

safety), accessible both locally for palliative care teams to support service planning and bench-marking, and nationally for policy and strategy judgements.

### 17 ONE STEP AT A TIME; USING COMPASSIONATE COMMUNITIES' MODEL (COMPASS GHANA) TO IMPACT ON THE DELIVERY OF PALLIATIVE AND END-OF-LIFE CARE IN RESOURCE-POOR SETTING

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**Introduction** Access to end-of-life care is particularly challenging in resource-poor countries where palliative care is at an embryonic state. Lack of access to affordable palliative care leads to inequity at end of life with consequential financial hardship for families and communities. There are access barriers, which have direct implications on how a society views life and death and how it prioritises health and community care.

**Aims** To develop a sustainable model of end-of-life care that empowers communities, in a manner that is embedded within mainstream provision.

**Methods** A series of stakeholder consultations, supported by in-country visits resulted in the development of a culturally appropriate model called 'Compassionate Palliative Services'. The consultation included private and public health care professionals, regulatory agencies, patients and family caregivers' groups, faith-based organisations and community influencers.

**Results** A two-arm charity has been established. One, registered in the UK (Charity Reg No: 1199633) is focused on fund raising, strategy and governance; the other registered in Ghana to support the delivery. This non-westernised palliative care model has been embraced with the consent and buy in of key providers, the patients, caregivers, families, and communities.

**Conclusions** The creation of 'COMPASS Ghana', is a critical step in enabling the delivery of palliative care in a non-westernised context. It directly involves all in developing the future construct of care, in a manner that reflects government and regional health priorities, current infrastructure and community behaviours. Sustainable, reducing the financial impact (direct and indirect) to which resource-poor communities are exposed to.

**Impact** COMPASS Ghana combines innovation and best practice to improve palliative care in Ghana and the wider region. It pioneered gathering and analysing public health data to inform palliative care decision-making. Impact is delivered through advocacy around death and end-of-life care and a solution through the establishment of Mobile Multidisciplinary Palliative Care Teams (MMPCTs).

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### 18 ACCESSING BEREAVEMENT SUPPORT: A SECONDARY ANALYSIS OF UK COMMISSION ON BEREAVEMENT (UKCB) EVIDENCE

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**Introduction** There are significant social and healthcare inequalities in the provision and access to bereavement services. With the increase in deaths and experiences of bereavement, the Covid-19 pandemic accelerated the need to address this crucial area of psychological, social and healthcare support. The UKCB was set up to respond to the challenges of the pandemic by hearing about the lived experience of bereavement.

**Aims** The study aimed to draw on UKCB data to analyse the experiences of those bereaved in the last five years to explore how age, gender, ethnicity, and sexual orientation were associated with inequalities relating to access, effectiveness, satisfaction, and delivery of services.

**Methods** An in-depth qualitative thematic secondary analysis was conducted of free text data from 1119 individual and 130 organisational UKCB survey responses.

#### Results

**Age** Those over 50 reported not wanting to cause a fuss, saw seeking help as a weakness and were reluctant to access digital support. Family pressures, lack of time, and perceptions of less support available for younger people were reported in respondents under 50 years. **Ethnicity:** The value of support was compromised where there were language barriers and a lack of cultural and religious understanding. **Sexuality:** LBGTQ + respondents valued non-judgemental understanding and a feeling of belonging from support where this is lacking on a wider level. **Gender:** Men leaned toward a preference for more informal and practical support. In more formal support they found difficulties in talking with those unconnected with family and friends.

**Conclusions** Age, gender, ethnicity, or sexual orientation affected many respondents' access to formal and informal bereavement support as well as the effectiveness, satisfaction, and delivery of services.

**Impact** The study contributed recommendations which add to those of the UKCB, that can help to reduce inequalities in effective bereavement support.

### 19 LAUNCH OF THE PUBLIC INVOLVEMENT IN RESEARCH IMPACT TOOLKIT

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**Introduction** Patient and Public Involvement positively shapes research. By sharing personal experience, public contributors ensure that research is relevant to people's needs and concerns. The UK Standards for Public Involvement in Research highlights the need to assess the difference public involvement makes. Yet, there is a recognised gap in pragmatic tools to support impact planning and reporting in practice.

**Aims** To develop and test pragmatic tools to support researchers working with public contributors to:

- 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.

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## 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.

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## 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.