

Learning from staff reflections: Supporting people at the end of life



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Foreword

In 2019, Health Education England (HEE) and the Academic Health Science Network (AHSN Network) originally commissioned a review of improvements related to supporting and preparing staff to work with patients and families at the time of death.

Just as we were about to publish our report, the global COVID-19 pandemic hit. Our original working title 'Learning from Deaths' took on a new meaning. We therefore paused the publication of this report to take into consideration the current context and to review our recommendations in light of the pandemic.

Some learning from the report contributed to the development of [support for breaking unwelcome news](#) training, which came about after a chance question posted on an end-of-life care forum and led to a small group developing a framework in just ten days for professionals giving unwelcome news during COVID-19.

It is outside of the scope of this report to address issues specific to COVID-19, but we have made our recommendations universal to take into account the learning from this pandemic, as well as recognise the individual psychological toll this has had on health and care staff.

There is so much to learn and improve about the way we approach death, and compassionately manage the last few days of life, which has been brought into sharp focus during the pandemic. We hope that the recommendations within this report and the good practice examples will be helpful.

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Executive summary

Health Education England, working with the Academic Health Science Network (AHSN Network), commissioned a review of improvements related to supporting and preparing staff to work with patients and families at the time of death.

Two patient safety fellows were recruited to explore factors that enable good practice and continued learning at and around the time of death.

Within the scope of this review we wanted to understand what makes it easier, and what makes it harder, for staff to support people and their families at the time of death and to better understand clinicians' experience of this. Between April and November 2019, approximately 200 staff from over 40 healthcare organisations across England took part in a mix of focus groups and conversations to explore best practice. These staff came from a variety of professions, grades, provider settings and clinical specialties.

Within the focus groups a number of open questions were asked to explore experiences of supporting patients and their families at the time of death. These data were analysed and four clear themes emerged:

- Communication
- Cross-system learning and working
- Culture
- Staff wellbeing

What we found was that there was real variance in the perceived levels of confidence and competence related to communication within staff groups. Some staff felt able to have open, honest and compassionate conversations about what mattered to people at the end of their lives, while others reported feeling worried and fearful of adding to patient and family distress. It was also noted that conversations may be started by senior members of the team and need to be expanded. Communication around the time of death should be seen as a team dialogue rather than a one-off event.

Staff also spoke about the challenges of cross-system working and learning, recognising that learning is often restricted to the place of death or lead clinical specialty, rather than having a wider perspective which examines the whole patient's journey.

The importance of a culture where staff could be open and feel free from blame was explored. Staff talked about sometimes feeling a sense of fear at the time of a death. Death is still being perceived as a negative and blameworthy outcome in some organisations. There was also a recognition that staff can generate their own internal sense of blame, worrying that they had not done enough. This can impact on their own wellbeing.

Staff spoke about the levels of support that they receive at the time of a patient dying and the personal impact of being in close proximity to emotional trauma and distress. Support varied widely with some staff having access to a range of accessible options and others nothing at all; the experience of caring for patients at the end of life being "part of the job".

A roundtable event was held to gain an expert view from system leaders and front-line clinicians to confirm and challenge the themes identified in the study, and to agree recommendations and next steps. There was resounding agreement that the themes resonated with those present and suggestions were made about how we might address these.

Recommendations

1. **Communication:** to improve the communication between families, the clinical setting, staff and external agencies (barriers were lack of staff confidence, omission of the family voice and continuity of care).
2. **Learning and communication across systems:** to improve learning and working across systems and service providers – seeing the patient's journey.
3. **Supporting a learning culture:** for learning from deaths to be everyone's business supported in an open and learning culture.
4. **Promote staff wellbeing:** to ensure that staff feel valued and that their wellbeing is promoted when there is death.

Methodology

In 2018, Health Education England approached the AHSN Network to work collaboratively to identify learning, best practice and identify gaps, to improve safety for patients by exploring the education, training and development improvements in respect of learning from deaths.

Two patient safety fellows were recruited to:

- Identify the good educational practice taking place whilst simultaneously identifying the gaps and obstacles to learning from deaths.
- Identify what practice and education enhances openness, transparency and candour to support the current and future workforce.

The aim of this work was to identify, using staff insight, factors that enable good practice and continued learning at and around the time of death. The project focused specifically on exploring clinicians' experience of supporting people and their families at the time of death. It was supported from the outset by an expert reference group, consisting of representatives from HEE, AHSNs, NHS England and Improvement, and clinical providers.

This report summarises the work of the patient safety fellows and the themes drawn from engagement with clinical staff. It is based on the feedback gained through national engagement events with clinical staff talking about supporting aspects of learning from deaths. It includes the feedback gained at a roundtable event with system leaders and educators.

The hope is that by identifying challenges to good practice as well as examples of innovations to address these challenges, health and social care organisations can be stimulated to continue their focus on and commitment to learn from deaths.

After establishing appropriate governance mechanisms, 200 staff were recruited to focus groups and conversations from over 40 healthcare organisations across England between August and November 2019. Participants came from a variety of professions, grades and provider settings. Many clinical specialties were represented plus staff from acute, community, mental health, hospices, care homes and ambulance trusts. Non-clinical staff including chaplains, charities and a bereaved family were also involved in the project.

A discussion guide provided structure and consistency to the engagements. Emerging themes from early stakeholder engagement led to the development of 10 open questions related to communication, learning and culture. The guide was piloted within two trusts to refine the questions before wider implementation.

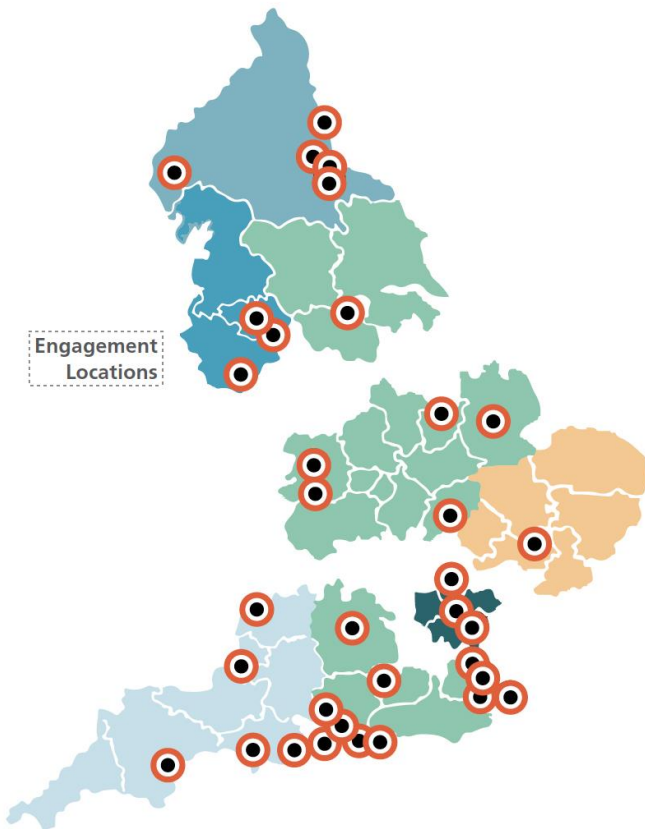


Image: A map showing the engagement locations across England.

The focus groups were conducted using an explorative style and either took place face-to-face or by telephone. Some were based within trusts and others at meetings and conferences. Utilising the extensive networks provided through the AHSN Network and Patient Safety Collaboratives helped facilitate staff engagement. The researchers created a safe environment that allowed participants to reflect on and share their thoughts, ideas and practice examples.

The discussions were recorded and transcribed. A thematic analysis was undertaken on this material and accompanying contemporaneous notes. In line with the agreed data governance, all recorded data was securely deleted following thematic analysis.

A live Twitter chat asking questions related to learning from deaths was hosted by [@WeNurses](https://twitter.com/WeNurses) using the [#WeNurses](https://twitter.com/hashtag/WeNurses) and had 35 participants. The Twitter chat provided significant informal ratification of the themes arising from the engagement events.

Roundtable feedback

A roundtable event chaired by Professor Gary Ford, Chair of the AHSN Network, was held to discuss the interim findings.

The aim of the event was to firstly gain an expert view from system leaders and front-line clinicians to clarify and confirm the themes identified, and secondly to agree recommendations and next steps.

Participants were asked to discuss four key themes linked to the study findings:

1. How do we equip staff to provide effective and compassionate communication?
2. How do we improve learning and communication across systems?
3. What can we do to shape leaders' conversations from a blame to learning culture?
4. What can organisations do to promote staff wellbeing in respect of learning from deaths?

There were 31 attendees¹ who generated a great deal of discussion and enthusiasm. The main study findings resonated with those present and suggestions were made about how we might address these.

Cross-system learning and working remains a challenge and communities of practice, cross-system forums, and learning from the patient's journey were agreed to be positive approaches. The Medical Examiners system is seen as one that can add real value, with a wider perspective and family focus. An open, just culture supporting leaders to challenge blame language will support learning. Staff wellbeing impacts on patient safety and should be promoted in all clinical areas. There was a real richness in the conversations from the roundtable and the [notes are available here](#).

All the recommendations and next steps summarised below were supported.

Findings from focus groups and conversations

Four themes were identified from the conversations with staff:

1. Communication
2. Cross-system learning and working
3. Culture
4. Staff wellbeing

1. Communication

Staff need to have an awareness of end-of-life care and should consider patients' individual wishes and concerns. Staff should work in an open and collaborative manner, with patients and their families included in the planning and delivery of care.

¹ Attendees represented: HEE, AHSN Network, Gosport Learning and Assurance Board, NHSE&I, Medical Examiners, clinical providers, CQC, End of Care Leads, Academy of Medical Royal Colleges, NHS Resolution, Patient Safety Learning and Public Health England

Much More than Words (NHSI 2018) reports in detail the complex nature of communication in healthcare settings and its clear link to patient safety: a social interaction dependent on the context, environment and skills of those engaged in it.

We asked participants about communication with both the patient and family, and responses highlighted a real variance in staff skills and confidence when communicating at the time of dying.

Palliative care staff recognised that they are often seen as experts in these discussion areas with referrals received from other staff groups to break bad news and discuss dying. They felt able to have open, honest conversations and discuss preferences and plans. Some community staff were also keen to start the conversation early and begin to future plan with patients and families.

In contrast, other staff reported that they can feel afraid of talking about death and dying. They told us that they were worried that their communication might cause more distress or frighten the patient and family. Opportunities to gather information and better understand what really mattered were not always taken. As a result, families were not always encouraged or enabled to ask questions, to share information or to prepare for the imminent death of their loved one.

We heard that initial conversations about the end of life are often led by the most senior member of the team and that other team members lack confidence when undertaking conversations. Many recognised that communication must be an ongoing process not a one-off event. Newly qualified staff, and those working in isolation or out-of-hours, stated feeling vulnerable without support or guidance when having a conversation about death.

The importance of language was discussed by many participants. Clear written information describing the dying process and care options was seen as valuable to supplement face-to-face conversations, with many units designing their own resources. Staff reported a marked difference between communication at ward level and communication at a corporate level, especially in the aftermath of a patient safety incident. The latter often seeming insensitive to staff and families, causing further distress. One participant talked of a death by suicide described in a letter to a mother as “a sad incident”. Another participant recalled how a mother, following a still birth, was discharged from their maternity service using a template letter.

“Staff are worried that they will frighten the patient if they talk about dying.” **GP**

“I think it’s about using the word dying, saying you are going to die ... I often use the words you are very frail, you are very poorly ... would be a struggle to say you are going to die, that would be a real struggle for me and even with the family.” **District Nurse**

“Being open with a family can be frightening and can create worry for them. You have to be brave – people will not want to hear what you have to say.” **RGN**

2. Cross-system learning and working

Cross-system working can be a challenge, often with disparate organisations involved. Staff should ensure there is effective communication between the different parts of the system, and highlight where systemic problems in the wider health arena need to be addressed.

Of the staff we spoke to, some have developed an approach to learning based on the patient's journey, providing an opportunity to reflect as a group about what had gone well and areas for improvement across service boundaries. At their best, mortality reviews were multi-disciplinary and considered family and other providers' feedback. This allowed both for a focus on the clinical aspects of the death and the wider learning around communication and family support. This learning was then shared both within the organisation and with wider partners.

The majority of staff we spoke to however, felt that services remain fragmented with a lack of communication and learning across services and boundaries. A patient's journey may involve contact with a care home, GP, ambulance trust and emergency department within a local acute hospital. It was rare to find a systemic approach to learning, with many staff focusing on only their contact or intervention, so the patient's wider story and learning was lost.

"The patient's story is not visible across organisations." **Practice Nurse**

"Sometimes feels like we are left in the dark about the patient and the discharge home to die is patchy – hit and miss." **GP**

3. Culture

It is accepted that a culture of openness and honesty, where staff can speak up and speak out, is vital to patient safety and quality of care and improvement (Learning, Candour and Accountability, CQC 2016).

We asked staff about the culture they worked in and some of the barriers to learning. Some groups were very positive about the culture they worked in, feeling they had permission to use their initiative and go "above and beyond" what was expected of them. They felt empowered to develop ideas, question existing practice and suggest new ways of working. These staff were able to reflect on practice and used this to improve services. They saw learning from deaths as everyone's business.

Some teams spoke about how they had adopted a positive focus on celebrating success and learning from when things went well. However, few formally acknowledged approaches such as Learning from Excellence, appreciative inquiry or the Safety II approach. This was dependent on the culture and leadership of the team.

Other staff talked about feeling worried and fearful when there is a death, with the sense that blame can still be apportioned to individuals in the face of such outcomes and not on poor systems or wider human factors.

"When there is a suicide, there is only ever one person who was the last to speak to them. You worry that you will be shown to have done something wrong." **AHP Community Mental Health Team**

There was a clear sense from several respondents, that they felt an internal sense of blame, which then affected their mental wellbeing:

"Staff can generate their own sense of blame. They feel culpable. Did I do everything I could? I feel like I failed." **RGN**

Below is a word cloud analysis of free text comments of what staff perceived as the barriers to learning:



4. Staff wellbeing

Staff need both adequate supervision and training, and to be able to work in a culture where concerns are both heard and valued.

There is no doubt that the more psychologically safe a staff group is, the more effective and productive it is and the higher the quality of care delivered to patients (NHS Patient Safety Strategy 2019). Conversely, poor mental wellbeing and high levels of stress link to poorer safety outcomes. The NHS Staff and Learners' Mental Wellbeing Commission report (HEE 2019) focuses on the wellbeing of the NHS learners and workforce. It notes that of the 1.3 million people in the NHS workforce, many work in front-line healthcare and "see the horrors of extreme trauma; they see the aftermath of major road traffic accidents, suicide, and they see children in distress or dying and they help families cope with the loss of a loved one."

The Interim NHS People Plan (2019) recognises that in order to maintain a healthy workforce, leaders must value, support, develop and invest in staff and pay attention to people's health and wellbeing.

We asked staff about the types of and access to support they received after a death. Many had access to a number of options for support, recognising different staff preferences and needs. Examples of best practice included reflective, supportive forums which were prioritised, responsive and supported by senior leaders. Other areas described an absence of support or available services being inconsistent or inaccessible.

When speaking about the culture they worked in and the support that was available, staff were open about their own wellbeing. They recognised the resilience required to support people at the end of their lives and to be in such close proximity to high levels of trauma and distress. It was recognised that supporting patients and their families through this time can be a real privilege; there is a significant impact on mental wellbeing that often went unrecognised.

“The brutal reality is that after a death, the next patient arrives – no time for thinking.”

Paediatric Nurse ITU

“Serious incident panels are regular and held without fail, why don't they do a debrief – why are these not seen as a priority?” **RGN**

“People are busy and it's about making time. It is difficult to get people off the wards.”

Consultant ITU

“Does it have a cost when someone dies? Yes, it does.” **Consultant ITU**

“We are not invincible, just because we are wearing a uniform.” **Paramedic**

“If people are stressed, then I take the view that either ‘it's part of the job’ or you need to move on to another clinical area.” **Consultant ED**

“I felt I had the confidence to say how I felt and what my thoughts were, having seen this role modelled by leaders.” **RGN ED**

The Interim NHS People Plan (2019) recognises that in order to maintain a healthy workforce, leaders must value, support, develop and invest in staff and pay attention to people's health and wellbeing.

Best practice exemplar

In order to support the development of recommendations, we have provided some examples of good practice. Recommendations need to be practical, affordable, specific and time-limited. They are presented under the themes outlined in this report.

1. Communication: to improve the communication between families, the hospital, staff and external agencies.

Early and ongoing conversations

Guy's and St Thomas' NHS Foundation Trust and the Royal College of Physicians project "Second Conversations" was designed to improve training around end of life care communication for junior doctors. The Second Conversation, led by a junior doctor, gives patients, carers and family members the time and space to reflect on information they have received, whilst providing doctors in training with a valuable educational opportunity that builds their skills and confidence in handling end of life care discussions.

This is a three-step training intervention: observation, experiential learning and reflection. This model can be a useful educational tool in breaking the barriers around talking about end of life care.

Support for the family

A number of the teams we spoke to have a version of a patient or family diary for use when end of life had been identified. Some focused on engagement with the family, giving them a voice to support collaboration and to provide a place for sharing of information, thoughts and feedback, which can be addressed at that moment.

One example was the Family's Voice in **North Tees and Hartlepool NHS Foundation Trust** which has been embedded in practice since 2010. Its aim is to improve open and sensitive communication in end of life care. It has been adopted by other trusts nationally and 69% of families offered this will use it. The diary gives ownership to the family member and a commitment to address the issues they have highlighted.

Continuity of care: Family Liaison Officer

A number of trusts have established the post of Family Liaison Officer, who supports families after a death or a complaint.

One of these is **Southern Health NHS Foundation Trust** which established this role in 2016. The family are offered contact with the Family Liaison Officer and this is often provided face to face with the focus on supporting, signposting and navigating processes and systems. This can continue until after an inquest and can support the family to share their story and hear the learning.

Working alongside the Triangle of Care (a working collaboration between staff, patients and carers/family), this approach addresses the clear evidence from carers that they need to be listened to and consulted more closely, emphasising the importance of communication between

the family and the trust. These posts are extremely valuable and staff need training and support to undertake these.

Simulation training

Some clinical staff talked about having experienced simulation training and had found this very helpful. **The North West Simulation Education Network (NWSEN)** is funded by NHS HEE to increase the capacity and capability of simulation-based learning across the North West. As part of this work, Health Education England funded a two-year collaborative pilot with Liverpool University, Marie Curie and the NWSEN to develop and evaluate a blended learning initiative for multidisciplinary staff supporting the dying patient. The pilot was delivered both for staff from acute wards and hospices.

The day was a safe space to explore learners' concerns and worries about symptom management and communication when dealing with the dying patient. The session developed confidence and competence for staff in dealing with difficult situations, challenged unwritten rules, and empowered and recognised the role of junior staff.

Part of the material developed for this session is now also used in a regional course for junior doctors in several sites across the North West.

2. Learning and communication across systems: to improve learning and working across systems and service providers.

Service wide learning: clinical message of the month

Sussex Partnership NHS Foundation Trust has developed a clinical message of the month. The theme of the message links to learning from mortality reviews and has covered a wide range of topics including dehydration and constipation. It is an A4 document with visuals and the feedback from staff is that they like the fact that a patient story is included so that they can relate the topic to their own workplace.

Cross-provider learning: shared mortality reviews

Staff within the **Safer Salford Programme** are developing a cross-system mortality review between primary and secondary care clinicians. This shared mortality review process looks broadly at the whole patient pathway.

These reviews provide an opportunity for reflection on the interface between services and communication with family in the care of patients with complex health issues. Specific learning outcomes include improving communication between GP practices and district nursing and improving communication of information on referral to the acute hospital.

Regional learning: Medical Examiners Collaborative

Wessex AHSN supported the development of a collaborative bringing together Medical Examiners across the region virtually by webinar. This allows for sharing of practices and learning. Themes across services, such as intravenous fluid management and use of treatment escalation plans can be identified and ideas shared about how to address these.

3. Supporting a learning culture: for Learning from Deaths to be everyone's business and this be supported in an open and learning culture.

Learning from deaths everyone's business: Swan bereavement model of care

Northern Care Alliance NHS Group bringing together Salford Royal NHS Foundation Trust and The Pennine Acute Hospitals NHS Trust developed the Swan model for end of life and bereavement care. It is used to support and guide the care of patients and their loved ones at the end of life and after they have died. It has been implemented in a few organisations and is supported by a full implementation pack and monthly training sessions to support all staff within the trust to implement this model of care. It is a tool that makes end of life and bereavement care everyone's business.

Reflective practice templates: Living Well

To support staff learning, a reflective template is used which focuses on seven core capabilities at the end of life and encourages staff to reflect on how confident they felt with these and what made it both easier and harder to achieve them.

The Living Well template was developed by Dr Saskie Dorman, Consultant in Palliative Care at **Poole Hospital NHS Foundation Trust** and Andi Stone, Specialist Palliative Care Nurse, as part of Results through relationships – a collaboration between NHS Dorset CCG, NHS England personalised care group, Dorset End of Life Care Partnership, Andy Brogan at Easier Inc, the Poole Locality MDT and the local community. The template has been used to structure shared reflective practice which has changed the focus of conversations, supporting learning and collaboration.

Support for staff: Learning from Excellence

South Tees Hospitals NHS Foundation Trust have a section within their morbidity and mortality meetings (M and M): Awesome and Amazing (A and A). A simple idea to learn, share and celebrate good practice.

Culture of support: Gosport Learning and Assurance Board

Gosport Learning and Assurance Board was established by the **Hampshire and IOW CCG Partnership** response to the publication of the Gosport Independent Panel Report (2018). There were a number of key themes identified: listening to and learning from staff and patients concerns, medicines management, partnership working, clinical oversight, effective team working, quality of information – using what we know, excellence in the care of older people and end of life care. A charter of cultural commitments was designed to represent the learning:



Image: Diagram of the charter showing 'our commitments':

- We will treat each other with kindness, compassion and respect.
- We will be curious and open to challenge and we will listen, understand and act on what people tell us and what we know about our services.
- When things go wrong, we will say sorry, seek to understand what happened, be open in what we find and ensure we learn from our mistakes.
- We will do everything we can to keep everyone safe by delivering high-quality care.
- We will support all staff to be able to confidentially and safely raise concerns and act on these.
- We will support staff to value and use all of their skills and to reflect on what they do so they can continually learn and improve.
- We will work with our local communities to continue to shape and improve local health and social care services.

4 Promote staff wellbeing: to ensure that staff feel valued and that their wellbeing is promoted when there is death.

Accessible, flexible support: Schwartz rounds

Schwartz rounds are used by trusts to support staff to reflect on the impact their practice has on themselves and to help them provide compassionate care. **Milton Keynes University Hospital NHS Foundation Trust** has embedded Schwartz rounds into their trust culture. Mobile

Schwartz rounds are offered to staff who are unable to attend at a conventional time/location. A variety of professions are represented each time and feedback is extremely positive.

Opportunity for reflection: staff feedback

Dorset Healthcare University NHS Foundation Trust has developed a postcard to encourage staff to share their reflections about a death. This has not only shaped learning, as it is considering as part of the mortality review, but also can highlight if staff might need some support.

Staff support: Well and Resilient Doctors

Well and Resilient Doctors (WARD) was founded in 2017 in Bristol and is now operating throughout the **Severn Deanery** to provide wellbeing and mental health support to junior doctors. It was started due to concerns that the system was not focusing on staff wellbeing. With the aim of teaching things they wish they had known, a small group of registrars set up a programme of workshops covering topics such as safe reflection, mindfulness and physical health. There is time after the workshop for people to stay and talk. These local teams form a larger regional support and wellbeing network that learn from each other and improve the workshops and support available to all junior doctors. This is also important because as every junior doctor moves throughout the deanery, local support services differ but at least one thing will remain the same – there will always be WARD to help support and guide them.

The project has a set of principles:

- Be kind and helpful
- Look out for your colleagues
- Stop and ask twice

The aim is that these core principles and values become embedded within junior doctor practice to try to improve the culture amongst doctors and the NHS.

Recommendations

The recommendations in this report reflect the findings within it; that learning from deaths is a system-wide issue that requires a system response. The recommendations need to be considered by a wide range of stakeholders so that they can work together to coordinate and develop services to improve the experience for patients' families and staff at the end of life. This aligns well with the current NHS focus on patient safety, learning for improvement, and just culture.

1. **Communication:** improving the communication between families, the clinical setting, staff and external agencies (barriers were lack of staff confidence, omission of the family voice and continuity of care).

Taking into account the number of people who died in isolation from their families and loved ones during the first wave of the pandemic, it is vital to ensure that we never repeat this. The need for closeness, compassion and being with loved ones is so important, and should be facilitated through an effective communication process.

2. **Learning and communication across systems:** to improve learning and working across systems and service providers – seeing the patient's journey.

More than at any other time, this is of paramount importance to understand individuals' wishes and express requests, and to ensure these are communicated across systems and organisations. Just as important is the need to respect cultural norms and values inherent in our different populations, across different ages and settings.

3. **Supporting a learning culture:** for learning from deaths to be everyone's business, supported in an open and learning culture.

The pandemic has reinforced the need to continue to learn and improve. Ensuring the right culture allows individuals to express their concerns in a psychologically safe way is so important if we are to continuously learn and improve. Staff can only feel supported when the culture is right, when they are listened to and their concerns are acted upon.

4. **Promote staff wellbeing:** to ensure that staff feel valued and that their wellbeing is promoted when there is death.

The pandemic has put staff wellbeing in the spotlight, and a number of initiatives have been set up to support staff to deal with these extremely difficult situations. We must continue this and not forget that our staff also deserve compassion and respect. Their wellbeing is important not just through a pandemic, but helping staff to deal with death in a sensitive and compassionate manner also requires a focus on their wellbeing when there is no pandemic.

This report will be shared with the following stakeholders:

- Health Education England
- NHS England and Improvement
- The AHSN Network

It will be published widely through a variety of media and stakeholders will be encouraged to make a pledge to support the recommendations within this report.

Acknowledgements

We would like to thank all the staff who gave their time and shared their thoughts so openly, those who shared their good practice examples and to those who participated in the roundtable event.

Also thanks to HEE, The AHSN Network, Patient Safety collaboratives, Professor Gary Ford, Dr Helen Hogan and the expert reference group for their support in achieving this work.

Patient Safety Fellows and report authors: Heather Stacey and Stephanie Millichope.

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