Abstracts

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.

Protocol to Evaluate the Implementation of the Daffodil Standards in General Practice

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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Introducing the Experiences of Providing End-of-Life Care in Primary Care

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.

Understanding the Experiences of Providing End-of-Life Care in Primary Care

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

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.
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)

Challenging inequity in palliative and end of life care

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.