

# Palliative care education in neonatal units: impact on knowledge and attitudes

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## ABSTRACT

**Objective** To facilitate improved and earlier access to palliative care for babies, a 4-h workshop on the principles, practice and resources in palliative care was delivered in 21 neonatal units across London. This paper assesses the impact of these workshops.

**Design** As part of mixed methods, processual evaluation of a series of education workshops, a pre and post survey instrument was developed, consisting of open and closed questions assessing knowledge of services and attitudes towards palliative care. Before and after each workshop attendees were invited to complete the survey.

**Setting** Neonatal units in hospitals across London, including examples of intensive care, high dependency and special care units.

**Results** 331 healthcare professionals attended the sessions, and 264 (80%) completed questionnaires. The majority of attendees were experienced neonatal nurses working in neonatal intensive care (61% more than 7 years) but with limited experience of palliative care services. Over 79% of respondents reported that the workshop completely met their learning needs. Post-session 80% of respondents felt confident referring to palliative care services, compared with 46% before ( $p < 0.001$ ). Analysis of open and closed text responses revealed a shift in attitude after the sessions from a focus on dying/end-of-life, towards integrating palliative care as part of a holistic treatment plan.

**Conclusions** A short (half day), locally delivered workshop can change attitudes and increase knowledge in neonatal staff. Such a workshop can serve as a first step in facilitating access to and utilisation of a variety of palliative care services.

## INTRODUCTION

More children die in the neonatal period than at any other period of childhood.<sup>1</sup> Most die in the acute care setting or

in neonatal intensive care (NICU)<sup>1–3</sup>. Improvements in perinatal medicine have led to increased survival for those born at lower gestations, low birth weight and with complications associated with birth asphyxia and some congenital abnormalities.<sup>4–6</sup> Despite these improvements, perinatal health professionals continue to be faced with significant mortality in the neonatal period and a cohort of survivors with complex health needs.<sup>2,4</sup> Increasingly, policy and practice guidance advocates palliative care as an integral part of perinatal service provision.<sup>7</sup>

Perinatal palliative care focuses on the prevention of pain and distress of the infant, and on the psychological, social and spiritual support of the family.<sup>7–10</sup> The aim is to provide active neonatal care concurrently with palliative and supportive care, ideally from time of diagnosis of a life-limiting or life-threatening condition.<sup>8,11,12</sup> Although neonatal staff are experienced in managing seriously ill babies, including attending to symptom management during their final hours of life, research has shown that infants who receive a palliative care consultation undergo fewer medical procedures and receive more supportive services than those without a palliative care consultation.<sup>13</sup>

The British Association of Perinatal Medicine has outlined the following candidate conditions for which palliative care referral is appropriate: (1) an antenatal or postnatal diagnosis of a condition which is not compatible with long term survival; (2) an antenatal or postnatal diagnosis which carries a high risk of significant morbidity or death; (3) babies born at the margins of viability, where intensive care has been deemed inappropriate; (4) postnatal conditions with a severe impairment of quality of

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life and when the baby needs or may need life-support; (5) postnatal conditions where the baby experiences 'unbearable suffering'. Similar guidelines have been issued by organisations in the US.<sup>14 15</sup>

While several organisations have endorsed the need for perinatal palliative care referral<sup>7 11</sup> and the education of neonatal healthcare staff in the principles of palliative care,<sup>14 16</sup> palliative care provision in neonatal care is often 'ad hoc'.<sup>17</sup> For example, a retrospective service review of NICU patients at a hospital in Wisconsin over a 2-year period found that only 24% of critically ill infants were referred to palliative care.<sup>18</sup> In the UK, neonatal referral to palliative care services is known to be disproportionately low compared with paediatric referrals.<sup>19</sup>

Lack of knowledge of services among neonatal nurses and the association of palliative care with the end of 'active' care have been found to be barriers to palliative care referral.<sup>17</sup> In part, this appears to stem from a lack of education and training.<sup>20 21</sup> In a survey conducted in the US with 285 neonatal physicians and nurses, two thirds of respondents reported that education on the palliative care process would enhance referrals.<sup>21</sup> Another survey of 50 NICU nurses in the US found that 100% reported educational needs around palliative care, and only 46% had received any previous training.<sup>20</sup> Likewise evaluations of residency programmes have found a lack of palliative care education offered to paediatricians and neonatologists.<sup>22-24</sup>

There is, however, very limited empirical research on educational interventions in NICU settings<sup>1 13 25 26</sup> as well as in paediatric settings. Rogers *et al*<sup>27</sup> evaluated a 6 month educational course in end-of-life care delivered by a hospital ethics committee and hospice specialists to NICU nurses. The evaluation showed promising results, with nurses reporting increased comfort and knowledge in pain and symptom management and in ethical and legal issues. Bagatell *et al*<sup>28</sup> evaluated a discussion-based seminar series conducted with paediatric residents. The eight participating residents reported increased comfort in the delivery of palliative and end-of-life care after the programme.<sup>28</sup> The sum total of research on enhancing professionals ability to deliver palliative care, together with research that has shown that nurses who have experience with paediatric palliative care services are more likely to refer children before the end-of-life,<sup>29</sup> would suggest that an intervention aimed at both increasing understanding of the principles of palliative care and improving links with local services could make a difference in practice and the utilisation of palliative care services.

In this paper, we report the results of an evaluation of a half-day educational programme delivered to neonatal staff across London, UK. The aim of the programme was to increase knowledge of palliative care principles and to familiarise neonatal staff with the range of services available to them in their area (including specialist, community and children's

hospice services), as a first step in facilitating access to and utilisation of palliative care services in the perinatal period.

## METHODS

### Educational programme

The educational programme was designed by a neonatal nurse (AM) and a palliative care consultant (FC). It was piloted in seven NICU units in London and was modified based on feedback.<sup>30</sup> A brief summary of the course content is outlined in table 1. The sessions were tailored to reflect each unit's local needs and resources.

Twenty-five neonatal units were invited to host a session. Participating NICU units were asked to provide a room and refreshments for attendees, and to advertise the session in their unit with a poster provided by the project team. AM followed up with individual invitations in writing and by telephone. Twenty-one units were able to accommodate a session. The sessions were also advertised on the UK London-wide Neonatal Network website. Attendance was voluntary, free and did not require pre-booking. Hand-outs of course content and certificates of attendance were provided for participants.

### Evaluation methods

Evaluation of the half-day (4 h) workshop/educational intervention included a pre- and post-survey of workshop attendees, systematic observation of the education sessions, and tracking of referrals to palliative care services. In this article we report the findings from the survey.

The survey instrument was developed by three authors (MB-L, PK and AM) in consultation with experts in paediatric palliative care, following a review of recent literature.<sup>23 31</sup> Face and content validity of the developed instrument was pre-tested with eight neonatal healthcare professionals not involved in the educational programme. The instrument included a mixture of multiple choice, Likert scale and open-ended questions addressing: (1) Demographic

**Table 1** Workshop session overview

Topics covered	Presenters
<i>Principles of Palliative Care</i> Antenatal and perinatal palliative care definitions and guidelines; care plans; informed choice; family support.	Consultants in Paediatric Palliative Care from a specialist palliative care team in a tertiary care centre (Including MK, FC)
<i>Services provided locally</i> Services and resources available.	Presenters from hospices and community teams serving the unit catchment area
<i>Referral &amp; Resources</i> Useful documents and legislation; care planning.	Neonatal Matron (AM)
<i>Neonatal Case Presentation and Discussion</i>	Neonatal Matron (AM) and attendees

background, (2) clinical and palliative care experiences, (3) knowledge of palliative care services and resources, (4) attitudes to palliative care, (5) confidence in skills related to palliative care, (6) perceived barriers and facilitators to integrated neonatal palliative care and (7) perceived impact and learning from the education session. The instrument is available from the corresponding author.

Attendees were asked to complete the pre-session questionnaire on arrival at the session, and the post-session questionnaire immediately following the session. Those who needed to leave the session early were provided with a stamped addressed envelope to return their post-session questionnaire by mail. The survey responses were anonymous, with pre and post questionnaires linked by an identification number.

Analyses of the quantitative data were performed with the statistical package for social sciences SPSS V.18.0. To compare the responses with Likert scale questions in the pre and post questionnaires, the mean response scores were calculated for each question and paired samples *t*-tests conducted with a 95% CI. In relation to a statement respondents were asked to select one of five options: strongly disagree, disagree, neither agree or disagree, agree, and strongly agree. In analysis, the minimum score was one (strongly disagree) and the maximum score was five (strongly agree). McNemars test was used to detect any change in responses to binary variable questions. Responses to the open-ended questions were imported into the qualitative software package NVivo, and coded thematically by two members of the evaluation team (BM and KT). Differences between pre and post-session open-text responses were interrogated for how they related to barriers and facilitators to referral to palliative care services.

## RESULTS

### Characteristics of sample

Three hundred and thirty-one healthcare professionals attended an education session in one of the 21 neonatal units in London. Overall, 264 filled in a survey—a response rate of 80%. Two hundred healthcare professionals returned both questionnaires, 44 returned the pre-session questionnaire only, 20 returned the post-session questionnaire only, and 67 returned neither questionnaire. Non-respondents to individual surveys are counted as missing data.

Table 2 shows the gender, profession, clinical service specialty, years of work experience of respondents and those respondents who had no previous experience of referring to palliative care services. The majority were nurses and doctors from NICU. We asked participants who were working in NICU units to identify the type of neonatal service they worked in, these included units that focussed on: (1) babies with complex health needs, requiring mechanical ventilation and continuous supervision by nursing and

**Table 2** Characteristics of respondents (n=264)

Characteristics	No. of respondents	Percent
Gender		
Female	228	86
Male	12	5
Missing*	24	9
Profession		
Nurse	173	66
Doctor	27	11
Other†	39	15
Missing*	25	10
Clinical service speciality		
Neonatal intensive care	193	73
Paediatric hospital services	24	9
Maternity services	12	5
Other‡	14	5
Missing*	21	8
Work experience		
>7 years	123	47
1–6 years	42	16
<1 year	36	14
Missing*	64	24
Experience of referring to palliative care services		
Never	160	60
Rarely	28	11
Occasionally	18	7
Regularly	6	2
Missing*	52	20

\*Missing data includes those who arrived late and did not fill in the pre-education questionnaire (n=20)—only the pre-questionnaire contained demographic questions—and those who did not respond to individual questions.

†Included: student (n=7), nursery nurse (n=6), midwife (n=6), chaplain (n=4), health visitor (n=2), paramedic (n=2), psychologist (n=2), counsellor (n=2), speech therapist (n=2), occupational specialist (n=1), family support worker (n=1), care coordinator (n=1), play specialist (n=1), project manager (n=1), and a visiting fellow (n=1).

‡Included: Community Children's Nursing Services (n=5), Community Health Services (n=4), Children's Hospices (n=2), Paramedic (n=2), Bereavement services (n=1).

medical staff (2) babies requiring continuous monitoring and potential non-invasive ventilation or recovering from procedures and (3) babies not yet able to be cared for at home. Analysis of responses by the level of dependency routinely managed in the unit showed no differences in knowledge or attitudes to palliative care.

There were varying levels of work experience reported by the respondents, but the majority had at least 7 years of experience. Most of the sample (60%), however, had never referred to a specialist palliative care team, a community based palliative care team, or a children's hospice.

### Respondents' evaluation of the education session

One hundred and eighty four (86%) respondents reported in the post-education questionnaire that

**Table 3** Expectations met during the education session

Expectations met (n)	Completely	Somewhat	Not at all
How well did the session meet your expectations? (214)	184 (86%)	30 (14%)	0 (0%)

overall the session had completely met their expectations, and 30 (14%) that the sessions had somewhat met their expectations. No respondent reported that the session had 'not at all' met their expectations (table 3).

#### New learning and confidence

Table 4 shows how respondents rated the degree to which their learning needs were met in the education session. An average of 78% felt that their learning needs were met 'completely' across the different topics. More specifically, the majority of participants reported that their need for 'additional knowledge on the potential for antenatal palliative care' had been completely met (n=180, 83%). Fewer reported that 'insight into parents' information needs' had been completely met (n=159, 74%).

A comparison of responses to statements designed to assess attendees' knowledge of palliative care services and referral procedures before and after the session is recorded in figure 1. A higher score represents a greater level of agreement. The results show a significant increase in healthcare professionals reporting familiarity with the various services available for palliative neonates in their unit (statements 1–4), and about resources to support palliative care (statement 5) ( $p<0.0001$  for each statement) post the education session. In considering the opportunities for parents and the scope of palliative care, post the education session fewer agreed with statement six 'In my unit parents are informed about palliative care

**Table 4** Learning needs met in the education session

Learning needs (n)	Completely	Somewhat	Not at all
Additional knowledge on the potential for antenatal palliative care (217)	180 (83%)	36 (17%)	1 (0%)
Information about palliative care relevant to your practice (216)	174 (81%)	41 (19%)	1 (0%)
Insight into the potential for integrating palliative care in the neonatal environment (216)	171 (79%)	44 (20%)	1 (0%)
Resources to enhance palliative care provision (214)	170 (79%)	42 (20%)	2 (1%)
New learning about palliative care for babies receiving neonatal care (217)	167 (77%)	47 (22%)	3 (1%)
Insight into parents' information needs (215)	159 (74%)	55 (26%)	1 (0%)

options' ( $p<0.001$ ) and statement seven 'addressing pain and symptom management is the main goal of palliative care' ( $p<0.0001$ ).

Attendants reported increased confidence in referring to palliative care services after the session (figure 2;  $p<0.001$  for each service). In the post-education questionnaire, 90% of respondents reported having enough information to now make a referral to a tertiary based paediatric palliative care team, 87% to a children's hospice, and 81% to their local community children's nursing service and community palliative care team. Less than half the sample reported feeling confident in referring to these services before the session.

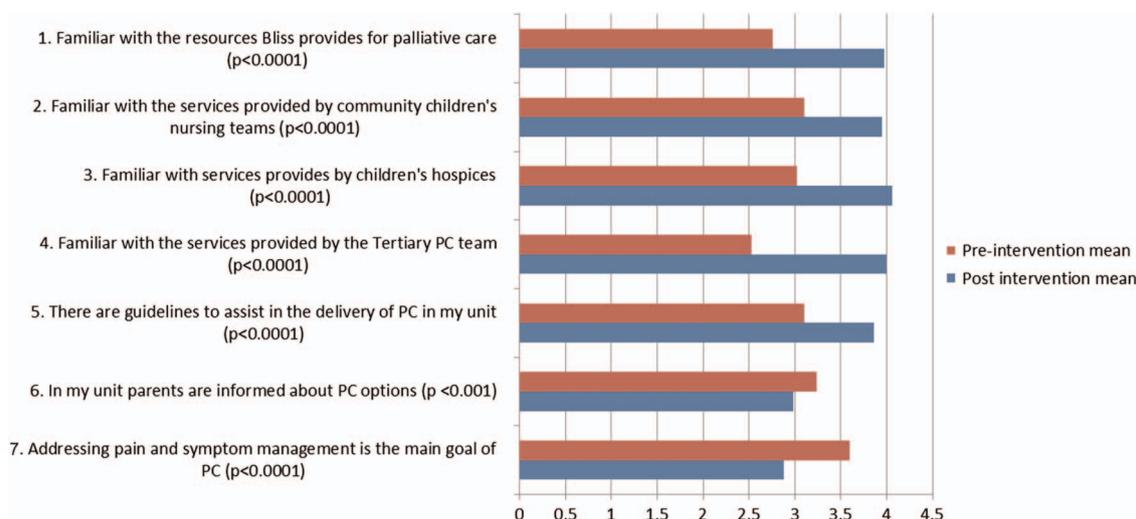
#### Impact on attitudes

Survey responses post-session demonstrated a more positive attitude to palliative care than before the session (figure 3). Fewer participants agreed with the statements: 'Referring babies to palliative care will undermine parents' hope' (pre 21% vs post 8%;  $p<0.001$ ) and palliative care is primarily about providing care at the end-of-life (pre 34% vs post 12%;  $p<0.001$ ). Both before and after the session, most respondents agreed with the statement 'Palliative care is as important as curative care in the neonatal environment' (pre 86% vs post 85%).

Similarly, respondents' views on barriers for integration of palliative care in neonatal services did not change significantly following the session with respect to agreement with the statement: 'There are major barriers to integrating palliative care services into neonatal care' (pre 45% vs post 43%). However in relation to opportunities for integration again a more positive view was demonstrated, with significantly more respondents agreeing with the statement: 'There are significant opportunities for integrating palliative care services into the neonatal environment' (pre 77% vs post 92%;  $p<0.001$ ). These results are illustrated in figure 3.

One hundred and forty-three (54%) participants responded to the open text question 'What comes to your mind when you think of palliative care?' Pre-session, the majority of responses indicated an association of palliative care with death and dying with the words 'terminal', 'incurable', 'dying/death' or 'end-of-life' used by 88 (62%) participants. Post-session these words and phrases appeared in only 18 (13%) participants' responses. Eleven (8%) respondents explicitly noted that palliative care was about more than just end-of-life (which none did in the pre-education survey).

Where participants' responses showed a shift in attitude, emphasis moved away from a focus on dying/end-of-life and towards enhancing the life of neonates and their families, and towards integrating palliative care as part of a holistic treatment plan from diagnosis. For example, in the pre-workshop questionnaire

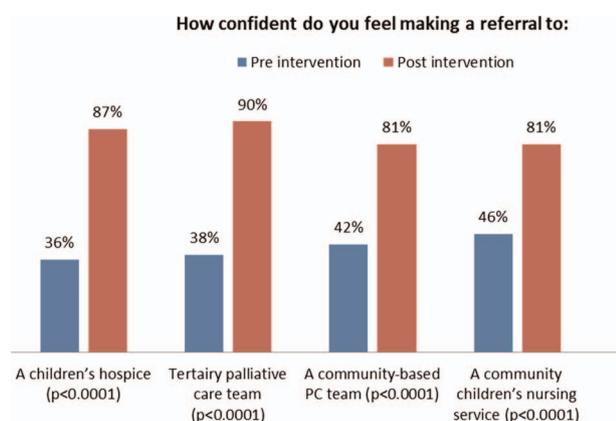


**Figure 1** Knowledge of palliative care (PC) services before and after the education session (n=200).

one respondent wrote: 'Death is the first thing that comes to my mind whenever I think of palliative care and also a supportive management of end of life.' In the post-education questionnaire she/he wrote: 'I now have insight and knowledge about palliative care, that it is not just about death but more about supporting families when dealing with the medical diagnosis of their loved ones.' Another wrote in the pre-questionnaire: 'End of life care' but in the post, 'Quality of life for children/babies with life limiting conditions and choice for parents'. And another: 'The end of life, grieving parents and family', changing to 'Support, integrated care, respite for families' after the session.

## DISCUSSION

After the 4-h session respondents reported increased knowledge of palliative care services, more confidence in their ability to make referrals, and expressed a

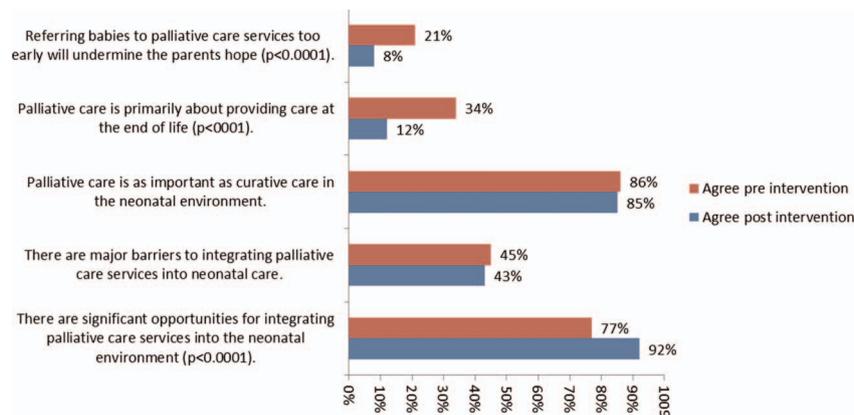


**Figure 2** Confidence in referring to palliative care services before and after the intervention (n=200).

more positive attitude to the role of palliative care for neonates. Feedback on the session was also positive, indicating that the session was well received. These results echo those of previous studies which also report increased knowledge and confidence<sup>27 28</sup>, even as the educational session reported here was considerably shorter than those given and reported elsewhere.

Still to be determined is the impact or role that such an intervention plays on behaviour, more specifically on referral to palliative care services. Theories and studies of behavioural change and learning point to multiple factors necessary to bring about change<sup>32-35</sup>; a change in knowledge and attitudes, such as evinced by this intervention, are necessary but not sufficient<sup>33 34 36</sup>. Other factors, factors in fact commented on by the participants themselves, also play a role in behaviour change and more specifically referral to palliative care services. Among these factors are: clinicians' own understandings of professional roles and responsibilities, their views of parents' preferences and attitudes towards palliative care<sup>32</sup> as well as organisational barriers to palliative care referrals including the hierarchical structure and division of labour within and across clinical teams.<sup>37</sup> Overcoming such barriers will require different kinds of interventions, certainly more than a 4 h workshop provides.

Given the myriad factors which contribute to clinicians' behaviour, it may not be surprising that reviews of interventions to change clinical behaviour have found that multi-component interventions are more effective than educational interventions alone<sup>35 38</sup>. But importantly, a change in knowledge and attitudes acts as a foundation which other intervention strategies can build upon.<sup>39</sup> Education can raise awareness of the need for change, even if on its own it is not



**Figure 3** Impact of intervention on respondents attitudes to palliative care (n=200).

sufficient to effect change.<sup>35 36</sup> Awareness of new knowledge and the need for change was clearly evident in attendees' responses to the open-text question 'What comes to your mind when you think of palliative care?', with some respondents explicitly reflecting on their newly acquired appreciation of the benefits of palliative care referral.

In summary, the educational intervention described here achieved a substantial increase in knowledge of services, confidence in referring to these services as well as a reported change in attitudes towards palliative care. Change in practice will require further work beyond institution of these educational workshops. We are currently conducting an in-depth analysis of the discussions held during the education session with particular attention to the ramifications of the topics raised for practice, and to the barriers participants anticipate in bringing about change. Their remarks were, in part a result of newly acquired knowledge about the benefits of palliative care referral, as well as the opportunity afforded by the session to discuss this information with neonatal colleagues they work with on a daily basis. The analysis will help shape future education and clinical interventions.

Although the attendees were comprised of a self-selected group of primarily neonatal health care professionals who were motivated to attend, the sample was sufficiently large and the differences in knowledge and attitudes were appreciable enough to warrant concluding that a short, locally targeted and delivered educational session can fulfil a felt need by participants that is both beneficial and timely. Moreover, this intervention can serve as an important starting point for perinatal health care professionals to link and engage with a variety of palliative care services; acting as catalyst for change in practice and referral. In short, based on the differences in knowledge and attitudes pre and post the workshop and on previous research on clinical behaviour change, we would recommend such a half-day locally delivered programme as a first step in facilitating access and utilisation of a variety of palliative care services.

### What is already known about this topic

- ▶ More children die in the neonatal period than at any other period of childhood. However despite the benefits of palliative care, few neonates are referred to palliative care services.
- ▶ The majority of these deaths occur in a hospital setting and moreover within a NICU environment.
- ▶ Although educational programmes for perinatal staff in the principles of palliative care are advocated there is minimal evidence on their impact in practice.

### What this study adds

- ▶ A short educational programme delivered within a neonatal unit setting results in high attendance rates and positive attendee feedback on learning needs.
- ▶ A reported change in knowledge and attitudes of neonatal staff offers the potential for improved access to palliative care services for babies and their families.
- ▶ Paediatric palliative care services are positive about working in collaboration with perinatal services to provide palliative care for babies and families, at all points in the illness trajectory from diagnosis (including antenatal) to death and bereavement.

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**Contributors** MBL, FC and AM were responsible for conception and design of the study. MBL, PK and AM developed the survey instrument. RM and PK collected the data. KT and RP analysed the quantitative elements of the survey data. KT and RM

analysed the qualitative survey data. KT, MBL, PK and MK provided interpretation of the data. KT and MBL drafted the article. KT, PK, RM, AM, FC, MK, RP and MBL reviewed and revised the article critically for important intellectual content. All authors provided final approval of the version to be published. MBL supervised the study from conception to completion and is the guarantor.

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**Competing interests** None.

**Ethics approval** The project was registered with the joint university & NHS trust R&D department, approved and conducted as a service development project in accord with National Research Ethics Service guidance (2009) Defining Research. National Patient Safety Agency. NHS.

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## Palliative care education in neonatal units: impact on knowledge and attitudes

Katherine Twamley, Paula Kelly, Rebecca Moss, et al.

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