Oral Presentations

Parallel session 1.1 – Evidence at the core; questions, routes to answers and reflections
(Monday 6 November 2023, 13:30 – 14:45)

### O-01
IDENTIFY UNANSWERED QUESTIONS FOR PALLIATIVE AND END OF LIFE CARE RESEARCH – A JAMES LIND ALLIANCE PRIORITY SETTING PARTNERSHIP REFRESH PROJECT

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**Background**
In 2015, Marie Curie and partners reported the results of the Palliative and end of life care Priority Setting Partnership (PeolcPSP) with the James Lind Alliance (JLA) that identified the top 10 unanswered research questions in palliative and end of life care. Prioritised questions were mapped onto funded research (Fordham, Candy, McMillan, et al. Health Open Res. 2020; 2(17): 17) and have been influential in the field of palliative and end of life care research, informing strategic funding opportunities for palliative and end of life care research in the UK, and also providing insights into public opinions of palliative and end of life care (Nelson. Health Open Res. 2020; 2(15):15).

**Aims**
To undertake a refresh of the Palliative and end of life care Priority Setting Partnership to identify current priorities for palliative and end of life care research, in partnership with the JLA and other organisations.

**Methods**
Sequential surveys open to members of the public and health and social care professionals to elicit potential research questions. A range of approaches will be used to try and reach a diverse sample. Identified questions will be checked against existing research and prioritised. The final priorities will be identified through a workshop attended by people affected by dying, death and bereavement and health and social care professionals. A group of people with lived experience has been set up to inform the project across all stages.

**Results**
Interim findings from the first survey will be shared, including emerging topics and characteristics of the sample recruited to date.

**Conclusions**
This work will explore, from the perspectives of people affected by dying and bereavement and health and social care professionals, what the current priorities for palliative and end of life care should be. This will provide vital insights to inform the direction of future research and ensure that research is shaped by the voices of those it is intended to benefit.

### O-02
THE DEVELOPMENT OF A TOOL TO STREAMLINE ANALYSING AND DISPLAYING PATIENT CENTRED OUTCOME MEASURES IN END OF LIFE CARE SERVICES


10.1136/spcare-2023-HUNC.2

Patient Centred Outcome Measures (PCOMs) such as Phase of Illness or IPOS are highly valued for individual patient level clinical care but seldom used to test or demonstrate cumulative impact of an end of life care service in more strategic conversations (Bradshaw, Santarelli, Mulderrig, et al. Palliat Med. 2021; 35(2): 397–407). PCOMs enable a service to demonstrate quality personalised care alongside more traditional activity analysis such as the avoidance of acute bed days and admissions.

We aspired to build a tool to streamline analysing and sharing aggregate PCOMs for end of life care services; both to enable easier cumulative measurement of quality care beyond individual patient experiences and to assist with suitable adaptations and scale of service models. The project team identified four widely used PCOM measures to build an alpha version of the tool in PowerBI (Pearson, et al. Pro Microsoft Power Platform. 2020). Whilst building the overarching tool, it was identified that different organisations and service teams had different levels of resource and expertise. We thus produced three additional resources alongside the tool to ensure it is pragmatic for a variety of organisations outside of academic research. The tool has a Creative Commons License to ensure all organisations can shape and use the tool for their own needs.

The tool and the supporting materials are publicly available and ready for use. We anticipate having preliminary results from tool use in Summer 2023. We have started to use the tool’s analysis and visuals with three partner organisations to explore how best they can collect, analyse, display and share PCOMs. We aspire to share the initial results from this process and our evaluation of the tool’s strengths and weaknesses by November 2023.

Conclusions from our initial design of the tool have highlighted that this methodology can be used for wider PCOMs. A dynamic dataset that is attractively presented and easily interrogated can effectively engage clinicians in service improvement.

### O-03
UNCOVERING THE EVERYDAY EXPERIENCES AND EMOTIONAL ENGAGEMENTS OF CLINICAL AND NON-CLINICAL HOSPICE STAFF

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Appreciating the everyday experiences of hospice staff can help to illuminate their emotional engagements and needs for emotional support. Existing research on emotional work in healthcare and hospice contexts tends to focus on clinical staff, such as doctors and nurses. This study adopted an ethnographic approach to uncover the day-to-day working lives of both clinical and non-clinical hospice staff. In doing so, the findings appreciate the subtle, sensory and intimate practices of hospice staff.

The study involved 6 months of observations and 18 in-depth interviews in a hospice situated in the North of England. Since then, consultation work has also been carried out to consult with staff on the findings and develop recommendations for the emotional support of hospice staff in various roles.

This paper will draw on quotes and fieldnotes to illuminate the everyday work of hospice staff. The findings appreciate the small practices, such as silence, touch and the preparation of food, to highlight how such acts are less acknowledged, yet
significant, forms of care in the hospice context. In appreciating such practices as forms of care, we are also able to acknowledge the non-clinical staff that provide care in the hospice context. The paper will also draw on consultation work completed during 2023, to bring the voices of hospice staff to the forefront. The consultation work has demonstrated the need to acknowledge and support non-clinical staff in their engagements and emotional interactions with patients and families.

Overall, this research and consultation work with hospice staff shows a continued need for emotional support and the acknowledgement of the significance of emotional work – in the roles of all hospice staff.

**DEVELOPMENT OF ‘USE-CASES’ FOR A DIGITAL PALLIATIVE CARE BEREAVEMENT SERVICE**

**Background** Grief is a natural process, in which many people will cope with help from their friends and family. However, many people will need professional help (Aoun, Breen, Howting, et al. PloS one. 2015;10(3):e0121101). Good bereavement care is important to ensure that people get the support they need when they are grieving (Pattison, White, Lone. J Intensive Care Soc. 2020; 1751143720928898). Digital tools can potentially provide support for bereaved people, however, this has not been extensively studied. In computer systems design, ‘use-cases’ describe individual event steps a user needs to navigate to complete an action or goal on a digital system (Clausen, Apel, Dorchain, et al. Energy Inform. 2018, 1 (1):273–283). Well-designed use-cases can improve the efficacy and effectiveness of the developed system (Cockburn. Writing effective use cases. 2001). Use-cases for digital bereavement support have not been established, therefore, there is potential that their use could facilitate development of digital bereavement services.

**Aims** We aim to develop ‘use-cases’ to describe the ‘event steps’ needed to design a digital service to provide three tiers of bereavement support, based on recommendations of the UK National Institute for Health and Care Excellence (NICE).

**Methods** We will review national UK relevant policy on palliative care bereavement services, and we will conduct semi-structured interviews with key stakeholders, to inform the development of infographic ‘use-cases’, which will support future development of digital bereavement services.

**Results** In the short term, this work will inform how palliative care services can best use existing digital systems to support bereavement care. In the medium to long term, this work will support the development, and evaluation, of new digital models of care, which will provide support for bereaved people.

**Conclusion** This study will lead to the development of digital bereavement services. Future studies can utilise the ‘use case’ method to improve the evidence base for digital health studies in palliative care.

Lancashire South Cumbria is one of the most deprived areas of the country with some of the worst health outcomes. We also receive some of the lowest grant funding from the NHS. However, our communities deserve much better and they are demanding improvement. We know there is no silver bullet, white knight, magic formula or money tree. So our hospices decided to take matters into their own hands and work together. It has not been the easiest thing to do because previously we’ve competed and sometimes not got on.

However, now all nine of the adult and children hospices in Lancashire and South Cumbria (LSC) have come together to form a new hospice provider collaborative that we call Lancashire South Cumbria Hospices Together (LSCHT). LSCHT are the new regional focus for end of life care and, in response to the NHS regional changes, we’ve jointly invested to make working with our hospices easier.

We realise hospices are well represented at local and national levels, but that an ocean of opportunities exist from learning and working more closely with each other at a regional level. Of course, we also want excellent patient care, better finance settlements, more sustainable working practices and improved staff outcomes. Our story is about how we created a shared vision and jointly developed, funded and delivered our regional partnership, our successes and failures and future plans. How we infiltrated our ICB and made ‘Dying Well’ one of our five regional priorities.

**CREATING A POLYPHONIC STRATEGY FOR PAEDIATRIC PALLIATIVE CARE. A NEW ORGANISATIONAL DIRECTION CREATED THROUGH STORYTELLING AND ARTWORK**

Will McLean. Children’s Hospices Across Scotland, Kinross, UK

**Background** New models of care, developed using child-centred research methods, are required for dying children (Together for Short Lives. A guide to children’s palliative care. 2018, 4th ed). We are creating a new strategic plan to deliver paediatric palliative care, informed by numerous voices through a storytelling approach to engage children.

**Aims** To create a ‘polyphonic narrative strategy’ (Weidinger. Polyvocal narrative strategy: Turning many voices into durable change. 2020) – an organisational strategic plan, told through storytelling and visual art (Boje. Storytelling organizations. 2008), embodied by the many voices of the children and families who access our hospice services, and the staff and volunteers who deliver them.

**Methods** A project team, including people with lived experience, used Most Significant Change (MSC) (Davies & Dart.