



A workforce in crisis: children's palliative care in 2019

A report from Together for Short Lives

October 2019

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Executive summary

Seriously ill children can have complex and unpredictable conditions and often need round the clock care provided by their families, seven days a week. They may need palliative care from the point at which their condition is diagnosed or recognised until the end of their lives. This care is mainly provided by families at home, 24 hours a day. They are supported by medical, nursing and other professionals in a mix of settings that include hospitals, children's homes and children's hospices.

The number of children with life-limiting conditions who are likely to need palliative care is growing. Worryingly, however, too few children's palliative care services in England are sustainably staffed. This means that too many children and families are missing out on the care and support they need, when and where they need it. There is a children's palliative care workforce crisis:

- 1. There are too few community children's nurses (CCNs) employed by the NHS:** CCNs provide the bedrock of children's palliative care in England. If safe staffing levels recommended by the Royal College of Nursing (RCN) were being adhered to, 5,500 CCNs would be working in England. Yet there are only 574 community children's nurses employed by the NHS in England. While other NHS nurses do provide community-based care to children, this is an indicator of the shortages in this crucial part of the sector.
- 2. There are too few specialist children's palliative care consultants:** The Royal College of Paediatrics and Child Health (RCPCH) estimates that 40-60 specialist children's palliative care consultants are needed in the UK. Worryingly, there are currently only 15. This suggests a significant deficit of 25-45 consultants.
- 3. The growing nursing vacancy rate in children's hospice charities is higher than in the NHS – and posts are increasingly difficult to fill:** The average vacancy rate for children's hospices charities in England is 12.2%, compared to just over 11% in 2016 and 10% in 2015. The NHS nursing vacancy rate is 11%, which is also worryingly high. Over two thirds (67%) of vacant posts are proving hard to fill (vacant for three months or more). This is an increase on the 65% who reported that posts were hard to fill in 2016, and the 57% who reported the same in 2015. A quarter (25%) of posts have been vacant for over 12 months.
- 4. There are too few skilled children's nurses to fill vacant posts in children's hospices:** Over half (58%) of children's hospices cite an overall lack of children's nurses as a significant factor in the vacancy rates they are experiencing.
- 5. There are shortages among other health and care professionals who support seriously ill children and their families:** in England, the vacancy rate for allied health professionals (AHPs, including physiotherapists, occupational therapists, and psychological therapists) is 14%. In 2018, the overall vacancy rate for children and family social workers in England was 16%.

These workforce shortages are having a negative impact on the palliative care that seriously ill children and families are able to access:

- Parents of seriously ill children with personal budgets have told us how difficult they find it to employ the staff their children need. Despite being assessed as needing 24-hour support by the NHS, some children and young people cannot access it because they cannot find carers to have the skills to provide it.

- Some parents of seriously ill children have told us that their access to vital short breaks for respite have been cut as a result of workforce shortages; some providers have confirmed this.
- The RCPCH has stated that a lack of access to fully trained specialists for advice and support is resulting in a lack of equitable and standardised clinical practice.

In September 2019, the Chancellor of the Exchequer announced a £210 million package of measures designed to better educate and train NHS staff. This included funding for a £1,000 personal development budget for every nurse, midwife and allied health professional to support their personal learning and development needs over three years.

Despite this, Together for Short Lives is concerned by the extent to which the government, NHS England and NHS Improvement, Health Education England and universities in England are taking the action needed to address the shortfall in children's palliative care professionals:

- There is no evidence to suggest that Health Education England (HEE) has made any strategic plans to address the current workforce crisis in children's palliative care across the NHS. Additionally there is no parallel assessment of the shortages in voluntary sector children's palliative care sector (medical and nursing) clinical workforce in modelling the demand for appropriately skilled professionals. While we welcome the competency framework for end of life care which HEE commissioned and which Skills for Health and Skills for Care published in 2017, we are concerned that it only relates to care for adults who are likely to die within the next 12 months.
- We are concerned that a paucity of education, learning and development opportunities specific to children's palliative care is hindering local access to quality training.
- There is a lack of training posts available for specialist paediatric palliative medicine consultants, nor is there additional training opportunity available to give general paediatricians specialist interest training in children's palliative care. This is being caused by a dearth of funding for these posts from NHS England and NHS Improvement's specialised commissioning team.

Overall, the RCPCH has identified what it considers to be an incoherent and inconsistent approach to planning for the child health workforce¹. The RCN has identified the lack of legislation on safe nurse staffing as a barrier to establishing in law who is accountable for safe patient care².

Together for Short Lives welcomes the work of 'Managing Complexity in Children's Healthcare: A Partnership for Change'³, a group of individuals and organisations committed to working together and sharing good practice and resources. This collaborative aims to improve the healthcare of children with medical complexity and their families – and provide support and educational materials for the professionals looking after them.

1 Royal College of Paediatrics and Child Health. 2018. Workforce briefing. Available to download from: <https://www.rcpch.ac.uk/resources/workforce-briefing-2018>

2 Royal College of Nursing. 2019. Public urged to pressure government to fix the nursing workforce crisis. Available to download from: <https://www.rcn.org.uk/news-and-events/news/uk-safe-staffing-public-campaign-launch-170919>

³ Managing Complexity in Children's Healthcare: A Partnership for Change. 2019. <https://collaborative.whitefuse.net/>

We also welcome the work of the Children's Palliative Care Education and Training National Action Group. This is supporting work to design, develop and manage a sustainable, standardised approach to educating and training children's palliative care professionals in the UK. We ask HEE and the Council of Deans of Health to work with us to make sure that this approach becomes embedded in education and training for all children's palliative care professionals in England.

We believe that the government, HEE and others have a vital role to play helping to reduce the vacancy rates among key groups of children's palliative care professionals – and making it easier for providers to recruit the staff they need. To make sure that seriously ill children and their families are well supported by children's palliative care professionals, Together for Short Lives calls on ministers to end the children's palliative care workforce crisis by making sure the following measures are included in the NHS People Plan:

1. HEE to:
 - urgently assess the gaps in the children's palliative care workforce
 - make sure there is a sustainable pathway for the training of paediatric palliative medicine specialist consultants and generalist paediatricians with an interest in palliative care who have the appropriate capability to care for these complex children.
 - specifically include the demand for professionals from children's hospice organisations and the independent sector in their planning models
 - develop a core skills education and training framework for children's palliative care; this could help employers to identify key skills for roles and teams, conduct training needs analysis and plan, design and commission appropriate levels of and systems for training. This could also ensure that robust peer review systems are established.
 - focus specifically on outlining career pathways and providing guidance for delivering outcomes-led education for children's palliative care nurses.
2. NHS England and NHS Improvement specialised commissioning team and Health Education England to urgently fund NHS trusts to create specific medical training posts. This would help to make sure that paediatric palliative care special interest training (SPIN) can take place.
3. Education providers to make sure that children's palliative care is embedded in and postgraduate medical and nursing courses; we note that children's palliative care should be embedded in nursing courses in a way that is consistent with existing regulations.
4. The government to:
 - make sure that HEE has the resources to invest in the medical, nursing and allied health workforce and take the action we call for above
 - make sure that the UK's exit from the European Union does not have an adverse impact on the supply of children's palliative care professionals from across the world

- boost overall nursing numbers by taking the action recommended by the RCN to:
 - invest at least £1 billion a year into nursing higher education
 - invest at least £360m per year for nurses' continuing professional development
 - legislate for accountability for workforce supply and planning in England.

About Together for Short Lives

1. Together for Short Lives is the UK charity for children's palliative care. We are here to support and empower families caring for seriously ill children, and to build a strong and sustainable children's palliative care sector. We support all the professionals and children's palliative care services that deliver lifeline care. We have over 1,000 members, including children hospices, voluntary sector organisations and statutory service providers. Together for Short Lives is the secretariat for the [All-Party Parliamentary Group \(APPG\) for Children Who Need Palliative Care](#).

The palliative care that seriously ill children need – and the professionals they need to provide it

2. Hearing the news that your child has a life-limiting condition and is likely to die young is devastating. It is an incredibly distressing and confusing time. These children have very complex and unpredictable conditions and often need round the clock care, seven days a week. In 2010, there were 49,000 babies, children and young people in the UK with life-limiting or life-threatening conditions⁴, including 40,000 in England. A new study is underway which will shortly provide an updated figure⁵.
3. Families have to cope with the knowledge that their child will die before them, and daily life for the whole family can become challenging. Although there are many excellent services helping them, many families still have difficulties accessing the care and support they need.
4. Children with life-limiting conditions may need palliative care from the point at which their condition is diagnosed until the end of their lives. Families also need care and support throughout the trajectory of their child's illness, including bereavement care after they have died. Palliative care for children includes, but is not limited to, end of life care, and the two terms should not be used interchangeably.
5. These children and their families rely on palliative care being provided in hospital, children's hospices and in the community, by the statutory and voluntary sectors. Children's palliative care providers offer a range of services, including supporting families to manage their children's pain and distressing symptoms, providing children and their families with life-line short breaks and offering bereavement support both before and after the child has died.
6. Families want to be able to choose where they receive the lifeline children's palliative care services that they rely on, when they need and want them. They also want to choose who cares for their child and which treatments they receive.
7. This means that seriously ill children rely on a range of professionals who have the skills and experience to provide palliative care. In particular, this includes:

4 Fraser LK, Parslow RC, McKinney PA, Miller M, Aldridge JM, Hain R, Norman P. 2012. Life-limiting and life-threatening conditions in children and young people in the United Kingdom; final report for Together for Short Lives. Available to download from: <http://bit.ly/1z24ZQw>

5 True Colours Trust. 2018. Making every seriously ill child count: UK-wide study to highlight the number of children with life-limiting or life-threatening conditions. Available to download from: <http://www.truecolourstrust.org.uk/making-every-seriously-ill-child-count-uk-wide-study-to-highlight-the-number-of-children-with-life-limiting-or-life-threatening-conditions/>

- Specialist paediatric palliative care medicine consultants
 - Paediatric consultant specialists in disease specific conditions such as neurologists and cancer specialists
 - General paediatricians who have received special interest training in children's palliative care
 - General practitioners (GPs)
 - Children's nurses, including:
 - those working in NHS community children's nursing teams
 - hospital-based children's palliative care teams
 - hospital outreach services
 - nurses working in children's hospices
 - children's hospice at home teams.
 - Pharmacists, including those with expertise in specialist children's palliative care
 - Allied health professionals (for example physiotherapists, occupational therapists, and psychological therapists)
 - Chaplains
 - Experts in child and family support who have experience in end of life care (for example in providing social, practical, emotional, psychological and spiritual support)
 - Social care practitioners
 - Education professionals.
8. Children and their families can only achieve the best quality of life and end of life care if they can access doctors, nurses and other professionals with the skills and experience to provide the palliative care they need. Securing a sustainable workforce is also critical to releasing public policies designed to make sure children can access palliative care across England. These include:
- the government's end of life care choice commitment to children⁶
 - National Institute for Health and Care Excellent guidance⁷ and quality standards⁸
 - the NHS Long Term Plan⁹, which states that children's palliative care is an important priority for the NHS.

6 Department of Health. 2016. 'Our Commitment to you for end of life care: The Government Response to the Review of Choice'. Available to download from: <http://bit.ly/2oOU5fj>

7 The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: <http://bit.ly/2ODg2hY>

8 The National Institute for Health and Care Excellence. 2017. End of life care for infants, children and young people – NICE quality standard [QS160]. Available to download from: <http://bit.ly/2M6BHx3>

9 NHS Long Term Plan. 2019. Available to download from: <https://www.longtermplan.nhs.uk/>

The workforce crisis that Together for Short Lives has found

NHS community children's nurses (CCNs)

9. CCNs are crucial in supporting families to care for seriously ill children at home.
10. The Royal College of Nursing (RCN) recommends that for an average-sized district, with a child population of 50,000, a minimum of 20 Whole Time Equivalent (WTE) community children's nurses are required to provide a holistic community children's nursing service¹⁰. The Office of National Statistics estimates that there are 13,770,873 children aged 0-18 in England¹¹. If the RCN recommendation were to be met, this would require approximately 5,508 community children's nurses.
11. However, there are just 574 community children's nurses employed by the NHS in England¹².
12. It is important to note that, depending upon the services a CCN team provides, they may comprise a range of other staff. These could include other registered children's nurses, registered learning disability nurses and allied health professionals (AHPs). However, there are only 1,928 community learning disability nurses working in England. There is an overall dearth of children's nurses in England.
13. In the report 'Facing the Future audit 2017'¹³, the RCPCH identified significant variability in the types of children's community nursing (CCN) teams available; both in relation to their role and the hours they provide the service. In the audit respondents revealed that the majority of CCN services operate less than 12 hours per day, five days a week.
14. RCPCH has also identified that the shortage of children's nurses means that many CCN teams lack the time to build key relationships with GP practices.

Paediatric Palliative Medicine consultants

15. NICE states that children with life-limiting conditions should be cared for by defined multidisciplinary teams (MDT)¹⁴ which include members of specialist children's palliative care teams. NHS England and NHS Improvement states¹⁵ that specialist children's

10 RCN. 2014. The future for community children's nursing: challenges and opportunities. P.10. Available to download from: <http://bit.ly/1QgLhZb>.

11 Office for National Statistics. 2018. Population Estimates Analysis Tool. Available to download from: <http://bit.ly/2KhPnE5>

12 NHS Digital. 2019. NHS Workforce Statistics - May 2019. Available to download from: <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics/may-2019>

¹³ RCPCH. 2017. Facing the Future Audit 2017: Facing the Future: Standards for acute general paediatric services: Facing the Future: Together for child health. Available to download from: <https://www.rcpch.ac.uk/sites/default/files/2018-04/Facing%20the%20Future%20audit%202017%20-%20report%20%28April%202018%29.pdf>

14 The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: <http://bit.ly/2ODg2hY>

15 NHS England. 2013. E03/S/h – 2013/14 NHS standard contract for paediatric medicine: palliative care particulars, schedule 2 – the services, A – service specifications. Available to download from: <http://bit.ly/11yjtVS>

palliative care teams should be led by specialist medical consultants¹⁶. These specialist consultants are vital because they:

- have specialist expertise in managing life-threatening illness and life-limiting conditions across the paediatric spectrum
- the ability to manage the full range of symptoms experienced as disease and illness progresses
- lead and develop services within their region
- enable, support, teach and train other health care professionals.

16. We estimate that there are currently 18 specialist paediatric palliative medicine consultants in the UK and a very limited number of paediatric consultants who practice with an interest in palliative care. There are many regions in the UK with no access to paediatric palliative medicine specialists. Many single-handed consultants have no cover for leave or sickness and 'reprieve' from service requirement can be very challenging.

17. RCPCH have previously reported that paediatric palliative medicine specialists are very concerned about paediatricians taking on the 'lead' for palliative care services without having key capabilities and training in place. It states that a lack of access to fully trained specialists for advice and support is resulting in some unintended poor practice¹⁷.

18. During the third oral evidence session of the APPG for Children Who Need Palliative Care inquiry into the extent to which the government's end of life care choice commitment was being met for children in England, Dr Simon Clark, Officer for Workforce Planning at RCPCH, made a conservative estimate that between 40-60 children's palliative care consultants were needed in the UK¹⁸. This suggests a significant deficit of 25-45 consultants. A full mapping process is currently underway to consolidate this data. We estimate that five full time equivalent specialist children's palliative care consultants are needed in every region to maintain a level of service 24 hours a day, seven days a week. This would be consistent with the standard of quality set out by NICE¹⁹.

19. Specialist consultants have expressed their concern at the low number of national GRID training posts available for paediatric palliative medicine consultants. There are currently three GRID posts in the UK; as it takes two years to train following run through paediatric training, three whole time consultants are produced every two years. This is not enough to fill the existing number of consultant posts available in the UK.

16 Association for Paediatric Palliative Medicine Education Subgroup And Paediatric Palliative Medicine College Specialty Advisory Committee, Royal College of Paediatrics and Child Health. 2015. Curriculum in Paediatric Palliative Medicine. Available to download from: <http://bit.ly/2AvDzOJ>

17 RCPCH. 2018. Written evidence to the APPG for Children Who Need Palliative Care. Available to download from: https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/06/PolRes_RCPCH.pdf

18 The All-Party Parliamentary Group for Children Who Need Palliative Care. 2018. Oral evidence: how the government is meeting its commitment to choice for babies, children and young people who need palliative care. Session 5: 7 March 2018. Available to download from: https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/10/Pol_Res_Transcription_APPG_inquiry_session_five.pdf

19 The National Institute for Health and Care Excellence. 2017. End of life care for infants, children and young people – NICE quality standard [QS160]. Available to download from: <http://bit.ly/2M6BHx3>

20. Opportunities for general paediatricians to undertake special interest training in children's palliative care is also compromised by a lack of training posts. This is despite considerable interest to develop capability in this field²⁰. This is being caused by the lack of paediatric palliative medicine consultants and a dearth of funding for these posts from NHS England and NHS Improvement's specialised commissioning team.
21. This paucity of speciality palliative medicine consultants means that it is particularly challenging for NHS trusts to provide and maintain specialist children's palliative care services within their organisations.

Allied health professionals

22. Allied health professionals (AHPs) include physiotherapists, occupational therapists, and psychological therapists. Depending on a child and their family's needs, they may be vital members of the multidisciplinary team that provide palliative care to the child²¹.
23. According to NHS Digital, the total number of advertised full-time equivalent vacancies for AHPs in England in April, May and June 2019 was 10,726²². The number of full time equivalent (FTE) AHPs employed in the NHS June 2019 was 67,057²³. This indicates a vacancy rate of 14%.

Child and family social workers

24. The social care workforce includes palliative care social workers and support workers who work directly with families. Social workers will play an important role in assessing the social care needs seriously ill children, including for short breaks for respite, personal care and home adaptations.
25. According to the Department for Education, there were 29,470 FTE children and family social workers at 30 September 2018, an increase of over 3% from the same date in 2017. The number of children and family social worker FTE vacancies at 30 September 2018 was 5,810, which was relatively unchanged from the 5,820 reported at the same point in 2017²⁴.
26. The Department for Education calculates the overall FTE vacancy rate at 30 September 2018 was 16%, which again was relatively unchanged from 2017.

²⁰ The All-Party Parliamentary Group for Children Who Need Palliative Care. 2018. Oral evidence: how the government is meeting its commitment to choice for babies, children and young people who need palliative care. Session 5: 7 March 2018. Available to download from: https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/10/Pol_Res_Transcription_APPG_inquiry_session_five.pdf

²¹ The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: <http://bit.ly/2ODg2hY>

²² NHS Digital. 2019. NHS Vacancy Statistics England, February 2015 - June 2019, Provisional Experimental Statistics. Available to download from: <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-vacancies-survey/february-2015---june-2019-provisional-experimental-statistics>

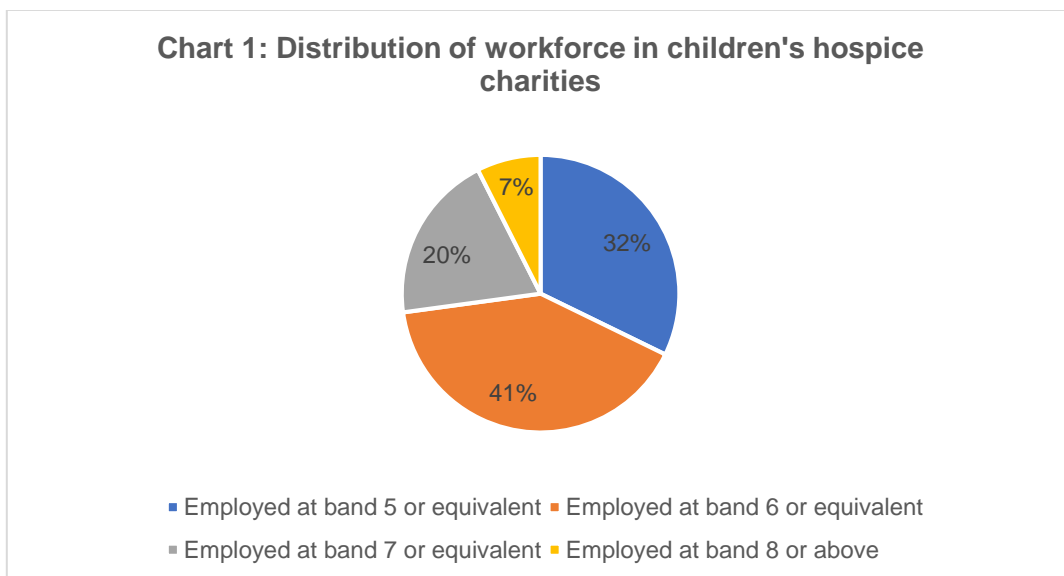
²³ NHS Digital. 2019. NHS Workforce Statistics - June 2019. Available to download from: <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics/june-2019>

²⁴ Department of Education. 2019. Experimental statistics: Children and family social work workforce in England, year ending 30 September 2018. Available to download from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/782154/Children_s_social_work_workforce_2018_text.pdf

Nursing vacancies in children's hospice organisations

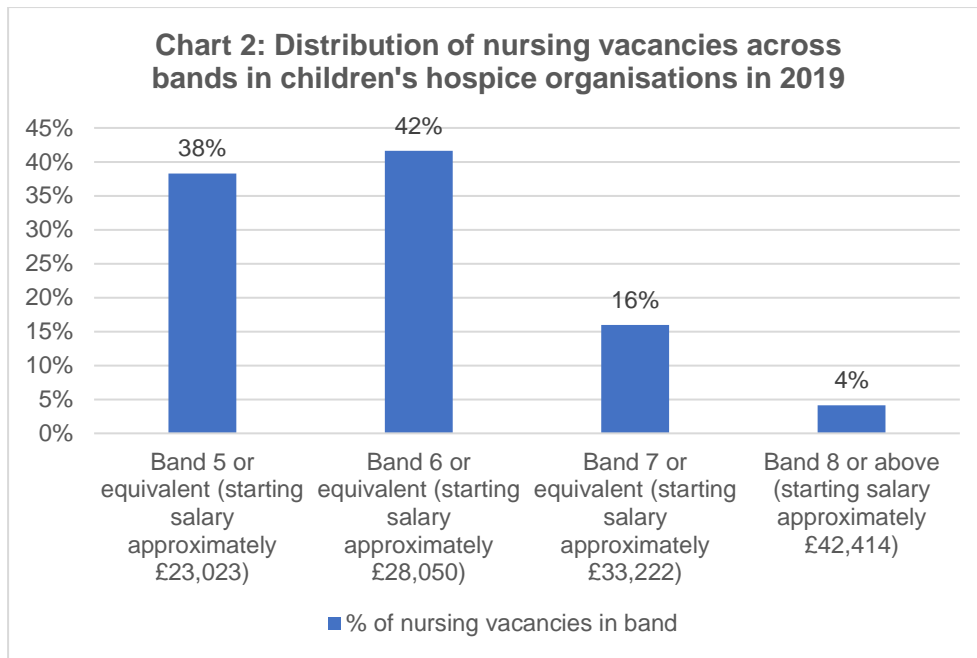
Children's hospice nursing workforce size

27. Together for Short Lives carried out a survey of children's hospice organisations in April 2019. In the survey we asked about the nursing vacancy rate currently being experienced by these organisations and how this was having an impact on the services they were able to provide.
28. The current nursing workforce employed across all 34 children's hospice organisations is approximately 872.6 WTE (extrapolated from responses of 24 hospices).
29. As shown in Chart 1, The highest proportion of these (41%) are employed in Band 6 or equivalent (starting salary approx. £28,050), with the second highest proportion (32%) employed at Band 5 or equivalent (starting salary of approximately £23,023).

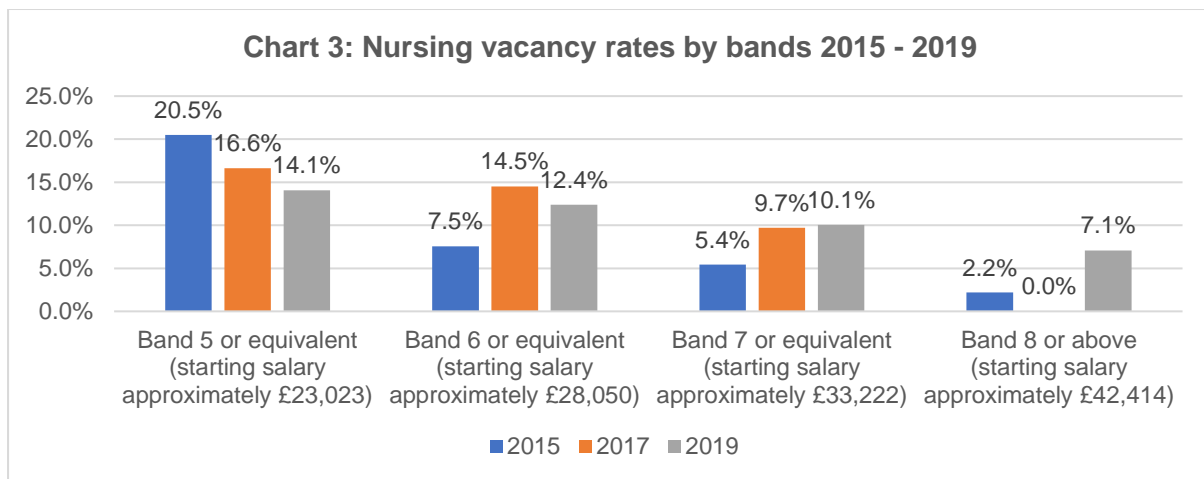


Most nursing vacancies still appear at lower grades, but vacancy rates at higher grades are increasing

30. There are an estimated 120.3 WTE nursing vacancies across the 34 children's hospice charities (extrapolated from responses of 24 hospices).
31. A third of responding hospices (eight, 33%) have a nursing vacancy number of five WTE nurses or more. One hospice reported 16 WTE nursing vacancies, representing half of their workforce.
32. As Chart 2 shows, nursing vacancy numbers are higher in lower bands. 38% of reported vacancies are among those in Band 5 (starting salary approximately £23,023), while a further 42% are in Band 6 (starting salary approximately £28,050).



33. Chart 3 shows how this distribution has changed since 2015 and 2019. While nursing vacancies are more common in the lower bands (bands 5 and 6), there has only been an increase in share of vacancies in bands 7 and 8 since 2017. While the proportion of nurses employed in Band 8 (starting salary approx. £42,414) is low, it is this band that has seen the most significant increases from 2015 and 2017 (7.1% of vacancies in 2019, compared to 0% in 2017 and 2.2% in 2015). These percentages equate to 5 WTE Band 8 vacancies in 2019, 0 in 2017, and 1.5 in 2015.

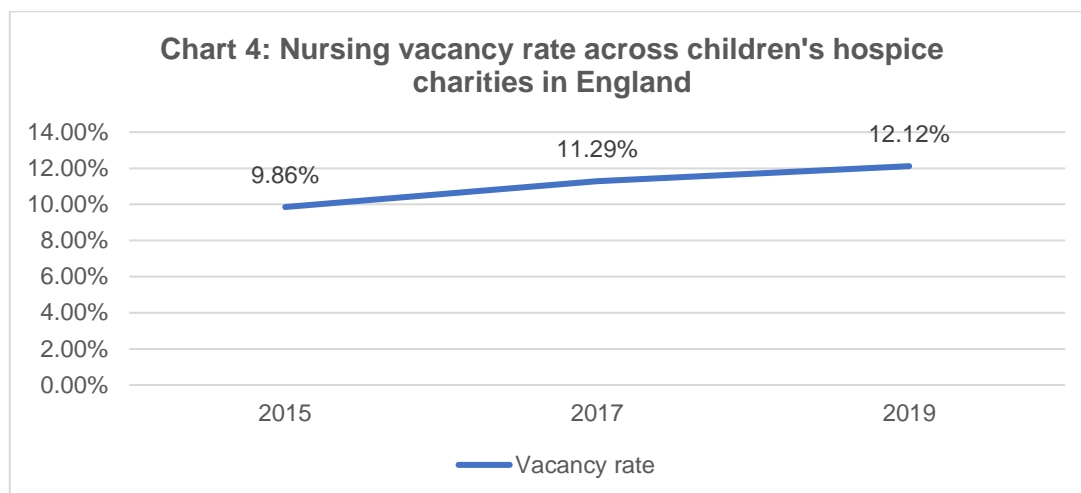


The overall vacancy rate in children’s hospice organisations is increasing and remains higher than the NHS

34. From the 24 responses we received, we calculate that there are approximately 120.3 nursing vacancies and 872.6 nursing posts filled across the 34 children’s hospice organisations in England. This brings the total potential workforce (current workforce + current vacancies) to 992.9 WTE nurses.

35. The overall nursing vacancy rate in children’s hospice organisations is increasing. The vacancy rate for children’s hospice organisations in England is 12.12%, compared to just

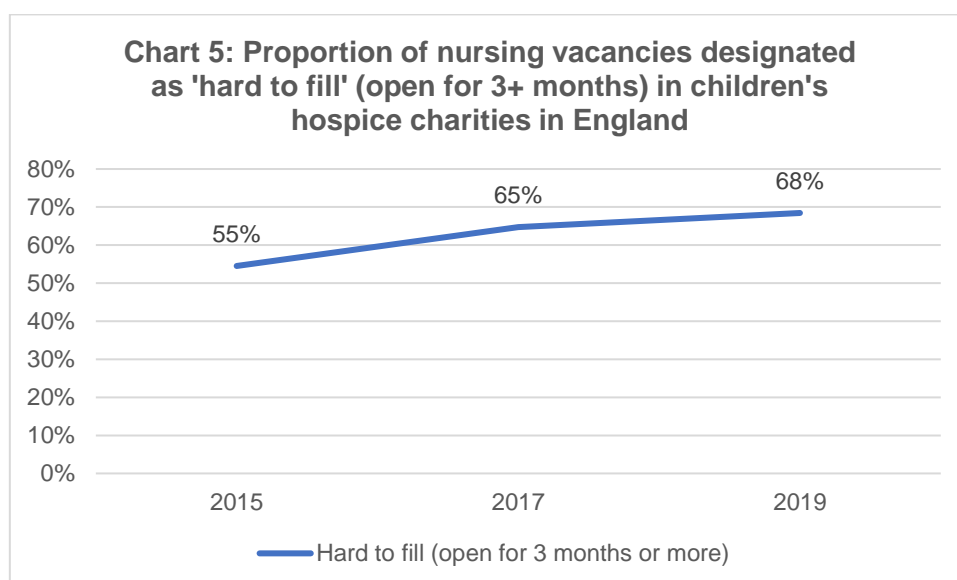
over 11% in 2016 and just under 10% in 2015 (Chart 4). This represents 84.9 WTE nursing vacancies across the 24 children’s hospice organisations we heard from.



36. The overall NHS nursing vacancy rate in England was 11% in Q3 of 2018/19^{25 26}, which is also worryingly high.

Vacant posts are increasingly difficult to fill

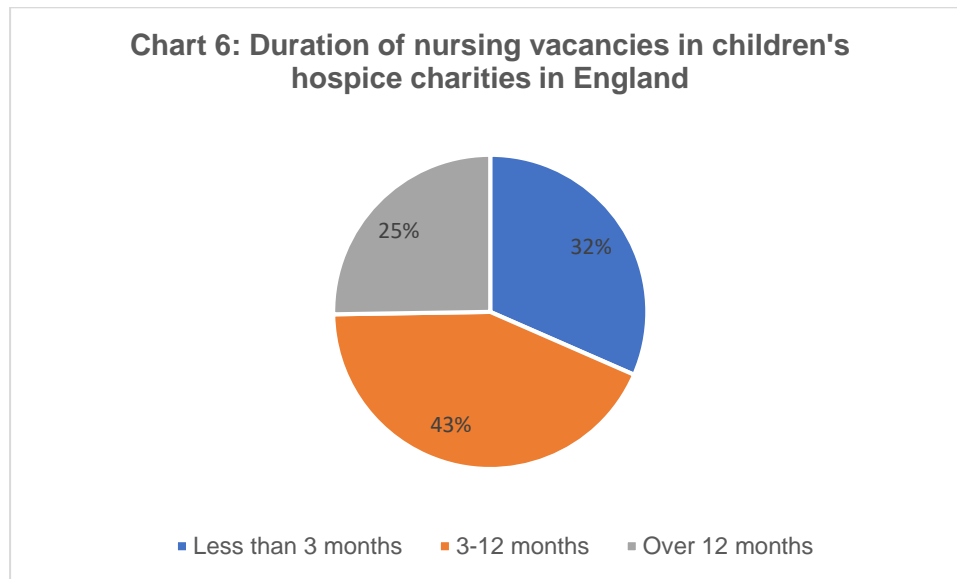
37. It is getting harder for children’s hospice organisations to fill vacant nursing positions. Children’s hospice organisations reported that 68% of vacant posts were hard to fill (vacant for three months or more at the time of reporting). This is an increase on the 65% who reported that posts were hard to fill in 2017, and the 55% who reported the same in 2016 (Chart 5).



²⁵ NHS Digital. 2019. NHS Vacancy Statistics England, February 2015 - June 2019, Provisional Experimental Statistics. Available to download from: <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-vacancies-survey/february-2015---june-2019-provisional-experimental-statistics>

²⁶ NHS Digital. 2019. NHS Workforce Statistics - June 2019. Available to download from: <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics/june-2019>

38. 25% of vacant posts have been unfilled for over a year (Chart 6). This proportion was the same in 2017, but in 2015 no vacancies had been left unfilled for more than a year.



39. Prolonged short-staffing like this can have a big impact on the levels of service children's hospices can offer, and their capacity. It means children's hospice services may rely on locum staff to fill gaps, impacting on the cost-effectiveness and sustainability of their services.

40. The difficulty filling these vacancies also has implications for the welfare of the existing workforce who can be overstretched in trying to deliver quality services to as many families as possible without the necessary resources or support.

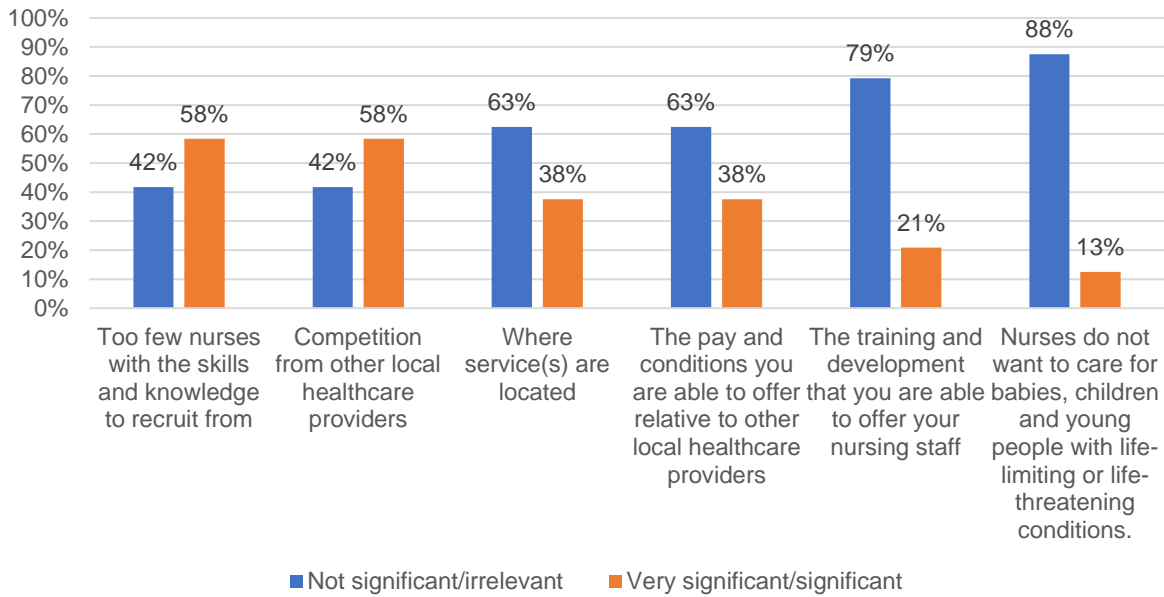
There is a lack of skilled nurses to fill the posts, and competition with other healthcare services is presenting challenges

41. As Chart 7 shows, the most common explanation for children's hospices' nursing vacancies was that there are too few nurses with the skills and knowledge to fulfil the roles. 14 of the 24 (58%) children's hospices we heard from reported that this had had a significant or very significant impact on their vacancy rate.

42. The same number cited competition from other local healthcare providers as the other major reason for their vacancy rate.

43. The most insignificant reason was 'nurses do not want to care for babies, children and young people with life-limiting or life-threatening conditions'. Only three hospices (13% of the 24 we heard from) felt this was significant.

Chart 7: Challenges facing children's hospice charities when recruiting nurses



The impact of the crisis on seriously ill children, young people and their families

44. Young people and families have told us about the impact that the children's palliative care workforce crisis is having on the services they are able to access. The following are a selection of quotes which give a sense of the issues that thousands of children and families are facing:

"I am on NHS Continuing Care. Three years ago I was sent a letter confirming that I am entitled to 24 hour care. However, this just hasn't materialised. I have been fighting for the last 21 months in order to get 64.5 hours a week of care, which is nowhere near 24 hour care. Every time I have tried to ask for more hours or more support for our family I have been threatened with a care home, at the age of 21. This is wielded as a threat across CCG's to young people all over the country. It's unfair to play with someone's life like that."

Hannah Hodgson, a young person with a life-limiting condition

"Sam was approved for continuing health care as his medical needs have increased. We opted to have agent care cover but so far neither of the two who have been engaged have managed to find any staff for the times we need them.

"Ideally we would like Sam to have somewhere overnight away from the house to go. This gives us a proper break and him some independence, he is almost a teenager now. We do have hospice care but this is very limited.

"My husband is a nurse and has had to all but give up his job to be a carer."

Jenny, a parent of a child with a life-limiting condition

"Daniel requires a lot of complex medical care. Agencies weren't able to provide this and we were left with no overnight care most nights. We moved onto a personal health budget and have found carers now, although this was difficult: the pay we could offer them was nowhere near suitable for the amount of responsibility they have. I have had to resign from work and receive no financial help, which again puts a strain on things.

"We have had hospice respite stays cancelled quite often due to staffing issues. As a member of the parent's forum at our children's hospice staffing issues are always addressed but attraction and retention of support workers and nurses is difficult when they aren't able to match the salary and package they would get in other roles, NHS for example.

"To attract staff which are absolutely vital to support us then we and our hospices need to be able to offer them a package to reflect the difficult mental/physical aspects of the role and the responsibilities they have.

"A nurse left to work in a supermarket. Less responsibility, better hours, attractive pension, higher salary. This makes me incredibly sad."

Jodie Smith, a parent of a child with a life-limiting condition

“As my son has recently reached the continuing care threshold the CCG are providing a care package for us for the next 6-8 weeks. It is a problem finding the right staff and making sure they turn up for day and night shifts. However it has also opened my eyes to how little help we get on a regular basis and I am battling to try and get more help long term - both day and night. We presently have no respite provision so we never get a break from 24/7 care for Fergus. This not only affects me and my husband but more importantly his 17 year old twin brother and sister who are constantly woken up at night and don't have as much of me as they should.”

“We live in a rural area, and therefore it is difficult to recruit the right people to meet Fergus' needs and for him to mix with his peers and have any sort of 'social life'. The carers we do have have to be trained by us to administer his medication and be able to feed him through his gastrostomy feeding tube.”

Gail Bedding, a parent of a young person with a life-limiting condition

The impact of the crisis on children's palliative care services

45. Children's palliative care providers have also spoken publicly about the negative impact that workforce shortages are having on the care and support they are able to provide. Some have stated that a lack of access to fully trained specialists for advice and support is resulting in some poor practice.

"With support, people are really willing, but actually there is an enormous amount of work. The teams who are working in this area are overwhelmed. We've got many single-handed consultants, nationally, who are totally overwhelmed, with actually being the only one who is holding up their region and that is not sustainable."

Dr Renée McCulloch

The All-Party Parliamentary Group for Children Who Need Palliative Care oral evidence session: how the government is meeting its commitment to choice for babies, children and young people who need palliative care

Session 5: 7 March 2018

"I think that's so important because it touches on burnout from two angles, there's the burnout that could affect a single specialist managing a patient who then are overstretched. But, actually it's really well known that people who are inexperienced and haven't had enough training are being asked to care for dying children themselves. They face discomfort, burnout, you know sick leave will increase."

Dr Emily Harrop (Chair, NICE Clinical Guideline Development Group). Dr Harrop is also Consultant in Paediatric Palliative Care at Helen and Douglas House Hospices.

The All-Party Parliamentary Group for Children Who Need Palliative Care oral evidence session: how the government is meeting its commitment to choice for babies, children and young people who need palliative care

Session 5: 7 March 2018

46. Understaffed CCN services often provide round the clock care to children at the end of lives through good will:

“You’ve got our nursing team and physios that are doing their day job, with all the other children they’re looking after, and then they get a child for end-of-life care. The nurses that actually do the day job are providing the on-call at night...so I could be working all day today and then I’m also on call and then could be called out for quite a period in the night... Because of the goodness in our hearts and the care that we have for our families, we provide family choice and that’s because of the care and dedication of the team, not because there’s resources and things set in place.”

Julie Potts (Diana Service Palliative Care Lead Nurse, Leicestershire Partnership NHS Trust)

The All-Party Parliamentary Group for Children Who Need Palliative Care

Oral evidence: how the government is meeting its commitment to choice for babies, children and young people who need palliative care

Session 3: 21 February 2018

47. Children’s hospices concerned about their nursing vacancy rates cite them as a factor in the decisions they have made to cut short breaks for respite and hospice at home services in the community:

“As a hospice charity committed to caring for the most medically complex children and young adults, and doing so in the most challenging of situations, a shortage of skilled nursing staff can significantly affect our service. There are occasions where we are unable to fill all beds due to the acuity and complexity of those in need of our care, and it is true to say that a shortage of nurses has resulted in us having to take some difficult decisions in the ways we expand and develop our service.”

Naomi House & Jacksplace

The extent to which the government, health workforce planners and education providers are acting to resolve this crisis

48. In September 2019, the Chancellor of the Exchequer announced a £210 million package of measures designed to better educate and train NHS staff in England²⁷. This included funding for a £1,000 personal development budget for every nurse, midwife and allied health professional to support their personal learning and development needs over three years.
49. Despite this, Together for Short Lives is concerned by the extent to which the government, health workforce planners and universities in England are taking the action needed to address the shortfall in children's palliative care professionals.
50. There is no evidence which suggests that Health Education England (HEE) is assessing shortages in voluntary children's palliative care sector medical or nursing workforce as part of its work to model the demand for professionals.
51. While we welcome the competency framework for end of life care which HEE commissioned and which Skills for Health and Skills for Care published in 2017, we are concerned that it only relates to care for adults who are likely to die within the next 12 months.
52. We are concerned that a paucity of education, learning and development opportunities specific to children's palliative care which is hindering local access to training.
53. Overall, the RCPCH has identified what it considers to be an incoherent and inconsistent approach to planning for the child health workforce²⁸.
54. The RCN has highlighted to us three issues which is it particularly keen for the government to address:

Funding for nursing higher education in England

55. RCN states that investing in nursing higher education for all nursing students, without isolating different fields of nursing over another, is the only way to grow the nursing workforce at the scale and pace needed to increase the overall supply across the system in England. It states that nursing students need better financial support which is better than the previous bursary system.

Funding for nursing professional development

56. RCN states that the recent funding increase announced by the government²⁹ must be put in the context of large decrease of continuous professional development (CPD) funding for HEE in the past five years: RCN states that the budget for the non-medical workforce has fallen from £205 million in 2015/16 to £114.5 million in 2019/20.

27 HM Government. 2019. Career boost for almost half a million frontline NHS staff. Available to download from: <https://www.gov.uk/government/news/career-boost-for-almost-half-a-million-frontline-nhs-staff>

28 Royal College of Paediatrics and Child Health. 2018. Workforce briefing. Available to download from: <https://www.rcpch.ac.uk/resources/workforce-briefing-2018>

29 HM Government. 2019. Career boost for almost half a million frontline NHS staff. Available to download from: <https://www.gov.uk/government/news/career-boost-for-almost-half-a-million-frontline-nhs-staff>

Accountability for workforce planning and supply in law in England

57. RCN expresses its concern that there is currently no legal accountability for provision of staffing for taxpayer funded services. It cites the lack of a legal framework that clarifies roles, responsibilities, and accountability for supplying, recruiting, retaining and paying nursing staff and the wider workforce.

The action we recommend

58. We are concerned about the fact there are too few professionals with the skills and experience needed to provide children's palliative care in different settings. We believe that the government, HEE and others have a vital role to play helping to reduce the vacancy rates among key groups of children's palliative care professionals – and making it easier for providers to recruit the staff they need.

59. Together for Short Lives supports the call from RCPCH that, to meet the challenges of making sure that there enough professionals who have the skills, knowledge and experience to meet the needs and wishes of children and families:

- The existing workforce should be mapped to establish a baseline and service delivery assessed against required standards
- General paediatric consultants with an interest in paediatric palliative care should be available in all paediatric centres as part of a formalised, commissioned managed clinical network
- A strategic group of stakeholders should develop clear service specifications (from secondary to specialist level) alongside an education and training plan for expanding the workforce
- A robust process for training and assessing children's palliative care professionals should be developed. There is an urgent need to develop a training and education model that delivers a fit-for-purpose workforce, able to support the complex clinical care of children with life limiting conditions across the spectrum of paediatric practice, including in hospitals and critical care units and also in hospices and at home.

60. Together for Short Lives welcomes the work of 'Managing Complexity in Children's Healthcare: A Partnership for Change'³⁰, a group of individuals and organisations committed to working together and sharing good practice and resources. This collaborative aims to improve the healthcare of children with medical complexity and their families – and provide support and educational materials for the professionals looking after them.

61. We also welcome the work of the Children's Palliative Care Education and Training National Action Group. This is supporting work to design, develop and manage a sustainable, standardised approach to educating and training children's palliative care professionals in the UK. We ask HEE and the Council of Deans of Health to work with us to make sure that this approach becomes embedded in education and training for all children's palliative care professionals in England.

62. Together for Short Lives believes that the forthcoming NHS People Plan should set out the actions that are needed to make sure seriously ill children and their families are well supported by children's palliative care professionals. NHS Long Term Plan states that children's palliative care is a priority. Statutory, voluntary and independent sector providers will all be crucial in making sure that seriously ill children are able to access the palliative care they need. On this basis, it is vital that the NHS People Plan helps to secure a sustainable children's palliative care workforce across all of these sectors. We ask that the plan commits to the following:

³⁰ Managing Complexity in Children's Healthcare: A Partnership for Change. 2019. <https://collaborative.whitefuse.net/>

Health Education England

- Urgently assess the gaps in the children's palliative care workforce across the range of professions who care for seriously ill children, across hospitals, children's hospices and community services.
- Assess the demand for nurses from children's hospice organisations and the independent sector and include it in their planning models.
- Develop a core skills education and training framework for children's palliative care; this could help employers to identify key skills for roles and teams, conduct training needs analysis and plan, design and commission appropriate levels of and systems for training. This could also ensure robust peer review systems can be established.
- Focus specifically on outlining career pathways and providing guidance for delivering outcomes-led education for children's palliative care nurses.

NHS England and NHS Improvement

- NHS England and NHS Improvement specialised commissioning team and Health Education England to urgently fund NHS trusts to create specific medical training posts. This would help to make sure that paediatric palliative care special interest training (SPIN) can take place.

Education providers

- Education providers should make sure that children's palliative care is embedded in undergraduate and postgraduate medical and nursing courses; we note that children's palliative care should be embedded in nursing courses in a way that is consistent with existing regulations³¹.
- If it is found that there are too few children's nurses likely to fill posts across all types of healthcare provider, for example, universities should increase the number of places they offer to undergraduates.

The government

- The government to make sure that the UK's exit from the European Union does not have an adverse impact on the supply of children's palliative care professionals from across the world.
- The government should follow the RCN's recommendations and:
 - invest at least £1 billion a year into nursing higher education
 - invest at least £360m per year for nurses' continuing professional development
 - legislate for accountability for workforce supply and planning in law in England.
- The government should make sure that HEE has the resources to take the action we call for above.

³¹ Nursing and Midwifery Council. 2019. Standards. Available to download from: <https://www.nmc.org.uk/standards/>

For more information

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