

group which is fundamental to their best care, ultimately this often does not make it as far as the discharge letter.

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### PALLIATIVE CARE IN MESOTHELIOMA: CREATIVE DISSEMINATION OF A MIXED-METHOD STUDY

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**Background** Mesothelioma is a rare incurable cancer caused by exposure to asbestos. Patients with mesothelioma have palliative care needs throughout the course of their illness, however patients and their families are often reluctant to engage with palliative care. In addition, due to the rarity of the disease, health professionals may not recognise the role of palliative care in mesothelioma. The aim of this work was to use creative co-produced methods to disseminate the findings from a mixed methods study of palliative care in mesothelioma.

**Methods** A mixed methods study of palliative care in mesothelioma was undertaken in 2019–2022 across the UK. Findings from the study were synthesised and used to inform the co-production of a short patient facing animation and an infographic for health care professionals.

**Results** Results from the mixed methods study found: (i) patients with mesothelioma have significant palliative care needs; (ii) patients/carers are often reluctant to engage with palliative care due to negative preconceptions; (iii) early engagement with palliative care can be hampered by variable referral pathways and uncoordinated care. A three-minute animation was developed by a creative design company in collaboration with patients/carers, researchers and clinicians. The animation explains the role of palliative care in mesothelioma, addresses common myths, and encourages patients to engage. In addition an infographic aimed at healthcare professionals was developed, which provides easily digestible information about mesothelioma and the role of palliative care, and points to sources of support.

**Conclusion** Our work demonstrates the importance of co-designed, creative outputs in research dissemination and public engagement in palliative care. The animation and infographic are being used by the charity Mesothelioma UK as part of their on-line resource centres for patients and health professionals. Subsequent work will use web analytics to capture evidence of impact, and assess broader applicability to other cancers.

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### SHARING CARE AT THE END OF LIFE FOR ADOLESCENT PATIENTS WITH NEURO-DISABILITY: A CASE SERIES

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**Background** Adolescents with long term conditions are recognised to have unique needs and to experience particular health risks as they transfer to adult services. Some young people with complex neuro-disability may live years following transfer to adult services; for others however, reaching adulthood coincides with a significant deterioration in their health. Identifying the best team to support the patient in this situation can be controversial.

Community and hospital adult palliative care teams may have an important role to play in supporting these patients, yet clinicians may lack experience working with this age group or managing the symptoms associated with paediatric neurodisability.

We present reflections from a series of 6 young adults who received shared-care from adult and paediatric palliative teams and raise discussion about the strengths and learning needs of the different teams involved.

**Intervention** Over a period of 2 years, patients who were between the age of 15 and 19 years and experiencing a significant deterioration in their health were referred to the children's palliative care team for the North East North Cumbria region. Where appropriate, the children's team identified a local adult palliative care team and established a model of shared-care with this team.

**Findings** Across the region 3 adult hospital palliative liaison teams and 4 adult community palliative care teams were involved in shared end of life care.

**Cross-team debriefs identified benefits including** • Improved continuity of care

- Access to out of hours support
- Avoiding hospital admission/Safe discharge planning
- Confidence with medication for symptom management
- Access to local family support and bereavement services
- Building relationships for future joint working
- Support for adult and children's community nursing teams

**Conclusion** Sharing end of life care between adult and paediatric palliative care services can improve the experience of young adults and their families.

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### VIEWS AND EXPERIENCES OF PALLIATIVE CARE HEALTHCARE PROFESSIONALS OF SUPPORTING PATIENTS TO MANAGE DIGITAL LEGACY AS PART OF ADVANCE CARE PLANNING

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**Background** The need for palliative care is increasing<sup>1</sup> and it is essential to look at how emerging technologies can improve care for palliative patients and their carers in the future.<sup>2</sup> With an increasing use of personal technology, many people are spending time creating their own online content.<sup>3</sup> This online content is often described as a digital legacy, the digital information that is available about someone following their death.<sup>4</sup> There is limited evidence around the experiences of digital legacy amongst palliative care healthcare professionals and the benefits of supporting patients in managing their digital legacy.

**Aim** This constructivist grounded theory study aims to identify palliative care healthcare professionals experiences of

supporting palliative patients in managing digital legacy as part of advance care planning discussions.

**Method** Semi-structured interviews were conducted with ten (n=10) palliative care healthcare professionals working in a hospice in the North West of England. Interviews were recorded and transcribed and data was analysed using NVIVO.

**Findings** Four theoretical categories emerged from the data describing why palliative care healthcare professionals view digital legacy as an important topic. These four categories; 'accessing digital legacy', 'becoming part of advance care planning', 'impacting grief and bereavement' and 'raising awareness of digital legacy' were found to revolve around a core category 'understanding the impact of digital legacy'. Digital assets, with both monetary and sentimental value, were viewed as being equally as important as physical assets and should be considered as part of advance care planning conversations.

**Conclusions** The emerging theory 'understanding the impact of digital legacy' offers an insight into the knowledge and experiences of healthcare professionals working in a palliative care setting. Further work is needed to explore palliative patients and their carers' views on digital legacy and how they can be supported to manage this better in the future.

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