

National Audit of Care at the End of Life

Northern Ireland
Health and Social Care Trusts
(HSCTs)

Northern Ireland Summary Report
April 2019

First round of audit (2018/19)



Palliative Care
in partnership



Benchmarking Network

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Citation for this document: NHS Benchmarking Network, National Audit of Care at the End of Life – Northern Ireland: First round of audit report, 2019.

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1. Introduction

The National Audit of Care at the End of Life (NACEL) was commissioned in October 2017 by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government. The Northern Ireland Public Health Agency on behalf of the Regional Palliative Care in Partnership Programme commissioned the NHS Benchmarking Network to deliver NACEL in Northern Ireland with the five Health and Social Care Trusts (HSCTs). As this was commissioned on a later cycle than the England and Wales project, the Northern Ireland cohort participated in the organisational level audit only in year 1.

Delivery of the audit is managed by the NHS Benchmarking Network (NHSBN), supported by a multi-disciplinary Steering Group and Advisory Group. Dr Suzanne Kite, Consultant in Palliative Medicine, and Elizabeth Rees, Lead Nurse for End of Life Care, Leeds Teaching Hospitals NHS Foundation Trust, provide joint clinical leadership of the audit.

The overarching aim of NACEL is to improve the quality of care of people at the end of life in acute, mental health and community hospitals. The audit monitors progress against the **Five priorities for care** set out in **One Chance To Get It Right** and **NICE Quality Standards 13 and 144**. The **Five priorities for care** reflect the Northern Ireland Department of Health circular HSS(MD) 21/2014 **Advice To Health And Social Care Professionals For The Care Of The Dying Person In The Final Days And Hours Of Life – Phasing Out Of The Liverpool Care Pathway In Northern Ireland By 31 October 2014** setting out five principles that should underpin high quality care in the final days and hours of life. The principles reflected the good practice outlined in the Department's **Living Matters; Dying Matters** (LMDM), Palliative and End of Life Care Strategy for adults, published in 2010.

The five principles in the Department of Health circular are:-

1. There should be timely identification that a person is dying and is probably in the final days and hours of life.
2. Sensitive and clear communication should be at the centre of quality care.
3. People who are identified as dying should have their physical, psychological, spiritual and social needs identified and be involved in decisions about how those needs can best be met. The person's needs should be regularly reviewed and re-assessed throughout the last days and hours of life.
4. Care in the last days and hours of life should be planned and co-ordinated with a focus on symptom control, comfort management and ensuring that psychological, social and spiritual support is provided to meet the person's needs.
5. Support for family and carers should be provided during their loved one's last days and into bereavement.

NICE Guideline **NG31 Care of Dying Adults in the Last Days of Life** was published in December 2015 and endorsed by the then DHSSPSNI for implementation in 2016. The guideline seeks to improve care for people in their last days of life and is intended to be used by health and social care professionals who are involved in the care of a person who is nearing death in any care setting. The NG31 guideline includes 72 statements grouped under 6 key recommendations:

- Recognising when a person may be in the last days of life
- Communication
- Shared decision-making
- Maintaining hydration
- Pharmacological interventions
- Anticipatory prescribing

1. Introduction (cont.)

The aims of the three elements of NACEL in the first cycle were:-

- To establish whether appropriate structures, policies and training are in place to support high quality care at the end of life.
- To assess compliance with national guidance on care at the end of life.
- To determine what is important to dying people and those important to them.
- To provide audit outputs which enable stakeholders to identify areas for service improvement.
- To provide a strategic overview of progress with the provision of high quality care at the end of life Northern Ireland.

Components of NACEL

Whilst the first round of the audit taking place in 2018/19 included three components, the Northern Ireland cohort participated in the organisational level audit only in year 1.

An organisational level audit, which covered trust and submission level questions relating to 2017/18 data. Participants were able to set up 'submissions' for separate sites (e.g. hospitals). This was the only element which the Northern Ireland HSCTs participated in the first round of the audit.

A case note review, completed by acute and community providers only in England and Wales, which reviewed all deaths in April 2018 (acute providers) or deaths in April – June 2018 (community providers). The following categories of deaths were included: -

1. It was recognised that the patient may die - it had been recognised by the hospital staff that the patient may die imminently (i.e. within hours or days). Life sustaining treatments may still be being offered in parallel to end of life care.
2. The patient was not expected to die - imminent death was not recognised or expected by the hospital staff. However, the patient may have had a life limiting condition or, for example, be frail, so that whilst death wasn't recognised as being imminent, hospital staff were "not surprised" that the patient died.

Deaths which were classed as "sudden deaths" were excluded from the case note review. These were deaths which were sudden and unexpected; this included, but was not limited to, the following:

- all deaths in Accident and Emergency departments
- deaths within 4 hours of admission to hospital
- deaths due to a life-threatening acute condition caused by a sudden catastrophic event, with a full escalation of treatment plan in place.

These deaths would not fall into either category 1 or 2 above.

Acute providers were requested to complete up to 80 case note reviews, with participating organisations being asked to ensure the number of case notes reviewed was no less than 5% of the total annual deaths. This was not applicable to Northern Ireland but is included for context.

A Quality Survey, the NACEL Quality Survey was developed with the assistance of the Patients Association. The survey was designed to gain feedback from relatives, carers and those close to the person who died, on their experiences of the care and support received at the end of life in England and Wales. The Quality Survey was linked to the case note review, so that the same deaths were covered. Again, this was not completed by Northern Ireland but is included for context.

1. Introduction (cont.)

Mental Health providers, for the England and Wales project, were requested to complete the **organisational level audit** only.

Whilst the main scope, content and structure of NACEL had been agreed upon prior to Northern Ireland joining NACEL, it was agreed that the content of the organisational level data collection would be applicable to the Northern Ireland policy context, subject to some additional definitional guidance for the Northern Ireland services, to align with regional programmes and priorities. Northern Ireland will have the opportunity to contribute to the three elements of the audit in future years.

2. Policy context in Northern Ireland

Palliative and end of life care focuses on the person and their needs rather than the disease(s), and aims to ensure quality of life for those living with an advanced non-curative condition. Good palliative and end of life care is an important part of health and social care. The provision of good palliative care requires a whole system approach and depends on partnership working between primary and secondary care, voluntary sector, independent, and urgent care services.

At any one time, it is estimated that around 1% of the population are in the last year of their life and could benefit from a palliative care approach; this equates to around 19,000 people in Northern Ireland each year. There are a number of recognised methods for calculating population based palliative care need based on mortality statistics, symptom and disease prevalence. Using these methods it is estimated that between 75-80% of all deaths have palliative care needs, this would equate to between 12,026 and 12,828 people in Northern Ireland in 2017.

The palliative and end of life care strategy for adults in Northern Ireland entitled ***Living Matters, Dying Matters*** (LMDM) was published by the Department of Health (formerly the Department of Health, Social Service and Public Safety) in March 2010 and is the key policy framework for providing these services. The strategy sets out a vision for palliative and end of life care across all conditions and care settings, based on what people value most and expect from such care.

The LMDM strategy contained 25 recommendations which emphasised the importance of:

- Understanding palliative and end of life care;
- Best and appropriate care supported by responsive and competent staff;
- Recognising and talking about what matters;
- Timely information and choice;
- Co-ordinated care, support & continuity.

Following an independent review of Health & Social Care in Northern, the ***Transforming Your Care*** (TYC) report was published in 2011. ***Transforming Your Care*** aimed to make changes which would have the greatest beneficial impact for patients, users and carers, and ensuring Northern Ireland has a safe, resilient, high quality and sustainable health and social care system for the future. TYC further supported the work of LMDM and identified key actions to be taken forward within palliative and end of life care.

In 2013, the ***Transforming Your Palliative and End of Life Care*** (TYPEOLC) programme was launched in Northern Ireland. TYPEOLC was a partnership between the Health & Social Care Board, the Public Health Agency and Marie Curie. TYPEOLC was based on the ***Delivering Choice*** approach which had been used in 19 sites across the UK where it had contributed to improved experiences for people with palliative and end of life care needs and their families.

The aim of TYPEOLC programme was to support the redesign and delivery of coordinated services to enable people across Northern Ireland with palliative and end of life care needs to have choice in their preferred place of care. In line with LMDM and TYC, the programme used a collaborative whole system approach by working with stakeholders including Department of Health, the Health and Social Care Trusts, independent providers, voluntary and community sector, and patients and their carers, and made significant progress in building the evidence base and direction for transformational change.

The Regulation and Quality Improvement Authority (RQIA) published their ***Review of the Implementation of the Palliative and of Life Care Strategy*** in January 2016. RQIA concluded:

'Significant progress was made during the period 2010 to 2015 towards implementing the recommendations of the [LMDM] strategy. This was facilitated by strongly committed leaders from

2. Policy context in Northern Ireland (cont.)

both statutory and voluntary sector organisations. There is clear evidence of strong partnership working to achieve the objectives of the strategy’.

RQIA made 8 recommendations for ongoing improvement and progress in palliative and end of life care as a result of the review, including a recommendation that an ongoing action plan should be developed to build on the work which has been completed since the LMDM strategy was developed in 2010.

In March 2016, the [Palliative Care in Partnership](#) (PCIP) programme was launched in Northern Ireland. The PCIP programme amalgamated a number of governance structures from LMDM and the TYPEOLC programme to form one collaborative programme representing the key stakeholders in palliative care across Northern Ireland. The overarching programme objective is to support people with palliative and end of life care needs to improve the quality of life of those with palliative and end of life care needs and improve the experience of those important to them.

The regional PCIP programme board members represent the Department of Health, the Public Health Agency, Health and Social Care Board, the five Health and Social Care Trusts (Acute and Community services), independent hospice sector, care home sector, Integrated Care Partnerships, NI Ambulance Service, community and voluntary sector, General Practice and specialist palliative care practitioners. The PCIP structure also includes a Clinical Engagement Group, a service users and carers forum ([Voices4Care](#)) and five Locality Palliative Care Boards working conterminously with the five HSCTs in Northern Ireland. The regional PCIP Programme Board is co-chaired by Mary Hinds, Director of Nursing and Allied Health Professionals, Public Health Agency and Dr Miriam McCarthy, Director of Commissioning, Health and Social Care Board.

The work of the PCIP programme is based on LMDM & TYC, the service improvement initiatives designed with the TYEPOLC programme and the recommendations of the RQIA review to form one collaborative structure, agenda and direction for palliative and end of life care in Northern Ireland.

The aim of the Palliative Care in Partnership Programme is:

“To provide regional direction so that everyone in Northern Ireland identified as likely to benefit from a palliative care approach (regardless of their condition) is:

- Allocated **keyworker**
- Has the opportunity to discuss and record their **advance care planning** decisions
- Be supported by appropriate **generalist and specialist palliative care services** (across all care settings)

Underpinned by:

- Regional good practice tools and guidance
- Communication
- Public health approach to palliative care

Care in the last days/hours of life

In 2014, the Department of Health in Northern Ireland set out **Five Principles for Quality Care in the Final Days and Hours of Life**. The principles are similar to the **Five Priorities for Care** set out in **One Chance to get it Right**

2. Policy context in Northern Ireland (cont.)

The Department of Health five principles are:

1. There should be timely identification that a person is dying and is probably in the final days and hours of life.
2. Sensitive and clear communication should be at the centre of quality care.
3. People who are identified as dying should have their physical, psychological, spiritual and social needs identified and be involved in decisions about how those needs can best be met. The person's needs should be regularly reviewed and re-assessed throughout the last days and hours of life.
4. Care in the last days and hours of life should be planned and co-ordinated with a focus on symptom control, comfort management and ensuring that psychological, social and spiritual support is provided to meet the person's needs.
5. Support for family and carers should be provided during their loved one's last days and into bereavement.

Research shows that given the choice most people would prefer to die at home (including care homes) at the end of life. The percentage of deaths occurring in hospitals has been steadily reducing in Northern Ireland - from 53% of all deaths in 2006, to 47% of all deaths in 2017. However, increasing population based mortality rates means there has been little reduction in the actual number of people dying in hospitals each year.

It is recognised that hospital wards may not be the most appropriate environment for people to die and that in many cases it is not medically necessary for the person to be in hospital at the end of their life. The priorities of the Palliative Care in Partnership programme aim to identify people with palliative care needs early and provide appropriate support, which may enable them to die in their preferred place of care. However it is also recognised this may not always be practical or appropriate and therefore planning for co-ordinated and dignified deaths in hospital is an important part of transforming palliative care services.

In December 2015, the [**NICE NG31 Care of Dying Adults in the Last Days of Life Guideline**](#) was published. The guideline outlines best practice in the clinical care of adults (18 years and over) who are dying during the last 2 to 3 days of life. The guidance offers 72 statements which aim to improve care for people in their last days of life by communicating respectfully and involving them, and the people important to them, in decisions and in maintaining their comfort and dignity. The guideline also covers how to manage common symptoms without causing unacceptable side effects and how to maintain hydration in the last days of life.

The **NICE NG31 guideline** was endorsed in Northern Ireland by the Department of Health (DoH) (formerly DHSSPS) in the **Circular HSC (SQSD) (NICE NG31) 9/16** in February 2016. With agreement from within the NICE implementation structure in Northern Ireland, a NICE NG31 Regional Workshop was organised by the Palliative Care in Partnership programme and held in June 2016. The guest speaker at the workshop was Professor Sam Ahemdzaï from the University of Sheffield, who chaired the NICE NG31 guideline committee.

The workshop was attended by a range of stakeholders from a range of organisations across Northern Ireland representing the key settings where people with palliative care needs normally spend their last days of life. There was representation from acute and community professionals from all five of the Health and Social Care Trusts, three of the four hospices were represented as well as a number of nursing homes. Other stakeholders who attended included representatives from primary care, the Health and Social Care Board, Public Health Agency, Regulation & Quality Improvement Authority (RQIA), General Medical Council (GMC), Patient Client Council and the All Ireland Institute of Hospice and Palliative Care (AIHPC).

2. Policy context in Northern Ireland (cont.)

The workshop was based on a self-assessment methodology enabling the participants to openly discuss how/if the statements of NG31 were current practice in their settings/organisations and highlighting areas of good practice or challenges to implementation. The findings of this collaborative approach to assessing the current implementation status of the 72 statements within **NICE NG31** found there to be varying degrees of implementation between the different care settings in which people are cared for in their last days of life.

It was evident there were areas of best practice in which many of the statements of the guideline were being implemented (i.e. hospices). The findings also indicated varying degrees of implementation particularly in the acute setting where a significant number of people in Northern Ireland currently die, and also in the community setting where the majority of people would choose to die. An on-going priority of the Palliative Care in Partnership programme is to improve implementation of the guideline across all settings to ensure a consistency of care and equity of best practice for people in their final days of life.

Many of the elements of the **NG31 guideline** are being progressed within the regional palliative care work plan. The National Audit for Care at the End of Life being undertaken by NHS Benchmarking Network offered an opportunity for formal benchmarking in the provision of care in the last days of life across the Northern Ireland hospitals and to assist the regional programme and HSCTs to identified tangible areas for improvement at regional and locality level moving forward.

3. Project content and process

3.1 Eligibility, recruitment and registration

All Health and Social Care Trusts in Northern Ireland providing acute, community and mental health inpatient care were eligible to take part in the audit.

At the request of the Northern Ireland Public Health Agency on behalf of the Regional Palliative Care and End of Life Care Programme, an engagement event was held in July 2018 with key members of the Health and Social Care Trusts, the Public Health Agency and the Health and Social Care Board. This event involved trust End of Life clinical leads, clinical staff, transformation, information and governance leads, business leads and heads of service. Information about participating in NACEL was provided at this meeting and lead contacts for each Health and Social Care Trust were identified, to co-ordinate data collection in their patch. In addition, a representative was also agreed for the National NACEL Steering Group, and four representatives selected for the National NACEL Advisory Group. All Northern Ireland HSCTs and submissions were identified and subsequently registered. The NHS Benchmarking Network completed the registration online using the web-based data entry tool on behalf of the HSCTs.

3.2 Data collection

Data collection opened on the 4th June 2018 and closed on the 12th October 2018 for all three elements of NACEL. The Northern Ireland cohort began entering their HSCT data for the organisational level audit following the engagement event in July. The later sign up to NACEL did not preclude the Northern Ireland HSCTs from making full data submissions. No extensions were given due to timescales required to complete analysis and reporting. The Northern Ireland contacts reviewed the data specification for the organisational level audit to ensure that the definitions were fit for purpose for the Northern Ireland cohort. Definitions were updated where necessary on the online data collection pages. Where questions didn't apply to Northern Ireland, the HSCTs were requested to leave these blank.

3.3 Data validation and cleansing

Data validation controls were implemented on several levels within the online data collection tool. Information buttons next to each metric contained definitional guidance of the data required to ensure consistency of the data collected. In addition, system validation was implemented to protect the integrity of the data collected, including allowable ranges, expected magnitude of data fields, numerical versus text completion, appropriate decimal point placing and text formatting.

An extensive data validation exercise was undertaken from mid-October to the end of December 2018. As part of the validation process, charts were generated which assisted with identifying outlying positions on selected metrics. These were queried with NACEL participants. A draft online toolkit was made available to NACEL participants at the beginning of December 2018 to assist with refining data submissions.

3.4 Data confidentiality and security

As required by the Data Protection Act and GDPR, the NHS Benchmarking Network has registered with the Information Commissioners Office (ICO) as an organisation which processes data.

The NHS Benchmarking Network adheres to Cyber Security Essentials, a government sponsored programme which ensures adequate storage and security of data.

Participating trusts were requested to provide the NHS Benchmarking Network with key personnel they wished to have access to the online data collection tool. Entry to the online data collection tool was restricted via unique identifiers and passwords assigned to individuals during the registration process.

4. Project outputs

Bespoke dashboard

A bespoke dashboard is available for each submission registered by the Northern Ireland HSCTs.

All five Health and Social Care Trusts took part in the first round of NACEL for the organisational level audit only. Between them, they registered 25 submissions. The table below indicates how many submissions by type of provider were registered in Northern Ireland.

Type of submission	Northern Ireland
Acute	13
Community	4
Mental health	8

This Summary Report provides findings from the five HSCTs in Northern Ireland in aggregated form (i.e. average positions reported). As mentioned earlier, results from the organisational level audit only are presented. For the organisational level audit, two elements of data collection were requested:-

Trust/UHB overview. This data collection covered the organisation as a whole and was completed once per organisation, regardless of the number of submissions. The trust/UHB overview collected data on trust/UHB organisational policies and protocols.

Hospital/site overview. This data collection covered hospital/site data and was completed for each submission registered. The hospital/site overview collected data on activity, workforce, quality and outcomes and good practice.

The full list of indicators shown in this Summary Report, the number of responses to each possible answer and the number of responses used in the denominator are included at Appendix 2.

Other audit outputs

In addition to this Summary Report, participants will have access to the following outputs for the first round of NACEL:

- Online toolkit accessible via the members' area of the NHSBN website. The final version of the toolkit is now available. All data is anonymised in the online benchmarking toolkit and participating organisations know their own position only. Participant codes for the toolkit have not been shared amongst participants.
- Bespoke dashboards for each HSCT, comparing each submission's response to the nationally reported Northern Ireland positions.

5. Key findings – Health and Social Care

Trust level

Trust level questions were asked once, irrespective of the number of submissions registered. The following findings are reported.

In line with the palliative and end of life care strategy in Northern Ireland, all five HSCTs reported that they had an identified member of the trust board with overall responsibility for end of life care. Two HSCTs reported that they had a lay member of the board with a role around end of life care. Only one HSCT reported having a non-executive director with responsibility for end of life care. All organisations were represented on the regional end of life care network, which is the key driver for strategic change in Northern Ireland for palliative and end of life care.

The five HSCTs in Northern Ireland reported strong compliance with questions asked about the use of policies and procedures; all reported they had policies regarding responding to and learning from deaths, their approach to undertaking case note reviews, how to document a DNACPR decision (the HSC *Advance Care and Planning Summary* document used through the region covers decisions regarding CPR), for providing relatives and carers with verification & certification of death and finally, guidelines for viewing a body immediately following a death. Where the HSCTs tended to be less compliant with having policies/procedures available was on how they respond to the death of an individual with a mental health need or a Learning Disability (two HSCTs only responded that they had a policy which covered this). However, it is noted that within Northern Ireland, the palliative care strategy applies to all conditions and is not condition specific.

Not surprisingly, given the nature of the *Advance Care Planning Summary* document, all five HSCTs reported using tools/prompts to recognise and provide palliative care for patients whose recovery was uncertain, arrangements for rapid discharge home, process to create personalised recommendations for a future care emergency, tools/prompts to plan the care of a patient who is thought to be in the last months of life, and locally developed programmes to improve and support end of life care. Two HSCTs reported that they had a care plan which supported the *Five priorities for care*, suggesting these priorities are less embedded within Northern Ireland, given the regional priorities which are underpinned by the five principles which support high quality care in the final days and hours of life.

All five HSCTs reported that they had guidance for the prescription of medication for patients in the last few days and hours of life. These covered agitation/delirium, dyspnoea/breathing difficulty, nausea/vomiting, pain and noisy breathing/death rattle.

5.1 Representation (Trust)

Figure 1: % of organisations who have an identified member of the trust board with a responsibility/role for End of Life Care?

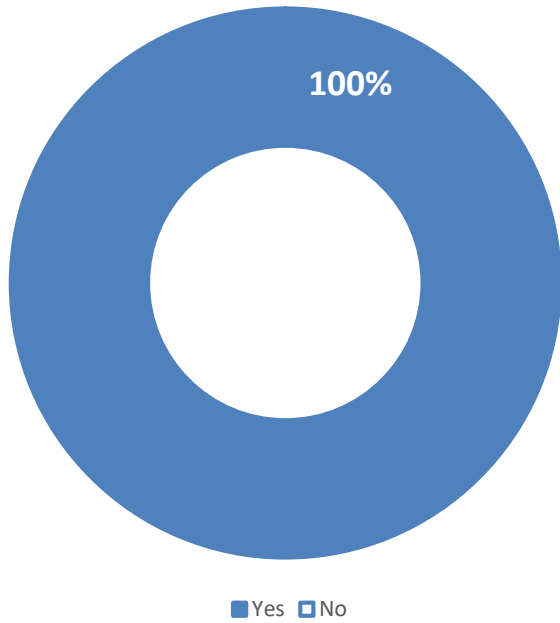


Figure 2: % of organisations who have a lay member on the trust board with a responsibility/role for End of Life Care?

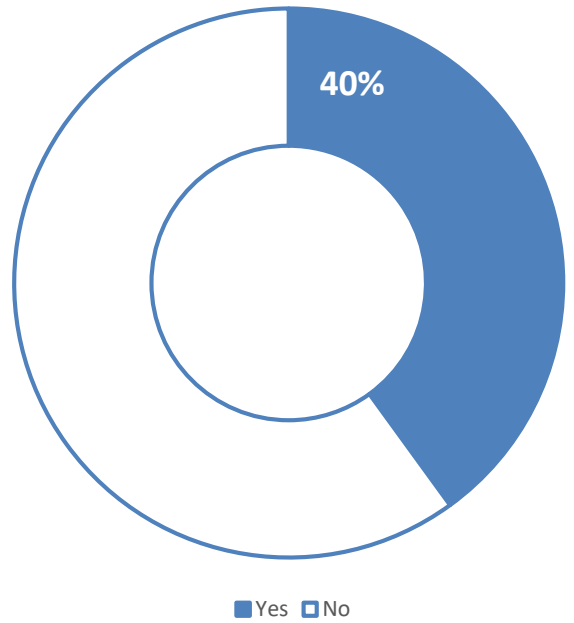


Figure 3: % of organisations who have a non-executive director with responsibility for End of Life Care?

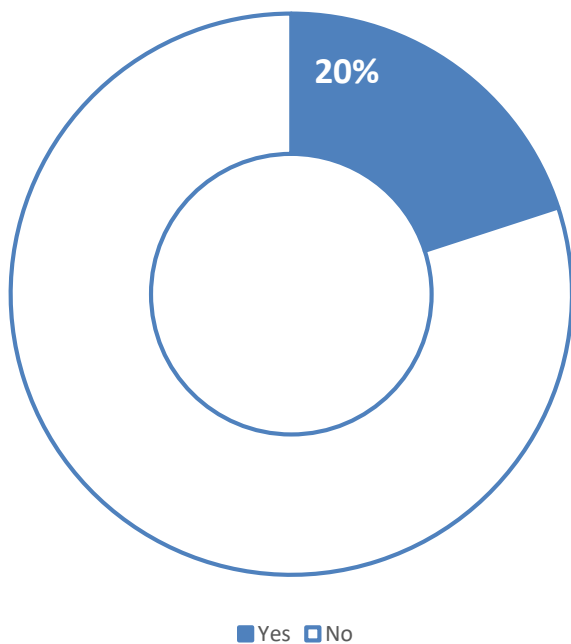
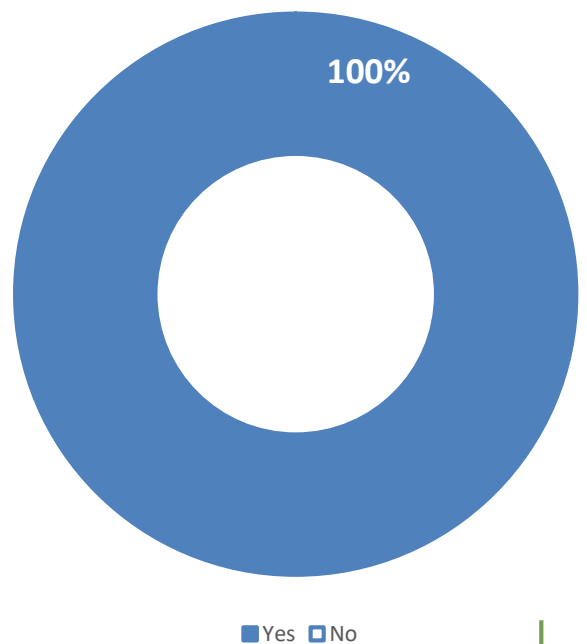
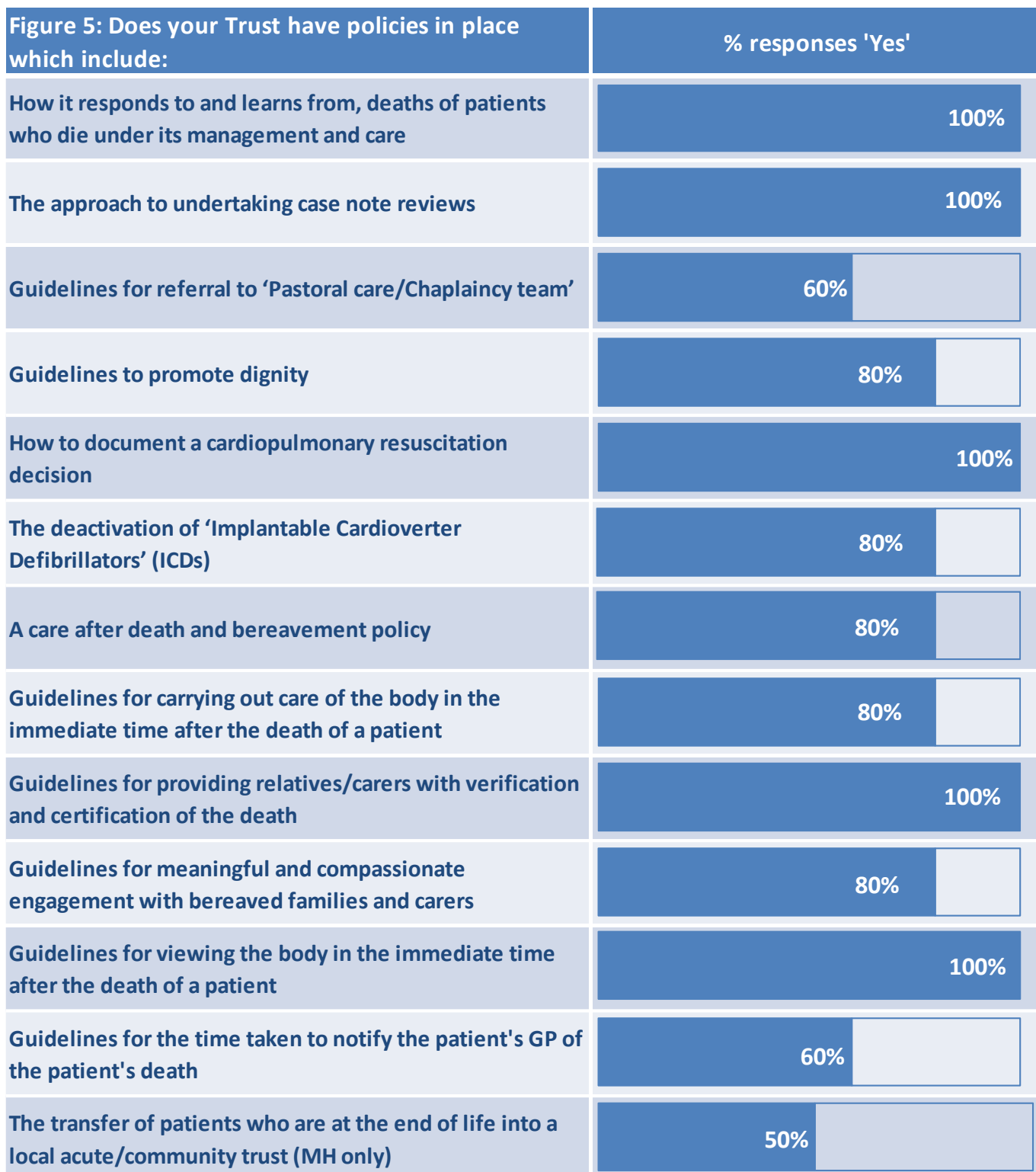


Figure 4: % of organisations who have representation on a local or regional End of Life Care group/network?



5.2 Policies (Trust)



5.3 Tools and processes (Trust)

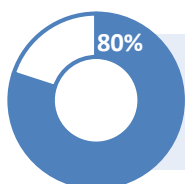


Figure 6: % of organisations who use Advance Care Planning (ACP) processes

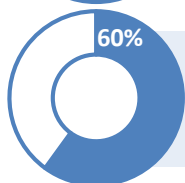


Figure 7: % of organisations who use Electronic Palliative Care Co-ordination System (EPaCCS)

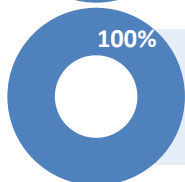


Figure 8: % of organisations who use tools/prompts to recognise and provide palliative care for patients whose recovery is uncertain

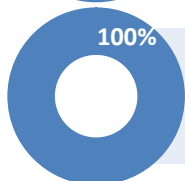


Figure 9: % of organisations who use specific care arrangements to enable rapid discharge home to die

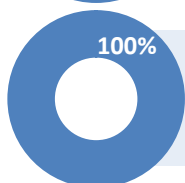


Figure 10: % of organisations who use processes to create personalised recommendations for a person's clinical care in a future emergency

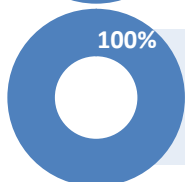


Figure 11: % of organisations who use tools/prompts to plan the care of those patients thought to be in the last months of life

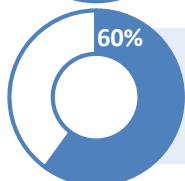


Figure 12: % of organisations who use opportunities for staff to reflect on the emotional aspects of their work

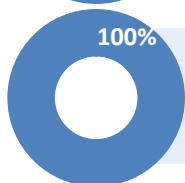
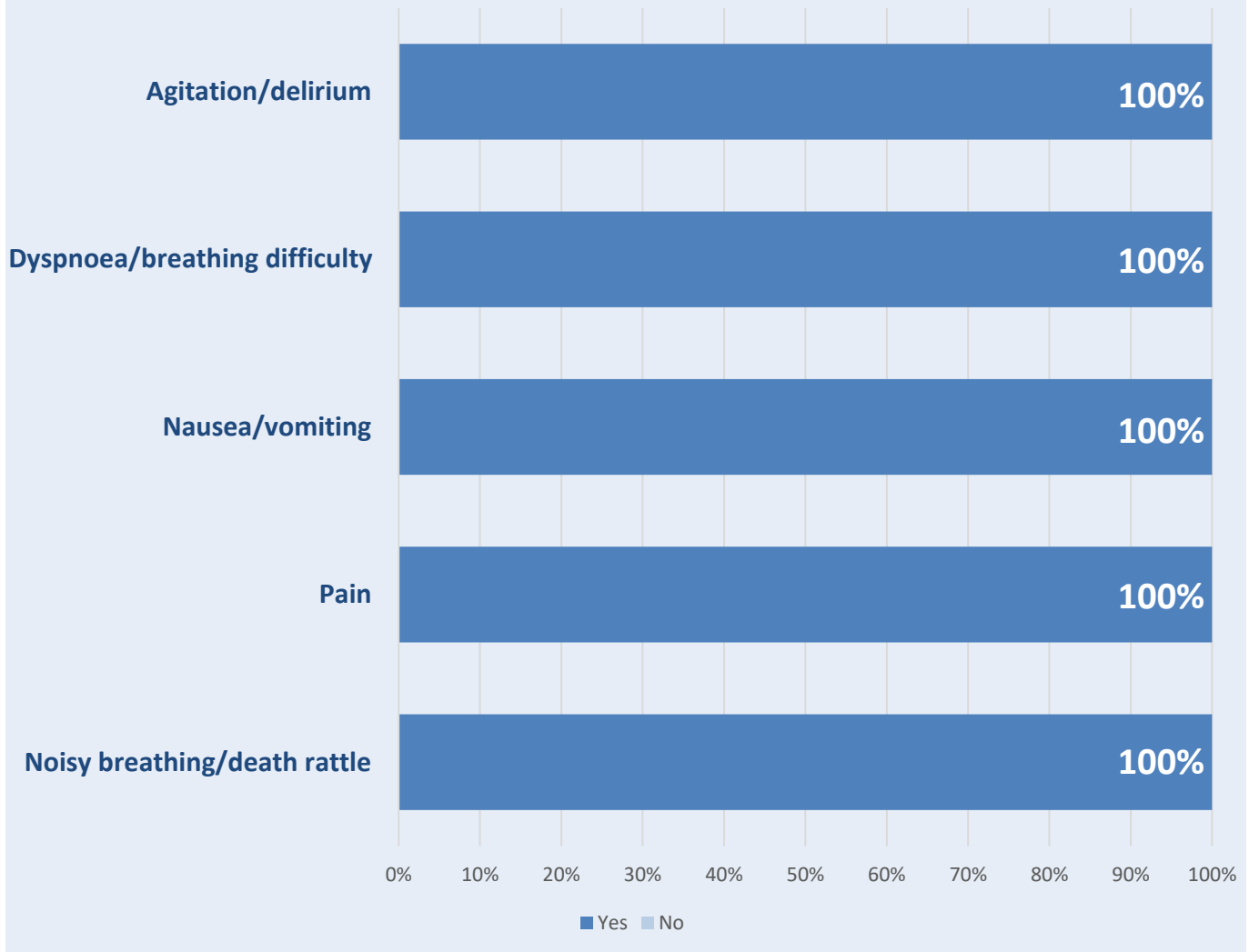


Figure 13: % of organisations who use locally developed programmes of work to improve and support End of Life Care

5.4 Prescription guidance (Trust)

Figure 14: **Guidance for the prescription of medications for patients in the last hours or days of life with:**



6. Key findings - Acute & Community submissions

Participation

The five HSCTs registered 13 acute and 4 community submissions between them. For the purpose of this report, these submissions are reported jointly, however, further detail/findings in relation to acute submissions only and community submissions only can be found in the online benchmarking toolkit.

Deaths in acute and community providers

The total number of acute and community beds (in the requested NACEL categories) in Northern Ireland ranged from 36 to 578. A full breakdown of bed types can be found in the online benchmarking toolkit. Single patient occupancy rooms as a proportion of all available beds were reported at 45% (median 29%). The total number of deaths per 100 beds is far higher, as would be expected, in acute and community hospitals than in mental health providers. This averaged 160 per 100 beds in Northern Ireland, although ranged from 14 to 330 deaths per 100 beds. Service models and bed offer must be taken into account here when interpreting this finding. Deaths in A&E accounted for 5% of total deaths reported annually. The majority of deaths occurred in respiratory and care of the elderly wards (15% and 11% respectively). However the Northern Ireland cohort reported deaths occurring in “other” locations at 25% which may mean that this designation of beds potentially requires review for future iterations of NACEL.

Specialist palliative care workforce

Access to the specialist palliative care workforce was provided in house by the hospital in 88% of cases. 60% of acute/community providers reported that they did have access to specialist palliative care services outside of the hospital. 82% of acute/community providers reported that they had access to one of more end of life facilitators (or their equivalent in Northern Ireland). In 62% of cases, the end of life facilitators sit within the specialist palliative care teams. In terms of the availability of these teams, 63% of acute/community providers report that medical staff are available 9-5, Monday to Friday only on a face-to-face basis. 56% of acute/community providers reporting a 9-5, Monday to Friday availability of nursing staff face-to-face. As regards telephone availability, for doctors, only 18% of acute/community providers report a 24 hour, 7 days per week service. 59% of acute/community providers report that a telephone service from nurses is available 9-5 Monday to Friday only. However, it is noted that PCIP work programme will shortly be commencing a piece of work on scoping out of hours provision for palliative and end of life care in both hospital and community settings to increase the standardisation of the availability of services across Northern Ireland.

The discipline mix of these specialist palliative care teams is 18% medical, 66% nursing, 13% AHPs and 3% other. Within the medical provision, on average there are 5.6 PAs per 100 beds. However, there is wide variation reported. Nursing resource is reported as 1.5WTE per 100 beds. With the exception of one service having a higher resource, the range of nursing staff exhibits less variation. Chaplaincy staff are a key resource for patients/families at end of life; the mean reported is 1.3 chaplaincy staff per 100 beds. Again, significant variation is noted from 0.3 to 4.4 chaplaincy staff per 100 beds. Seven hospitals reported that they had end of life care facilitators, ranging from 0.06 to 1.4 WTE per 100 beds. End of life facilitators (nursing staff) reported that on average, 17% of their time was spent on patient facing activity; 53% of their time was spent on the education and training of other staff in the hospital.

6. Key findings - Acute & Community submissions

End of life training and education

A number of questions were asked about availability of end of life training and education in acute/community hospitals. 82% of acute/community providers reported that relevant training was included in induction programmes, 41% reported that it was included in mandatory/priority training. Only 25% reported that they had access to eELCA resources to support staff training, however, the [All Ireland Institute of Hospice and Palliative Care \(AllHPC\) HPC Hub](#) is available to all staff in Northern Ireland, which may reflect this finding. 100% of acute/community hospitals reported that they held training to improve the communication skills of staff. 94% reported that other training on end of life care was available locally.

Trust board engagement

Encouragingly, there was complete compliance with production of action plans to promote improvement in end of life care, and sharing those action plans with clinical teams and the trust board, highlighting good two way communication. It is not surprising therefore that 100% of acute/community providers reported that end of life care was reported on at board level during the 2017/18 financial year. Another encouraging finding is that all acute/community providers reported public and carer representation in these reporting processes with the trust board. Only 35% of trust boards had a formal process for discussing and reporting on the **Five priorities for care**, reflecting that this has been adapted more widely in England and Wales, and given the regional priorities which are underpinned by the five principles that should underpin high quality care in the final days and hours of life.

Engagement with bereaved friends/family

100% of acute community providers reported that they had actively engaged with bereaved relatives/friends during the last two financial years; 55% were using an in-house survey, whilst 54% reported using VOICES. 82% of acute/community providers reported having a leaflet outlining the changes which may occur in patients in the hours before death, and all providers reported having a leaflet explaining the local procedures to be undertaken after the death of a patient. It is noted that there is regional bereavement network resources for HSCs use and AllHPC resources. In addition, the PCIP programme board recently commissioned AllHPC to review the resources available for the care of the dying for public/professionals

Support processes

All acute/community providers report having bereavement cards/leaflets and having multi-faith/religious support. Only 41% of acute/community providers report having comfort care packs and less than half (47%) report having access to counselling services available for the bereaved. Volunteers are in evidence with 82% of acute/community providers reporting that they utilise them.

In relation to staff and volunteers, access to bereavement services/bereavement team are in evidence with 65% of acute/community providers reporting they are available to both staff and volunteers. Debriefing sessions are available to staff in 76% of acute/community providers and health and wellbeing teams are available to support both staff and volunteers in around half of the acute/community providers. Use of a last days of life care planning support process is available to staff in 100% of acute/community providers.

6.1 Service models (Acute & Community)

Beds

Figure 15: Average number of beds

Bed type	Regional
Acute assessment ward	82
Acute medical admissions ward	32
Rehabilitation ward	28
Oncology ward	11
Cardiology ward	21
Respiratory ward	28
Renal ward	3
Care of the elderly ward	31
Specialist palliative care ward	3
Trauma ward	24
Neurological ward	12
Orthopaedics ward	20
Intensive care	10
Other hospital location	111

Figure 16: Bed type % split

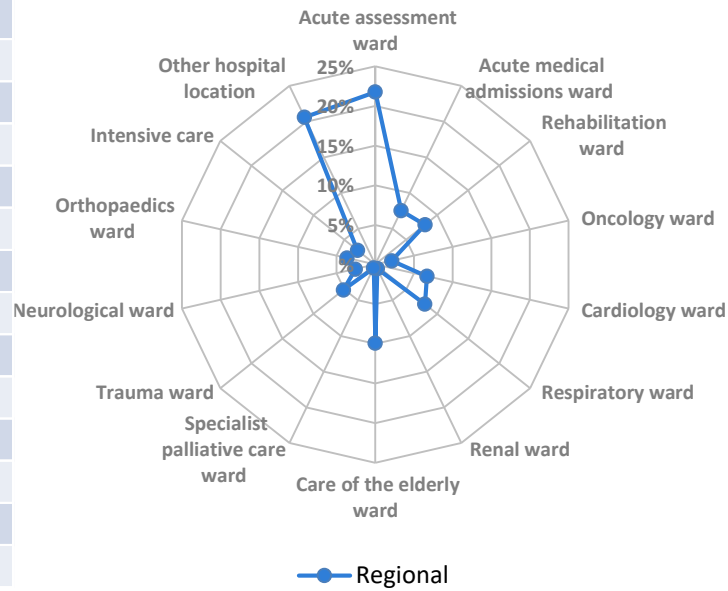


Figure 17: Total number of beds 2017/18

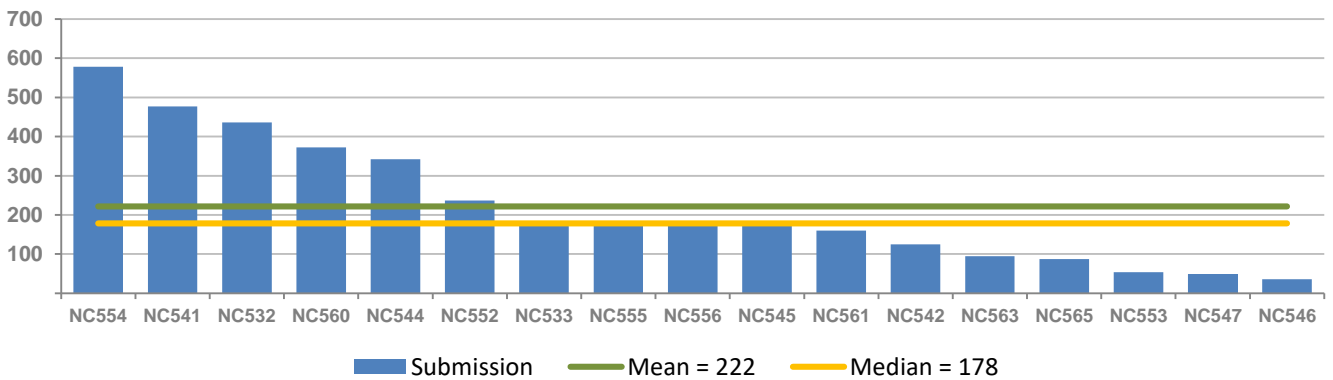
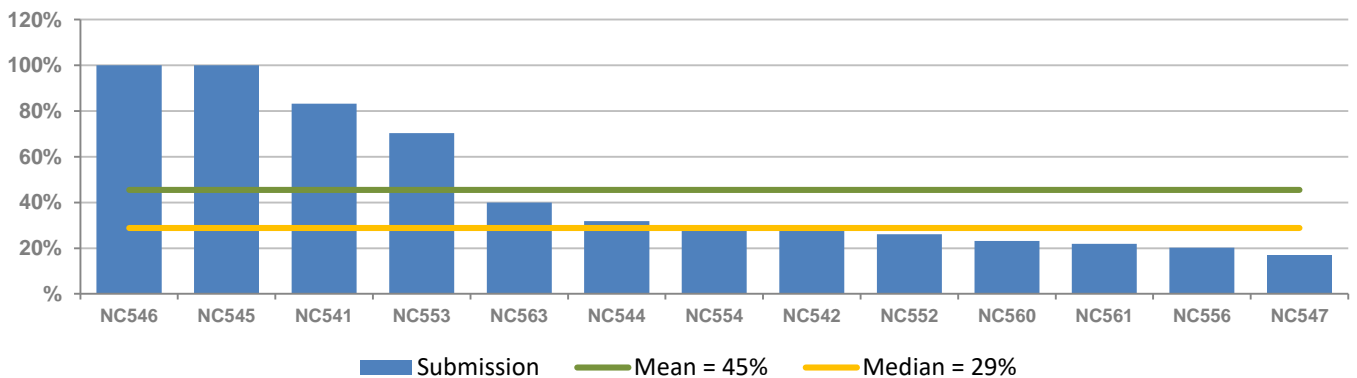


Figure 18: Adult single patient occupancy rooms as a % of total beds



6.1 Service models (Acute & Community)

Deaths

Figure 19: Total number of deaths per 100 beds 2017/18

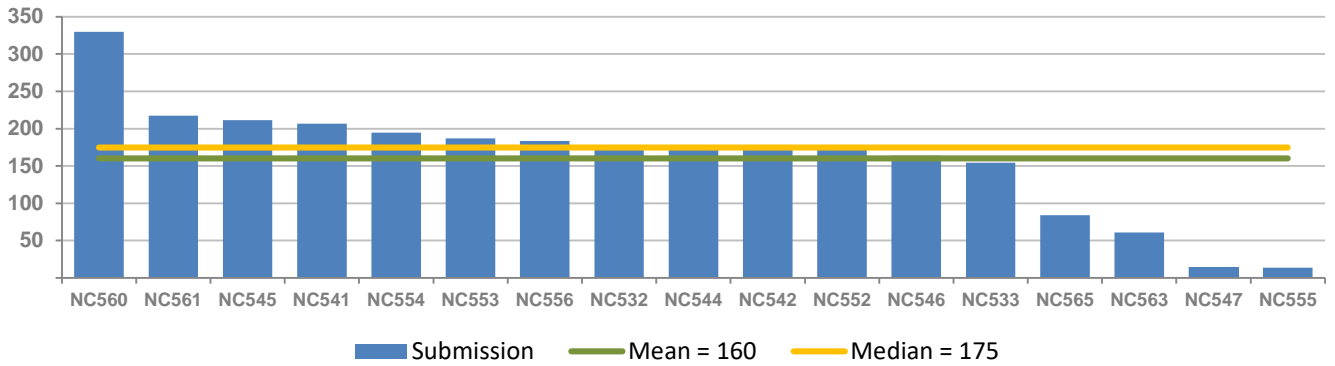


Figure 20: Number of deaths in A&E as a % of total deaths

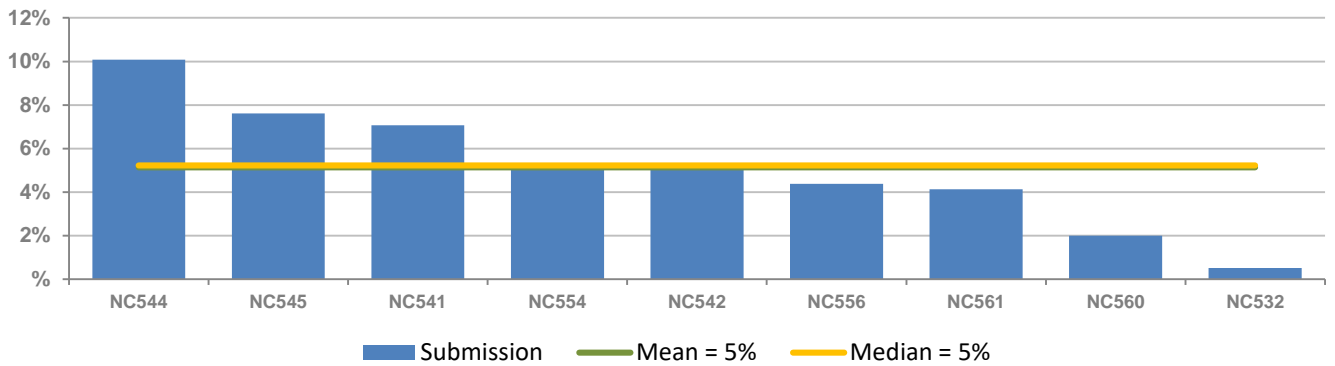


Figure 21: % of deaths by bed type

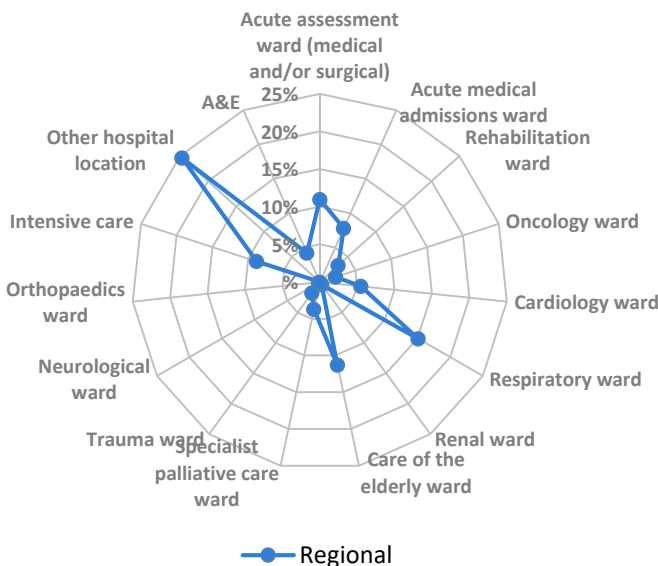


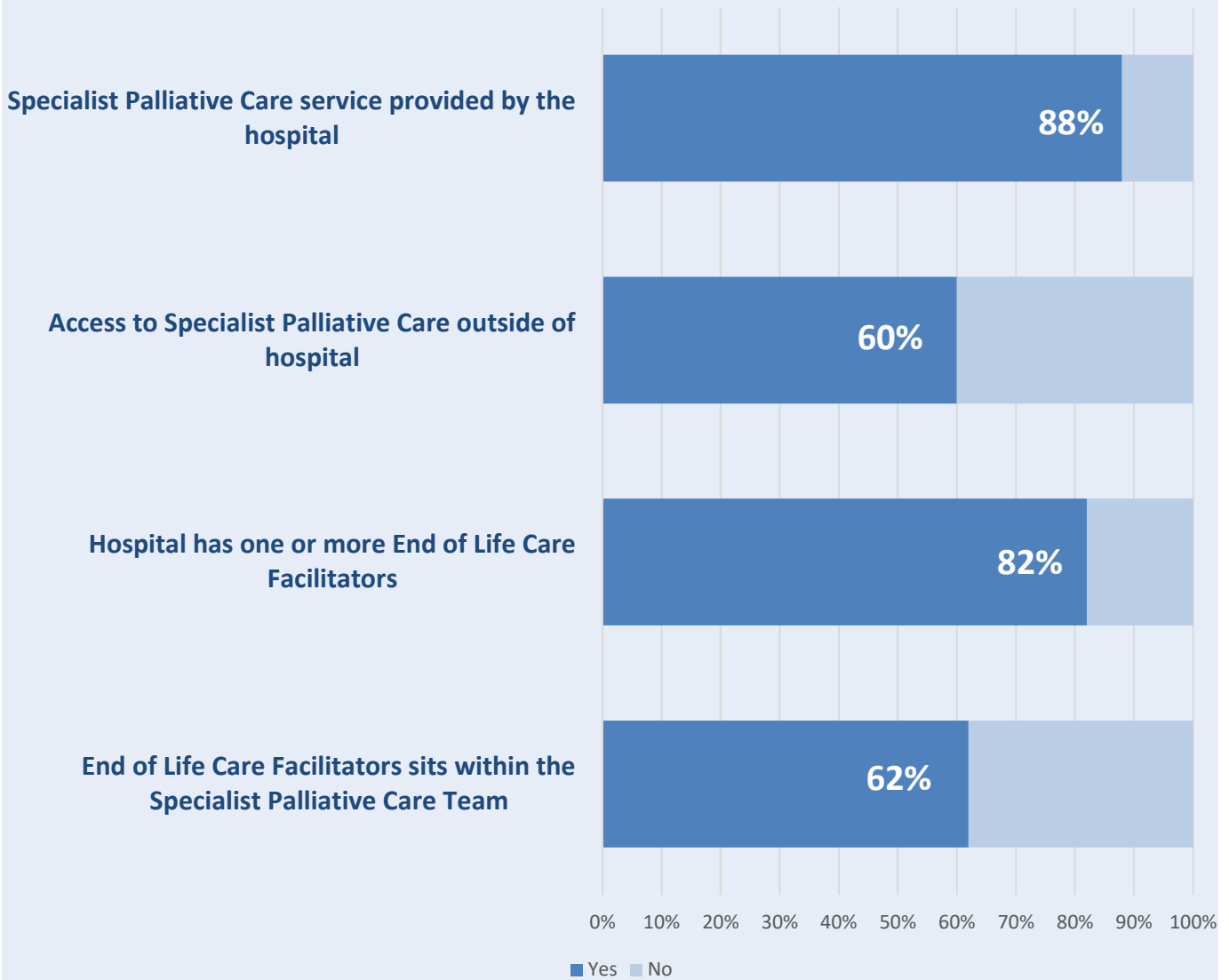
Figure 22: Average number of deaths

Bed type	Regional
Acute assessment ward	67
Acute medical admissions ward	44
Rehabilitation ward	17
Oncology ward	15
Cardiology ward	29
Respiratory ward	85
Renal ward	3
Care of the elderly ward	59
Specialist palliative care ward	25
Trauma ward	11
Neurological ward	1
Orthopaedics ward	0
Intensive care	46
Other hospital location	138
A&E	22

6.2 Workforce (Acute & Community)

Specialist Palliative Care Team - Access

Figure 23: Does your hospital/site have:



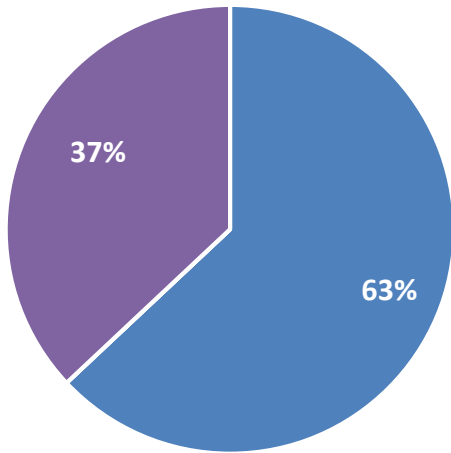
6.2 Workforce (Acute & Community)

Specialist Palliative Care Team (SPCT) - Availability



Figure 24: Face to face availability -

Doctor

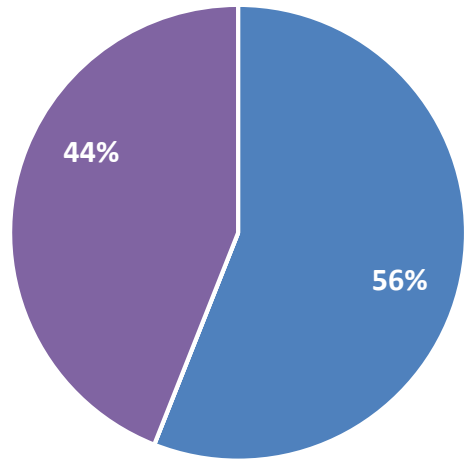


- 9-5, Monday to Friday only
- 9-5, Monday to Saturday only
- 9-5, 7 days a week
- Other



Figure 25: Face to face availability -

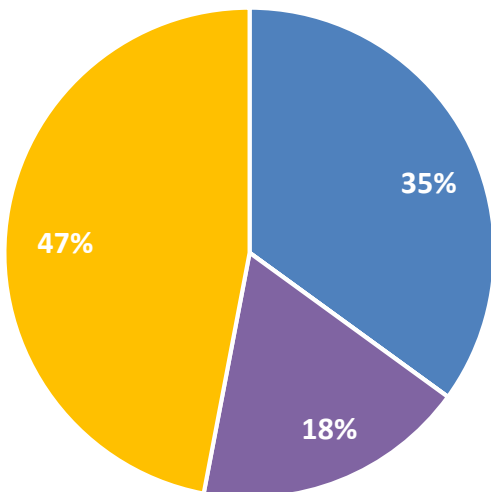
Nurse



- 9-5, Monday to Friday only
- 9-5, Monday to Saturday only
- 9-5, 7 days a week
- Other



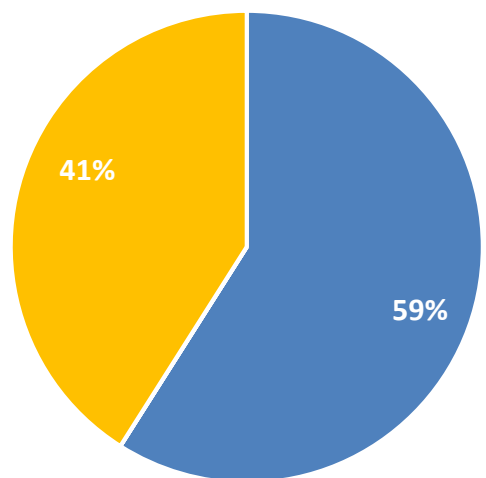
Figure 26: Telephone availability - Doctor



- 9-5, Monday to Friday only
- 9-5, Monday to Saturday only
- 9-5, 7 days a week
- 24 hours per day, 7 days a week
- Other



Figure 27: Telephone availability - Nurse



- 9-5, Monday to Friday only
- 9-5, Monday to Saturday only
- 9-5, 7 days a week
- 24 hours per day, 7 days a week
- Other

6.2 Workforce (Acute & Community)

Specialist Palliative Care Team (SPCT)

SPCT skill mix by banding	
Banding	Regional %
Band 2	0.0%
Band 3	1.5%
Band 4	4.0%
Band 5	0.0%
Band 6	3.0%
Band 7	70.3%
Band 8a	3.0%
Band 8b	0.0%
Band 8c	0.0%
Band 8d	0.0%
Band 9	0.0%
Medical	18.1%

Figure 28: Specialist Palliative Care Team – skill mix by banding

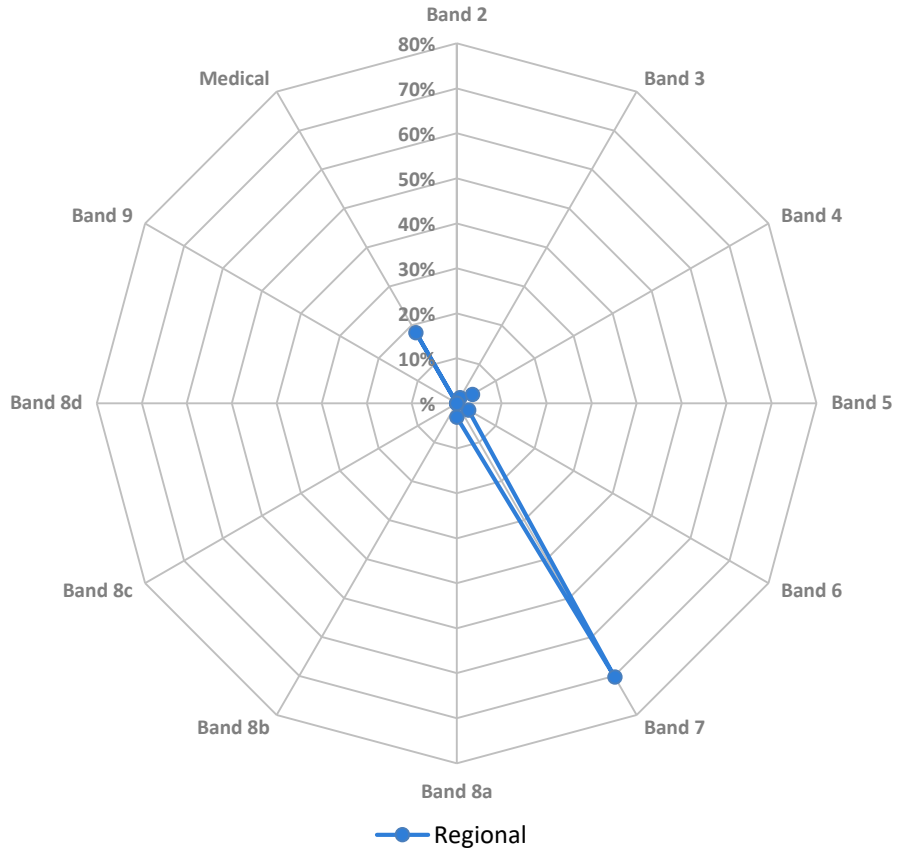
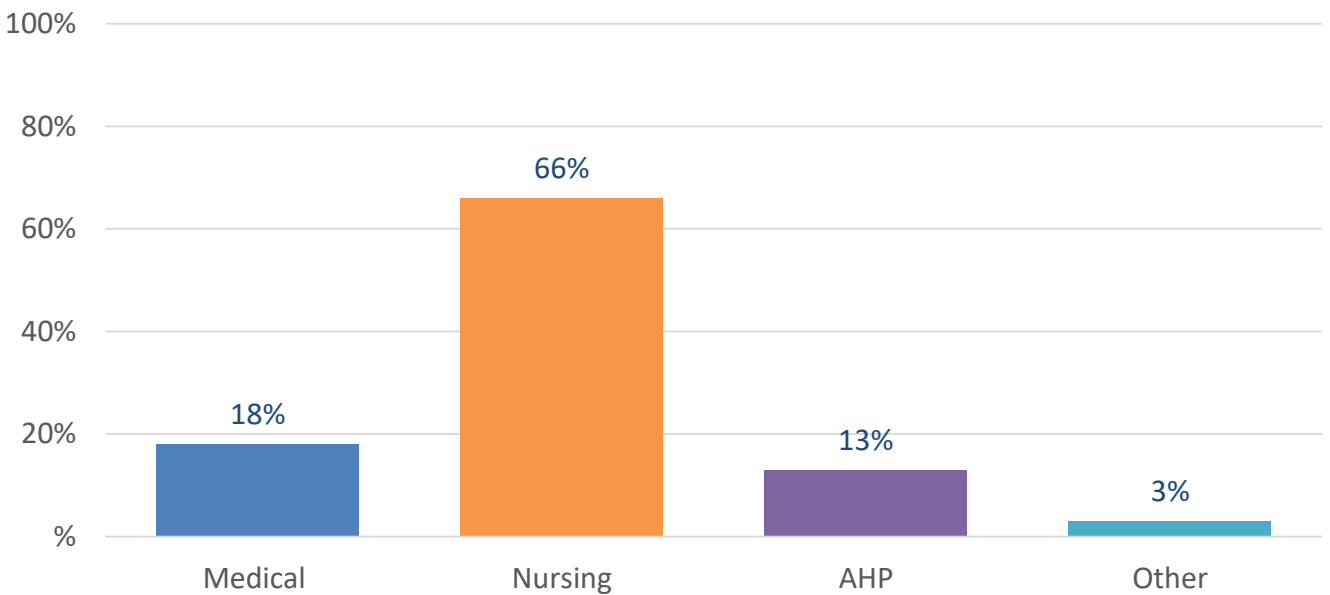


Figure 29: SPCT skill mix by discipline



6.2 Workforce (Acute & Community)

Specialist Palliative Care Team (SPCT)

Figure 30: Medical staff in the Specialist Palliative Care Team (PAs) per 100 beds 2017/18

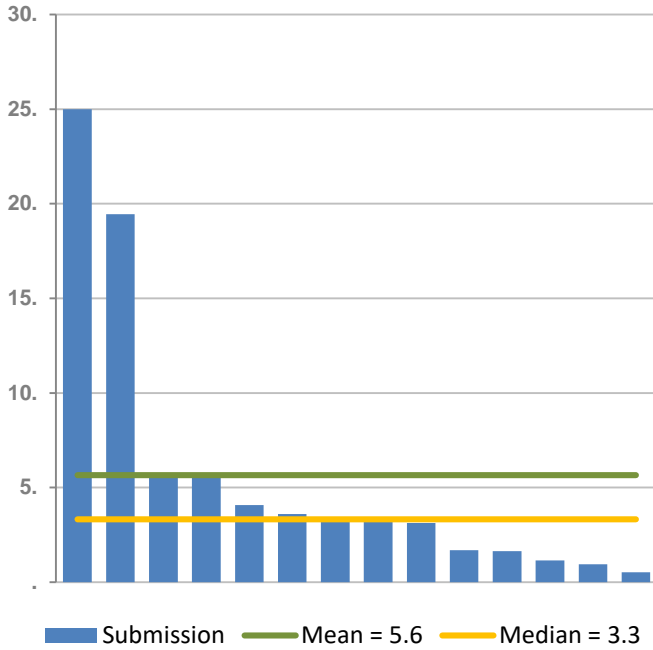


Figure 31: Nursing staff in the Specialist Palliative Care Team (WTE) per 100 beds 2017/18

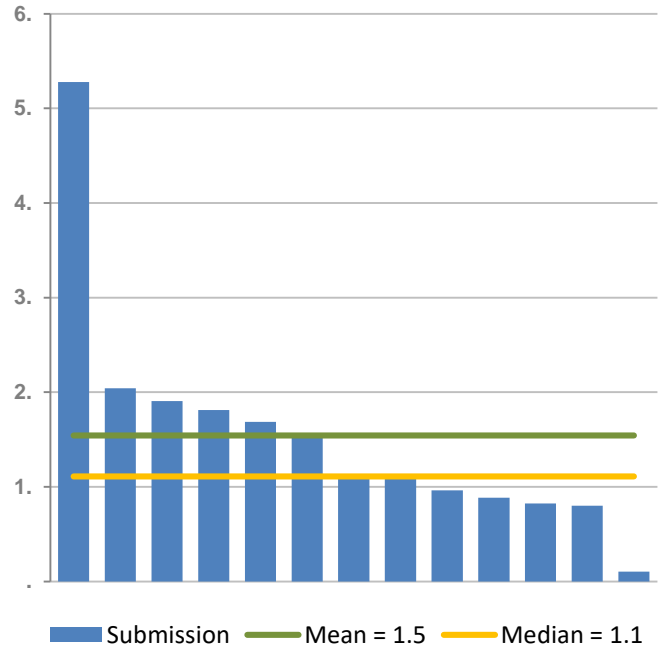


Figure 32: AHP staff in the Specialist Palliative Care Team (WTE) per 100 beds 2017/18

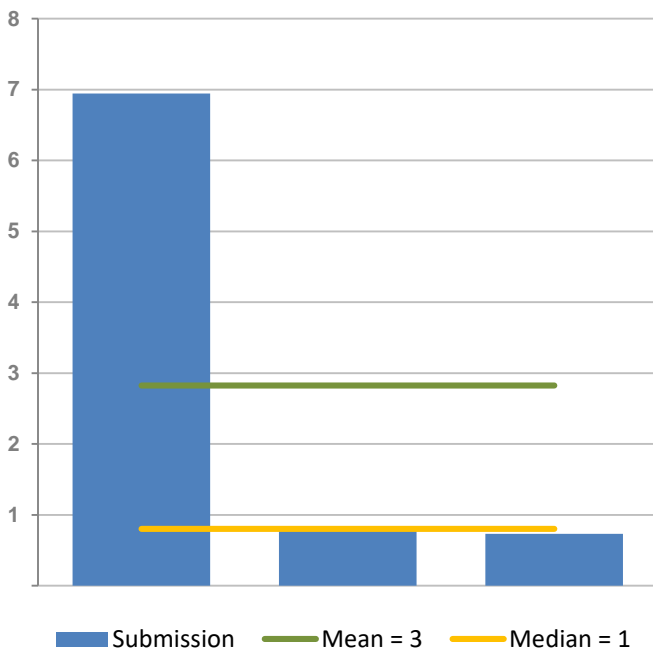
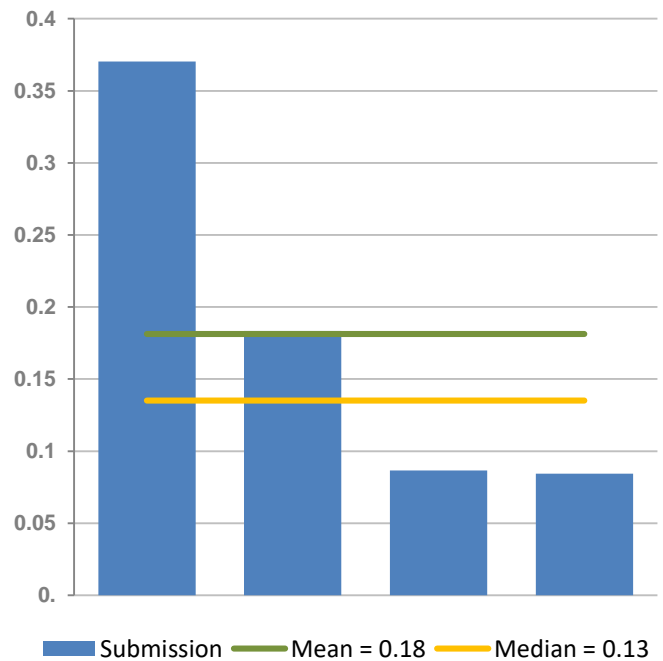


Figure 33: Other staff in the Specialist Palliative Care Team (WTE) per 100 beds 2017/18



6.2 Workforce (Acute & Community)

Other workforce

Figure 34: Chaplaincy staff per 100 beds 2017/18

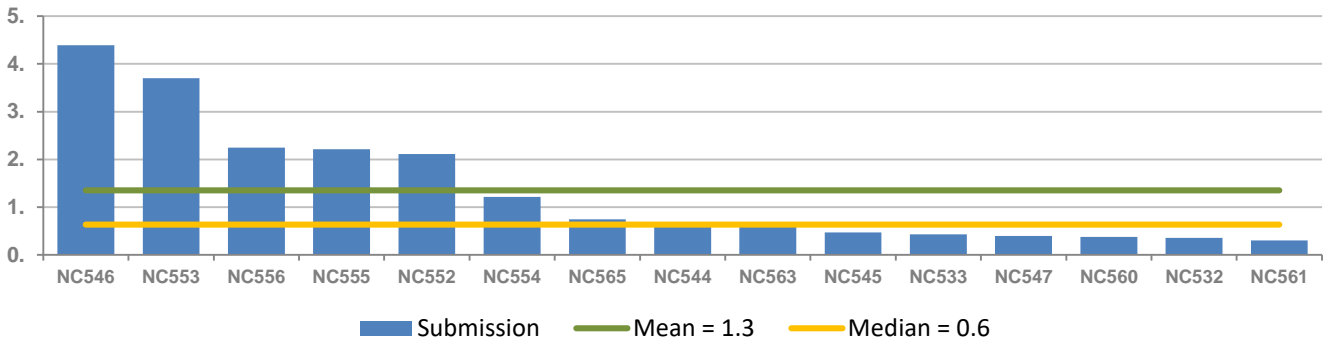


Figure 35: End of Life Care Facilitators per 100 beds

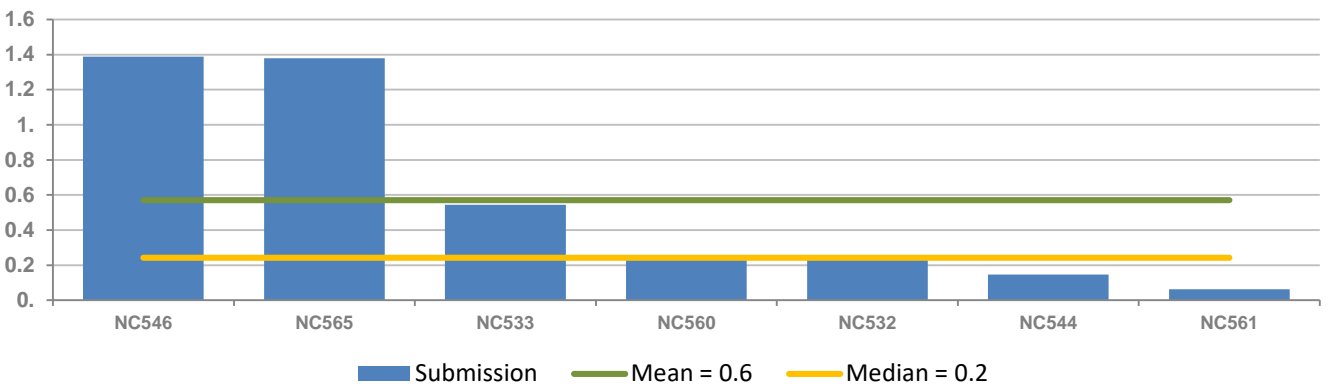


Figure 36: End of Life Care Facilitators - % Patient facing time (Nursing Staff)

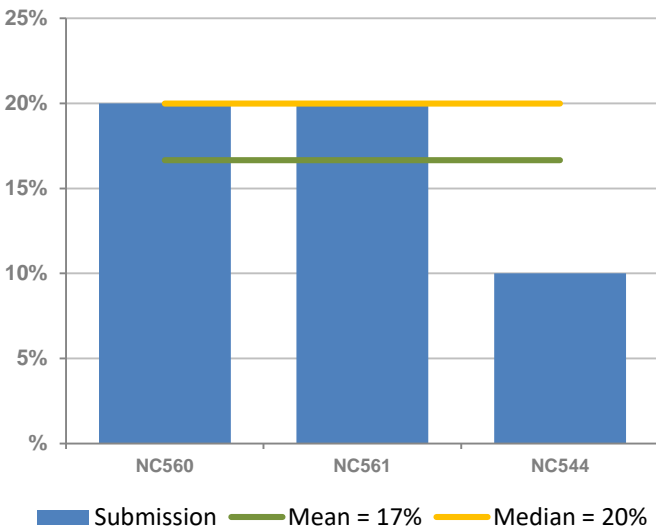
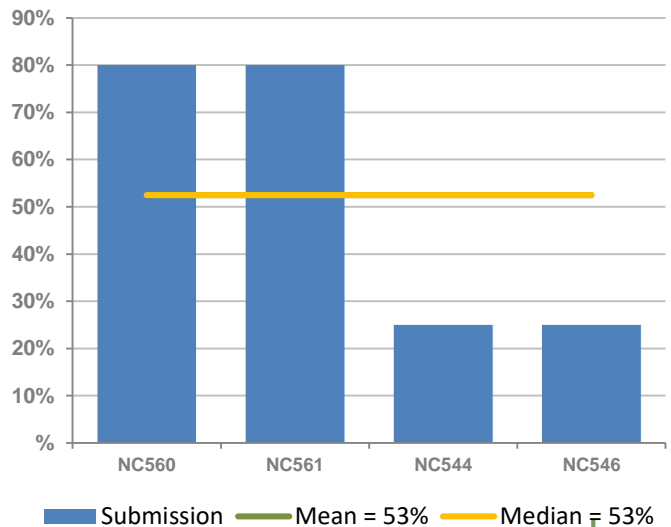


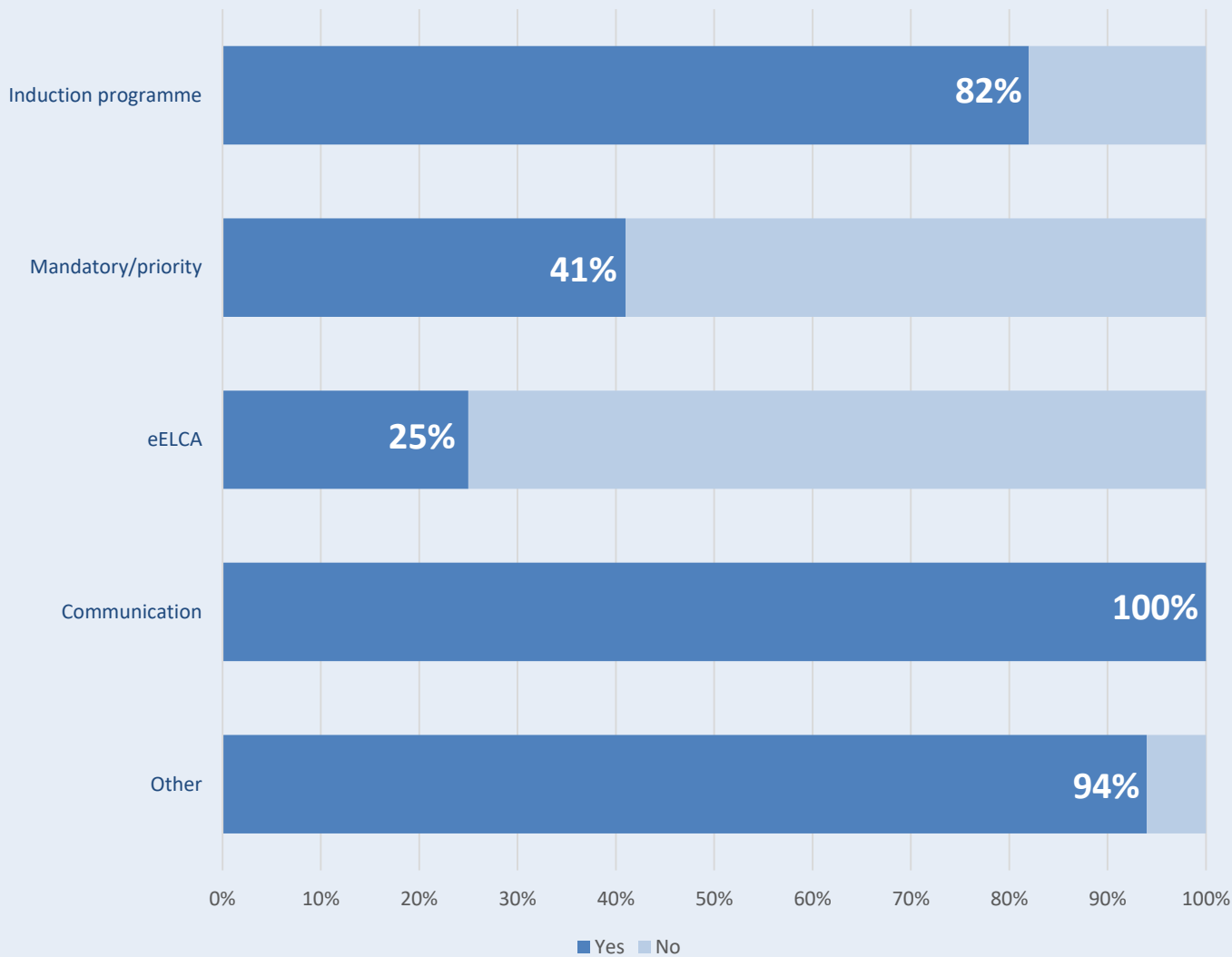
Figure 37: End of Life Care Facilitators - % Teacher/training facing time (Nursing Staff)



6.2 Workforce (Acute & Community)

Training

Figure 38: In the period between 1st April 2017 and 31st March 2018 what continuing End of Life education and training was available:



6.3 Quality and outcomes (Acute & Community)

EoLC board level reporting

Figure 39: Was an action plan produced to promote improvement in End of Life Care?

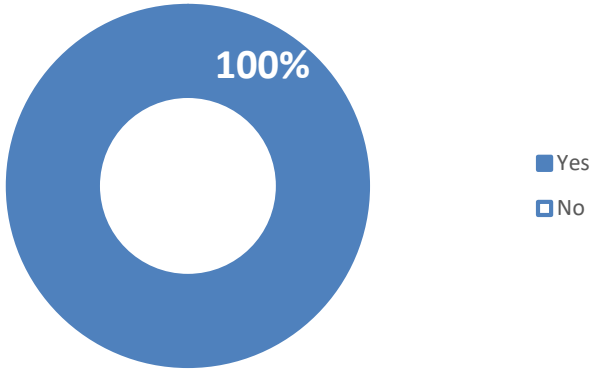


Figure 40: Was this action plan fed back to clinical teams?

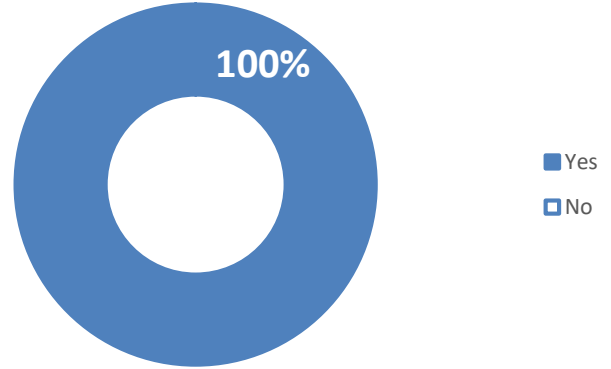


Figure 41: Was this action plan fed back to the trust board?

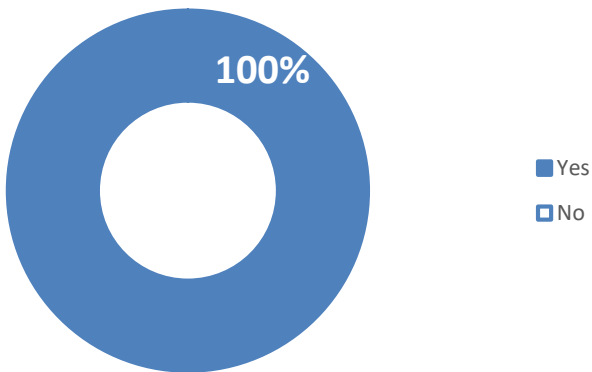


Figure 42: Was End of Life Care reported on at trust level between April 2017 and March 2018?

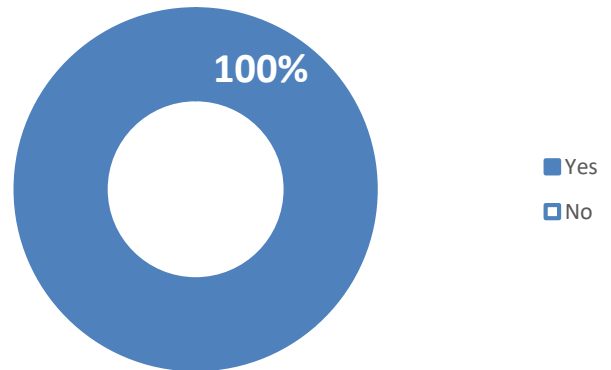
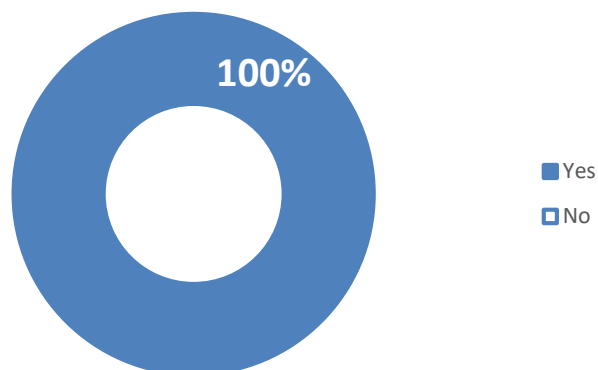


Figure 43: Was there carer and public representation within these discussions/reporting processes?



6.3 Quality and outcomes (Acute & Community)

Engagement with bereaved relatives/friends

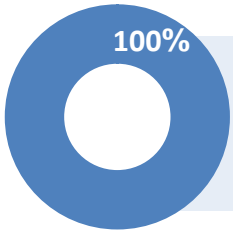


Figure 44: % of hospitals who sought bereaved relatives' or friends' views during the last two financial years

Figure 45: % of hospitals/sites who used feedback survey

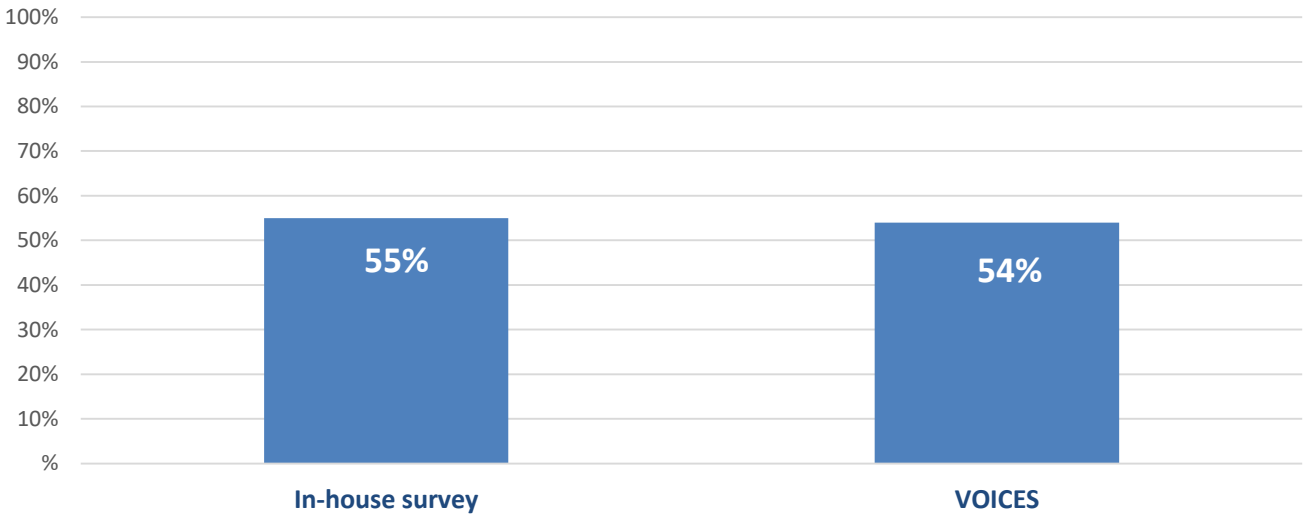
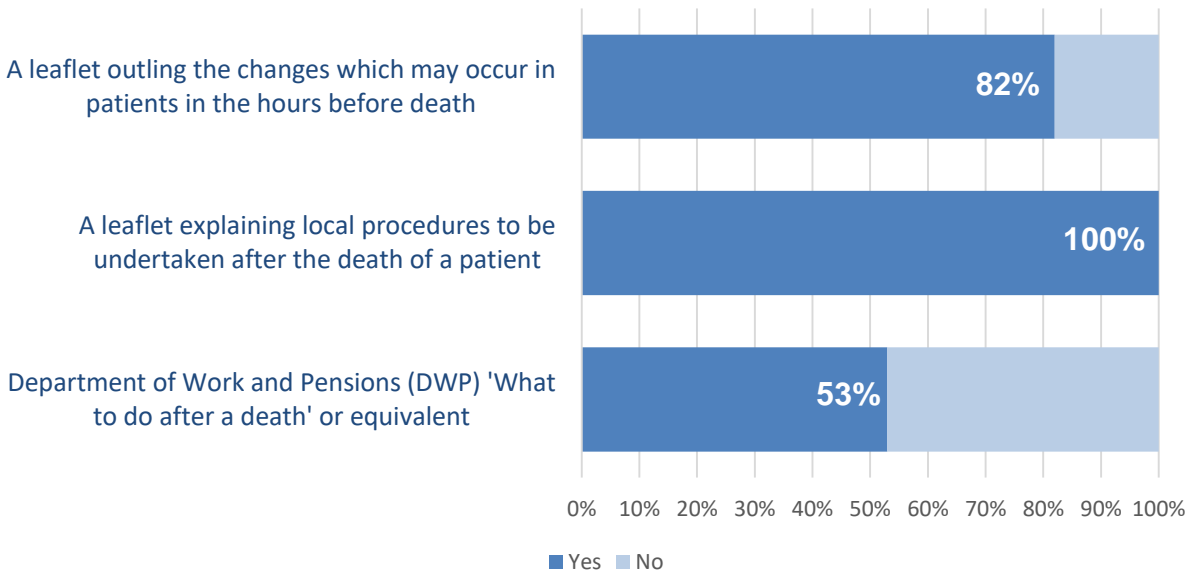
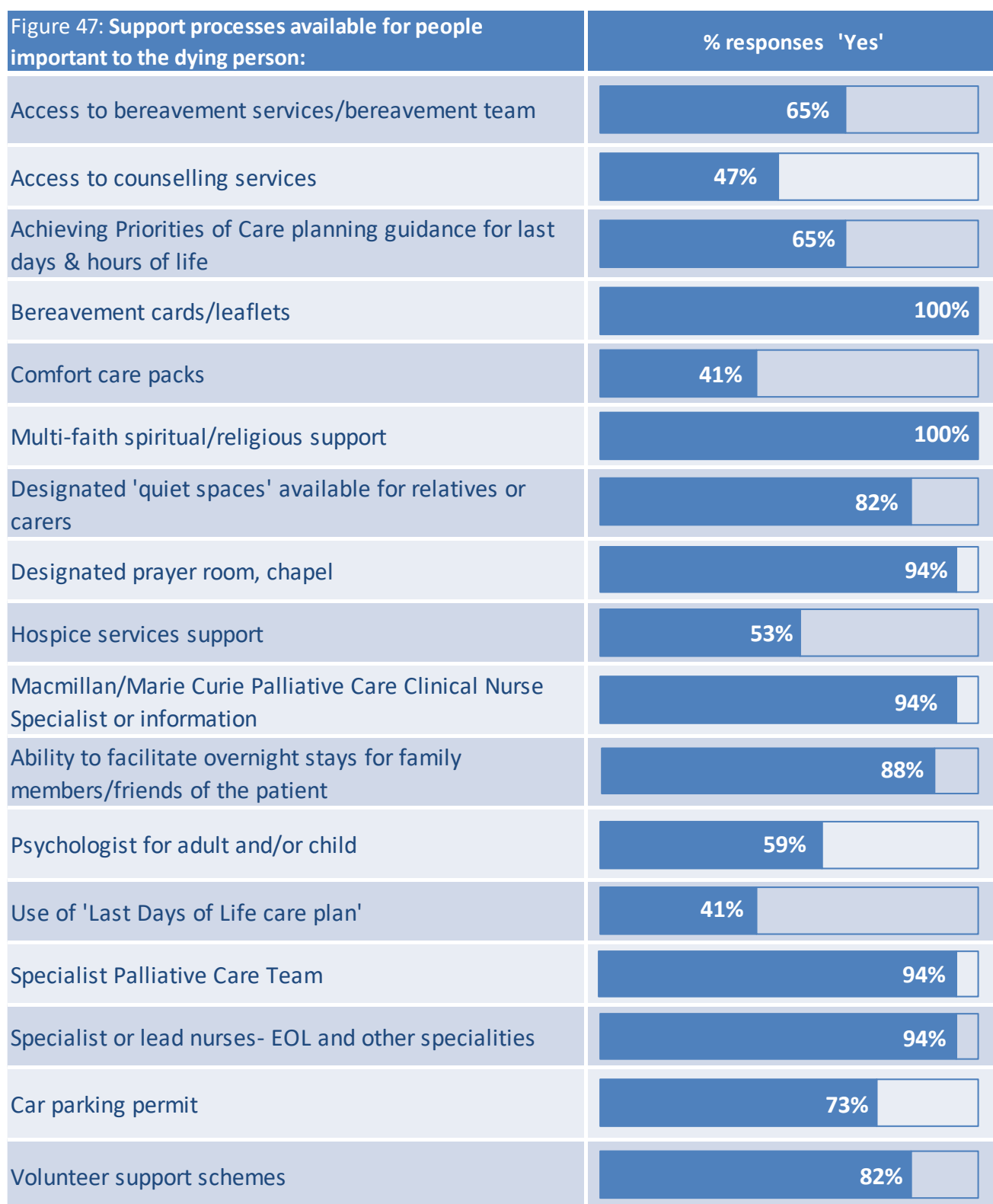


Figure 46: Written support provided to those important to the patient:



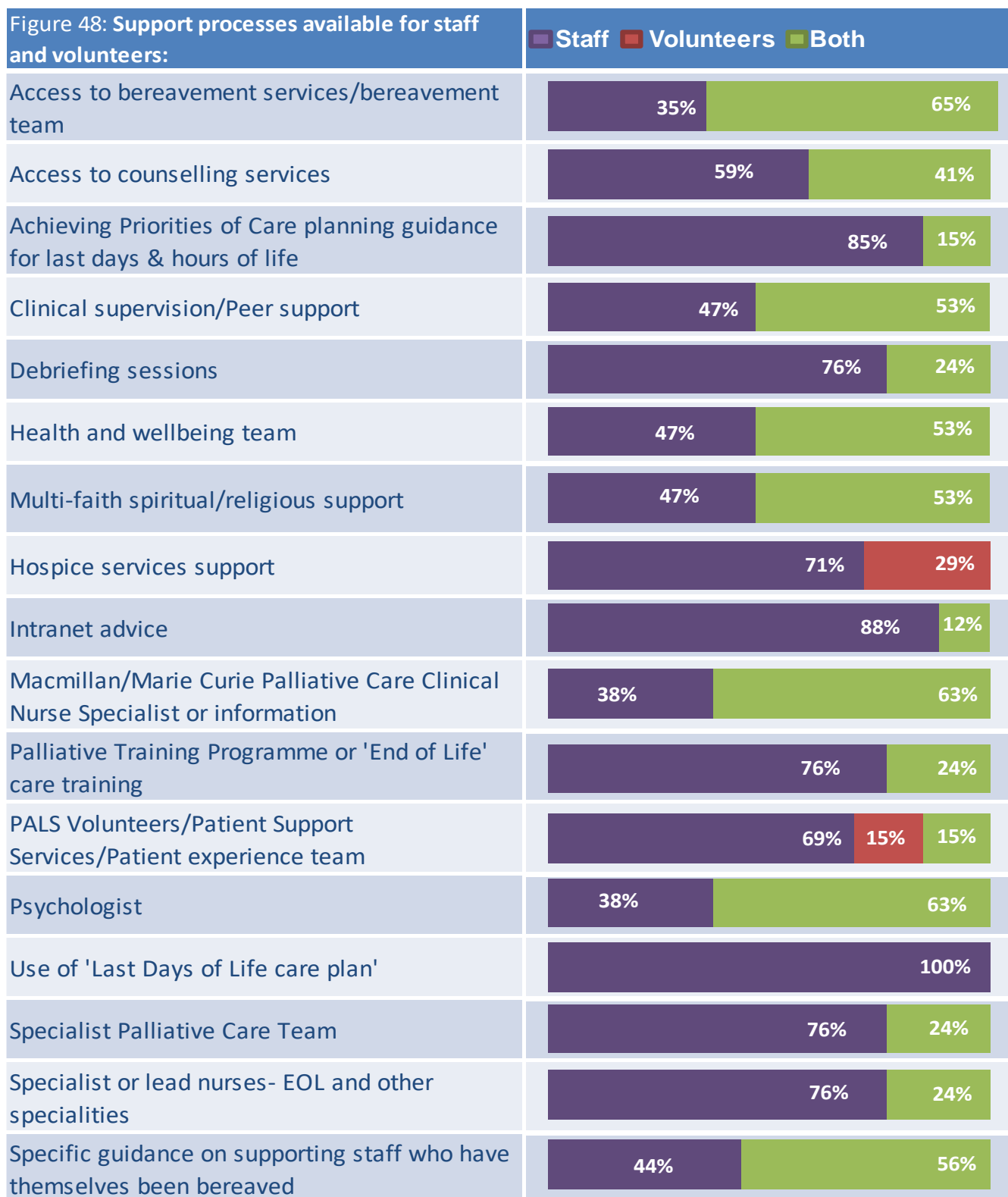
6.3 Quality and outcomes (Acute & Community)

Support processes – friends/family



6.3 Quality and outcomes (Acute & Community)

Support processes – staff/volunteers



7. Key findings - Mental health submissions

Participation

There were 8 mental health submissions in total. Different questions were asked of the mental health providers to reflect the different nature of care. There were a total of 619 designated mental health beds in Northern Ireland at the time of NACEL. By far and away the biggest proportion of these were adult acute beds, followed by older adult acute beds. Within the mental health bed cohort, around half of the capacity is available as a single patient occupancy room.

Deaths in mental health facilities

There were 8 deaths per 100 mental health beds in Northern Ireland, with significant variation noted – from 1 to 33 deaths per 100 beds. Half of the deaths in mental health facilities occurred in older person acute beds.

Specialist palliative care workforce

With reference to the specialist palliative care workforce available to the mental health providers, just over a third (38%) reported they were provided by the same organisation/hospital. The most common model of provision was access to specialist palliative care teams from outside of the hospital. End of Life Facilitators (or their Northern Ireland equivalent) were available in half of the mental health facilities. Access to the specialist palliative care team, in line with regional recommendations, should be available 24/7. It was reported that for both doctors and nursing staff, face-to-face availability was 9–5, Mondays to Fridays only in 80% of respondents. When the availability by telephone was taken into consideration, 12% of the mental health providers reported that doctors were available 24 hours per day, 7 days per week.

In terms of training resources available for staff, the following was reported in relation to the mental health providers:-

- 60% covered end of life training in induction programmes
- 20% included end of life training in mandatory/priority training
- 20% used eELCA to support staff training, and
- 100% of providers included training to improve communication skills.

Trust board engagement

It is important that the trust board engages with and listens to how end of life care is being delivered within their organisation. 63% of mental health providers reported that an action plan had been produced to promote improvement in end of life care. This action plan was fed back to clinicians in three-quarters (75%) of mental health providers and 100% fed back to the trust board. 100% of mental health providers reported having some form of carer/public representation within these reporting processes. 88% of mental health providers report seeking bereaved relatives/friends views during the last 2 financial years. A third use a local survey whilst two-thirds report using VOICES.

Availability of resources

When considering resources available to friends/family of the bereaved person, there was high (100%) compliance with the use of designated quiet spaces and specialist or information available regarding Macmillan/Marie Cure support. Only 13% of mental health providers reported having some form of comfort care pack and less than half (43%) reported having the use of a last days of life care plan. However, 88% reported having access to multi-faith spiritual/religious support, and 71% reported having the facility for friends and family to stay overnight.

50% of mental health providers reported having access to bereavement services for both staff and volunteers, and access to a psychologist. 57% of mental health providers report they have guidance available for supporting staff and volunteers who themselves have been bereaved.

7.1 Service models (Mental health)

Beds

Figure 49: Average number of beds

Bed type	Regional
Mental health adult acute ward	51
Mental health older persons acute ward	25
Mental health rehabilitation ward	10
Psychiatric intensive care ward	8
Mental health forensic ward (any level)	15
Mental Health continuing care / long-term complex needs ward	18
Eating disorder ward	0
Other Mental Health hospital location	12
LD Forensic – all categories	9
LD acute admission	12
LD Complex continuing care and rehabilitation	16
Other LD service location	0

Figure 50: Bed type profile (%)

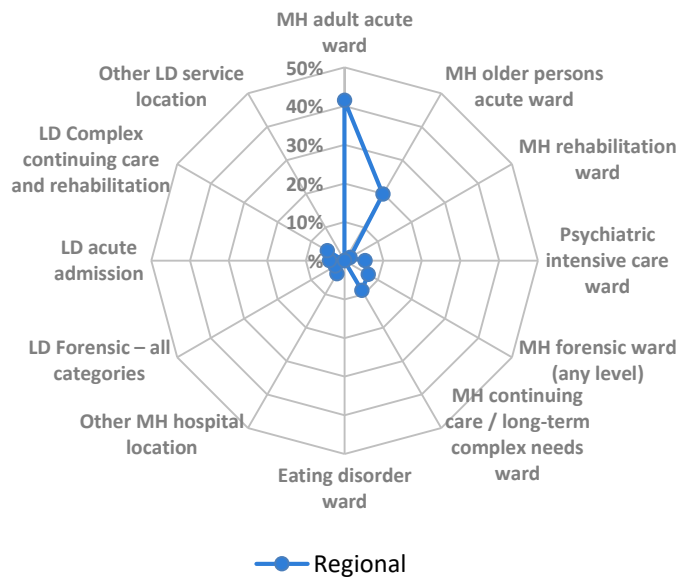


Figure 51: Total number of beds 2017/18

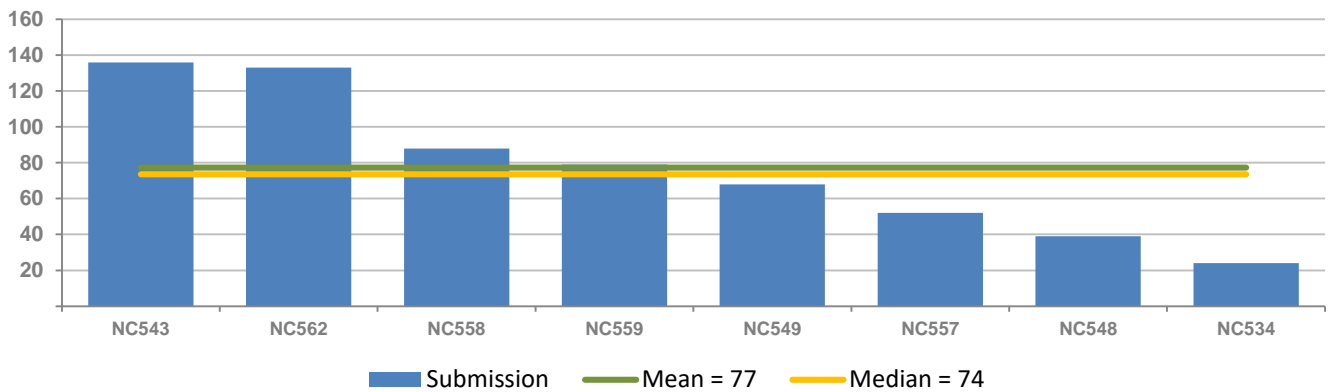
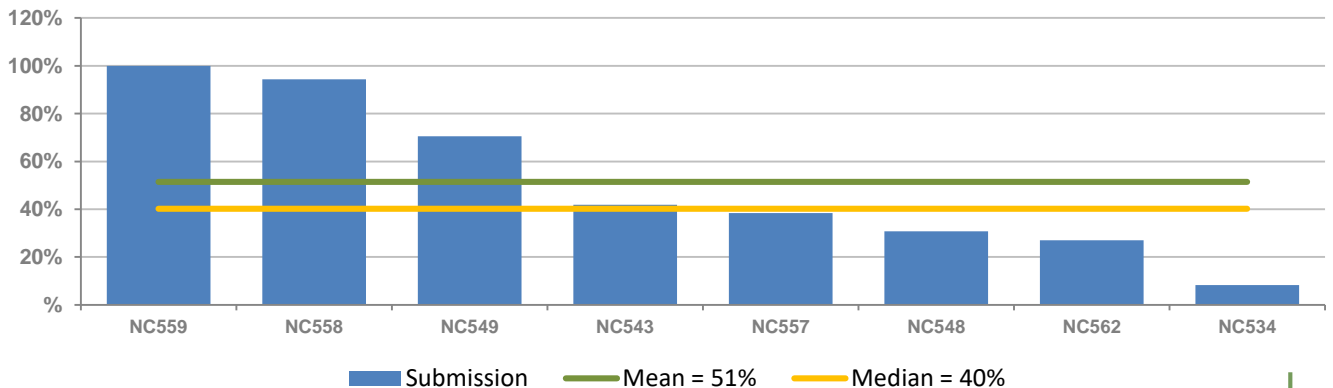


Figure 52: Adult single patient occupancy rooms as a % of total beds



7.1 Service models (Mental health)

Deaths

Figure 53: Total number of deaths per 100 beds 2017/18

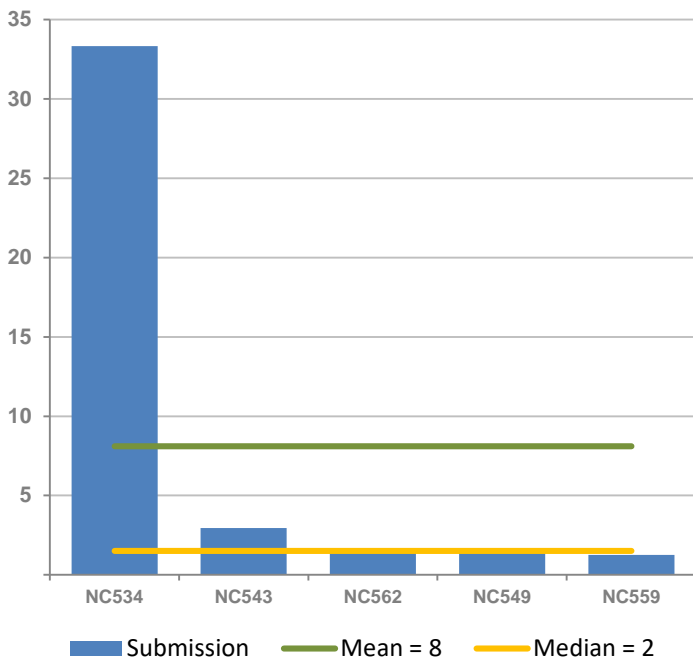
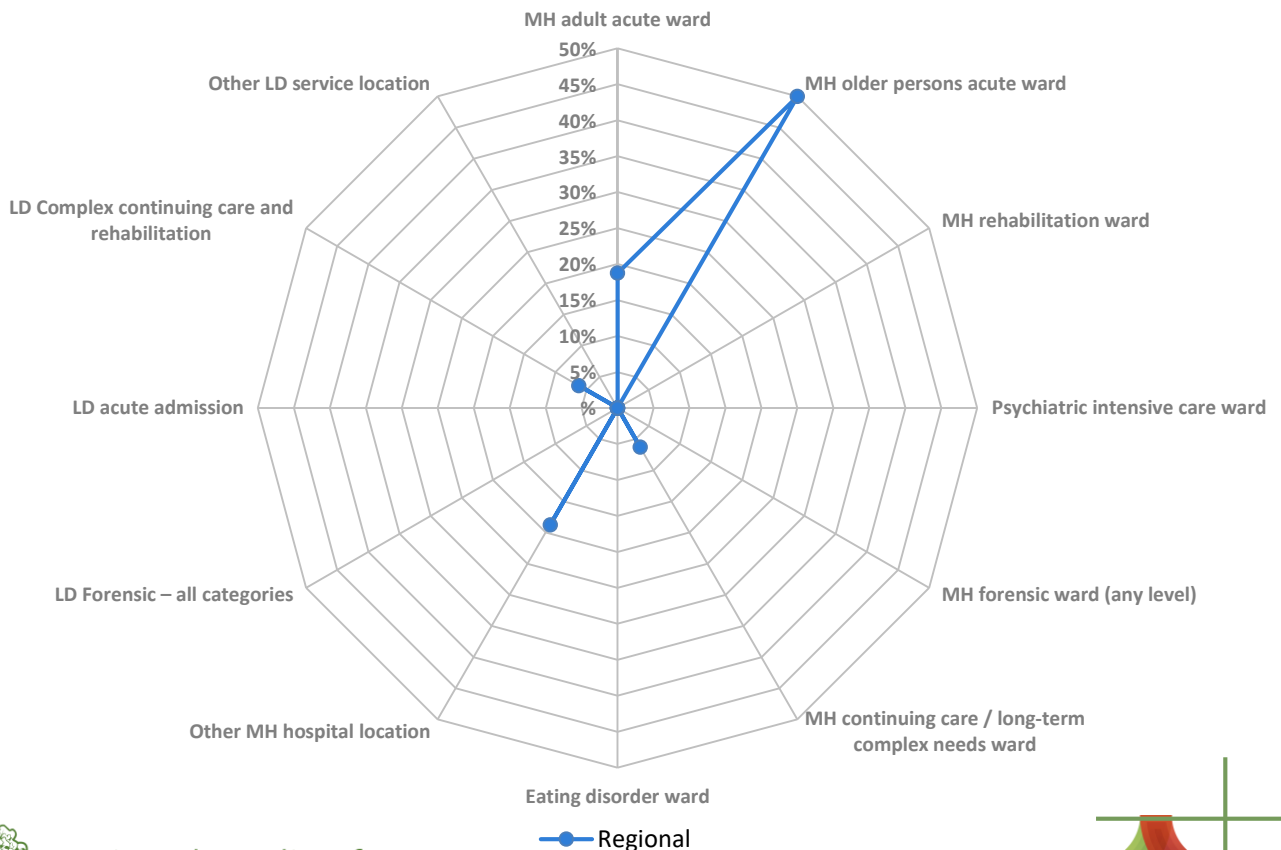


Figure 54: Average number of deaths

Bed type	Regional
Mental health adult acute	3.0
Mental health older persons acute	8.0
Mental health rehab	0.0
Psychiatric intensive care	0.0
Mental health forensic	0.0
Mental Health continuing care / long-term complex needs	1.0
Eating disorder	0.0
Other Mental Health hospital location	3.0
LD Forensic – all categories	0.0
LD acute admission	0.0
LD Complex continuing care and rehabilitation	1.0
Other LD service location	0.0

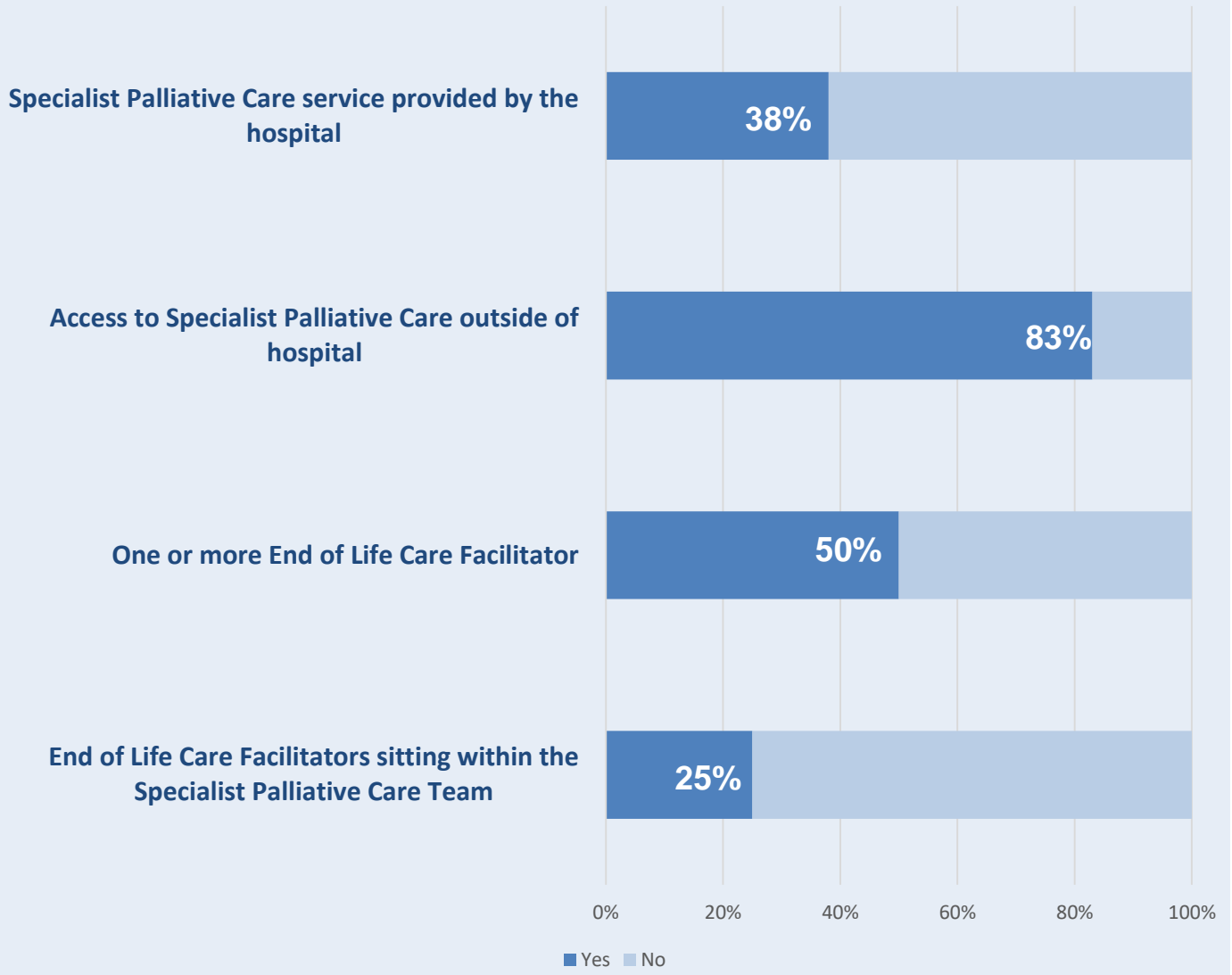
Figure 55: % deaths by bed type



7.2 Workforce (Mental health)

Specialist Palliative Care Team - Access

Figure 56: Does your hospital have:

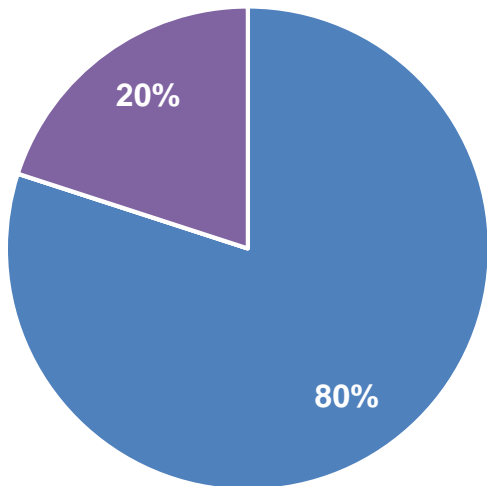


7.2 Workforce (Mental health)

Specialist Palliative Care Team - Availability



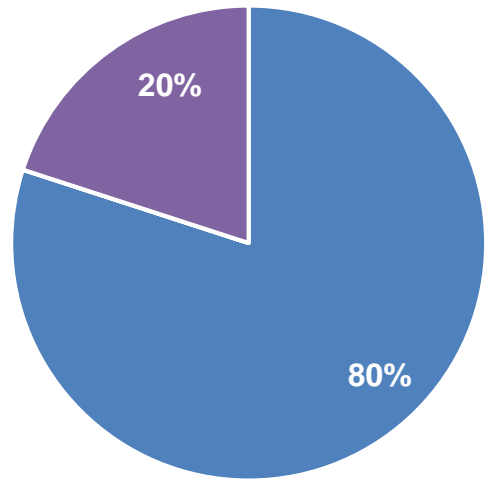
Figure 57: Face to face availability - Doctor



- 9-5, Monday to Friday only
- 9-5, Monday to Saturday only
- 9-5, 7 days a week
- Other



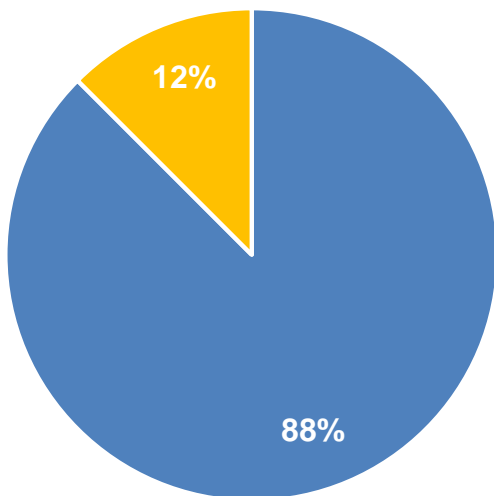
Figure 58: Face to face availability - Nurse



- 9-5, Monday to Friday only
- 9-5, Monday to Saturday only
- 9-5, 7 days a week
- Other



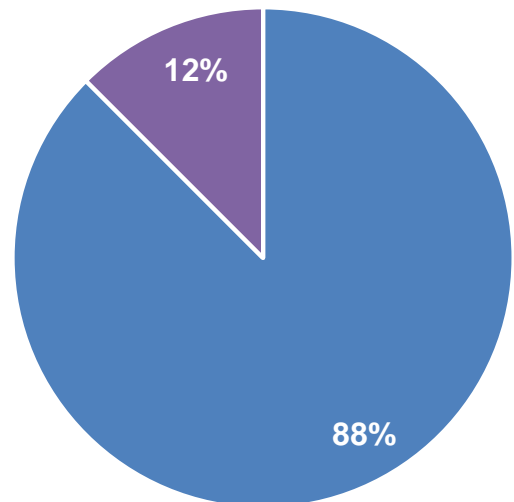
Figure 59: Telephone availability - Doctor



- 9-5, Monday to Friday only
- 9-5, Monday to Saturday only
- 9-5, 7 days a week
- 24 hours per day, 7 days a week
- Other



Figure 60: Telephone availability - Nurse



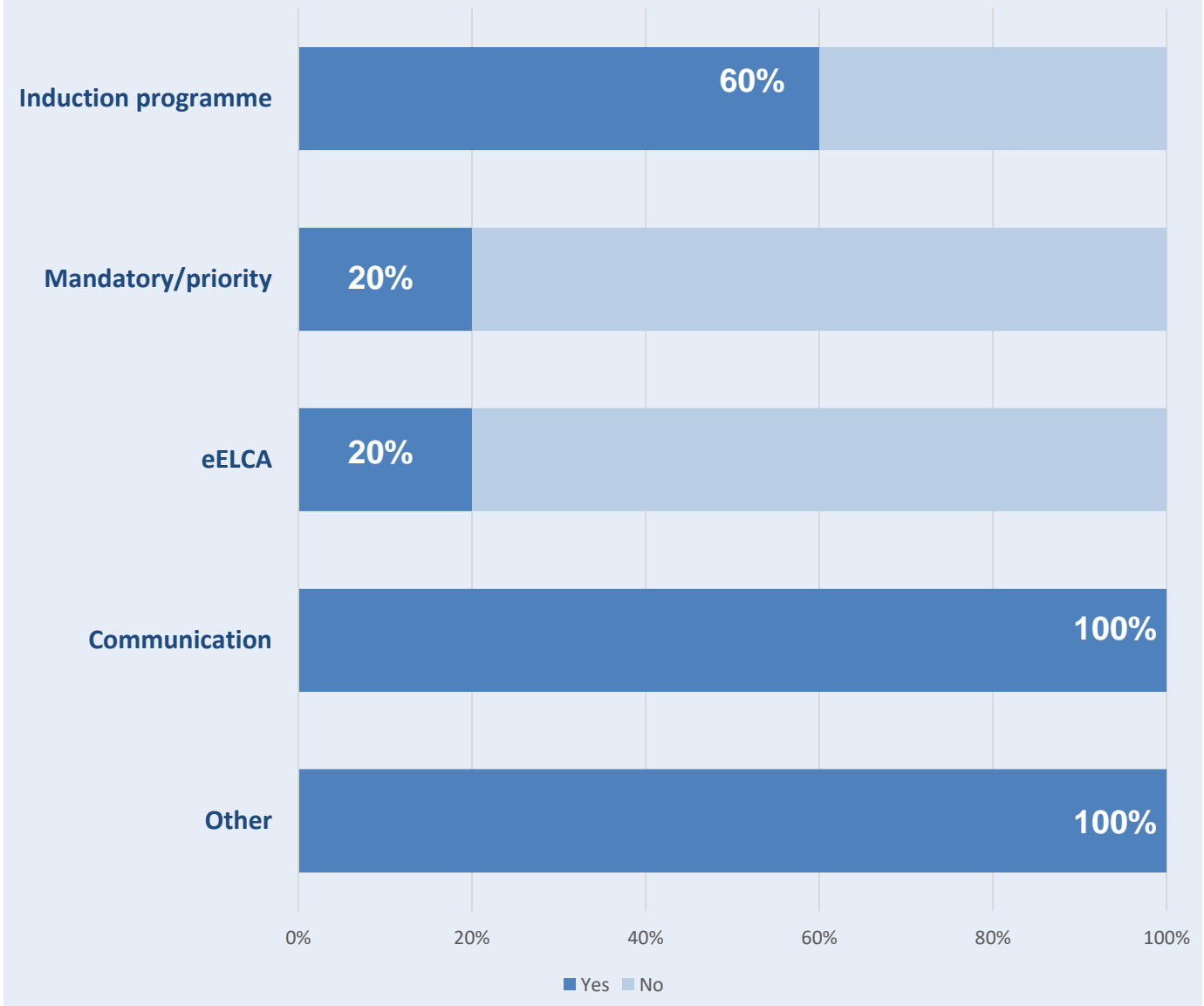
- 9-5, Monday to Friday only
- 9-5, Monday to Saturday only
- 9-5, 7 days a week
- 24 hours per day, 7 days a week
- Other



7.3 Workforce (Mental health)

Training

Figure 61: In the period between 1st April 2017 and 31st March 2018 what continuing End of Life education and training was available:



7.3 Quality and outcomes (Mental health)

EoLC board level reporting

Figure 62: % of hospitals produced an action plan to promote improvement in End of Life Care

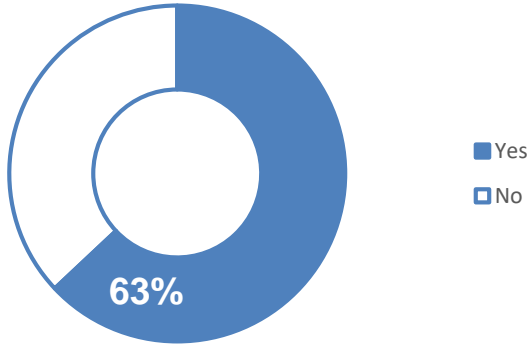


Figure 63: % of hospitals who fed back this action plan to clinical teams

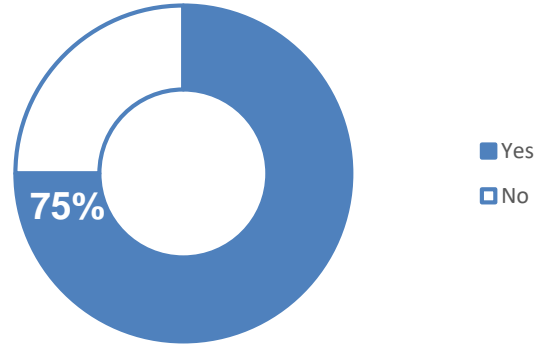


Figure 64: % of hospitals who fed back this action plan to trust board

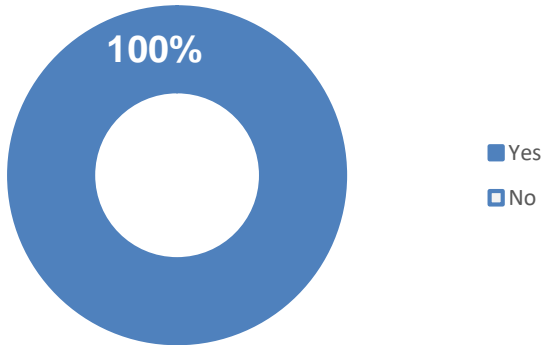


Figure 65: % of hospitals where End of Life Care was reported on at trust level between April 2017 and March 2018

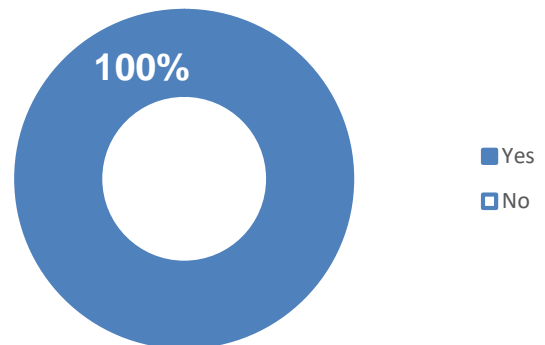
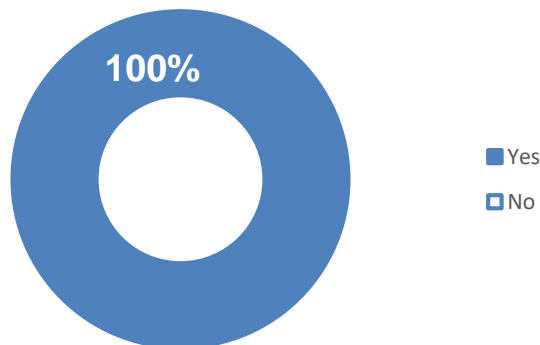


Figure 66: % of hospitals with carer and public representation within these discussions/ reporting processes



7.3 Quality and outcomes (Mental health)

Engagement with bereaved relatives/friends

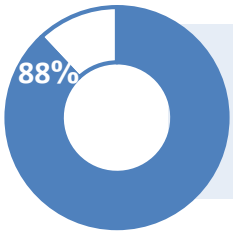


Figure 67: % of hospitals who sought bereaved relatives' or friends' views during the last two financial years

Figure 68: % of hospitals/sites who used feedback survey

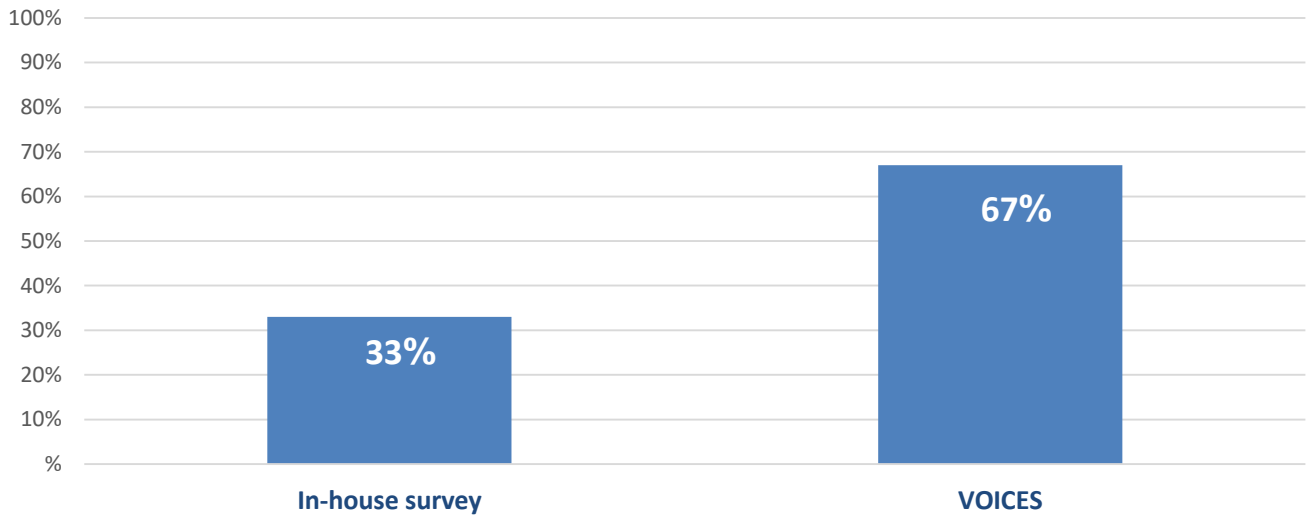
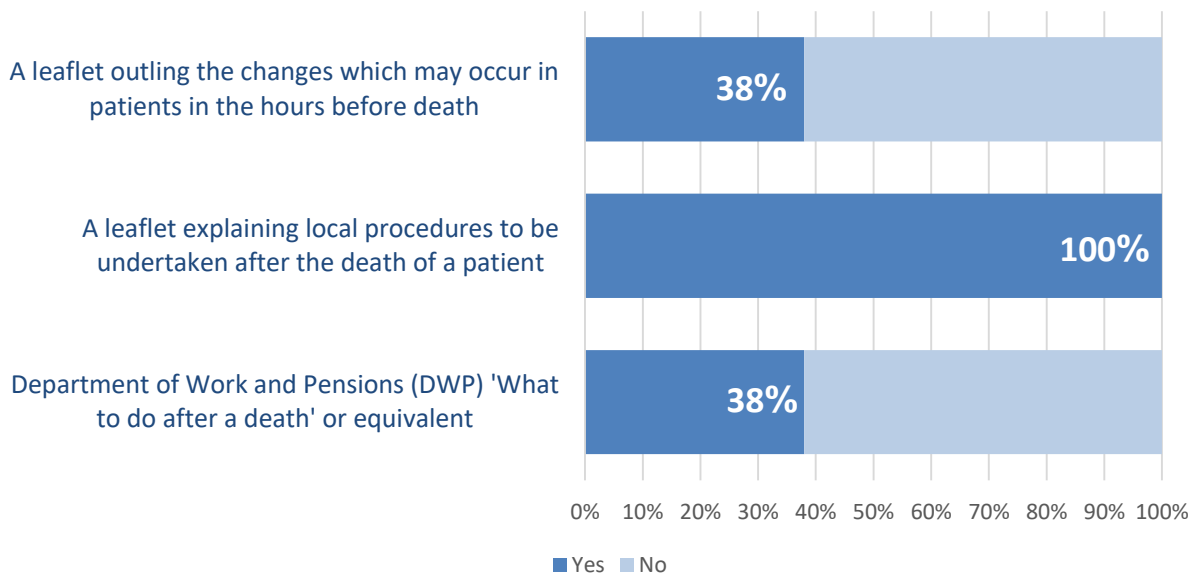
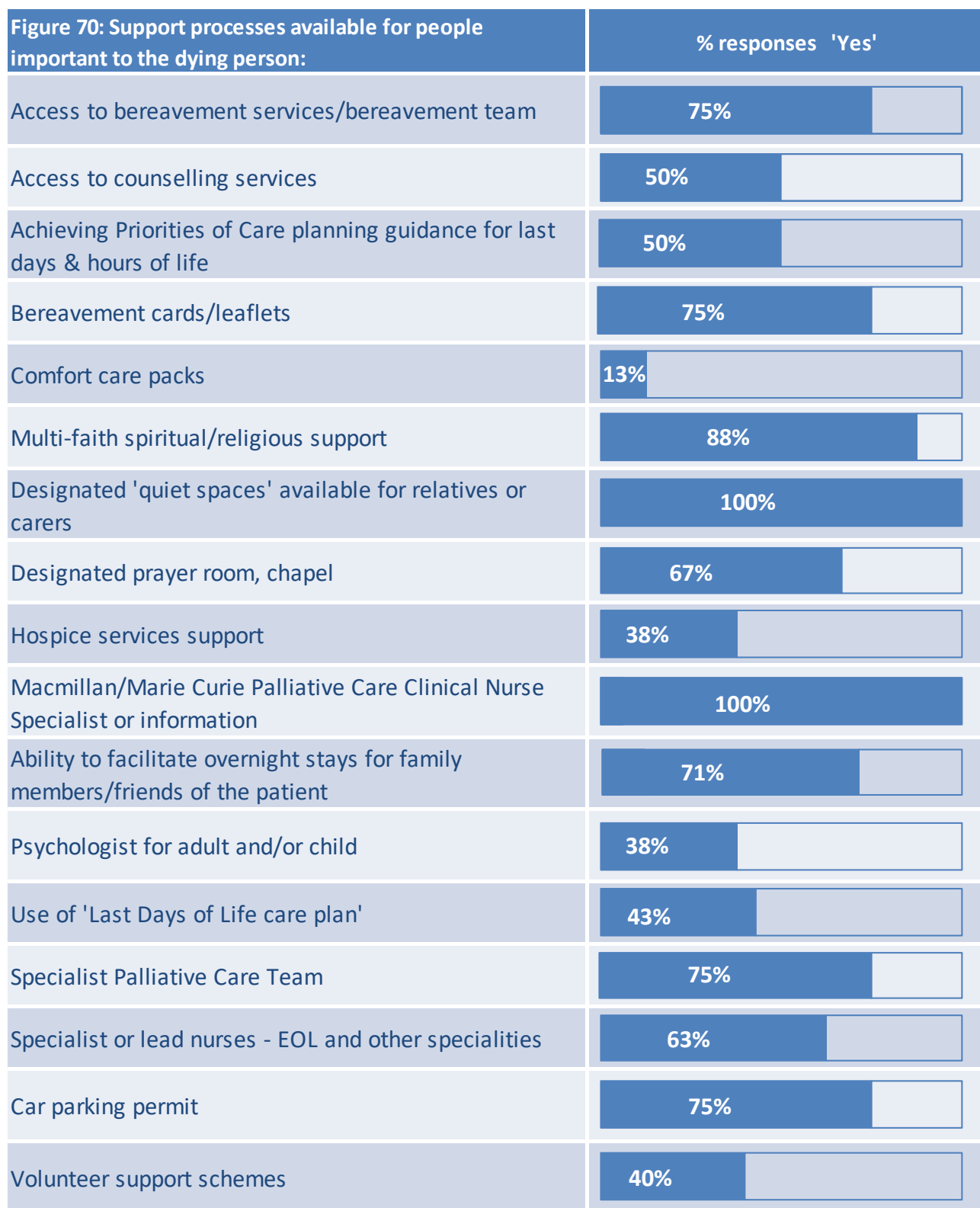


Figure 69: Written support provided to those important to the patient:



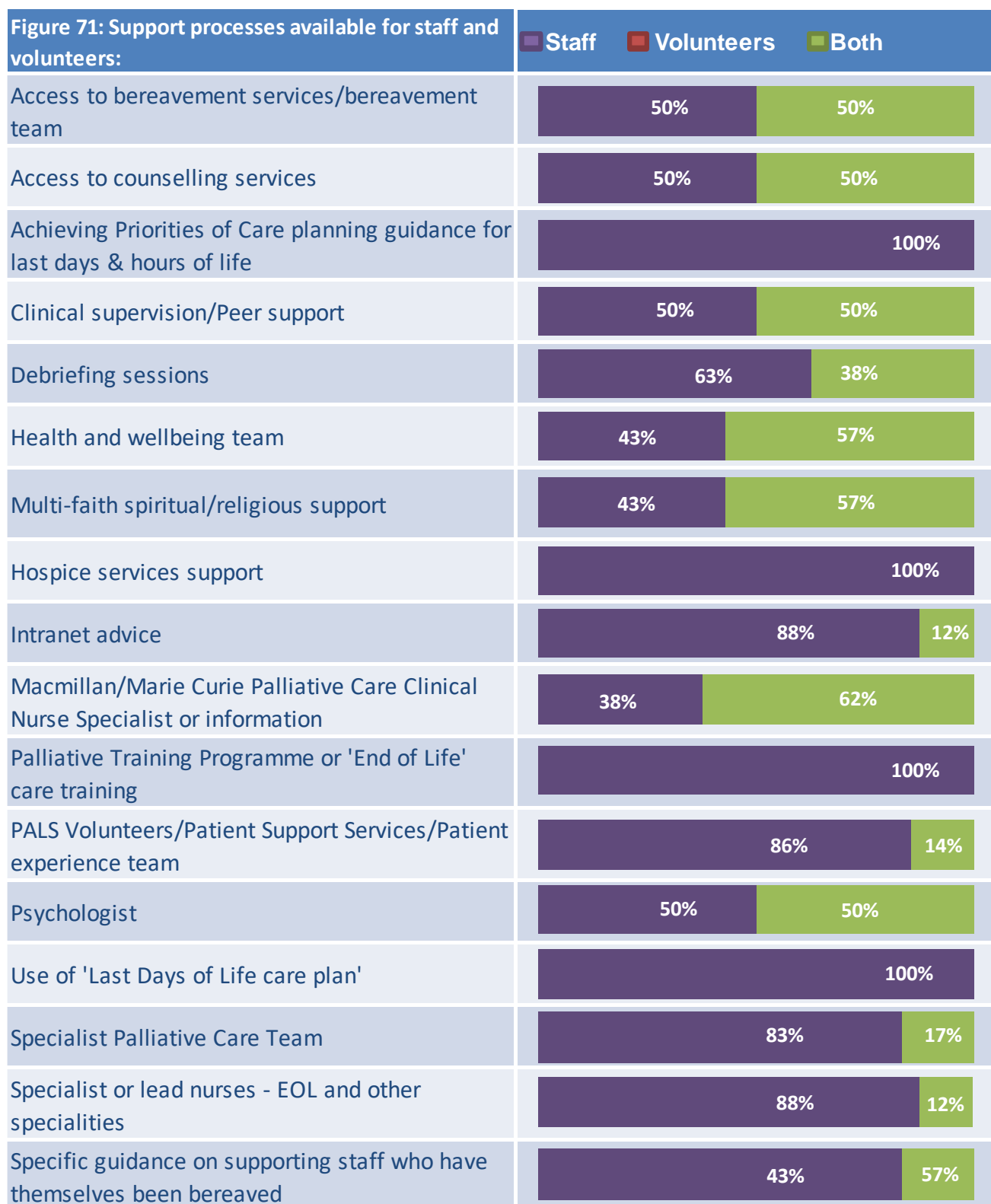
7.3 Quality and outcomes (Mental health)

Support processes – friends/family



7.3 Quality and outcomes (Mental health)

Support processes – staff/volunteers



8. Recommendations

1. **Ensure that all resources which have been/are available by the Regional Palliative Care in Partnership Programme are being utilised locally in Health and Social Care Trusts.**
2. **Promote the use of practices and methodologies such as Schwartz Rounds to ensure staff involved in the care of the dying feel emotionally supported.**
3. **Ensure that HSCTs consider the allocation of side rooms for people who are dying, if this is their wish, wherever possible.**
4. **Explore the options to ensure access to specialist palliative care teams during out of hours periods.**
5. **Palliative Care Locality Boards should ensure engagement, inclusion and implementation of regional and locality activities within Mental Health sites within each HSCT's organisational remit.**
6. **Ensure that all HSCTs have guidelines in place which indicate clearly the time taken to notify the patient's GP of the patient's death.**

9. Conclusion and next steps

This is the first iteration of the report outlining the key findings for Northern Ireland following participation in NACEL. This report gives an overview of how far Health and Social Care Trusts are progressing towards the **Five priorities for care** as outlined in **One Chance To Get It Right** and the **NICE Quality Standards QS13 and QS144**. Of key importance within the Northern Ireland setting is the palliative and end of life strategy and subsequent action plan as set out in **Living Matters, Dying Matters** and the five principles developed following the publication of the Department of Health circular HSS(MD) 21/2014.

This Summary Report consolidates the results of the first round of NACEL for the Northern Ireland cohort for the organisational level audit only.

The full results for all of the indicators of the organisational level audit included in NACEL this year can be found in the NACEL online toolkit accessible in the members' area of the Network website. If you require a log-in for the members' area, or any other assistance, please contact Joylin.brockett@nhs.net

A Northern Ireland NACEL Feedback Event was held on Wednesday 27th March 2019 in Newtownabbey. Attendance was by invitation only. The stakeholders invited to the Feedback Event considered the Northern Ireland findings and contributed to the formulation of the Northern Ireland recommendations on page 42.

The Northern Ireland Summary Report and recommendations was published following the Northern Ireland NACEL Feedback Event, along with bespoke dashboards for each HSCT setting out their local results. The online toolkit is also available and both should be reviewed by HSCTs to assist with the development of regional/local action plans, in line with the PCIP work plan.

Second round of the audit

The second round of the audit will take place in 2019. As in the first round, the audit will include an organisational level audit, case note review and NACEL Quality Survey. The scope and content of each of the components is currently under discussion with the Steering Group, however, it is likely that:

- The definition of deaths will be as for the first round of NACEL, to ensure comparability.
- The content of the organisational level and case note review will be reduced significantly to reduce the data burden for participants.
- The number of case notes to be reviewed will be reduced.
- The timescales will be as for the first round of NACEL, with minor amendments to allow a greater number of Quality Surveys to be collected.
- Mental health providers will not be required to submit data for the second round of the audit.
- The Northern Ireland cohort will participate in all elements of NACEL for the second round of the audit.

The NHSBN team will be contacting Northern Ireland participants after the 27th March 2019 event, with more information about the second round of NACEL.

10. References

The Leadership Alliance for the Care of Dying People. *One Chance to Get it Right. Improving people's experience of care in the last few days and hours of life.* June 2014

NICE. Guideline NG31, *Care of dying adults in the last days of life.* 2015

NICE. Quality Standard 13, *End of life care for adults.* November 2011

NICE. Quality Standard 144, *Care of dying adults in the last days of life.* March 2017

Department of Health. HSS(MD) 21/2014 - *Advice To Health And Social Care Professionals For The Care Of The Dying Person In The Final Days And Hours Of Life – Phasing Out Of The Liverpool Care Pathway In Northern Ireland By 31 October 2014.* 2014

DHSSP. *Transforming Your Care.* 2011

HSC Annual Commissioning Plans

DHSSP. *Living Matters Dying Matters.* 2010

RQIA. *Review of the Implementation of the Palliative and End of Life Care Strategy.* 2016

HSC Advance Care Planning Summary. V9.6.15

Macmillan Cancer Support & the Public Health Agency. *Your Life Your Choices.*

NCHSPCS. *Breaking Bad News. Regional Guidelines.* 2003

PHA/HSCB. *10,000 Voices Initiative.* 2015

Lets talk About https://aiihpc.org/our_work/policy-practice/lets-talk-about/

Appendix 1: Audit participants & submissions

Organisation	Submission	Submission type
Belfast Health and Social Care Trust	Belfast Health and Social Care Trust - Belfast City Hospital	Acute
Belfast Health and Social Care Trust	Belfast Health and Social Care Trust - Knockbracken Healthcare Park	Mental Health
Belfast Health and Social Care Trust	Belfast Health and Social Care Trust - Mater Hospital (Excluding Mental Health Wards)	Acute
Belfast Health and Social Care Trust	Belfast Health and Social Care Trust - Mater Hospital (Mental Health Wards)	Mental Health
Belfast Health and Social Care Trust	Belfast Health and Social Care Trust - Muckamore Abbey Hospital	Mental Health
Belfast Health and Social Care Trust	Belfast Health and Social Care Trust - Musgrave Park Hospital	Acute
Belfast Health and Social Care Trust	Belfast Health and Social Care Trust - Royal Victoria Hospital	Acute
Belfast Health and Social Care Trust	Belfast Health and Social Care Trust - The Cancer Centre	Acute
Northern Health and Social Care Trust	Northern Health and Social Care Trust - Antrim Area Hospital	Acute
Northern Health and Social Care Trust	Northern Health and Social Care Trust - Causeway Hospital	Acute
Northern Health and Social Care Trust	Northern Health and Social Care Trust - Community Hospitals	Community
Northern Health and Social Care Trust	Northern Health and Social Care Trust - Mental Health	Mental Health
South Eastern Health and Social Care Trust	South Eastern Health and Social Care Trust – Lagan Valley and Downe Hospitals	Acute
South Eastern Health and Social Care Trust	South Eastern Health and Social Care Trust – MH	Mental Health
South Eastern Health and Social Care Trust	South Eastern Health and Social Care Trust – Ulster Hospital	Acute
Southern Health and Social Care Trust	Craigavan Area Hospital	Acute
Southern Health and Social Care Trust	Daisy Hill Hospital	Acute
Southern Health and Social Care Trust	Gillis Memory Unit	Mental Health
Southern Health and Social Care Trust	Lurgan and South Tyrone Hospitals	Community
Western Health and Social Care Trust	Western Health and Social Care Trust - Altnagelvin Hospital	Acute
Western Health and Social Care Trust	Western Health and Social Care Trust - Mental Health	Mental Health
Western Health and Social Care Trust	Western Health and Social Care Trust - Older People's Mental Health	Mental Health
Western Health and Social Care Trust	Western Health and Social Care Trust - Omagh Hospital and Primary Care Complex	Community
Western Health and Social Care Trust	Western Health and Social Care Trust - South West Acute Hospital	Acute
Western Health and Social Care Trust	Western Health and Social Care Trust - Waterside Hospital	Community

Appendix 2: Indicators used in the report (Trust)

Page/ Figure	Chart title	Response	Regional	Regional n=
p14	Does your trust have:			
p14, 1	An identified member of the trust board with a responsibility/role for End of Life Care?	Yes	100%	5
		No	0%	0
		Total		5
p14, 2	A lay member on the trust board with a responsibility/role for End of Life Care?	Yes	40%	2
		No	60%	3
		Total		5
p14, 3	A non-executive director with responsibility for End of Life Care?	Yes	20%	1
		No	80%	4
		Total		5
p14, 4	Representation on a local or regional End of Life Care group/network	Yes	100%	5
		No	0%	0
		Total		5
p15	Does your trust have policies in place which include:			
p15, 5	how it responds to and learns from, deaths of patients who die under its management and care	Yes	100%	5
		No	0%	0
		Total		5
p15, 5	the approach to undertaking case note reviews	Yes	100%	5
		No	0%	0
		Total		5
p15, 5	guidelines for referral to 'Pastoral care/Chaplaincy team'	Yes	60%	3
		No	40%	2
		Total		5
p15, 5	guidelines to promote dignity	Yes	80%	4
		No	20%	1
		Total		5
p15, 5	how to document a cardiopulmonary resuscitation decision	Yes	100%	5
		No	0%	0
		Total		5
p15, 5	the deactivation of 'Implantable Cardioverter Defibrillators' (ICDs)	Yes	80%	4
		No	20%	1
		Total		5
p15, 5	a care after death and bereavement policy	Yes	80%	4
		No	20%	1
		Total		5

Appendix 2: Indicators used in the report (Trust)

Page/ Figure	Chart title	Response	Regional	Regional n=
p15, 5	guidelines for carrying out care of the body in the immediate time after the death of a patient	Yes	80%	4
		No	20%	1
		Total		5
p15, 5	guidelines for providing relatives/carers with verification and certification of the death	Yes	100%	5
		No	0%	0
		Total		5
p15, 5	guidelines for meaningful and compassionate engagement with bereaved families and carers	Yes	80%	4
		No	20%	1
		Total		5
p15, 5	guidelines for viewing the body in the immediate time after the death of a patient	Yes	100%	5
		No	0%	0
		Total		5
p15, 5	guidelines for the time taken to notify the patient's GP of the patient's death	Yes	60%	3
		No	40%	2
		Total		5
p15, 5	the transfer of patients who are at the end of life into a local acute/community trust	Yes	50%	2
		No	50%	2
		Total		4
p16	Which of the following are used within your trust:			
p16, 6	Advance Care Planning (ACP) process, specifically a framework to record a patient's wishes and preferences for care at the end of life	Yes	80%	4
		No	20%	1
		Total		5
p16, 7	Electronic Palliative Care Co-ordination System (EPaCCS)	Yes	60%	3
		No	40%	2
		Total		5
p16, 8	Tools/prompts to recognise and provide palliative care for patients whose recovery is uncertain (e.g. AMBER Care Bundle)	Yes	100%	5
		No	0%	0
		Total		5
p16, 9	Specific care arrangements to enable rapid discharge home to die, if this is the person's preference	Yes	100%	5
		No	0%	0
		Total		5
p16, 10	Processes to create personalised recommendations for a person's clinical care in a future emergency (e.g. ReSPECT)	Yes	100%	5
		No	0%	0
		Total		5

Appendix 2: Indicators used in the report (Trust)

Page/ Figure	Chart title	Response	Regional	Regional n=
p16	Which of the following are used within your trust:			
p16, 11	Tools/prompts to plan the care of those patients thought to be in the last months of life (e.g. Gold Standard Framework)	Yes	100%	5
		No	0%	0
		Total		5
p16, 12	Opportunities for staff to reflect on the emotional aspects of their work (e.g. Schwartz rounds)	Yes	60%	3
		No	40%	2
		Total		5
p16, 13	Locally developed programmes of work to improve and support End of Life Care	Yes	100%	5
		No	0%	0
		Total		5
p17	Guidance for the prescription of medications for patients in the last hours/days with:			
p17, 14	Agitation/delirium	Yes	100%	5
		No	0%	0
		Total		5
p17, 14	Dyspnoea/breathing difficulty	Yes	100%	5
		No	0%	0
		Total		5
p17, 14	Nausea/Vomiting	Yes	100%	5
		No	0%	0
		Total		5
p17, 14	Pain	Yes	100%	5
		No	0%	0
		Total		5
p17, 14	Noisy breathing/death rattle	Yes	100%	5
		No	0%	0
		Total		5

Appendix 2: Indicators used in the report (Acute and Community)

Page/ Figure	Chart title	Response	Regional	Regional n=
p20, 15	Average number of beds - Acute assessment	-	82	10
p20, 15	Average number of beds - Acute medical admissions	-	32	9
p20, 15	Average number of beds - Rehabilitation	-	28	11
p20, 15	Average number of beds - Oncology	-	11	7
p20, 15	Average number of beds - Cardiology	-	21	12
p20, 15	Average number of beds - Respiratory	-	28	11
p20, 15	Average number of beds - Renal	-	3	7
p20, 15	Average number of beds - Care of the elderly	-	31	12
p20, 15	Average number of beds - Specialist palliative care	-	3	7
p20, 15	Average number of beds - Trauma	-	24	8
p20, 15	Average number of beds - Neurological	-	12	8
p20, 15	Average number of beds - Orthopaedics	-	20	7
p20, 15	Average number of beds - Intensive care	-	10	11
p20, 15	Average number of beds - Other hospital	-	111	7
p20, 16	Bed type % split - Acute assessment ward	-	21.8%	10
p20, 16	Bed type % split - Acute medical admissions ward	-	7.5%	9
p20, 16	Bed type % split - Rehabilitation ward	-	8.0%	11
p20, 16	Bed type % split - Oncology ward	-	2.1%	7
p20, 16	Bed type % split - Cardiology ward	-	6.7%	12
p20, 16	Bed type % split - Respiratory ward	-	8.0%	11
p20, 16	Bed type % split - Renal ward	-	0.6%	7
p20, 16	Bed type % split - Care of the elderly ward	-	9.9%	12
p20, 16	Bed type % split - Specialist palliative care ward	-	0.5%	7
p20, 16	Bed type % split - Trauma ward	-	5.1%	8
p20, 16	Bed type % split - Neurological ward	-	2.6%	8
p20, 16	Bed type % split - Orthopaedics ward	-	3.6%	7
p20, 16	Bed type % split - Intensive care	-	2.9%	11
p20, 16	Bed type % split - Other hospital location	-	20.6%	7
p20, 17	Total number of beds 2017/18	-	222	17
p20, 18	Adult single patient occupancy rooms as a % of total beds	-	45.5%	13
p21, 19	Total number of deaths per 100 beds 2017/18	-	160	17
p21, 20	Number of deaths in A&E as a % of total deaths	-	5%	9

Appendix 2: Indicators used in the report (Acute and Community)

Page/ Figure	Chart title	Response	Regional	Regional n=
p21, 21	% deaths by bed type/location - Acute assessment	-	11.0%	12
p21, 21	% deaths by bed type/location - Acute medical admissions	-	7.8%	13
p21, 21	% deaths by bed type/location - Rehabilitation	-	3.3%	14
p21, 21	% deaths by bed type/location - Oncology	-	2.2%	11
p21, 21	% deaths by bed type/location - Cardiology	-	5.5%	14
p21, 21	% deaths by bed type/location - Respiratory	-	15.1%	13
p21, 21	% deaths by bed type/location - Renal	-	0.5%	10
p21, 21	% deaths by bed type/location - Care of the elderly	-	11.3%	14
p21, 21	% deaths by bed type/location - Specialist palliative care	-	3.7%	11
p21, 21	% deaths by bed type/location - Trauma	-	1.8%	12
p21, 21	% deaths by bed type/location - Neurological	-	0.2%	10
p21, 21	% deaths by bed type/location - Orthopaedics	-	0.0%	11
p21, 21	% deaths by bed type/location - Intensive care	-	8.8%	14
p21, 21	% deaths by bed type/location - Other hospital location	-	24.6%	13
p21, 21	% deaths by bed type/location - A&E	-	4.2%	14
p21, 22	Average number of deaths - Acute assessment	-	67	12
p21, 22	Average number of deaths - Acute medical admissions	-	44	13
p21, 22	Average number of deaths - Rehabilitation	-	17	14
p21, 22	Average number of deaths - Oncology	-	15	11
p21, 22	Average number of deaths - Cardiology	-	29	14
p21, 22	Average number of deaths - Respiratory	-	85	13
p21, 22	Average number of deaths - Renal	-	3	10
p21, 22	Average number of deaths - Care of the elderly	-	59	14
p21, 22	Average number of deaths - Specialist palliative	-	25	11
p21, 22	Average number of deaths - Trauma	-	11	12
p21, 22	Average number of deaths - Neurological	-	1	10
p21, 22	Average number of deaths - Orthopaedics	-	0	11
p21, 22	Average number of deaths - Intensive care	-	46	14
p21, 22	Average number of deaths - Other hospital	-	138	13
p21, 22	Average number of deaths - A&E	-	22	14
p21, 22	Average number of deaths - Total	-	429	17

Appendix 2: Indicators used in the report (Acute and Community)

Page/ Figure	Chart title	Response	Regional	Regional n=
p22, 23	Is there a Specialist Palliative Care service provided by the hospital?	Yes	88%	15
		No	12%	2
		Total		17
p22, 23	If not, does your hospital have access to a Specialist Palliative Care service funded and/or based outside of the hospital/site?	Yes	60%	3
		No	40%	2
		Total		5
p22, 23	Does your hospital have one or more End of Life Care Facilitators?	Yes	82%	14
		No	18%	3
		Total		17
p22, 23	If yes, does the End of Life Care Facilitator role sit within the Specialist Palliative Care team?	Yes	62.5%	8
		No	38.5%	5
		Total		13
p23, 24	Specialist Palliative Care workforce - Doctor availability - face to face	9-5, Mon - Fri	62.5%	10
		9-5 Mon - Sat	0.0%	0
		9-5, 7 days	0.0%	0
		Other	37.5%	6
		Total		16
p23, 25	Specialist Palliative Care workforce - Nurse availability - face to face	9-5, Mon - Fri	56%	9
		9-5 Mon - Sat	0%	0
		9-5, 7 days	0%	0
		Other	44%	7
		Total		16
p23, 26	Specialist Palliative Care workforce - Doctor availability - telephone	9-5, Mon - Fri	35%	6
		9-5 Mon - Sat	0%	0
		9-5, 7 days	0%	0
		24 hours, 7	18%	3
		Other	47%	8
		Total		17
p23, 27	Specialist Palliative Care workforce - Nurse availability - telephone	9-5, Mon - Fri	59%	10
		9-5 Mon - Sat	0%	0
		9-5, 7 days	0%	0
		24 hours, 7	0%	0
		Other	41%	7
		Total		17
p24, 28	Banding % - SPCT - Band 2	-	0%	0
p24, 28	Banding % - SPCT - Band 3	-	2%	1
p24, 28	Banding % - SPCT - Band 4	-	4%	3
p24, 28	Banding % - SPCT - Band 5	-	0%	0

Appendix 2: Indicators used in the report (Acute and Community)

Page/ Figure	Chart title	Response	Regional	Regional n=
p24, 28	Banding % - SPCT - Band 6	-	3.0%	1
p24, 28	Banding % - SPCT - Band 7	-	70.3%	14
p24, 28	Banding % - SPCT - Band 8a	-	3.0%	5
p24, 28	Banding % - SPCT - Band 8b	-	0.0%	0
p24, 28	Banding % - SPCT - Band 8c	-	0.0%	0
p24, 28	Banding % - SPCT - Band 8d	-	0.0%	0
p24, 28	Banding % - SPCT - Band 9	-	0.0%	0
p24, 28	Banding % - SPCT - Medical	-	18.1%	14
p24, 29	Discipline % - SPCT - Medical	-	18%	14
p24, 29	Discipline % - SPCT - Nursing	-	66%	13
p24, 29	Discipline % - SPCT - AHP	-	13%	3
p24, 29	Discipline % - SPCT - Other clinical	-	3%	4
p25, 30	Medical staff in the SPCT per 100 beds	-	6	14
p25, 31	Nursing staff in the SPCT per 100 beds	-	2	13
p25, 32	AHP staff in the SPCT per 100 beds	-	3	3
p25, 33	Other staff in the SPCT per 100 beds	-	0.2	4
p26, 34	Chaplaincy staff per 100 beds		1	15
p26, 35	End of Life Care Facilitators per 100 beds		1	7
p26, 36	End of Life Care Facilitators - % Patient facing time (Nursing staff)		17%	3
p26, 37	End of Life Care Facilitators - % Teacher/training facing time (Nursing staff)		53%	4
p27	In the period between 1st April 2017 and 31st March 2018 what continuing End of Life education and training was available:			
p27, 38	Induction programme	Yes	82%	14
		No	18%	3
		Total		17
p27, 38	Mandatory/priority Training	Yes	41%	7
		No	59%	10
		Total		17
p27, 38	eELCA resources to support staff training	Yes	25%	3
		No	75%	9
		Total		12
p27, 38	Training to help improve the culture, behaviours, attitudes around communication	Yes	100%	17
		No	0%	0
		Total		17
p27, 38	Other training	Yes	94%	16
		No	6%	1
		Total		17

Appendix 2: Indicators used in the report (Acute and Community)

Page/ Figure	Chart title	Response	Regional	Regional n=
p28, 39	Was an action plan produced in the financial year (i.e. between 1st April 2017 and 31st March 2018) to promote	Yes	100%	17
		No	0%	0
		Total		17
p28, 40	Was this action plan fed back to clinical teams?	Yes	100%	17
		No	0%	0
		Total		17
p28, 41	Was this action plan fed back to the trust board?	Yes	100%	17
		No	0%	0
		Total		17
p28, 42	Was End of Life Care reported on at trust board level	Yes	100%	17
		No	0%	0
		Total		17
p28, 43	Was there carer and public representation within these discussions/reporting processes?	Yes	100%	17
		No	0%	0
		Total		17
p29, 44	Did your hospital/site seek bereaved relatives' or friends' views during the last two financial years?	Yes	100%	17
		No	0%	0
		Total		17
p29	Type of feedback survey used:			
p29, 45	In-house survey	Yes	54.5%	6
		No	45.5%	5
		Total		11
p29, 45	VOICES	Yes	54%	7
		No	46%	6
		Total		13
p29	Written support provided to those important to the patient:			
p29, 46	A leaflet outlining the changes that may occur in patients in the hours before death?	Yes	82%	14
		No	18%	3
		Total		17
p29, 46	A leaflet explaining local procedures to be undertaken after the death of a patient?	Yes	100%	17
		No	0%	0
		Total		17
p29, 46	Department of Work and Pensions (DWP) leaflet 1027, 'What to Do After a Death in England and Wales' or equivalent?	Yes	53%	9
		No	47%	8
		Total		17

Appendix 2: Indicators used in the report (Acute and Community)

Page/ Figure	Chart title	Response	Regional	Regional n=
p30	Support processes available for people important to the dying person:			
p30, 47	Access to bereavement services/bereavement team	Yes	65%	11
		No	35%	6
		Total		17
p30, 47	Access to counselling services	Yes	47%	8
		No	53%	9
		Total		17
p30, 47	Achieving Priorities of Care planning guidance for last days & hours of life	Yes	65%	11
		No	35%	6
		Total		17
p30, 47	Bereavement cards/leaflets	Yes	100%	17
		No	0%	0
		Total		17
p30, 47	Comfort care packs	Yes	41%	7
		No	59%	10
		Total		17
p30, 47	Multi-faith spiritual/religious support	Yes	100%	17
		No	0%	0
		Total		17
p30, 47	Designated 'quiet spaces' available for relatives or carers	Yes	82%	14
		No	18%	3
		Total		17
p30, 47	Designated prayer room, chapel	Yes	94%	16
		No	6%	1
		Total		17
p30, 47	Hospice services support	Yes	53%	9
		No	47%	8
		Total		17
p30, 47	Macmillan/Marie Curie Palliative Care Clinical Nurse Specialist or information	Yes	94%	16
		No	6%	1
		Total		17
p30, 47	Ability to facilitate overnight stays for family members/friends of the patient	Yes	88%	15
		No	12%	2
		Total		17
p30, 47	Psychologist for adult and/or child	Yes	59%	10
		No	41%	7
		Total		17

Appendix 2: Indicators used in the report (Acute and Community)

Page/ Figure	Chart title	Response	Regional	Regional n=
p30	Support processes available for people important to the dying person:			
p30, 47	Use of 'Last Days of Life care plan'	Yes	41%	7
		No	59%	10
		Total		17
p30, 47	Specialist Palliative Care Team	Yes	94%	16
		No	6%	1
		Total		17
p30, 47	Specialist or lead nurses-EOL and other specialities	Yes	94%	16
		No	6%	1
		Total		17
p30, 47	Car parking permit	Yes	73%	11
		No	27%	4
		Total		15
p30, 47	Volunteer support schemes	Yes	82%	14
		No	18%	3
		Total		17
p31	Support processes available for staff and volunteers:			
p31, 48	Access to bereavement services/bereavement team	Staff	35%	6
		Volunteers	0%	0
		Both	65%	11
		Total		17
p31, 48	Access to counselling services	Staff	59%	10
		Volunteers	0%	0
		Both	41%	7
		Total		17
p31, 48	Achieving Priorities of Care planning guidance for last days & hours of life	Staff	85%	11
		Volunteers	0%	0
		Both	15%	2
		Total		13
p31, 48	Clinical supervision/Peer support	Staff	47%	8
		Volunteers	0%	0
		Both	53%	9
		Total		17
p31, 48	Debriefing sessions	Staff	76.5%	13
		Volunteers	0.0%	0
		Both	23.5%	4
		Total		17

Appendix 2: Indicators used in the report (Acute and Community)

Page/ Figure	Chart title	Response	Regional	Regional n=
p31	Support processes available for staff and volunteers:			
p31, 48	Health and wellbeing team	Staff	47%	8
		Volunteers	0%	0
		Both	53%	9
		Total		17
p31, 48	Multi-faith spiritual/religious support	Staff	47%	8
		Volunteers	0%	0
		Both	53%	9
		Total		17
p31, 48	Hospice services support	Staff	71%	5
		Volunteers	29%	2
		Both	0%	0
		Total		7
p31, 48	Intranet advice	Staff	88%	15
		Volunteers	0%	0
		Both	12%	2
		Total		17
p31, 48	Macmillan/Marie Curie Palliative Care Clinical Nurse Specialist or information	Staff	37.5%	6
		Volunteers	0.0%	0
		Both	62.5%	10
		Total		16
p31, 48	Palliative Training Programme or 'End of Life' care training	Staff	76.5%	13
		Volunteers	0.0%	0
		Both	23.5%	4
		Total		17
p31, 48	PALS Volunteers/Patient Support Services/Patient experience team	Staff	69%	9
		Volunteers	15%	2
		Both	15%	2
		Total		13
p31, 48	Psychologist	Staff	37.5%	3
		Volunteers	0.0%	0
		Both	62.5%	5
		Total		8
p31, 48	Use of 'Last Days of Life care plan'	Staff	100%	10
		Volunteers	0%	0
		Both	0%	0
		Total		10

Appendix 2: Indicators used in the report (Acute and Community)

Page/ Figure	Chart title	Response	Regional	Regional n=
p31	Support processes available for people important to the dying person:			
p31, 48	Specialist Palliative Care Team	Staff	76.5%	13
		Volunteers	0.0%	0
		Both	23.5%	4
		Total		17
p31, 48	Specialist or lead nurses-EOL and other specialities	Staff	76.5%	13
		Volunteers	0.0%	0
		Both	23.5%	4
		Total		17
p31, 48	Specific guidance on supporting staff who have themselves been bereaved	Staff	44%	7
		Volunteers	0%	0
		Both	56%	9
		Total		16

Appendix 2: Indicators used in the report (Mental health)

Page/ Figure	Chart title	Response	Regional	Regional n=
p33, 51	Average number of beds - MH adult acute	-	51	5
p33, 51	Average number of beds - MH older persons	-	25	5
p33, 51	Average number of beds - MH rehabilitation	-	10	1
p33, 51	Average number of beds - Psychiatric intensive	-	8	4
p33, 51	Average number of beds - MH forensic (any	-	15	3
p33, 51	Average number of beds - MH continuing care/long-term complex needs	-	18	3
p33, 51	Average number of beds - Eating disorder	-	0	1
p33, 51	Average number of beds - Other MH hospital	-	12	2
p33, 51	Average number of beds - LD Forensic – all	-	9	2
p33, 51	Average number of beds - LD acute admission	-	12	2
p33, 51	Average number of beds - LD Complex continuing care and rehabilitation	-	16	2
p33, 51	Average number of beds - Other LD service	-	0	1
p33, 50	Bed type % split - MH adult acute	-	41.5%	5
p33, 50	Bed type % split - MH older persons acute	-	19.9%	5
p33, 50	Bed type % split - MH rehabilitation	-	1.6%	1
p33, 50	Bed type % split - Psychiatric intensive care	-	5.3%	4
p33, 50	Bed type % split - MH forensic (any level)	-	7.1%	3
p33, 50	Bed type % split - MH continuing care/long-term complex needs	-	8.9%	3
p33, 50	Bed type % split - Eating disorder	-	0.0%	1
p33, 50	Bed type % split - Other MH hospital location	-	3.9%	2
p33, 50	Bed type % split - LD Forensic – all categories	-	2.8%	2
p33, 50	Bed type % split - LD acute admission	-	3.9%	2
p33, 50	Bed type % split - LD Complex continuing care and rehabilitation	-	5.2%	2
p33, 50	Bed type % split - Other LD service location	-	0.0%	1
p33, 51	Average number of beds 2017/18	-	77	8
p33, 52	Adult single patient occupancy rooms as a % of total beds	-	51%	8
p34, 53	Total number of deaths per 100 beds 2017/18	-	8	5
p34, 54	Average number of deaths - MH adult acute	-	3	6
p34, 55	Average number of deaths - MH older persons acute	-	8	6

Appendix 2: Indicators used in the report (Mental health)

Page/ Figure	Chart title	Response	Regional	Regional n=
p34, 54	Average number of deaths - MH rehabilitation	-	0	4
p34, 54	Average number of deaths - Psychiatric intensive care	-	0	5
p34, 54	Average number of deaths - MH forensic	-	0	4
p34, 54	Average number of deaths - MH continuing care/long-term complex needs	-	1	5
p34, 54	Average number of deaths - Eating disorder	-	0	4
p34, 54	Average number of deaths - Other MH hospital	-	3	5
p34, 54	Average number of deaths - LD Forensic	-	0	4
p34, 54	Average number of deaths - LD acute admission	-	0	4
p34, 54	Average number of deaths - LD Complex continuing care and rehabilitation	-	1	4
p34, 54	Average number of deaths - Other LD service location	-	0	4
p34, 55	% of deaths by bed type - MH adult acute	-	18.8%	4
p34, 55	% of deaths by bed type - MH older persons acute	-	50.0%	3
p34, 55	% of deaths by bed type - MH rehabilitation	-	0.0%	2
p34, 55	% of deaths by bed type - Psychiatric intensive care	-	0.0%	3
p34, 55	% of deaths by bed type - MH forensic	-	0.0%	2
p34, 55	% of deaths by bed type - MH continuing care/long-term complex needs	-	6.3%	3
p34, 55	% of deaths by bed type - Eating disorder	-	0.0%	2
p34, 55	% of deaths by bed type - Other MH hospital location	-	18.8%	3
p34, 55	% of deaths by bed type - LD Forensic	-	0.0%	2
p34, 55	% of deaths by bed type - LD acute admission	-	0.0%	2
p34, 55	% of deaths by bed type - LD Complex continuing care and rehabilitation	-	6.3%	2
p34, 55	% of deaths by bed type - Other LD service location	-	0.0%	2
p35	Does your hospital have:			
p35, 56	Is there a Specialist Palliative Care service provided by the hospital?	Yes	37.5%	3
		No	62.5%	5
		Total		8

Appendix 2: Indicators used in the report (Mental health)

Page/ Figure	Chart title	Response	Regional	Regional n=
p35	Does your hospital have:			
p35, 56	If not, does your hospital have access to a Specialist Palliative Care service funded and/or based outside of the hospital/site?	Yes	83%	5
		No	17%	1
		Total		6
p35, 56	Does your hospital have one or more End of Life Care Facilitators?	Yes	50%	4
		No	50%	4
		Total		8
p35, 56	If yes, does the End of Life Care Facilitator role sit within the Specialist Palliative Care team?	Yes	25%	1
		No	75%	3
		Total		4
p36, 57	Specialist Palliative Care workforce - Doctor availability - face to face	9-5, Mon -	80%	4
		9-5 Mon -	0%	0
		9-5, 7	0%	0
		Other	20%	1
		Total		5
p36, 58	Specialist Palliative Care workforce - Nurse availability - face to face	9-5, Mon -	80%	4
		9-5 Mon -	0%	0
		9-5, 7	0%	0
		Other	20%	1
		Total		5
p36, 59	Specialist Palliative Care workforce - Doctor availability - telephone	9-5, Mon -	87.5%	7
		9-5 Mon -	0.0%	0
		9-5, 7	0.0%	0
		24 hours,	12.5%	1
		Other	0.0%	0
		Total		8
p36, 60	Specialist Palliative Care workforce - Nurse availability - telephone	9-5, Mon -	87.5%	7
		9-5 Mon -	0.0%	0
		9-5, 7	0.0%	0
		24 hours,	0.0%	0
		Other	12.5%	1
		Total		8
p37	In the period between 1st April 2017 and 31st March 2018 what continuing End of Life education and training was available:			
p37, 61	Induction programme	Yes	60%	3
		No	40%	2
		Total		5

Appendix 2: Indicators used in the report (Mental health)

Page/ Figure	Chart title	Response	Regional	Regional n=
p37	In the period between 1st April 2017 and 31st March 2018 what continuing End of Life education and training was available:			
p37, 61	Mandatory/priority training	Yes	20%	1
		No	80%	4
		Total		5
p37, 61	eELCA resources to support staff training	Yes	20%	1
		No	80%	4
		Total		5
p37, 61	Training to help improve the culture, behaviours, attitudes around communication	Yes	100%	5
		No	0%	0
		Total		5
p37, 61	Other training	Yes	100%	5
		No	0%	0
		Total		5
p38, 62	Was an action plan produced in the financial year to promote improvement in End of Life Care in your Trust/ UHB?	Yes	62.5%	5
		No	37.5%	3
		Total		8
p38, 63	Was this action plan fed back to clinical teams?	Yes	75%	6
		No	25%	2
		Total		8
p38, 64	Was this action plan fed back to the trust board?	Yes	100%	8
		No	0%	0
		Total		8
p38, 65	Was End of Life Care reported on at trust board level?	Yes	100%	8
		No	0%	0
		Total		8
p39, 66	Was there carer and public representation within these discussions/reporting processes?	Yes	100%	8
		No	0%	0
		Total		8
p39, 67	Did your hospital/site seek bereaved relatives' or friends' views during the last two financial years?	Yes	87.5%	7
		No	12.5%	1
		Total		8
p39	Type of feedback survey used:			
p39, 68	In-house survey	Yes	33%	2
		No	67%	4
		Total		6

Appendix 2: Indicators used in the report (Mental health)

Page/ Figure	Chart title	Response	Regional	Regional n=
p39, 68	Type of feedback survey used:			
p39, 68	VOICES	Yes	67%	4
		No	33%	2
		Total		6
p39	Written support provided to those important to the patient:			
p39, 69	A leaflet outlining the changes that may occur in patients in the hours before death?	Yes	37.5%	3
		No	62.5%	5
		Total		8
p39, 69	A leaflet explaining local procedures to be undertaken after the death of a patient?	Yes	100%	8
		No	0%	0
		Total		8
p39, 69	Department of Work and Pensions (DWP) leaflet 1027, 'What to Do After a Death in England and Wales' or equivalent?	Yes	37.5%	3
		No	62.5%	5
		Total		8
p40	Support processes available for people important to the dying person:			
p40, 70	Access to bereavement services/bereavement team	Yes	75%	6
		No	25%	2
		Total		8
p40, 70	Access to counselling services	Yes	50%	4
		No	50%	4
		Total		8
p40, 70	Achieving Priorities of Care planning guidance for last days & hours of life	Yes	50%	4
		No	50%	4
		Total		8
p40, 70	Bereavement cards/leaflets	Yes	75%	6
		No	25%	2
		Total		8
p40, 70	Comfort care packs	Yes	12.5%	1
		No	87.5%	7
		Total		8
p40, 70	Multi-faith spiritual/religious support	Yes	87.5%	7
		No	12.5%	1
		Total		8
p40, 70	Designated 'quiet spaces' available for relatives or carers	Yes	100%	8
		No	0%	0
		Total		8

Appendix 2: Indicators used in the report (Mental health)

Page/ Figure	Chart title	Response	Regional	Regional n=
p40	Support processes available for people important to the dying person:			
p40, 70	Designated prayer room, chapel	Yes	67%	4
		No	33%	2
		Total		6
p40, 70	Hospice services support	Yes	37.5%	3
		No	62.5%	5
		Total		8
p40, 70	Macmillan/Marie Curie Palliative Care Clinical Nurse Specialist or information	Yes	100%	8
		No	0%	0
		Total		8
p40, 70	Ability to facilitate overnight stays for family members/friends of the patient	Yes	71%	5
		No	29%	2
		Total		7
p40, 70	Psychologist for adult and/or child	Yes	37.5%	3
		No	62.5%	5
		Total		8
p40, 70	Use of 'Last Days of Life care plan'	Yes	43%	3
		No	57%	4
		Total		7
p40, 70	Specialist Palliative Care Team	Yes	75%	6
		No	25%	2
		Total		8
p40, 70	Specialist or lead nurses- EOL and other specialities	Yes	62.5%	5
		No	37.5%	3
		Total		8
p40, 70	Car parking permit	Yes	75%	3
		No	25%	1
		Total		4
p40, 70	Volunteer support schemes	Yes	40%	2
		No	60%	3
		Total		5
p41	Support processes available for staff and volunteers:			
p41, 71	Access to bereavement services/bereavement team	Staff	50%	4
		Volunteers	0%	0
		Both	50%	4
		Total		8

Appendix 2: Indicators used in the report (Mental health)

Page/ Figure	Chart title	Response	Regional	Regional n=
p41	Support processes available for staff and volunteers:			
p41, 71	Access to counselling services	Staff	50%	4
		Volunteers	0%	0
		Both	50%	4
		Total		8
p41, 71	Achieving Priorities of Care planning guidance for last days & hours of life	Staff	100%	6
		Volunteers	0%	0
		Both	0%	0
		Total		6
p41, 71	Clinical supervision/Peer support	Staff	50%	4
		Volunteers	0%	0
		Both	50%	4
		Total		8
p41, 71	Debriefing sessions	Staff	62.5%	5
		Volunteers	0.0%	0
		Both	37.5%	3
		Total		8
p41, 71	Health and wellbeing team	Staff	43%	3
		Volunteers	0%	0
		Both	57%	4
		Total		7
p41, 71	Multi-faith spiritual/religious support	Staff	43%	3
		Volunteers	0%	0
		Both	57%	4
		Total		7
p41, 71	Hospice services support	Staff	100%	3
		Volunteers	0%	0
		Both	0%	0
		Total		3
p41, 71	Intranet advice	Staff	87.5%	7
		Volunteers	0.0%	0
		Both	12.5%	1
		Total		8
p41, 71	Macmillan/Marie Curie Palliative Care Clinical Nurse Specialist or information	Staff	37.5%	3
		Volunteers	0.0%	0
		Both	62.5%	5
		Total		8

Appendix 2: Indicators used in the report (Mental health)

Page/ Figure	Chart title	Response	Regional	Regional n=
p41	Support processes available for staff and volunteers:			
p41, 71	Palliative Training Programme or 'End of Life' care training	Staff	100%	8
		Volunteers	0%	0
		Both	0%	0
		Total		8
p41, 71	PALS Volunteers/Patient Support Services/Patient experience team	Staff	86%	6
		Volunteers	0%	0
		Both	14%	1
		Total		7
p41, 71	Psychologist	Staff	50%	4
		Volunteers	0%	0
		Both	50%	4
		Total		8
p41, 71	Use of 'Last Days of Life care plan'	Staff	100%	4
		Volunteers	0%	0
		Both	0%	0
		Total		4
p41, 71	Specialist Palliative Care Team	Staff	83%	5
		Volunteers	0%	0
		Both	17%	1
		Total		6
p41, 71	Specialist or lead nurses - EOL and other specialities	Staff	87.5%	7
		Volunteers	0.0%	0
		Both	12.5%	1
		Total		8
p41, 71	Specific guidance on supporting staff who have themselves been bereaved	Staff	43%	3
		Volunteers	0%	0
		Both	57%	4
		Total		7

Appendix 3: NACEL Steering group and Advisory Group members

The National Audit of Care at the End of Life Steering Group

Name	Title	Representing
Dr Suzanne Kite	Co-Clinical Lead – National Audit for Care at the End of Life	National Audit for Care at the End of Life
Elizabeth Rees	Co-Clinical Lead – National Audit for Care at the End of Life	National Audit for Care at the End of Life
Claire Holditch	Director	NHS Benchmarking Network
Debbie Hibbert	Programme Manager	NHS Benchmarking Network
Ellen Armistead	End of Life Lead	Care Quality Commission
Professor Mike Bennett	St Gemma's Professor of Palliative Medicine, Academic Unit of Palliative Care	University of Leeds
Sara Bernstein	Pharmacist	Peace Hospice Care
Tony Brookes	Chaplain	College of Healthcare Chaplain
Meg Burton	Chaplain	College of Healthcare Chaplain
Amanda Cheesley	Professional Lead for End of Life Care	Royal College of Nursing
Gloria Clark	Project Manager	The Patients Association
Dr Sarah Cox	Consultant in Palliative Care	Royal College of Physicians
Dr Andrew Davies	President	Association for Palliative Medicine
Dr Premila Fade	Consultant Geriatrician	British Geriatrics Society
Sherree Fagge	End of Life Care Lead	NHS Improvement
Annette Furley	End of Life Doula/Member of NICE guideline committee	NACEL lay representative
Corrina Grimes	Regional Palliative Care Clinical Lead	Public Health Agency, Northern Ireland
Professor Mike Grocott	Consultant Anaesthetist	Royal College of Anaesthetists/Faculty of Intensive Care Medicine
Dr Melanie Jefferson	Acting Clinical Lead for End of Life Care	NHS Wales
Dr Di Laverty	Chair	National Nurses Group (Palliative Care)
Giselle Martin-Dominguez	Professional Lead for End of Life Care	Royal College of Nursing
Dr Catherine Millington- Sanders	General Practitioner	Royal College of General Practitioners

Appendix 3: NACEL Steering group and Advisory Group members

The National Audit of Care at the End of Life Steering Group

Name	Title	Representing
Caroline Nicholson	Senior Clinical Lecturer: Supportive and End of Life Care (Nursing)	British Geriatrics Society
Eleanor Sherwen	Professional Lead for End of Life Care	Royal College of Nursing
Tina Strack	Associate Director, Quality & Improvement	Healthcare Quality Improvement Partnership (HQIP)
Kevin Tromans	Chaplain	College of Healthcare Chaplains
Professor Bee Wee	National Clinical Director for End of Life Care	NHS England

Appendix 3: NACEL Steering group and Advisory Group members

The National Audit of Care at the End of Life Advisory Group		
Name	Title	Representing
Dr Amit Arora	Consultant Geriatrician	University Hospital of North Midlands NHS Trust
Jennifer Beveridge	Analyst – Uptake and Impact	The National Institute for Health and Care Excellence (NICE)
Professor Adrian Blundell	Consultant and Honorary Associate Professor in the Medicine of Older People	University of Nottingham
Dr John Chambers	Consultant in Palliative Medicine	Northampton General Hospital NHS Trust
Leighton Coombes	Senior Programme Analyst – Adoption & Impact	The National Institute for Health and Care Excellence (NICE)
Becky Cooper	Assistant Director, Palliative Care	Norfolk Community Health and Care NHS Trust
Dr Thomas Cowling	Assistant Professor in Clinical Epidemiology	Royal College of Surgeons
Susan Dewar	District Nurse	Sussex Community NHS Foundation Trust
Mark Dexter	Policy Lead	General Medical Council
Ray Elder	Strategic Lead Palliative Care	South Eastern Health and Social Care Trust
Carol Gray	Nurse Consultant Palliative and End of Life Care	Royal Berkshire NHS Foundation Trust
Claire Henry	Director of Improvement and Transformation	Hospice UK
Dr Paul Hopper	Consultant Psychogeriatrician	Central and North West London NHS Foundation Trust
Johanna Kuila	Policy Analyst	General Medical Council
Dr Helen Livingstone	Consultant Palliative Medicine	Sue Ryder
Ryan Lord	Senior Audit Facilitator	Oxleas NHS Foundation Trust
Jean Maguire	Macmillan Nurse Team Leader	Belfast Health and Social Care Trust
Bernie Michaelides	Head of Intermediate Care/Lead Nurse	Western Health and Social Care Trust
Dr Ollie Minton	Macmillan Consultant and Honorary Senior Lecturer in Palliative Medicine	St George's University Hospitals NHS Foundation Trust
Dr Bill Noble	Chief Medical Director	Marie Curie
John Powell	End of Life Lead	Association of Directors of Adult Social Services (ADASS)
Dr Amy Profitt	Executive Secretary	Association of Palliative Medicine

Appendix 3: NACEL Steering group and Advisory Group members

The National Audit of Care at the End of Life Advisory Group		
Name	Title	Representing
Charlotte Rock	Macmillan Lead Nurse for Palliative & End of Life Care Yorkshire & Humber Joint Clinical Lead, Palliative & End of Life	Harrogate and District NHS Foundation Trust
Simon Roer	Policy Lead	General Medical Council
Dr Joy Ross	Consultant in Palliative Medicine	St Christopher's Hospice
Lucie Rudd	End of Life Specialist Advisor	Macmillan Cancer Support
Dr Rebekah Schiff	Consultant Geriatrician and General Medicine, Service Lead Ageing and Health	Guys and St Thomas' NHS Foundation Trust
Vivien Seagrove	Project Manager	Healthcare Quality Improvement Partnership (HQIP)
Lucy Sutton	End of Life Care Lead	Health Education England
Dr Elizabeth Teale	Clinical Senior Lecturer and Consultant in Elderly Care Medicine, Academic Unit of Elderly Care and Rehabilitation, University of Leeds	Bradford Institute for Health Research
Martina Thompson	Head of Primary Care Services	Southern Health and Social Care Trust
Dr Grahame Tosh	Executive Medical Director	Marie Curie
Julia Verne	Clinical Lead National End of Life Care Intelligence Network	Public Health England
Gail Warnes	EoL Commissioner	Wiltshire Clinical Commissioning Group