

- Plan and integrate public involvement in research
- Track public contributions and the difference they make to the research
- Report impact against the UK Standards for Public Involvement in Research

**Methods** The Public Involvement in Research Impact Toolkit (PIRIT) was co-developed by public contributors and staff members. Regular project team meetings were held and working groups were convened to develop and pilot the toolkit in practice.

**Results** The toolkit was developed and tested with three cancer-focused Cardiff University led studies. Feedback indicates that the tools are easy to understand and use. All test sites advocate future use.

PIRIT use was thought to:

- Formalise and integrate public involvement
- Support co-production of involvement plans, motivate dialogue and reflection
- Encourage familiarisation with the standards
- Provide a framework to set and monitor involvement objectives
- Help identify practice strengths and improvement areas
- Gather rich data to explicitly describe/report involvement activity, associated impact, and related standards.

Suggested enhancements included adding automation and notes sections to the Planning Tool, and guidance on how to collectively manage the Tracking Tool, and present data.

**Conclusions** PIRIT will be freely available. The toolkit provides a practical approach that supports public contributors and researchers to co-produce involvement plans, capture and describe contributions that effect change. Further testing will evaluate usage in wider practice to inform further refinement.

**Impact** The toolkit aims to fill a recognised gap in practical tools to support public involvement in research planning, tracking and impact reporting.

20

#### PROTOCOL TO EVALUATE THE IMPLEMENTATION OF THE ROYAL COLLEGE OF GENERAL PRACTITIONERS AND MARIE CURIE DAFFODIL STANDARDS IN UK GENERAL PRACTICE

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**Introduction** General Practitioners (GPs) provide a key role to facilitate end-of-life care. However, variable provision of palliative care in primary care settings may lead to both inequitable or suboptimal care. The Royal College of General Practitioners and Marie Curie launched the 'GP Daffodil Standards for Advanced Serious Illness and End of Life Care' in 2019 to improve and sustain practices delivering high-quality palliative and end-of-life care; we were commissioned to undertake an independent evaluation of the Standards.

**Aims** To evaluate the implementation of the Daffodil Standards in general practice, and how they sustained or improved end-of-life care activities;

To identify factors and processes which could lead to wider implementation of the Daffodil Standards.

**Methods** A multi-method study comprising three phases, underpinned by the Normalisation Process Theory:

Phase 1: online survey for UK GP practices (n=200 sample) to map end-of-life activities and levels of implementation of the Standards.

Phase 2: semi-structured interviews with a sub-sample of survey respondents (n=20–26) to refine and provide further information from the survey.

Phase 3: case studies (n=6–8), informed by Phases 1 and 2, to capture learning and identify exemplars of best practice to inform wider implementation of the Standards.

**Results** The study has commenced, running from 2022 to 2024. We will share lessons learnt from implementing our protocol, and reflect on any required adaptations, within a community context. We will actively involve and engage with our research partner and Service Users for Primary and Emergency care Research (SUPER) group (PRIME Centre Wales).

**Conclusions** We anticipate the learning will contribute a greater understanding of key enablers and barriers to implementing the Standards, capture lessons learnt, and build an evidence-base to encourage wider implementation across the UK.

**Impact** To improve care for those affected by serious illness and end-of-life care with realistic and practical support for primary care teams.

#### REFERENCES

1. Royal College of General Practitioners (2021). The Daffodil Standards. 10th October 2022. <https://rcgp.org.uk/learning-resources/daffodil-standards>
2. Marie Curie (2022). Daffodil Standards for GPs. 10th October 2022. <https://www.mariecurie.org.uk/professionals/working-in-partnership/royal-college-of-gps/daffodil-standards>

21

#### UNDERSTANDING THE EXPERIENCES OF PROVIDING END-OF-LIFE CARE IN UK GENERAL PRACTICES; PRELIMINARY DATA FROM AN INDEPENDENT EVALUATION OF THE DAFFODIL STANDARDS

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**Introduction** General Practitioners (GPs) are at the forefront of healthcare. However, GPs are facing extensive pressures, including ever-increasing patient demand and limited resources. We report the results of an online survey and interviews with GP practices to understand their experiences in providing palliative and end-of-life care. This work was undertaken as part of an independent evaluation of the 'Daffodil Standards for Advanced Serious Illness and End of Life Care,' (1,2) created by the Royal College of General Practitioners and Marie Curie.

**Aims** To map end-of-life activities and identify processes and mechanisms of implementation of the Daffodil Standards.

**Methods** An online survey was disseminated to GP practices in the UK (September 2022). Those signed up to the Daffodil Standards answered questions about their end-of-life care activities, and experiences of implementation and impact.

Those not signed up to the Standards were asked about their end-of-life care activities, their experiences, and challenges they have faced. We will undertake semi-structured interviews with a sub-sample of survey respondents to identify processes and mechanisms of implementation. We are prepared for pragmatic contingency plans should we experience poor engagement due to the challenges NHS primary care is facing, including focus groups with participants signed up to the Standards. Data will be analysed using descriptive statistics (survey) and Framework Analysis (survey, interviews, and/or focus groups).

**Results** Ten respondents have completed the survey to date. Preliminary data will be available for presentation in February 2023.

**Conclusions** The data will be used to inform and refine the design of a set of case studies to capture learning and identify exemplars of best practice for later phases of the study.

**Impact** Greater understanding of key barriers and enablers from existing efforts to sustain and improve end-of-life care in general practice, and identify exemplars of high-quality practice, building up an evidence-base to encourage wider implementation of the Standards.

#### REFERENCE(S)

1. Royal College of General Practitioners (2021). The Daffodil Standards. 10th October 2022. <https://rcgp.org.uk/learning-resources/daffodil-standards>
2. Marie Curie (2022). Daffodil Standards for GPs. 10th October 2022. <https://www.mariecurie.org.uk/professionals/working-in-partnership/royal-college-of-gps/daffodil-standards>

22

#### 'IT'S NOT OUR GRIEF TO HAVE...?' THE LIVED EXPERIENCES OF PROFESSIONAL GRIEF THAT PALLIATIVE CARE NURSES EXPERIENCE WHILST DELIVERING END OF LIFE CARE IN ACUTE HOSPITAL SETTINGS

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**Introduction** The world is experiencing an ageing population with the numbers requiring palliative and end of life care (PEOLC) increasing and many of those people will receive care and die in acute and generalist settings. The personal and lived experiences of the nurses delivering PEOLC in busy acute environments therefore need to be reflected upon, understood, and acknowledged.

Nurses experience grief for their patients but do so in a very different manner to that experienced by the patient's family. The nurse often finds them self in a conflicting role as they need to remain strong and offer support on one hand whilst managing their own emotions and acknowledge their loss on the other.

**Aims** This aim of this study was to understand the experiences of palliative care nurses delivering PEOLC in acute settings and how they make meaning of those experiences following the loss and death of their patients

**Methods** An Interpretive Phenomenological Analysis (IPA) methodology was used to understand the lived experience of the participants to illuminate and reveal their meaning making.

**Results** Following analysis of the findings, four main or super-ordinate themes were revealed which demonstrated that nurses

are sentient thinking beings whose lived experiences and feelings affect their thoughts and emotions.

**Conclusions** This in turn impacts not only on their personal life but also their professional identity and perceptions of good quality care. The caring processes they enact shapes and informs their understanding of the world and their experiences therein.

**Impact** The findings of this study point towards a need to understand and acknowledge that nurses can experience professional grief for their patients and it is necessary therefore to consider effective supportive mechanisms such as reflection and formal clinical supervision for generalist and palliative care nurses delivering PEOLC in acute settings.

## Challenging inequity in palliative and end of life care

23

#### ACCESS TO PALLIATIVE CARE FOR ACHD PATIENTS – A JOINT SERVICE REVIEW

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**Introduction** Adults born with congenital heart disease represent a remarkable success in the field of cardiology with a huge improvement in survival rates. However, many challenges remain and many adults with Adult Congenital Heart Disease (ACHD) are considered to have a chronic condition with associated reduced life expectancy.

**Aims** To set up a joint ACHD-palliative care service to increase earlier access.

**Methods** We designed a new joint service which consisted of simplification of the referral process, joint multidisciplinary team (MDT) discussion and a joint clinic. We recognised the value in a dedicated 'link' palliative care physician who had a specialist interest in this cohort. A multidisciplinary stakeholders group met, and key feedback gathered. A joint multidisciplinary meeting (MDM) between the ACHD team and a palliative care consultant and clinical nurse specialist was trialled; this was modified upon feedback to discussion of patients within a dedicated section of the palliative care MDM. After discussion, selected patients would be seen in ACHD clinic by both cardiology and palliative care. Inpatients were referred via the usual referral pathway but also with direct ACHD – palliative care discussion.

**Results** Service audit was between June 2021 – September 2022. 8 patients were reviewed by hospital palliative care; 2 of these were MDM reviews alone and 6 were with inpatient and/or outpatient reviews in addition. 100% had a symptom control and psychosocial assessment and 100% had an introduction to ACP discussion. 7 were referred to their local community palliative care service. 4 patients have died.

**Conclusions** It is recognised that palliative care needs to be offered early. Studies have demonstrated many ACHD patients recognise the value of this but it is often under-utilised. Our project demonstrates the benefits that a joint service can offer.

**Impact** This joint service is improving access to the benefits of earlier palliative care.