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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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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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.