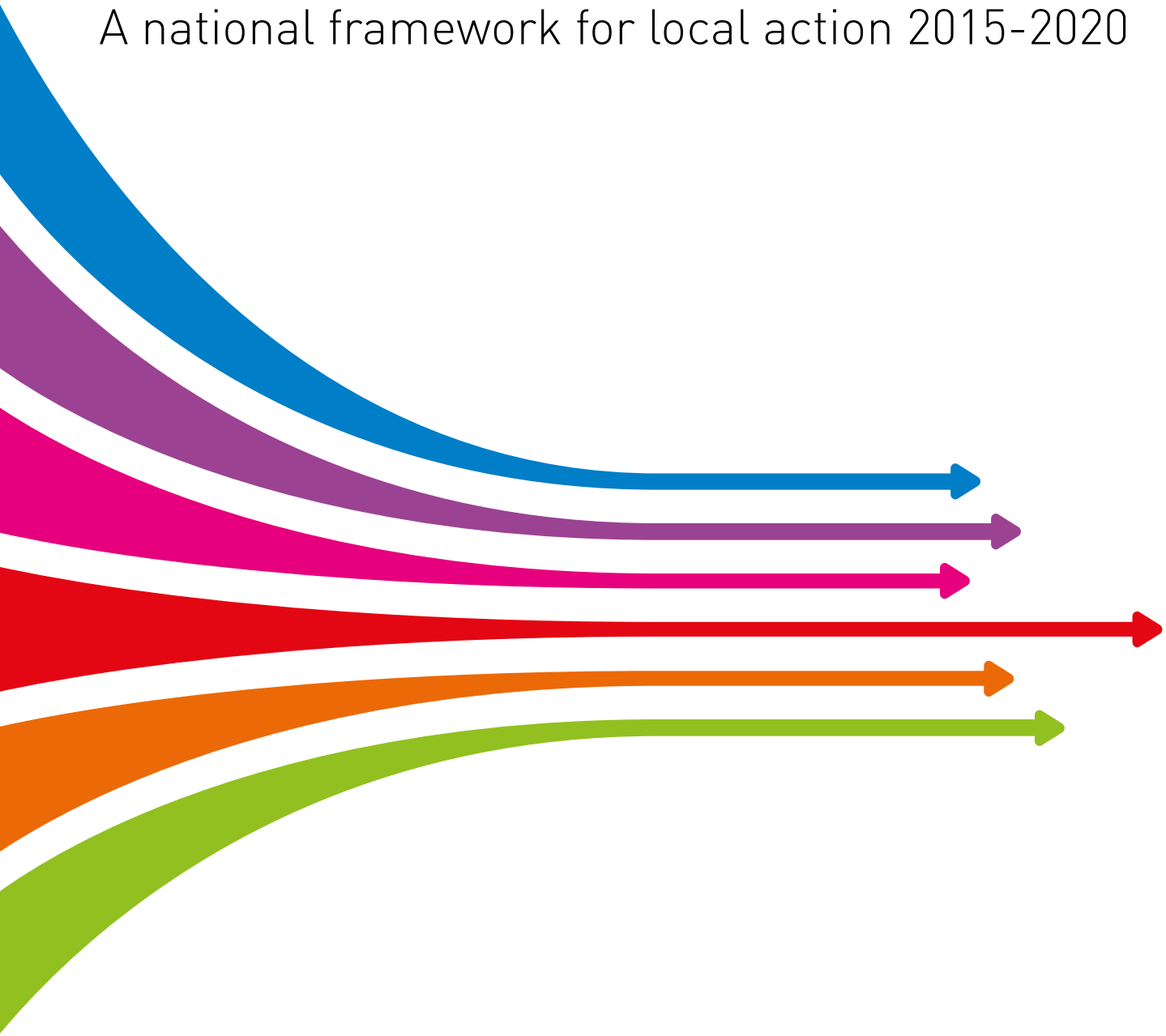
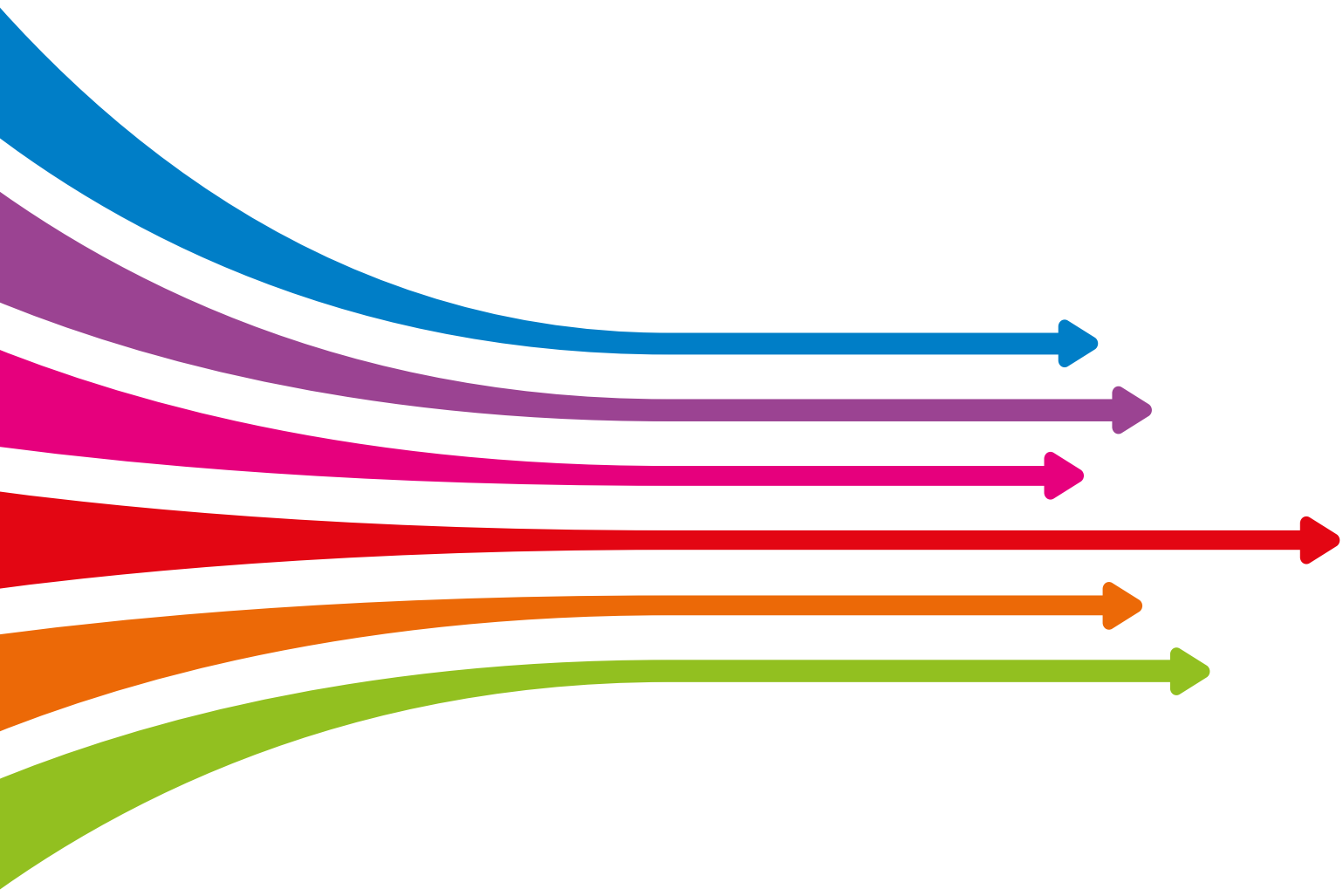
Ambitions for Palliative and End of Life Care:

A national framework for local action 2015-2020



National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk



National Palliative and End of Life Care Partnership

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
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Royal College of Physicians
Social Care Institute for Excellence
Sue Ryder
Together for Short Lives

Foreword

"How we care for the dying is an indicator of how we care for all sick and vulnerable people"
(National End of Life Care Strategy 2008)

Death and dying are inevitable. Palliative and end of life care must be a priority. The quality and accessibility of this care will affect all of us and it must be made consistently better for all of us. The needs of people of all ages who are living with dying, death and bereavement, their families, carers and communities must be addressed, taking into account their priorities, preferences and wishes.

As people, professionals and local leaders within the health and social care system and our communities, we must commit to these ambitions and to the framework that will enable their delivery. This framework is not a new strategy. It builds on the 2008 Strategy for End of Life Care and the improvements that have followed, but much more needs to be done. That Strategy was developed in a different world and a different NHS to the one that exists now.

Today, the emphasis is on local decision-making and delivery, so this document provides a national framework for local action. Constrained resources and increasing demands put all those who use, work in, and lead local organisations under an obligation to create new ways to build more effective systems of care, putting existing resources to more creative and effective use, aligning with wider changes flowing from the NHS Five Year Forward View.

We need a collective response. The will, determination and innovation of organisations working collaboratively to find new ways of delivering better care will, and must, make a difference. The essential challenge is to learn how to work together, collectively and differently to achieve these ambitions and the standard set out in the NICE Quality Standard for End of Life Care (2011). It is up to us. Engaging with the task, sharing good practice, using what we know and being prepared to learn what we haven't yet understood.

Palliative and end of life care requires collaboration and cooperation to create the improvements we all want. This is the approach we have used in our own new Partnership of organisations representing health and social care, statutory and voluntary bodies, and people with personal and professional experience, speaking with one voice.

Health and social care are equal partners in this endeavour. Cross-organisational collaboration is vital to design new ways of working that will enable each community to achieve these ends. These systems must reach out beyond the usual networks of organisations and communities to call upon contributions, ideas and actions from a wider spectrum of people. We need integrated health and social care systems that work with people, as well as for people.

We live in a world where improvement no longer comes about as a consequence of central direction. It is local leadership, in all that local leaders do, say and exemplify, that is vital to finding new ways of organising care and support for people.

We specifically require local professionals and local leaders to act. We expect you to designate a local lead, whether this is the Health and Wellbeing Board, Clinical Commissioning Group, Local Authority or some composite of these. The job is to lead and coordinate a process for working towards these ambitions, a process that is open, transparent and effective.

As a Partnership we are committed to act, help and support, both as individual organisations and by working together. This is the start of our collective engagement to turn ambitions that should by now have been standard, into a reality for all.

Our leadership, engagement and will, within and beyond the Partnership, are the most important mechanisms for change. They will all be needed if we are to create the care that we ourselves desire and should feel obligated to create for everybody.



Professor Bee Wee
National Clinical Director for End of Life Care, NHS England



Dr Jane Collins
Chief Executive, Marie Curie



John Powell
Policy Lead for End of Life Care Association of Directors of Adult Social Services

Introduction

In 2008 the first national strategy for end of life care in England galvanised the health and social care system with three key insights[1]: that people didn't die in their place of choice; that we needed to prepare for larger numbers of dying people and that not everybody received high-quality care. *'Some people experience excellent care in hospitals; hospices; care homes and in their own homes. But the reality is that many do not'.*

Since then other nation specific strategies and reports have followed. These have encompassed all ages, all four nations and all conditions[2, 3, 4]. New care processes have been developed[5]. New indicators of quality have been set[6]. New systems for scrutiny have been devised[7]. New systems for funding are under development[8]. Investment and innovation has led to significant progress particularly in reversing the long term increase in the numbers dying in hospital[9]. There is now a need for a relentless focus on improving outcomes, including people's experience and quality of care, wherever the setting.

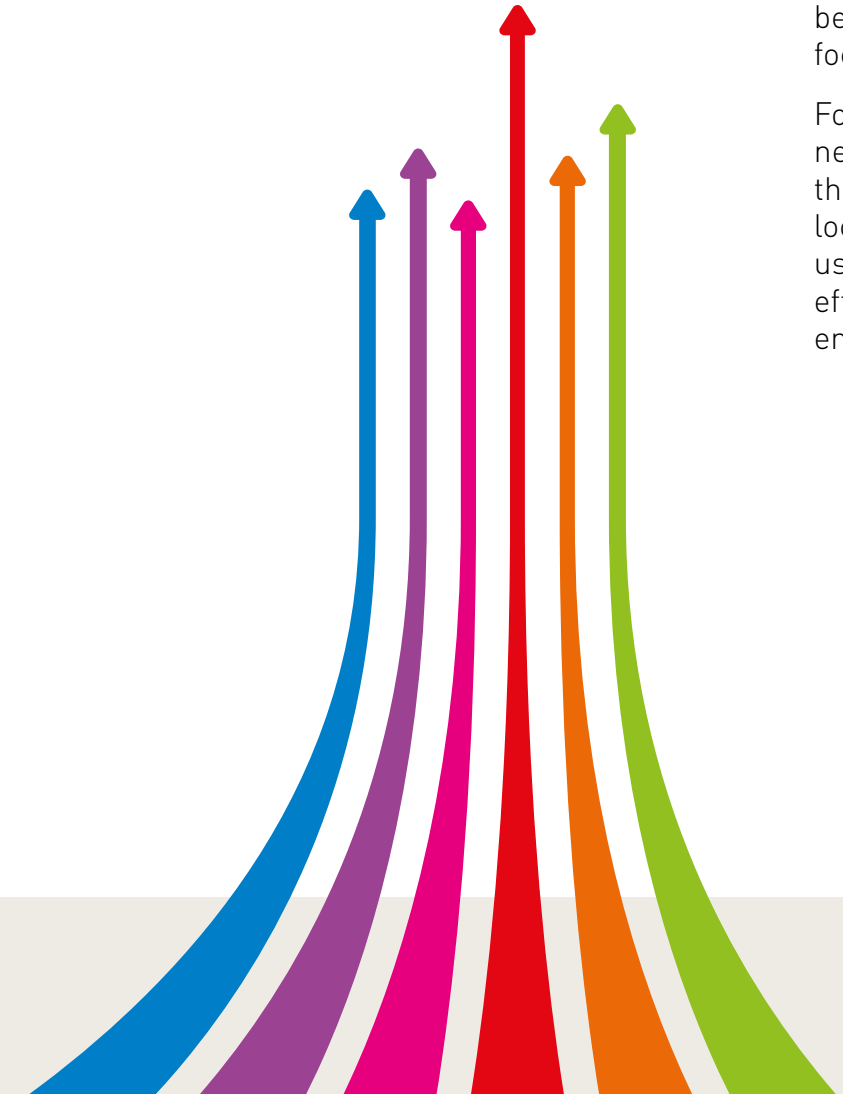
Recently the variation in quality of care at the end of life has become a point of national debate. Cumulatively the weight of independent reviews[10, 11], system-wide alliances[12], the Health Committee[13], the Health Ombudsman[14, 15], the work of national charities[16, 17, 18, 19, 20] and the government's own priorities for the NHS[21], have brought reflection and urged change, particularly in the context of the increasing needs of people as they approach the end of their lives. It is important to emphasise that while death may not be a failure, poor care is.

We are a broad Partnership of national organisations working in England and with a deep commitment to improving end of life care in our country. We understand the powerful descriptions of only partial success, and we recognise that the experience of good care is often patchy when it must be universal[22]. Since 2008 the focus on person centred care has rightly come to the fore and must now be reflected in everything we do[23]. We must continue to build on the strategy but we need to reframe this within today's context with its emphasis on local leadership, service delivery and accountability. So, in this document, we set out our ambitions for palliative and end of life care, based on our collective experience and the analysis of the many reviews and reports in this area, and present a framework for local action. Such action must be focused around the individual and those important to them, so it has to be locally led and delivered, supported by us all across all communities.

The case for change is irrefutable and recent developments bring opportunity. The NHS Five Year Forward View and the recent Directors of Adult Social Services' Next Five Years document, as well as numerous linked initiatives mean that we can put end of life care at the heart of an integrated approach to care and support[24, 25].

This is the right place for the care that each and every one of us may need. It is the right place for care that often needs to be delivered directly alongside the varied and complex circumstances of our life.

This opportunity must be grasped. We are sharing this framework for action with local leaders in every community whether they work in the statutory, private or voluntary sectors. We expect them to plan and act, using this framework, so that these ambitions can be brought into reality. Local organisations including CCGs, Local Authorities and in particular, Health and Wellbeing Boards are well placed to convene, activate and coordinate this local leadership[26, 27]. We want our ambitions to become their ambitions.



About our ambitions

The format is straightforward. We present our overarching vision and the six ambitions that we want to see achieved. We know that to succeed we must inspire a wide range of professionals and organisations to accelerate the pace of improvement. As individual organisations we are all committed to supporting this work and will be reviewing progress as well as using our own influence to bring about change.

For each ambition we summarise what we already know. We do not offer a systematic literature review but we give the references necessary to demonstrate the weight of agreement. It is not a lack of knowledge that is inhibiting our collective efforts; it is about the will and priority that must be given to applying that knowledge in a focused and purposeful way.

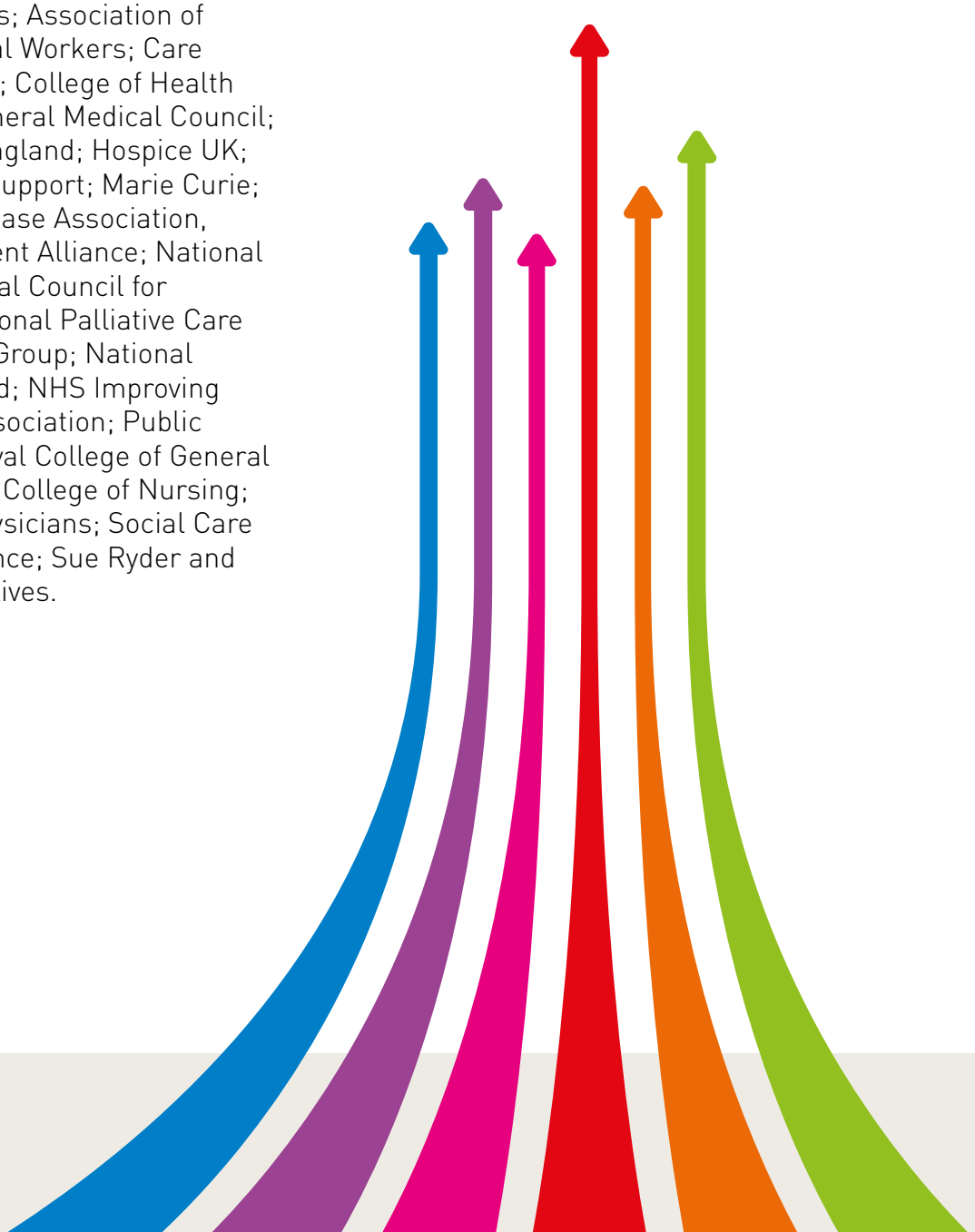
For each ambition we identify what is needed to realise that ambition. These are the foundations and building blocks which local health and social care leaders can use to build the accessible, responsive, effective, and personal care needed at the end of life.

About The National Palliative and End of Life Care Partnership

The National Palliative and End of Life Care Partnership is a group of national organisations with experience of, and responsibility for, end of life care. Its members have come together to produce a framework to improve palliative and end of life care in our country and have agreed to work together and with others to realise our ambitions. Its members are: 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 and Together for Short Lives.

This statement of our collective ambition represents the start of our work. Each member of the Partnership will respond to this statement of intent by developing their own actions and commitments to improve care.

We invite you to make this vision and these ambitions your own and become part of this 'coalition of the willing'[28]. Ultimately, there is nothing we can do to avoid death but we believe we can work collectively to make the care that surrounds that inevitability as good as possible, for all.



Executive Summary

End of life care is care that affects us all, at all ages, the living, the dying and the bereaved. It is not a response to a particular illness or condition. It is not the parochial concern of a particular group or section of society.

When it comes to death the statistics are stark. 100% of us will die. The question is what are we all going to do about that? How are we going to create confidence in the care that we may need? And how do we promote the wellbeing of those living with loss?

We cannot defeat death. However, we can change the way we talk about dying, death and bereavement and prepare, plan, care and support those who are dying and the people who are close to them. We must strengthen and improve our ability to provide care whatever the circumstances of our dying.

Reports and investigations too frequently identify poor care[10, 11, 13, 14, 15, 18].
The consistency of their critique tells us that we have a collective responsibility to do better[12, 29]. With a rapidly ageing society and changing patterns of illness many more people will live with long term conditions. Each year more of us will die and many more of us will face the challenges of dying, death and bereavement[30, 31]. We also know that more children are living with complex life-limiting illness with huge caring responsibilities placed on their families[32]. Now is the time for shared ambition and urgency.

Our vision for the many living with the foreseeable prospect, and consequence, of death, dying and bereavement draws upon the wishes of those with experience and seeks to ensure a personal experience of life that is as good as possible[6].

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).[23]"

For some, this is an apt description of how the system provides for them. For too many, it just doesn't match their experience. This should and does frustrate us. Our goal is to make this experience a consistent reality for all.

As organisations with experience of, and responsibility for, palliative and end of life care we have made a collective decision to act together to do all we can to achieve for everyone what we would want for our own families. We have worked to distil what is important and to grasp the opportunity created by the drive for more integrated care to provide a framework for change.

We need to break the cycle of reports asking for change. Our approach has to be different. We propose resetting our sights on six positive ambitions for palliative and end of life care. By setting out a framework for local action we want to create a new

impetus for better care. We also identify the eight foundations that underpin and are required to bring about this improvement. Different individuals and organisations can lay these foundations, either on their own or collectively.

These ambitions will guide us all on the next stage of our collective endeavour. That they are achievable makes us optimistic. We must be constantly restless until we can demonstrate that they are secure.

Our six ambitions

Each of our six ambitions includes a statement to describe the ambition in practice, primarily from the point of view of a person nearing the end of life. Although we have focused on the experience of the dying person, our concern is broader. Each statement should also be read as our ambition for carers, families, those important to the dying person, and where appropriate for people who have been bereaved.

The need for honest conversation and the importance of joined up care are as important for carers and families as individuals. The need for support from, and for, empathetic and competent health and care staff is as important for carers, families and those who are bereaved, as it is for the dying. As is the help that can be given by the communities of which we are part.

We need to have a nation where each death matters. This means extending our concern beyond the care required by those living with predictable life-shortening illness, to ensure a better response from the health and care system and from society, to sudden, unpredictable or very gradual dying.



01

Each person is seen as an individual

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

02

Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

03

Maximising comfort and wellbeing

My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

04

Care is coordinated

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

05

All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

06

Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

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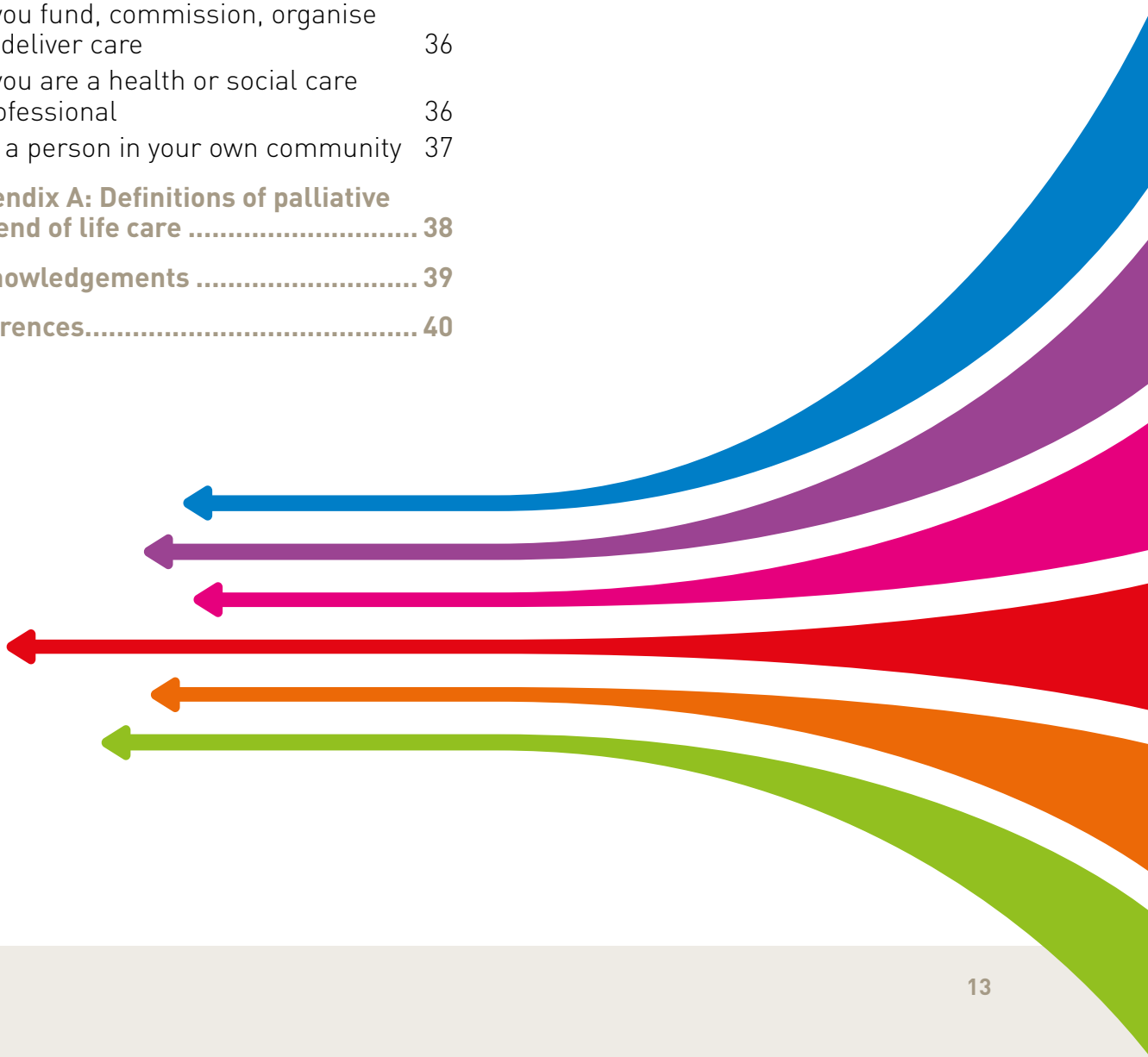
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The foundations on which our vision is built

When the end of life is in sight everybody should have the care and support to enable them to live to the end in the best way that they can.

National Voices, the National Council for Palliative Care and NHS England have produced a clear description of this vision in 'Every Moment Counts: A narrative for person centred coordinated care for people near the end of life'[23].

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."

This statement was created with extensive input from the widest range of individuals and organisations. It is based on existing literature, bespoke research and the engagement of people with experience. It has clarity and authority.

To realise our vision we have identified eight foundations that need to be in place to achieve our ambitions. They are necessary for each and underpin the whole.

These foundations are the pre-conditions for delivering the rapid and focused improvement that our Partnership seeks. For us they are the starting point from which our new and collective endeavour must be built.

1. Personalised care planning

Everyone approaching the end of life should be offered the chance to create a personalised care plan. Many people with long term conditions or complex needs will already have a care plan and this should be updated to reflect their changing needs. Although participation must be voluntary, the opportunity for informed discussion and planning should be universal. These discussions should be between the person nearing the end of life, those important to them (as they wish) and their professional carers.

The potential elements of the plan should be broad. It should allow people to express their preferences for care and set personal goals for the time they have left. The offer should include the possibility of recording preferences that might guide others if the person were to lose the mental capacity to make their own decisions (advance care planning). However, the offer should also encompass the chance to appoint a person with lasting powers of attorney or allow the person to trust their professional carers to act in their best interests. Such conversations must be ongoing with options regularly reviewed, revisited and revised.

2. Shared records

To ensure the plan can guide a person centred approach, it has to be available to that person, so that they can review, change and update it themselves. Subject to that person's consent, or, if they lack mental capacity, in their best interests, the plan should also be shared with all those who may be involved in their care. All electronic systems for sharing health related preferences must encompass the recording and sharing of preferences at the end of life. There should be ambitious local targets for the rollout of systems for sharing digital records. These targets should help ensure that the opportunity to have preferences recorded and shared is offered to an increasing number of people with non-malignant diseases. The widespread use of electronic systems should be encouraged across health and social care providers in the statutory, voluntary and private sector. This will require support for, and investment in, the use of IT.

3. Evidence and information

To ensure a better response to dying, death and bereavement, the local organisations that give care need accurate and up to date information that can help them improve services. Service providers across all sectors, as well as the professionals who work within them, should participate in national initiatives to collect comprehensive, robust and anonymous data. These data should inform judgements about the quality and the accessibility of services, and support quality improvements. All those who are part of the local health and social care system that cares for the dying and bereaved should also seek to sensitively collect and use a wide range of information so that they can assess progress towards our ambitions. Palliative and end of life care organisations need to take data seriously, become data literate and invest in collecting and using data.

This should include seeking insights from the people to whom they give care and those who are important to them. Those who provide services at the end of life should also regularly contribute to research as well as assessing and applying the growing evidence base arising from research into the most effective and innovative ways of ensuring a high quality service for all. Those who fund research must be cognisant of the need for strengthening the evidence base for palliative and end of life care.

4. Involving, supporting and caring for those important to the dying person

Good palliative and end of life care includes giving care and support to families, friends, carers and all those who are important to the dying person. This must encompass good bereavement and pre-bereavement care, including for children and young people. It must also respond to the needs of those who are affected by death caused by sudden illness or trauma, including suicide. As well as caring for them as individuals who are facing loss and grief, there needs to be recognition and support for their role as part of the person's caring team, if they and the dying person wish them to be regarded in that way.

5. Education and training

Every professional needs to be competent and up to date in the knowledge and practice that enable them to play their part in good end of life care. It is vital that every locality and every profession has a framework for their education, training and continuing professional development, to achieve and maintain this competence. That framework must allow expertise and professionalism to flourish in the culture of every organisation and every caring-contact. It should offer practical examples of how care can be delivered in a way that is tailored to the person. If our ambitions are to be achieved there must be a consistent and common use of such educational resources for palliative and end of life care. The Local Education and Training Boards must support educational and service providers to use to their full potential the opportunities for learning and development that exist locally, and where needed to develop new opportunities.

6. 24/7 access

Every person at the end of life should have access to 24/7 services as needed as a matter of course. The distress of uncontrolled pain and symptoms cannot wait for 'opening hours'. This is a necessary system-wide expectation and good end of life care cannot be achieved without it. All commissioners and providers have to engage in defining how their services will operate to ensure expert responsiveness to needs at any time of day and night.

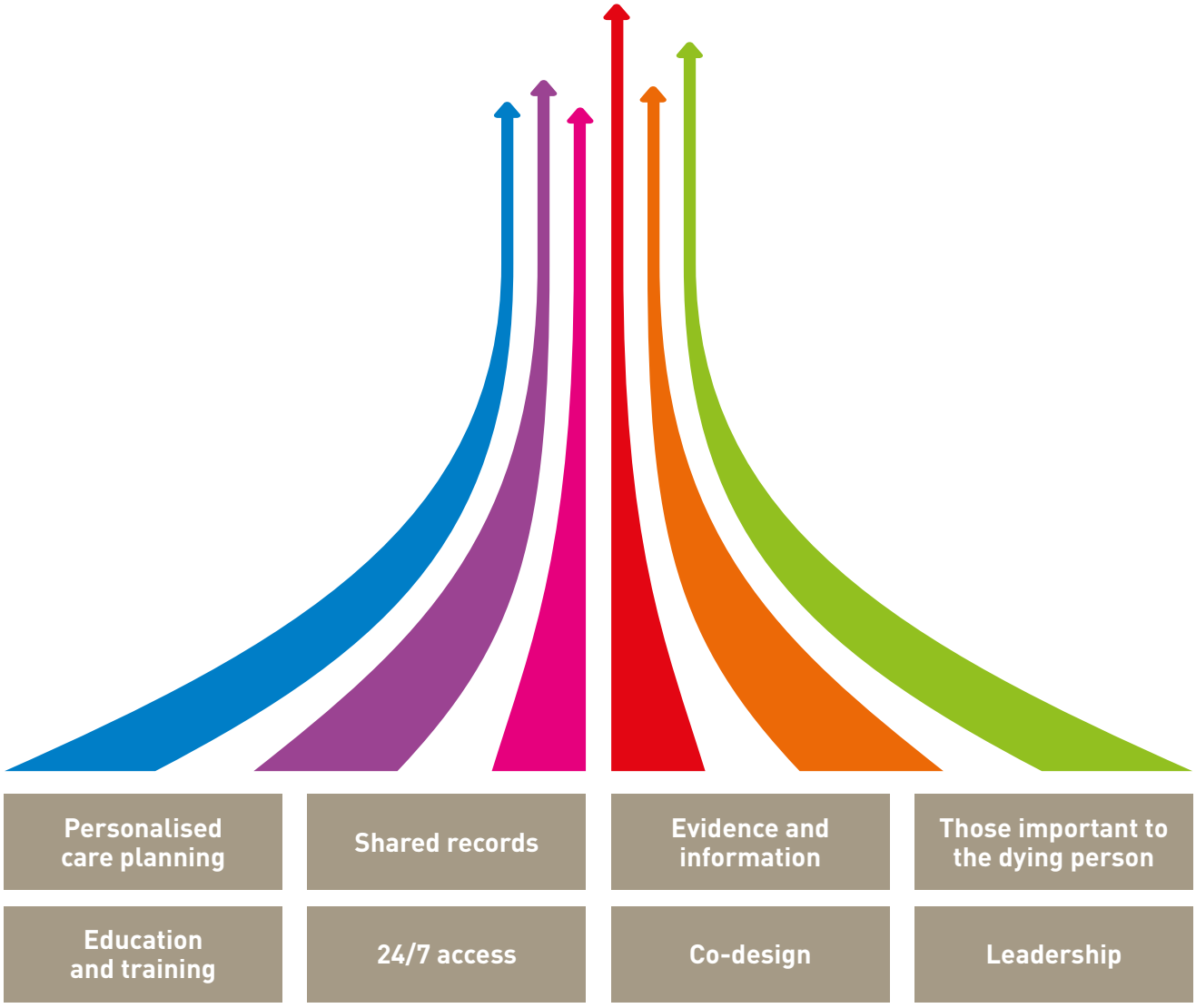
7. Co-design

Systems of end of life care are best designed in collaboration with people who have personal and professional experience of palliative and end of life care. Organisations that provide care should have these connections and clinicians will have valuable day-to-day relationships with patients and relatives. Many local and national voluntary organisations are built on the experience of such people and service providers will find they have similar aspirations to many of these organisations. New partnerships will create the new impetus for developing the care that people need at the end of their life. All health and social care systems should involve people who have personal experience of death, dying and bereavement.



8. Leadership

The leadership of CCGs and Local Authorities and, in particular Health and Wellbeing Boards, is needed to create the circumstances necessary for action. In our vision, these bodies will come to a local arrangement where there is clear responsibility either from one organisation or a number of organisations, to oversee the process. This would include identifying the local work needed to bring these ambitions into place, such as driving forward the use of personal budgets and working to support cross-organisational leadership and collaboration. It would mean championing an approach to commissioning that is collaborative, population based and proactive, and supporting the work of those who promote the public discussion of dying, death and bereavement. Clinical leadership must be at the heart of individual service provider organisations and is vital to ensuring that each person receives the care they need at the right time.



Foundations for the ambitions

01

Ambition One:
Each person is seen as an individual

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

What we already know

- Having our personal needs and wishes ignored or overridden is a deeply rooted fear for those who are dying, their families, and the many people who are carers, as well as those who have been bereaved[33].
- We know that much about recognising dying and impending death is uncertain and challenging. However, timely identification and honesty where there is uncertainty is key to the quality of care – all else follows[34].
- We know that despite the difficulty that can be associated with talking about death, people want repeated opportunities to consider whether to engage in such honest conversations about their future[11].
- We know that people want to be involved in their care, and should be given all the information, advice and support they need to make decisions about it[10, 11, 35, 36, 37, 38, 83].
- We know that with effort, collaboration and system leadership health and social care can be designed around the wishes of the person approaching death[39].
- We know that asking, recording and working to support choices requires those who lead organisations and the care professionals who work in them to be innovative in how to enable choices to be met, particularly within resource constraints[11].

The building blocks necessary to realise our ambition

Honest conversations

Everybody should have the opportunity for honest, sensitive and well-informed conversations about dying, death and bereavement, whether they are the person dying, their family, their carers or those important to them. We recognise that the 'when' and 'how' of such conversations need to take account of the preparedness and the perspective of the individual nearing the end of their life. However, professionals have to be sure that opportunities for honest and sensitive conversations about the future are clearly offered. Where possible these offers to talk should be early enough to enable people to reflect on their circumstances, to adapt and to plan. All local and national organisations with responsibility for the care of dying people should use their leadership to promote and encourage these conversations and to take steps to break down barriers about how dying, death and bereavement are discussed.

Systems for person centred care

Effective systems for person centred care need to encompass: systematic ways of reaching people who are approaching the end of life, effective assessment as well as effective decision making support, care coordination, care planning, and care delivery. It also requires effective ways of managing the timely and sometimes repeated input of Specialist Palliative Care services or dedicated children's palliative care services, when needed. Such systems should identify the goals of the person nearing death. Part of the approach should include the appropriate use of person centred tools to measure the quality and impact of care on the dying person within the context of local audit and reflection. We urge local health and care systems to adopt such approaches.

Clear expectations

People should know what they are entitled to expect as they reach the end of their lives. Those who commission local systems of care should tell people what they might reasonably expect of their health and care services as they approach death, and make sure this is publicised. This should include services to help people who are bereaved. This must be informed by the obligations and the legislation under which they act as well as the guidance from NICE. There is a significant and welcome shift towards recognising the importance of person centred care. In our view, making sure people are clear about what they can expect is crucial to enabling person centred care.

Access to social care

People must be supported with rapid access to needs-based social care. The reality of care at the end of life is that it encompasses what professionals see as a mix of 'health' needs and 'personal and social care' needs. Expertise in both is important for the best clinical assessment of need and the best delivery and management of hands-on care, in the right environment, right through until death. National and local statutory and voluntary organisations must find ways of working together to deliver all the personal care, health care and social care that people need to live their last days, weeks, months and years as well as possible.

Helping people take control

Helping people take control at the end of their life should be our goal. Although people can be vulnerable and less resilient as they die, this must not become a reason for not helping people to have control where possible, or at least supporting people to retain as much control as they wish to have. National and local organisations should see personal budgets and integrated personalised commissioning as potentially powerful tools for enabling the delivery of tailored and personal care for many more people. Education and training on the application of these tools should be widespread, as they can ensure that an improvement in personalised care is put at the heart of local plans.

Integrated care

Creating the individual person centred care that is at the heart of our ambitions means ensuring palliative and end of life care is part of the new models of integrated health and social care. Such systems are being promoted, supported and developed across

the NHS, the voluntary sector and the wider health and social care system over the next 5 years. We urge national and local organisations to use the planning guidance for the Better Care Fund and the Five Year Forward View. We also suggest they look at the Association of Directors of Social Services' proposals for the Next Five Years alongside a range independent reports and recommendations, many of which support plans for this integrated and personalised offer of holistic care, for every individual.

Good end of life care includes bereavement

Caring for the person as an individual means understanding and bringing sensitivity to the need to support their unique set of relationships with family, friends, carers, other loved ones and their community. Providers of palliative and end of life care must seek to support this network by helping them to help the person who is dying. Such help includes supporting them in their own preparation for bereavement. This support must be available, sensitive and tailored to the context of their own needs, and their individual lives. This obligation extends to the care that is needed in response to sudden death and suicide where good end of life care encompasses support to help people manage the impact of such unexpected or traumatic death on those who are bereaved.

Building blocks at a glance

Honest conversations

Everybody should have the opportunity for honest and well-informed conversations about dying, death and bereavement.

Systems for person centred care

Effective systems need to reach people who are approaching the end of life, and ensure effective assessment, care coordination, care planning and care delivery.

Clear expectations

People should know what they are entitled to expect as they reach the end of their lives.

Access to social care

People must be supported with rapid access to needs-based social care.

Helping people take control

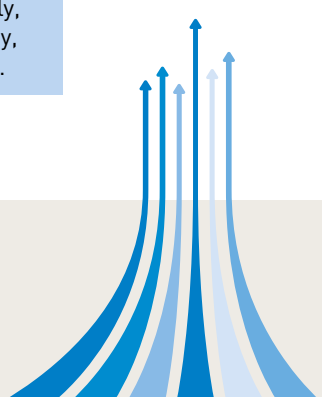
Personal budgets and integrated personalised commissioning are some of the potentially powerful tools for delivering tailored and personal care for many more people.

Integrated care

End of life care is part of new models of integrated health and social care being promoted across the health and social care system.

Good end of life care includes bereavement

Caring for the individual includes understanding the need to support their unique set of relationships with family, friends, carers, other loved ones and their community, including preparing for loss, grief and bereavement.



02

Ambition Two:
Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

What we already know

- People from black and minority ethnic (BAME) communities and deprived areas report a poorer quality of end of life care[40, 41, 42]; similarly those who are living with non-malignant illnesses, people living in more deprived areas[43], the homeless[44, 45] or imprisoned[46, 47], and those who are more vulnerable or less able to advocate for their own care[48].
- The quality of end of life care is poorer and harder to access for people who live in very rural or other isolated areas[49].
- There remain unacceptable inequities and inequalities in access to palliative and end of life care particularly for those with learning disabilities, dementia and non-malignant long term conditions[50, 51]. There is a collective responsibility on all of those involved in the commissioning and provision of end of life care to put this right[7].
- There are unacceptable variations in aspects of palliative and end of life care such as access to pain control, related to different care settings[9, 22, 51, 52].

The building blocks necessary to realise our ambition

Using existing data

Local end of life care organisations must use aggregate data to understand and remedy the partial reach of their services. Data collected by a range of organisations: the National Council of Palliative Care; the National End of Life Care Intelligence Network; Together for Short Lives as well as the Association of Directors of Social Services, can be used to shape the local plans that are needed to ensure fairness in care for those facing the last stage of their lives.

Community partnerships

Dying, death and bereavement affects everyone, so everyone must be able to get care that works for them personally, for their family and carers and for their communities. Local plans should include the development of community partnerships between different faith groups and cultural communities, as well as the diverse organisations that support children and young adults, people living with different life shortening illnesses, and those managing the difficulties of older age.

Generating new data

Individual organisations and local systems of care should engage with initiatives to generate much more robust and useful statistical data. A national data collection that records anonymised individual outcomes for a wide range of groups is vital. These data can inform local and national progress, can drive organisational strategies and guide care. Their utility far outweighs the burden of data collection and has multiplying positive impact.

Unwavering commitment

To achieve equity in access and responsiveness requires unwavering commitment. Local systems of care must demonstrate progress and establish accountability mechanisms to ensure this ambition is kept at the centre of the day-to-day organisation and delivery of care. This should be backed up by local contracts that embed evidence-based measures of equity in provision.

Population based needs assessment and commissioning

Locally, Health and Wellbeing Boards should lead the development of population based needs assessment for end of life care services. Commissioners and providers will need to demonstrate that this assessment has influenced their organisation of care and demonstrate outcomes to illustrate increasingly equitable outcomes.

Indeed when commissioning services, organisations should take into account the duties placed on them under the Equality Act 2010 with regard to reducing health inequalities, as well as duties under the Health and Social Care Act 2012. Service design and communications should be appropriate and accessible to meet the needs of diverse communities.

Person centred outcome measurement

National as well as local organisations have to find effective systems to embed this ambition into the incentives that shape organisational and professional actions – including the comprehensive use of person centred outcome measures. Such measures should be used to hold all services to account. With independent analysis of a consistent anonymised data set, improvement can be tracked and regulatory actions taken to ensure all providers are enabling fair access to care.

Building blocks at a glance

Using existing data

Local end of life care organisations must use aggregate data to understand and remedy the partial reach of their services.

Community partnerships

Local plans should include partnerships between different faith groups and cultural communities, as well as the diverse organisations that support children and young adults, people living with different life shortening illness, and those managing the difficulties of older age.

Generating new data

Individual organisations and local systems of care should engage with initiatives to generate much more robust and useful statistical data. This can guide care, drive organisational strategies and inform local and national progress.

Unwavering commitment

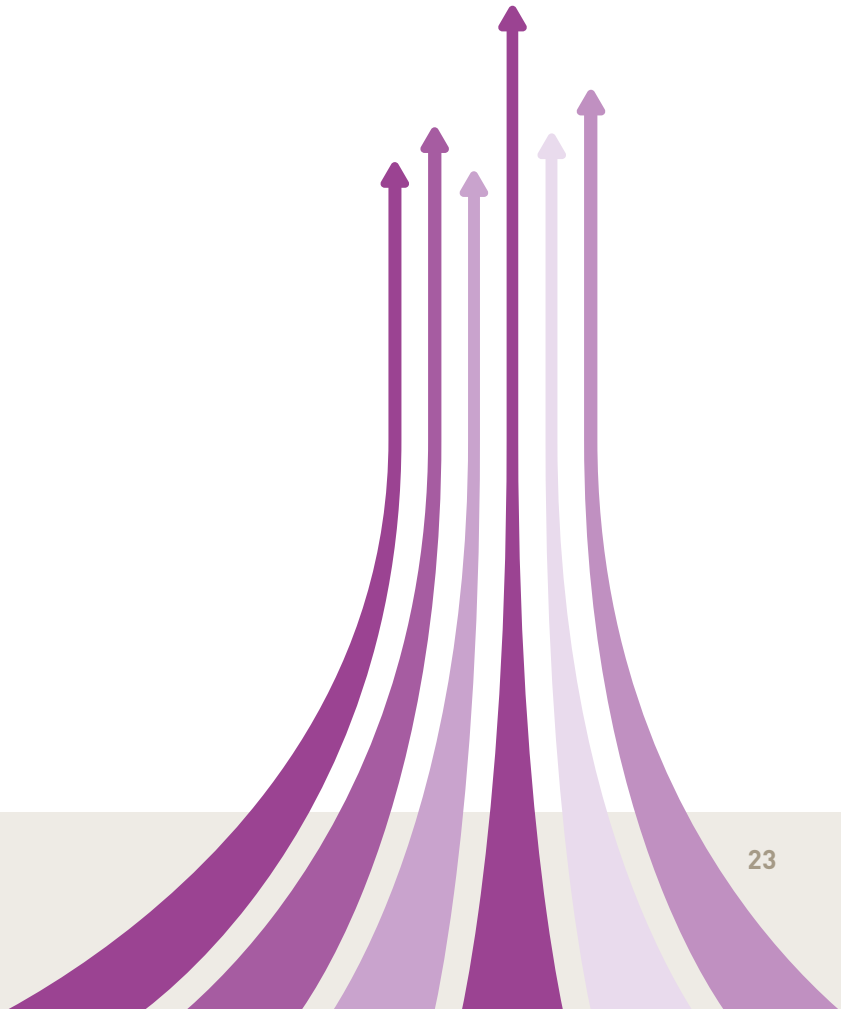
To achieve equity in access, provision and responsiveness requires unwavering commitment. This should be backed up by local contracts that embed evidence-based measures of equity in provision.

Population based needs assessment

Locally, Health and Wellbeing Boards should lead the development of population based needs assessment for end of life care services. Commissioners and providers need to use this to influence their organisation of care so that they can demonstrate increasingly equitable outcomes.

Person centred outcome measurement

The comprehensive use of person centred outcome measures will enable services to be held to account. With independent analysis of a consistent data set, improvement can be tracked and regulatory actions taken to ensure all providers are enabling fair access to care.



03

Ambition Three:
Maximising comfort and wellbeing

My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

What we already know

- Many people approaching death are fearful of being in pain or distress[53]. Dying and death can be powerful sources of emotional turmoil, social isolation and spiritual or existential distress[54].
- We know that distress from pain and symptoms can be relieved with expert palliative care and that inadequate and misguided clinical interventions are features of patients' and their families' poor experiences[10, 14, 55].
- We know that access to good and early palliative care can improve outcomes for life expectancy as well as improve the quality of life[56].
- A comfortable death can help those who are bereaved to adjust to their loss in ways that secure their future health and wellbeing[57, 58, 59].

The building blocks necessary to realise our ambition

Recognising distress whatever the cause

Many people with life shortening illness will experience some distress at some point, whether this is related to physical, psychological, emotional, social or spiritual reasons, or a combination of these. The distress may be related to the disease, treatment or the consequences of the illness or condition on the person, their life and those close to them. Promptly recognising, acknowledging and working with the person to assess the extent and cause of the distress, and considering together what might be done to address this is important. This must be available in every setting.

Skilled assessment and symptom management

Poorly controlled symptoms will dominate thoughts and feelings and prevent people addressing the things that are important to them. Attending to physical comfort, pain and symptom management is the primary obligation of clinicians at this time of a person's life and their skills and competence to do so must be assured and kept up to date, commensurate with their role and level of responsibility. Decisions about plans for symptom management and comfort measures that have been agreed between the attending clinician and person must be shared as appropriate with relevant others, and reviewed and updated regularly and shared with those providing care. Skilled assessment and an understanding of what matters most to the person will assist symptom management decisions.

Addressing all forms of distress

Bringing comfort has to include managing physical pain and symptoms but must also encompass and seek to alleviate all the different forms of distress. The experience of suffering associated with physical symptoms may be exacerbated, or sometimes caused, by emotional or psychological anguish, or social or spiritual distress. Addressing this requires professionals to recognise, understand and work to alleviate the multidimensional causes of such suffering. Attending to all sources of pain has to underpin efforts to ensure that our care is effective in alleviating distress wherever possible.

Priorities for care of the dying person

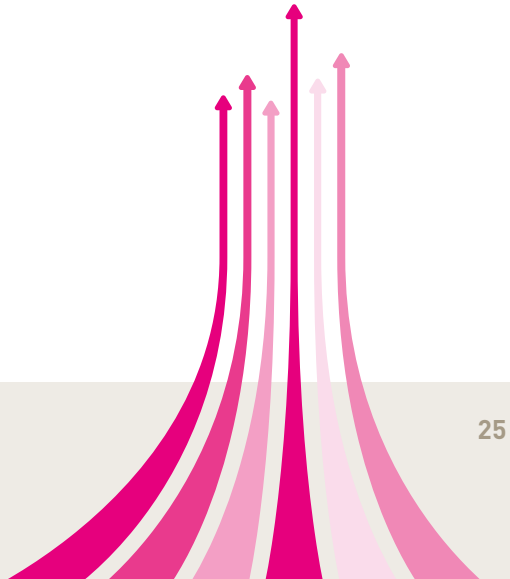
People approaching death should expect local systems to accord with the five priorities for care identified by the Leadership Alliance for the Care of Dying People. This should include developing individualised plans of care that include explicit consideration of food and drink, symptom control and the provision of psychological, social and spiritual support. Policies to ensure these priorities are addressed need to be in place wherever someone may be dying.

Specialist palliative care

People approaching the end of life should have access to Specialist Palliative Care when this is needed. Specialist Palliative Care staff should be able to demonstrate how they have met the duties upon them to develop the capability of generalist staff to understand and support the physical and psycho-social needs of dying people. This should include a clear understanding of how to access medicines, equipment and expert advice as part of the rapid response to changing needs.

Rehabilitative palliative care

All members of the health and social care team should work collaboratively to maximise the person's independence and social participation to the extent that they wish, even while acknowledging the inevitability of death. This includes working with, and supporting, the person, their carers and those involved in helping them to achieve their personal goals. All the local and national organisations that play a role in shaping care for long term conditions, frailty at any age, and care of older people, should ensure this rehabilitative approach. This should include a realistic assessment of the needs that people will have if, or when, their condition threatens to shorten their life, and how these needs can be addressed.



Building blocks at a glance

Recognising distress whatever the cause

It is important to recognise all sources of distress quickly, to acknowledge distress and to work with people to assess its extent, its cause and what might be done.

Addressing all forms of distress

The experience of suffering associated with physical symptoms may be exacerbated, or sometimes caused, by emotional, or psychological anguish, or social or spiritual distress. Addressing this requires professionals to recognise, understand and work to alleviate the causes.

Skilled assessment & symptom management

Attending to physical comfort, pain and symptom management is the primary obligation of clinicians at this time of a person's life and their skills and competence to do so must be assured and kept up to date.

Specialist palliative care

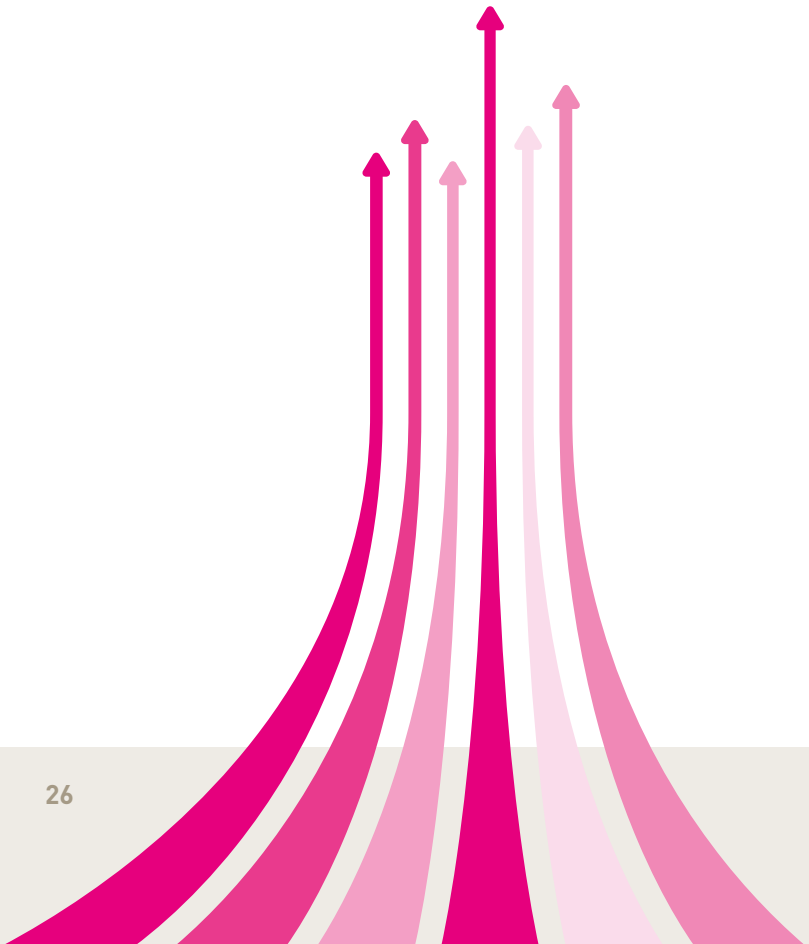
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Priorities for care of the dying person

People approaching death should expect local systems to accord with the priorities identified by the Leadership Alliance for the Care of Dying People.

Rehabilitative palliative care

Maximising the person's independence and social participation to the extent that they wish requires professionals to work with, and support, the person in helping them to achieve their personal goals.



04

Ambition Four:
Care is coordinated

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

What we already know

- Fragmented and disjointed care is a source of frustration and anxiety for the dying person and for all those important to them[14, 22].
- Carers often testify to the difficulties of multiple professionals and organisations working with little awareness of each other. This lack of coordination causes significant distress[15, 60].
- Poor communication and a failure to share information about the dying person is a recurrent failing when care is not good enough[14, 61].
- We have to find a way to provide the social care that people need regardless of financial circumstances[62, 63, 64].
- We know that 24/7 expert palliative and end of life care services need to be available and that their availability around the clock is key to building a system of high quality care[6, 65].
- We know that access and trust in the services available in the community are crucial to sustaining care outside of hospitals – most people's preferred environment[11].

The building blocks necessary to realise our ambition

Shared records

To move from ambition to actuality requires an ability to share care records for all people living with a long term condition – ensuring that their integrated primary health and social care record encompasses their needs as they near death. This sharing needs to be achieved electronically.

This should be with the consent of the person. When it comes to sharing access to information within the team providing care, then consent can be implied. However, if the person might be unsure about the team's make-up, or anything else, their explicit consent should be sought. If the person lacks the mental capacity to make the decision, sharing must only be in their best interests.

Local systems for the effective sharing of care plans should also include information about the services that are available to meet the needs of those who are dying. Variation and incompatibility between IT systems has to be rapidly resolved, as does the continued difficulty of access to statutory IT systems.

04

Clear roles and responsibilities

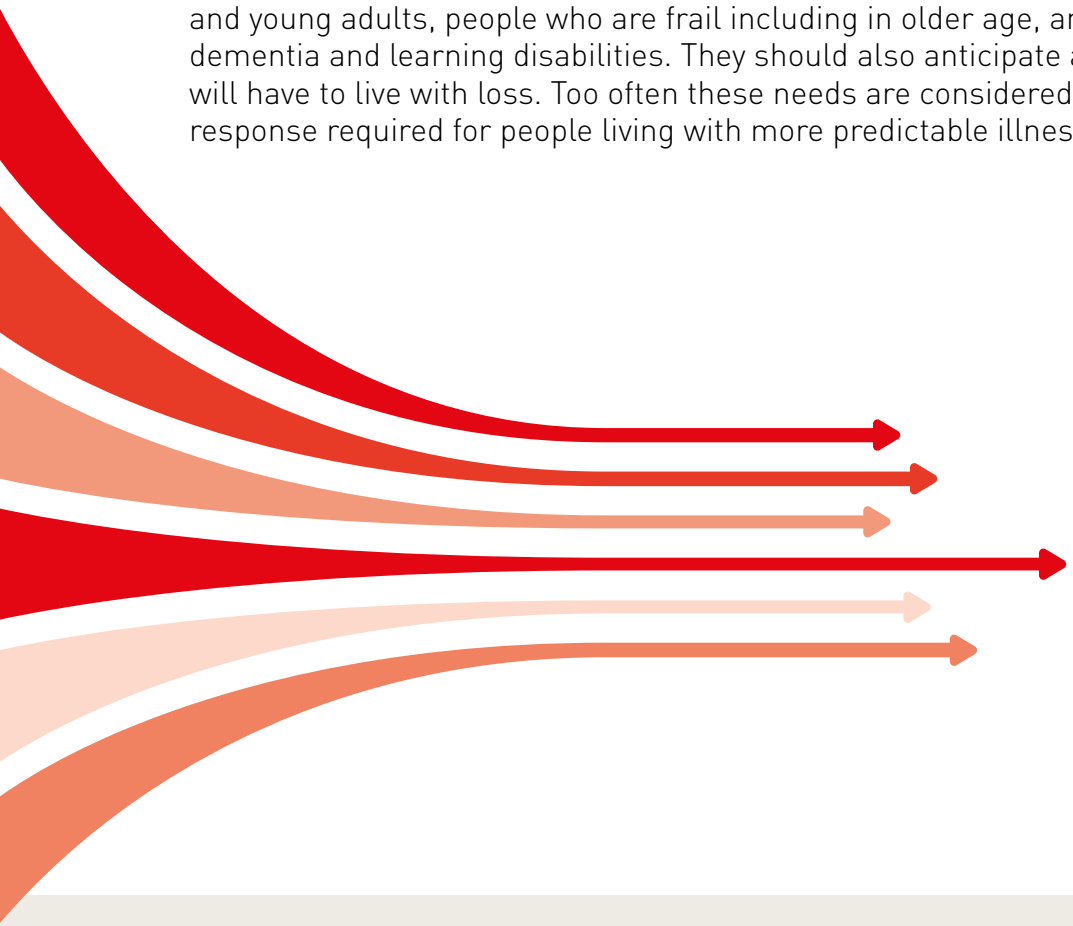
Systems of care may be immature in different respects and may need to be guided towards greater sophistication by the work of commissioning partnerships that are knowledgeable about the specific requirements of good palliative and end of life care. Organisational leadership is vital. Information for families, carers and individuals should be joined up in a way that provides a clear oversight of the respective roles and responsibilities of both service and education providers. The roles of these providers should reflect the frameworks set by national regulators.

A system-wide response

As new models of care emerge from the development of the NHS Forward View and the Directors of Adult Social Services' blueprint for the next five years, approaches have to develop to enable a better system-wide response to dying people, using a full range of coordinated services deployed in the community. To achieve this will require systems of care coordination that add to the effectiveness and speed of this community response. However, these need to be implemented in ways that do not inhibit or restrict responsiveness by adding extra layers of process to the delivery of care. These systems must also include enabling dying people and their families to access expert and experienced professionals as needed at any time of the day or night.

Everyone matters

Joined up care should mean an emphasis on responding effectively to the widest range of difficulties people experience, and an awareness of the need for anticipatory and pro-active care. Local systems of care have to encompass the needs of dying children and young adults, people who are frail including in older age, and people living with dementia and learning disabilities. They should also anticipate and support those who will have to live with loss. Too often these needs are considered peripheral to the response required for people living with more predictable illness.



04

Continuity in partnership

Delivering continuity of care requires individuals and organisations to think and work in a joined up way so that each is aware and acts in full knowledge of the other. This will require active partnerships particularly between the NHS, social care and the voluntary sector. These will be partnerships of provision and partnerships in commissioning. Expertise and insight should be shared to ensure that system wide specifications and joint accountability for outcomes for care are developed and delivered. This is at the heart of systems leadership.

Information sharing agreements will help support working together, although their absence should never obstruct necessary and appropriate sharing. Central to all this should be the appreciation that a person centred approach to care requires attention to the continuity of the relationships that are built with that person, the continuity of the information that is shared with and about them, and the continuity of how their care is managed.

Building blocks at a glance

Shared records

Care records for all people living with a long term condition must encompass their needs and their preferences even as they approach the end of life. With the person's consent, these records should be shared with all those involved in their care.

Clear roles and responsibilities

Organisational leadership is vital and information for families, carers and individuals should be joined up in a way that provides a clear oversight of the respective roles and responsibilities of providers within that system.

A system-wide response

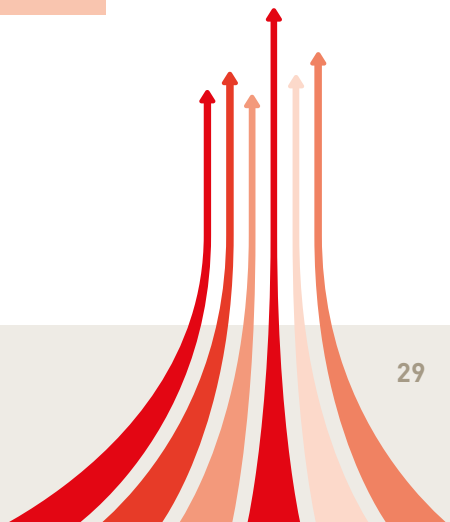
As new models of care emerge approaches have to develop to enable a better system-wide response to dying people, using a full range of coordinated services deployed in the community.

Everyone matters

Local systems of care have to put the needs of dying children and young adults, those living with frailty including at older age, and the need to anticipate and support those who will have to live with loss, at the centre of their thinking.

Continuity in partnership

Joined up care requires joined up thinking and working by individuals and by organisations. This will require active partnerships particularly between the NHS, social care and the voluntary sector.



05

Ambition Five:
All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

What we already know

- Caring for the dying, looking after the bodies of the dead and supporting people facing loss and grief, before and after death, is difficult and distressing. It challenges the resilience and fortitude of those working in end of life care[6, 66, 67, 84, 85].
- Most health and care staff look after people who are nearing death, so if care is to improve they must be trained in those aspects of end of life care that are appropriate to their role[12, 55, 68, 69].
- Too often the employers of health and care professionals have not acted systematically to help their staff avoid the debilitating effects of burn out, avoidance or helplessness resulting from lack of education, training and support[54].
- Staff can only provide compassionate care when they are cared for themselves and must be supported to sustain their compassion so that they can remain resilient, and use their empathy and apply their professional values every time[70].
- We know that good pain and symptom management benefits both the dying and those who spend time with them[10, 52, 71].
- If we are to make deaths at home more achievable, we know that we have to do more to ensure sufficient support for those paid carers who may be vital to sustaining the viability of care at home[11].

The building blocks necessary to realise our ambition

Professional ethos

To ensure people receive the care they need, end of life care has to be considered as everybody's business and all paid carers and clinicians at every level of expertise need to be trained, supported and encouraged to bring a professional ethos to that care. They should know how to listen to people and to help them make decisions. They must be allowed to use their judgement, their values and their authority to ensure that the care is right for the individual and that nothing is allowed to get in the way of that goal. To do this requires leadership and means ensuring that the needs of the dying person always come first.

05

Support and resilience

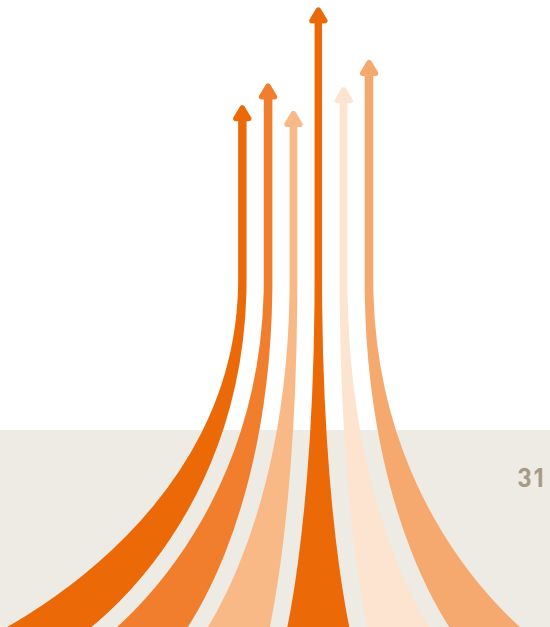
Delivering care at the end of life has its own difficulties. Providing such care for people with learning disabilities or dementia and giving care across a range of settings including the busy intensity of a hospital ward is demanding. Nobody is immune from the traumatic nature of death and dying. To give care day in and day out requires organisational and professional environments in all settings that ensure psychological safety, support and resilience. This could range from individual support through clinical supervision to communities of practice through networks. Local and national organisations are duty bound to pay attention to the health and wellbeing of all their staff if they are to remain engaged in this difficult and emotionally demanding work.

Knowledge based judgement

Only well-trained, competent and confident staff can bring professionalism, compassion and skill to the most difficult and intensely delicate physical and psychological caring. It is clear, knowledgeable, responsive and confident professional judgement that is the best guarantee of good care. Health and social care regulators, of both organisations and professions, need to ensure this is in place everywhere for people who are facing the last days, weeks, months and years of their lives. They must assure the education that people receive is good and well delivered and this must be part of their inspection of service providers. This is the starting point from which to secure support for each and every professional working with dying people, and those who are important to them.

Awareness of legislation

All those who provide palliative and end of life care should be aware not only of the encouragement towards person centred ways of doing things but of the legislation that seeks to ensure an individual approach. To secure our ambition, all organisations who provide end of life care should understand and ensure that they comply with – amongst others – the Children and Families Act, the Care Act and the Mental Capacity Act, as well as their duties for safeguarding adults and children. Similarly, it is vital that equality duties and commitments are understood and that diversity is put at the heart of service development and practitioner training. A widespread lack of knowledge about the way different communities may approach the challenges of dying, death and bereavement is not acceptable.



Using new technology

People access, use and expect information from across a wide range of platforms and in diverse formats. To support those delivering good palliative and end of life care we have to help them make safe use of new technology to build relationships with those who are approaching death. The better use of this technology can help to bring support directly to the person and their family and carers. Professionals have to adapt to new ways of interacting with the people they are supporting and they need help and guidance to do so.

Indeed, technology and simulation can also play a role in enhancing their own learning and development and they must be encouraged to take advantage of this, balancing these learning opportunities with face-to-face experiential learning.

Executive governance

The accountability for ensuring environments that support all professionals to give their best lies with the executive governance of the organisation. Every organisation should have clear governance at Board level for high quality palliative and end of life care and environments in which all staff can provide the best of their professionalism and humanity.

Building blocks at a glance

Professional ethos	Support and resilience
To ensure people receive the care they need paid carers and clinicians at every level of expertise need to be trained, supported and encouraged to bring a professional ethos to that care.	To give care day in and day out requires organisational and professional environments that ensure psychological safety, support and resilience.
Knowledge based judgement	**Using new technology**
Only well-trained, competent and confident staff can bring professionalism, compassion and skill to the most difficult and intensely delicate physical and psychological caring.	Professionals have to adapt to new ways of learning and of interacting with the people they are supporting and they need help and guidance to do so. Technology can also play a significant role in enhancing the professionals' own learning and development.
Awareness of legislation	**Executive governance**
All those who provide palliative and end of life care must understand and comply with legislation that seeks to ensure an individualised approach.	Every organisation should have clear governance at Board level for high quality palliative and end of life care and environments in which all staff can provide the best of their professionalism and humanity.

06

Ambition Six:
Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

What we already know

- Dying, death and bereavement are not primarily health and social care events; they affect every aspect of people's lives and experience[72].
- Dying and bereaved people often feel disconnected or isolated from their communities and networks of support[73, 74].
- Despite some real progress and the growing reach and impact of the Dying Matters Coalition there remains a continued need to address and dissolve the taboo that many people feel when it comes to talking about dying, death and bereavement and facing up to their own mortality and that of the people important to them[1, 10, 75].
- There are ways to foster and support compassionate communities and to put end of life care at the heart of community health and wellbeing[76, 77, 78, 79].
- Supporting and working with communities, to develop their capacity to play a significant role in supporting individuals and those important to them, at the end of life and through bereavement, can help achieve the best outcomes for those with pressing needs[11].
- Volunteers are a significant resource in creating good end of life care and must be valued more highly and used more effectively[80, 81, 82].

The building blocks necessary to realise our ambition

Compassionate and resilient communities

Much is known about helping to nourish compassionate and resilient communities, and build capacity to provide practical support. This is now being applied in palliative and end of life care, and we are starting to see public health approaches to palliative care in England, such as the Dying Well Community Charter pathfinders and the Compassionate Cities approach. This now needs to be accelerated and to become the norm. To achieve our ambition local initiatives must build both on the work of the Dying Matters Coalition and follow these public health approaches to capacity building in communities.

This means unleashing what the Five Year Forward View referred to as the "renewable energy" of people and communities to provide practical support. There is no doubt that the wider energy and resources of our communities can help. Recognising what

communities are already doing and supporting them to do more, as well as encouraging and developing the ability of all of us to discuss dying, death and bereavement in better-informed and more confident ways, will help dying and bereaved people be better supported and ensure that they do not become isolated from their communities.

Public awareness

Change will be informed by sharing stories that illustrate both the challenges of nearing the end of life and the possibility of excellent care and support. All relevant organisations should work to improve public awareness of the difficulties people face and create a better understanding of the help that is available. Every opportunity should be taken to use media of all types to encourage everyone to play a part in supporting people nearing the end of their lives, including what people can and want to do for themselves, such as making wills and advance care planning.

Practical support

Communities need greater recognition and support for the help that they can provide for people with end of life care needs. Local health, care and voluntary organisations should find new ways to work alongside families, neighbours and community organisations as well as to give them practical support, information and training. By the same token, care must be taken to respect privacy. Confidential personal information should only be disclosed, with explicit consent, to people not involved in direct care. Local action should include work with local employers, communities of all faiths and local schools. Commissioners should include public health approaches in their plans.

Volunteers

Palliative and end of life care has a strong attraction to a vast number of volunteers working across the statutory, private and voluntary sector. The volunteers' contribution can be used to far greater effect. To achieve our ambition more should be done locally and nationally to recruit, train, value and connect volunteers into a more integrated effort to help support people, their families and communities. This will need to be an area of future national and local initiative.

06

Building blocks at a glance

Compassionate and resilient communities

Public health approaches to palliative and end of life care need to be accelerated and support given to people and communities who can provide practical help and compassion.

Public awareness

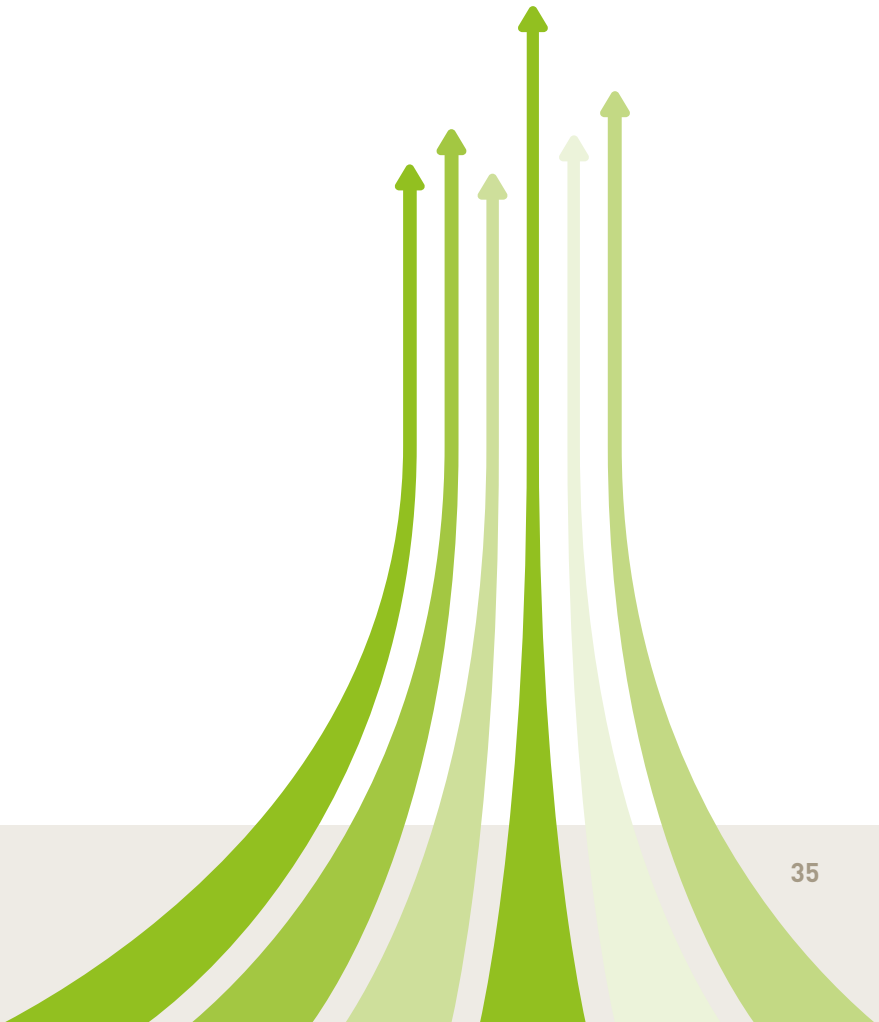
Those who share our ambition should work to improve public awareness of the difficulties people face and create a better understanding of the help that is available.

Practical support

Local health, care and voluntary organisations should find new ways to give the practical support, information and training that enables families, neighbours and community organisations to help.

Volunteers

To achieve our ambition more should be done locally and nationally to recruit, train, value and connect volunteers into a more integrated effort to help support people, their families and communities.



What should happen next?

We expect all those with influence over care for the dying and the bereaved, their families, their carers – both paid and unpaid, and their communities, to use our framework for local action to break the cycle of bad care highlighted in critical reports and recommendations. We need your help. As a Partnership we will also undertake to use our collective and individual influence to build and maintain momentum.

As a Partnership

These ambitions and the framework that supports them is a milestone on a longer journey for the Partnership. Our collaboration and drive will continue and we will hold ourselves to account as well as challenge others to show improvement.
Our determination to continue to act together in pursuit of these ambitions is agreed and we will work tirelessly both individually and collectively to reach them.
Many partners are national organisations who will support local action plans and seek opportunities to share best practice and inspirational examples.

If you are a CCG, Local Authority or a Health and Wellbeing Board

In a world characterised by less central direction and significantly more local collaboration, to achieve improvement we expect health and social care leaders to work together. We ask you to publicly designate an organisation to lead on making these ambitions the reality for the communities you serve.

In every local health and social care system we expect you to activate your partnerships with health, social care, commissioning, public health, and voluntary sector organisations to galvanise support. We expect you to work collectively and to create the new impetus that is needed. We expect you to bring people together and to publish a local action plan that includes the tangible steps that you and others will take to bring these ambitions to reality.

If you fund, commission, organise or deliver care

We ask you to join us, in thinking of good palliative and end of life care as a priority.

Care for the dying, those who are important to them, their carers and the bereaved, is the measure of a compassionate society. Death and dying is unlike any other part of our health and social care system because it affects us all. For these reasons end of life care must be fundamental to a responsive and integrated health and social care system.

We expect that you will use this framework for action to take strategic leadership, and purposeful and practical action, whether you are a commissioner, a provider, or a voluntary organisation (or all three).

If you are a health or social care professional

We recognise your determination, compassion and commitment to ensure the best care is delivered. We hope that these ambitions build on the motivations that inspire you to work in the jobs that you do, give you the courage to start those difficult conversations with people nearing end of life, and the courage also to speak up when things are not good enough.

We ask you for your personal and professional support, as individuals and as networks or communities of practice. We hope you will use the framework for local action to guide the way you behave and practise as professionals, and the way you contribute your personal leadership to improve the experience of palliative and end of life care, for the people themselves, those important to them and your colleagues.

As a person in your own community

We want you to know that we have heard from people with personal experience of palliative and end of life care and that their experiences have shaped our ambitions. To deliver on them we need everyone to help. This work is everybody's business.

By talking more openly about dying, death and bereavement and discussing your end of life wishes, and the wishes of those close to you, you can make a difference. Health and social care is important, but we all have a responsibility to support each other in times of crisis and loss. We encourage you to initiate timely conversations with honesty and openness.

We ask you to consider what it is that you can do within your own communities to help and support others, not only by being open to conversations but also through practical help and connection. If you lead a community group, consider what your group might do to contribute to this work.



Appendix A:
Definitions of Palliative and End of Life Care

The Partnership uses 'end of life' and 'palliative care' as they are defined in the One Chance to Get it Right report, produced in June 2014 by the Leadership Alliance for the Care of Dying People. For the avoidance of doubt these definitions are as follows:

End of life

Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with: a) advanced, progressive, incurable conditions; b) general frailty and co-existing conditions that mean they are expected to die within 12 months; c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition; d) life-threatening acute conditions caused by sudden catastrophic events. In General Medical Council guidance the term 'approaching the end of life' also applies to those extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death.

Palliative care

The World Health Organisation has defined palliative care as follows: Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families; enhances quality of life and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications. Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.

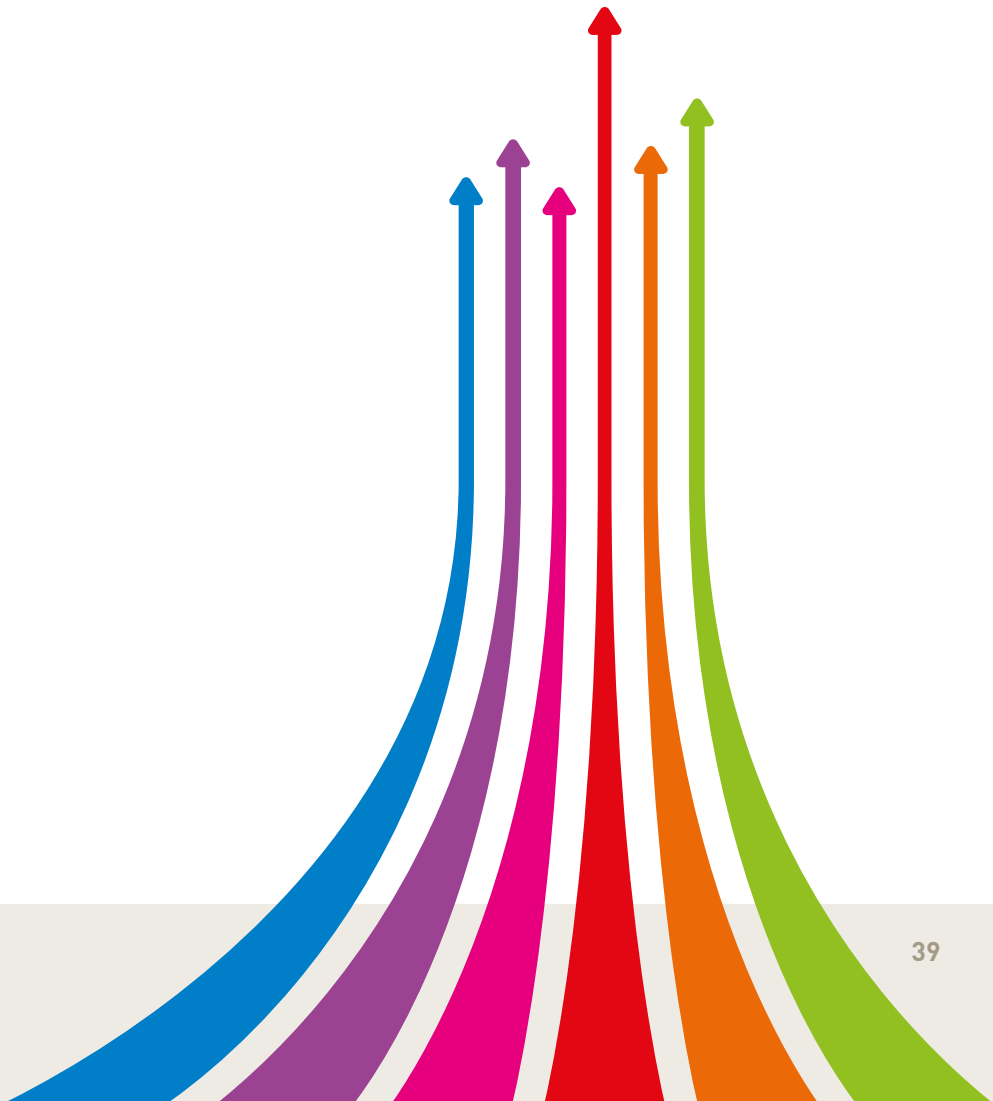
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