gain further insight into financial support. A total of 57 responses were received from experts including patients, family carers, academics, policy-makers and health care professionals.

Results Some form of financial support for caregivers was available in all six countries and included national and local support which was aimed at the carer or aimed at the patient and benefitted the carer. The type, extent and reach of financial support varied within and between the six countries and was administered by multiple agencies including healthcare providers, government and charities. Types of support included payments to cover prescription charges, transport costs, medical insurance fees, changes to employment and bereavement benefits.

Conclusion The findings highlight some novel examples of financial support available to family carers, alongside numerous gaps and inconsistencies, both within and between countries. In doing so, this study demonstrates the need for policy-makers, as well as palliative care providers, to learn from other countries' experiences.

Parallel session 2: Transforming palliative care: joint working and system-wide approaches

0-4 A DYING DISCREPANCY: THE ROLE OF THE LAW IN PALLIATIVE CARE PROVISION

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10.1136/bmjspcare-2018-hospiceabs.4

Background One hundred percent of people die, yet not everyone has a good death. Research and policy shows we understand what facilitates a good death. For example, specialist care will be available, symptoms will be managed and people will die in a place of their choosing. However, not everyone gets to die in their preferred place or even have access to adequate pain relief.

Aims (i) To assess, from a medico-legal and bioethical perspective the provision of palliative care funding in England. (ii) To assess the legal obligation of palliative care provision. (iii) To evaluate the role of new law in palliative care provision.

Methods January-March 2017: Assessment of literature, policy, law and practice. April-September: Evaluation of data to form and write an article on the topic of palliative care provision and the need for change in law.

Results There is an exponentially increasing demand for palliative care, (NHS England, 2014) but palliative care is not yet available to all of the current population. Trusts spend anywhere between £186/death to £6213/death, (Hughes-Hallett, Craft, Davies *et al.*, 2011) resulting in an extreme postcode lottery. Moreover, unlike many other parts of care, palliative care is largely provided by charities. As such, palliative care appears not to be a public funding priority and there appears to be a discrepancy in how palliative care is provided and valued.

Conclusion It is argued that the best way to ensure that everyone has equitable access to dying well and that good deaths are supported is to create a legal obligation. This is assessed by application of Human Rights Law and by enacting the Palliative Care Bill.

0-5 A JOINT COMMISSIONING APPROACH TO END OF LIFE CARE IN KIRKLEES

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10.1136/bmjspcare-2018-hospiceabs.5

Discussions with our local CCGs over the last three years have led to a change in our working relationship as part of the development of a Lead Commissioner model for end of life care. This forms a landmark achievement in establishing ourselves as leading end of life services in Kirklees.

This development provides us with the opportunities to:

- Work towards our vision to address unmet need in Kirklees
- Increase involvement in decision making around End of Life care
- Reach new people not currently accessing our services
- Protect existing NHS funding
- Receive commitment from CCGs to keep the development of end of life services at the forefront of their minds.

This will redress the traditional commissioner/provider relationship through:

- Sharing data – supporting and driving the assessment of needs as well as supporting a review of existing service provision in order to identify gaps. This will be the first time in Kirklees that data has been pooled to establish baselines for end of life care key performance indicators across the wider health and social system. System wide data being captured and reviewed jointly on a regular basis will not only improve understanding of overall demand but also help us evidence the impact of the care we provide.
- Agreeing a joint end of life commissioning plan – by establishing the overall system wide cost for end of life care and identifying a route to reinvesting savings, measures will be developed to better understand future demand. This plan will allow joined up approaches to key service development areas.
- Ensuring collaborative partnerships across health and social care – Kirkwood Hospice will take the lead on facilitating a provider alliance and scoping the development of a clinical network. Through alignment of contract monitoring measures there may be opportunity to impact on contract levers to ensure improved knowledge and understanding of end of life care.

0-6 WHY MISSING DATA MATTER-A GUIDE FOR PALLIATIVE CARE PRACTITIONERS

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Evidence-based palliative care is essential to improving the value of palliative care clinical practice. In order to provide this, we not only need *more* research in palliative care but also, crucially, we need *better quality* research. Missing data (MD) present a particular challenge to clinical studies as they reduce the power, precision and generalisability of study findings. Importantly, they can also introduce bias.

Aims This mixed-methods study aimed to (i) quantify the extent and risk of bias of MD in palliative care trials; (ii) explore the factors associated with MD, (iii) develop MD recommendations for patients, clinicians, researchers and policymakers.

Methods (i) Systematic review of MD in 108 palliative care trials (meta-analyses and meta-regression); (ii) individual participant-level data (IPD) meta-analysis of factors associated with MD in 10 palliative care trials (multi-level modelling); (iii) in-depth interviews with research personnel (thematic analysis).

Results (i) Systematic review: 23% of primary outcome data were missing at the primary end-point (95% CI 19, 27). Larger MD proportions were associated with increasing numbers of questions/tests asked of participants (odds ratio (OR) 1.2 per-doubling, 95% CI 1.1, 1.4) and longer study duration (OR 1.1 per-doubling, 95% CI 1.0, 1.2). There was evidence of differential rates of MD between trial arms, thus potentially introducing bias. (ii) IPD: Participants with previous MD (OR 17.2, 95% CI 8.6, 34.5) and poorer Karnofsky Performance Status (10-unit increase: OR 0.8, 95% CI 0.7, 0.9) were more likely to have MD. (iii) Interviews: themes included 'clinical vs research-role tension' and 'attention-to-detail vs attention-to-person'.

Conclusions MD pose a significant risk to palliative care trial findings but can potentially be reduced. It is therefore essential that multi-disciplinary team members can (i) critically assess the MD risk of bias and (ii) help to reduce MD – guidance on how to do these will be discussed.

0-7 HOW SYSTEM-WIDE ADVANCE CARE PLANNING SUPPORT CAN BE DELIVERED COST EFFECTIVELY

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10.1136/bmjspcare-2018-hospiceabs.7

Advance care planning (ACP) can promote person-centred care and better use of resources. ACP involving a facilitated conversation with a health or care professional is more effective than document completion alone. However, these conversations are time consuming. Evidence about how ACP support can be delivered by health and care professionals cost-effectively and at scale is currently lacking.

To explore this issue, we identified twelve international healthcare organisations with practical experience of resourcing, staffing and delivering system-wide ACP support. In each, we conducted an average 13 in-depth interviews with senior managers, ACP leads, dedicated ACP facilitators, physicians, nurses, social workers and other clinical and non-clinical staff. Data were thematically analysed using NVivo software.

Our findings emphasised the importance of strategic and dedicated day-to-day leadership for creating accountability and supporting professionals to deliver ACP support within their roles. Reliance on dedicated facilitators was not considered sustainable or scalable, although a degree of staff specialism improved efficiency and effectiveness and allowed the better targeting of training.

A lack of protected time was commonly experienced as a barrier. Incorporating ACP into existing care could mean it got 'squeezed out' or became too fragmented. Physician leadership was important, but entirely physician-led approaches were associated with late introduction and limited scope. Team-based approaches, involving nurses and social workers,

were recommended for cost-efficiency and quality of care, and were well-aligned well with new models of care.

When used by experienced staff, the choice of ACP conversation tool had limited influence on the length of a conversation. Participants' informational and educational needs, however, significantly influenced the time required for a conversation. There was scope for efficiencies here from the use of decision aids, educational events and activities in the community and group-based facilitations in community and clinical settings.

Parallel session 3: No child left behind? The challenges we face in caring for children

0-8 NURSES' PERCEPTIONS OF CARING FOR CHILDREN AFTER ORGAN DONATION IN CHILDREN'S HOSPICE COOL ROOMS

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10.1136/bmjspcare-2018-hospiceabs.8

Background In Yorkshire, there were five paediatric organ donors in 2017/18. Very limited bereavement support is offered to families whose children donate organs (Berntzen & Bjørk, 2014). Changes to the Specialist Nurse Organ Donation (SNOD) role meant that SNODs felt unable to provide donor families with adequate bereavement support. This led to a broadening of hospice acceptance criteria, where deceased children, without known life-limiting conditions (Widdas, McNamara & Edwards, 2013) could use the cool bedrooms (Forrester, 2008) for post-mortem care, and their families access bereavement support offered by the hospice. Since 2017/18, a total of four children have been cared for post-donation.

Aim To explore the perceptions and experience of registered nurses involved in caring for families of children and young people who have donated organs in children's hospice cool rooms.

Methods A semi-structured focus group was conducted with nurses from the Yorkshire Organ Donation Services Team, and Martin House in March 2018. Purposeful sampling was used (Richie, Lewis, McNaughton Nicholls *et al.*, 2013), based on nurses who either:

- Whilst working as a SNOD, referred a child and family to the hospice following organ donation
- Whilst working at the hospice, cared for the body of a child after organ donation, and their family.

Results Five core themes emerged from the thematic analysis: (i) barriers that prevented families from receiving the care they need, (ii) bereavement support, (iii) impact: on families, SNODs and professionals, (iv) influencers and enablers of change, and (v) sustainability of services.

Conclusions Nurses perceived that families gained much from the bereavement support offered by the hospice, and from being able to spend time with their child's body after death. Although some of the grief experiences of families was different to what hospice nurses were used to, staff gained confidence as their exposure increased. Joint working between the