

cancer or chronic obstructive pulmonary disease (n=12) identified what carers would have liked to have learnt, and sensitive ways to present this for potentially copresent patients. Transcripts analysed using content analysis; validation sought from the Carer Advisory Group (CAG) and Study Advisory Group (SAG: includes clinical experts). Follow-on workshops with current carers and patients reviewed resultant draft webpages for utility and sensitivity.

**Results** Regarding ‘the future’, carers wanted to learn about: coping with symptom deterioration, ‘future’ discussions with others, accessing care/support, administrative tasks (e.g. death registration), and bereavement. Findings were CAG and SAG validated. Current carers and patients provided valuable feedback on drafted webpages.

**Conclusion** Co-developed webpages on ‘What to expect in the future’ included subjects bereaved carers identified as key; current carers and patients confirmed utility and sensitivity. Follow-on work is testing the full prototype website with carers, patients and clinicians to enable refinement.

## REFERENCE

1. Farquhar M, Penfold C, Benson J, Lovick R, Mahadeva R, Howson S, ... Ewing G. Six key topics informal carers of patients with breathlessness in advanced disease want to learn about and why: MRC phase 1 study to inform an educational intervention. *PLoS One* 2017;12(5):e0177081.

## 23 IMPLEMENTING THE SUPPORT NEEDS APPROACH FOR PATIENTS (SNAP): PATIENT EXPERIENCES

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**Introduction** The Support Needs Approach for Patients (SNAP) is a complex intervention designed to enable person-centred care for patients with progressive non-malignant conditions, such as chronic obstructive pulmonary disease (COPD).

SNAP consists of:

1. the validated SNAP tool: designed for purpose, comprising 15 evidence-based questions to help patients consider areas where they may need more support.
2. the SNAP approach: a needs-led conversation between the patient and healthcare professional (HCP) to express, prioritise and address unmet support needs identified through the patient-completed tool.

Understanding patients’ experiences of the intervention is crucial.

**Aim** To explore patient experiences of SNAP within a pilot implementation study.

**Methods** SNAP-trained HCPs implemented SNAP with patients with COPD across three care settings (primary, community and secondary) in the East of England over four months (n=56). Topic-guided qualitative interviews were conducted with a purposive sample of patients (n=20) focusing on their experiences. Interview transcripts were analysed using thematic analysis.

**Results** SNAP helped patients recognise their unmet support needs and gave them ‘permission’ to discuss these needs with HCPs. Patients described being active participants in SNAP discussions and were positive about how identified

support needs were addressed. Patients without current support needs identified SNAP’s potential future utility. Patients who reported less gains were unclear about the purpose of the SNAP tool and could not recall a SNAP conversation.

**Discussion** Patients with COPD described a range of benefits from SNAP. Simultaneously collected HCP data is currently being analysed to enable further understanding of why some patients reported less gains.

## 24 WHAT INFORMATION SHOULD HOSPICES COLLECT RELATING TO THE IMPLEMENTATION OF BEREAVEMENT SERVICES? RESULTS FROM A DELPHI SURVEY

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**Background** A recent Marie Curie funded study identified two core outcomes for evaluating the impact of bereavement support on adult service users in adult palliative care. This project involved a systematic review, consensus days and a two round Delphi Survey with expert stakeholders (Harrop et al. 2018). Whilst the primary focus of the study was on establishing stakeholder agreement on service user outcomes, discussions that took place during the first consensus day also identified interest in what implementation and demographic data should be collected. The DELPHI questionnaire directed at researchers and service providers therefore also included a section around service implementation.

**Methods** Researcher and Service Provider respondents to the Delphi Survey were asked to rate the importance of recording information about: how the service was implemented; users’ sociodemographic information; unintended negative impacts and costs and value for money. The respondents answered a five-point Likert scale. Answers were grouped into categories of low and high importance. Low importance included ‘Not-important’, ‘Slightly important’ and ‘Moderately important’ answers. The high importance category comprised the answers ‘Important’ and ‘Very important’.

**Results** A total of 106 participants were classified as service providers. Over 80% of service providers thought it important or very important to collect information about: Accessibility of service/intervention (94%), details around the service provided/intervention (88%), knowledge and competency of staff/volunteers (93%), supportive relationships (83%), unintended negative impact of the service (83%) and users’ satisfaction with the service (93%). Opinion was more divided around the importance of collecting information around value for money and the environment.

In terms of user demographics respondents felt that it was very important or important to collect information about relationship to the deceased (86%) and caring role (81%), whereas they thought that collating information around age, gender, religion, ethnicity and socio-economic status was not paramount.

**Conclusions** Whilst a large percentage of respondents agree on the importance of collecting certain information, opinion is quite divided on other items, in particular socio-demographic

data. This needs to be investigated further because some of this information is important to assess issues of equity of access to bereavement services. Future work should define the minimum dataset of information which should be routinely collected by hospices.

## 25 INVOLVEMENT IN PALLIATIVE AND END OF LIFE CARE RESEARCH

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Involvement of those with experience of using care services is now an important and mandatory part of health and social care research, including palliative and end of life care. Those with direct experience of using palliative and end of life care (patients, carers, friends or family members), such as hospices and care homes can enhance and shape research (Goodman et al., 2011). The distinction is made between ‘participants’ in studies who provide ‘data’ and research carried out ‘with’ or ‘by’ members of the public (as defined by INVOLVE). Involvement in these research areas, has its own challenges (Backhouse et al., 2016; Mockford et al., 2016) and innovative approaches are needed (Brighton et al., 2018).

Seeking involvement from people with experience of care at an early stage of research development is key to ensure the research is user-friendly, feasible and has relevant outcomes. Three organisations ran a joint workshop focussing on palliative and end of life care to enable researchers to receive face to face comments from people with experience of palliative and end of life care on their research projects in a ‘dragon’s den’ style session. We will share 1) our experience of this approach to involvement, 2) the experiences of the people who took part and 3) findings from the post evaluation. We will also outline the challenges of involving people in this research area, the importance of ‘feedback’ to those taking part (Mathie et al, 2018) and our learning for the future.

## 26 PRESENT ABSENTEES: TREATMENT ESCALATION PLANNING

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**Introduction** Escalation planning and resuscitation decision-making is essential for effective patient management. Treatment escalation plan (TEP) provides an effective way of formalising timely decision-making regarding care and communicating ceilings of care. It is more holistic – clarifying a wider remit of treatment options than DNACPR offers (Lipar, T., 2013). This is especially important in cardiothoracic intensive care (CTICU) where CPR has an even lower success rate due to the particular patient population and co-morbidities usually present (Barclay, S. et al., 2011).

**Method** A retrospective notes review was undertaken of patients admitted to St. George’s CTICU from April – June 2019. The aims were to assess;

- Adequacy of End of Life Care (EoLC): recognition of dying, care planning, and provision of formalised anticipatory measures.
- whether Supportive and Palliative Care Indicators Tool (SPICT) and ‘frailty’ could have identified patients at risk of deteriorating health.

**Result** Of 107 patients sampled, less than 5% had TEP pre-admission. However, more than 80% required TEP on admission to ICU – with over 90% lacking capacity. SPICT identified 100% of patient requiring TEP while ‘frailty’ showed a lower percentage.

**Discussion** The above indicates that clinicians are missing the window where patients themselves can be involved in TEP discussions. The high percentage requiring TEP may also be indicative of the need for in-depth discussions around intensive palliative care, as awareness is raised about TEP.

**Conclusion** This study looks at the adequacy of EoLC and highlights the relevance of TEP form completion – especially at the ward level, where patients are more likely to have capacity. It also highlights the usefulness of SPICT and even stand-alone frailty in assessment of patient.

## 27 AN ADEQUATE ETHICAL BASIS FOR PALLIATIVE CARE PROVISION

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Currently, in England, palliative care provision could be argued to be unjust as it treats equals in need unequally. For example, those from black and ethnic minority groups (Public Health England, 2018), or those from a lower socioeconomic class (Macmillan, 2017), are much less likely to receive access to palliative care services. This paper sought an ethical framework that would adequately resolve this current injustice. An adequate ethical basis of palliative care would ensure a minimum baseline of care to all equals in need, without compromising palliative care’s aims. This paper argues that this can be provided by using a care ethics framework in conjunction with justice.

Care ethics argues that caring and being cared for is universal and intrinsic to humanity (Tronto, 1993). A framework of care ethics could encourage all individual caregivers to provide the deeply holistic, individualised care currently provided in hospices. However, providing palliative care only from a care ethics perspective may mean that some go without care, as caring under this framework is voluntary, with no obligation to meet everybody’s needs. Additionally, this may allow for the charitable basis of hospice funding to mask an unjust system, thus preventing social reform of palliative care services.

This paper argues that all should have equal access to highly individualised and holistic palliative care, as is currently provided in many hospices. An adequate ethical basis of palliative care provision would support this and would require both justice at the societal level and care ethics at the individual level.