

# Designing a population-based approach to integrated end of life care on a small island



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## Background

- ❖ Hospice Isle of Man is developing the Isle of Man's Integrated Palliative and End of Life Care Strategy
- ❖ As a small island of 83,000 residents, the Isle of Man faces unique opportunities and challenges in integrating care
- ❖ Population-based approaches provide the opportunity to join professional care with community resources<sup>1</sup>

**Aim:** To identify areas of need and what matters to the residents of the Isle of Man in order to design a strategy to enable patients and families to have the right end of life care, in the right place at the right time regardless of diagnosis.

## Methods

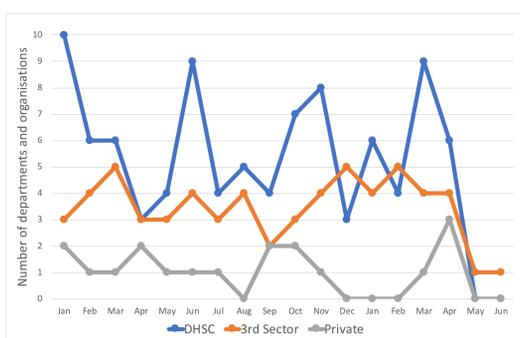
- ❖ Members of Department of Health and Social Care (DHSC), the Council of Voluntary Organisations (CVO) and Hospice staff participated in a workshop in December 2017
- ❖ Participants extracted general themes and identified areas of need based on a patient care experience of a recently deceased progressive supranuclear palsy (PSP) patient and her carer
- ❖ The case study was based on interviews with the patient's carer and family and the patient's diaries
- ❖ The workshop led to public engagement events, stakeholder focus groups and to the collection of additional patient experience journals and interviews

### Case Study



## Results

### Case Study



**Figure 1. Number of encounters per month by sector in the last 18 months of life of a PSP patient**

#### Identified gaps

##### Pre-diagnosis to diagnosis (2011-15)

- ❖ Identifying complex cases
- ❖ Triggers for signposting to community support
- ❖ Self-management programme

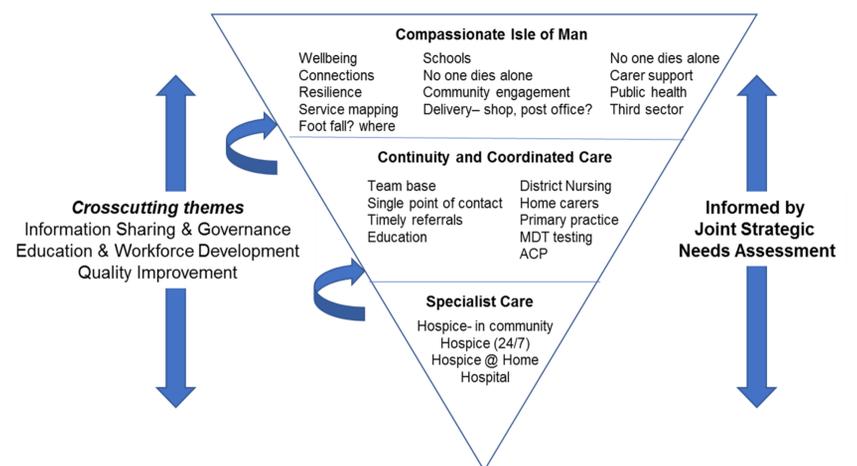
##### Increasing complexity and disability

- ❖ Care navigation – all sectors
- ❖ IV antibiotics at home
- ❖ Emotional wellbeing and respite
- ❖ Anticipatory care planning
- ❖ Carer support

##### Last year of life

- ❖ Out of hours service availability
- ❖ Review of preferred place of care

### Workshop



**Figure 2. Work streams and enabling activities for the development of the Isle of Man Strategy for Integrated Palliative and End of Life Care**

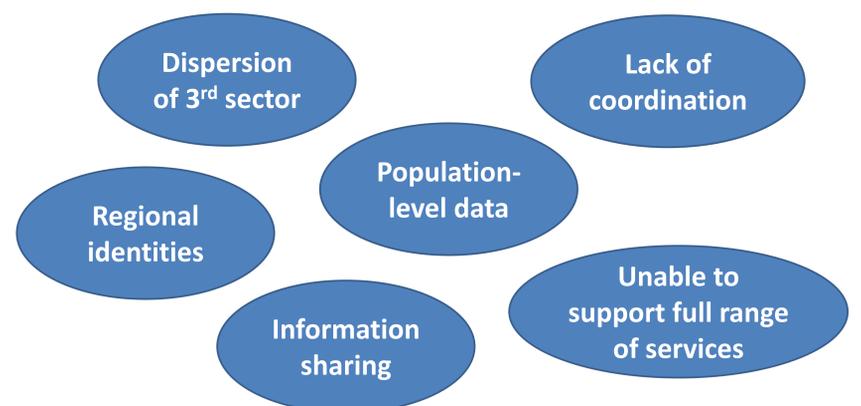
## What matters to the Isle of Man public?

- ❖ **Effective care** – Holistic, knowledgeable staff, continuity, quality of care regardless of location, symptom management, 24/7 service, communication
- ❖ **Person-centred care** – Dignity, preferred place of care, make the most of time left, spiritual care, "the small details", kindness
- ❖ **Equity** – Specialist care available for all who need it regardless of disease
- ❖ **Education** – Anticipatory care planning, help community to talk about death
- ❖ **Information** – To know what services are available, to know who to call and where to go when need arises, to know criteria for access to specialist care
- ❖ **Support** – For patients and families from diagnosis to after death, for carers, friends and co-workers, children, teachers and schools

## Conclusions

- ❖ As a small island we have some advantages such as clear geographic boundaries, personal connections and a sense of community but many of the same barriers to integration observed in other settings apply

## Challenges



## Next Steps

- ❖ Design the Joint Strategic Needs Assessment
- ❖ Pilot and evaluate the effectiveness of cross-sector integration initiatives in end of life care