

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 resources¹

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

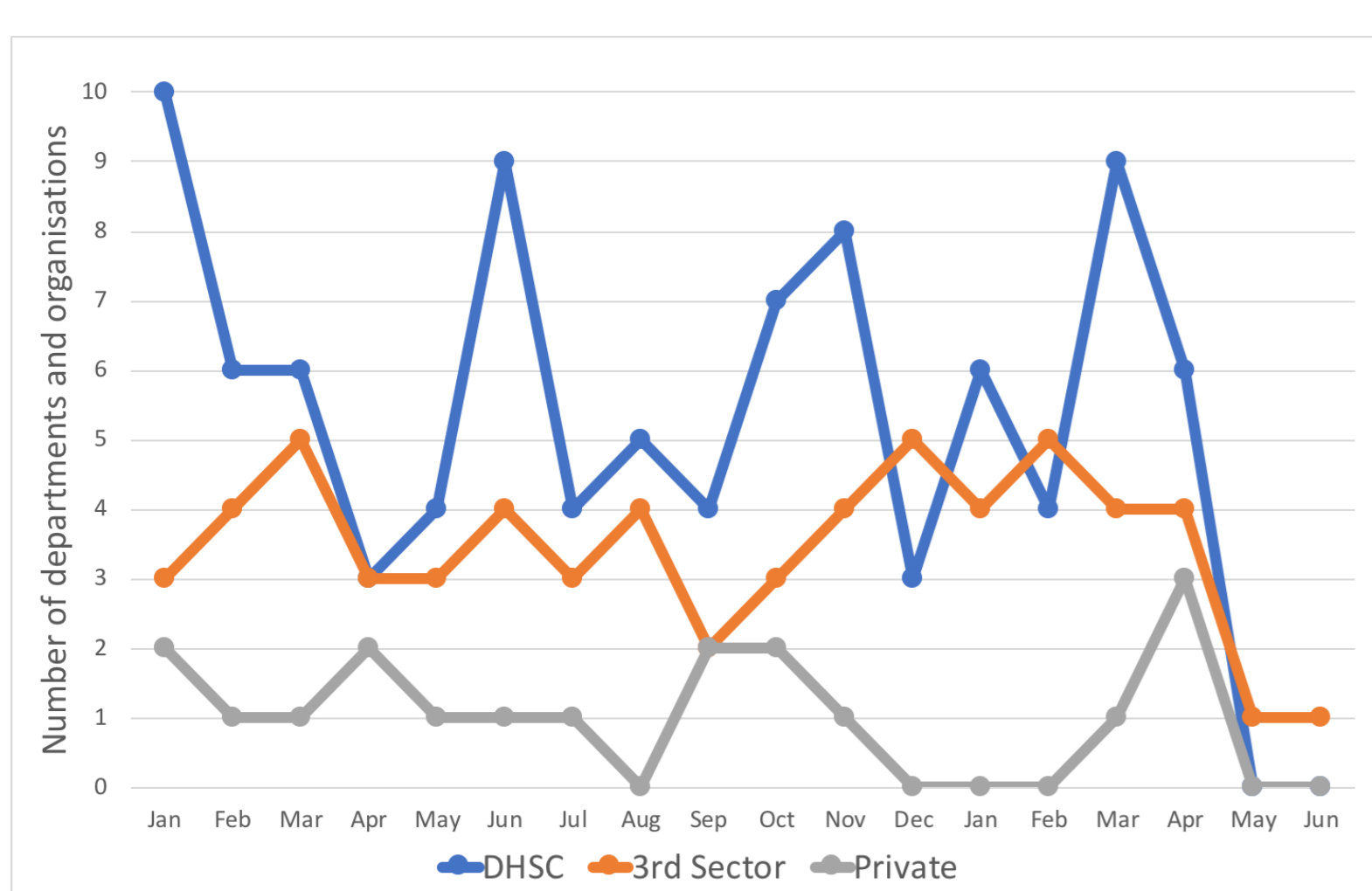


Figure 1. Number of encounters per month by sector in the last 18 months of life of a PSP patient

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

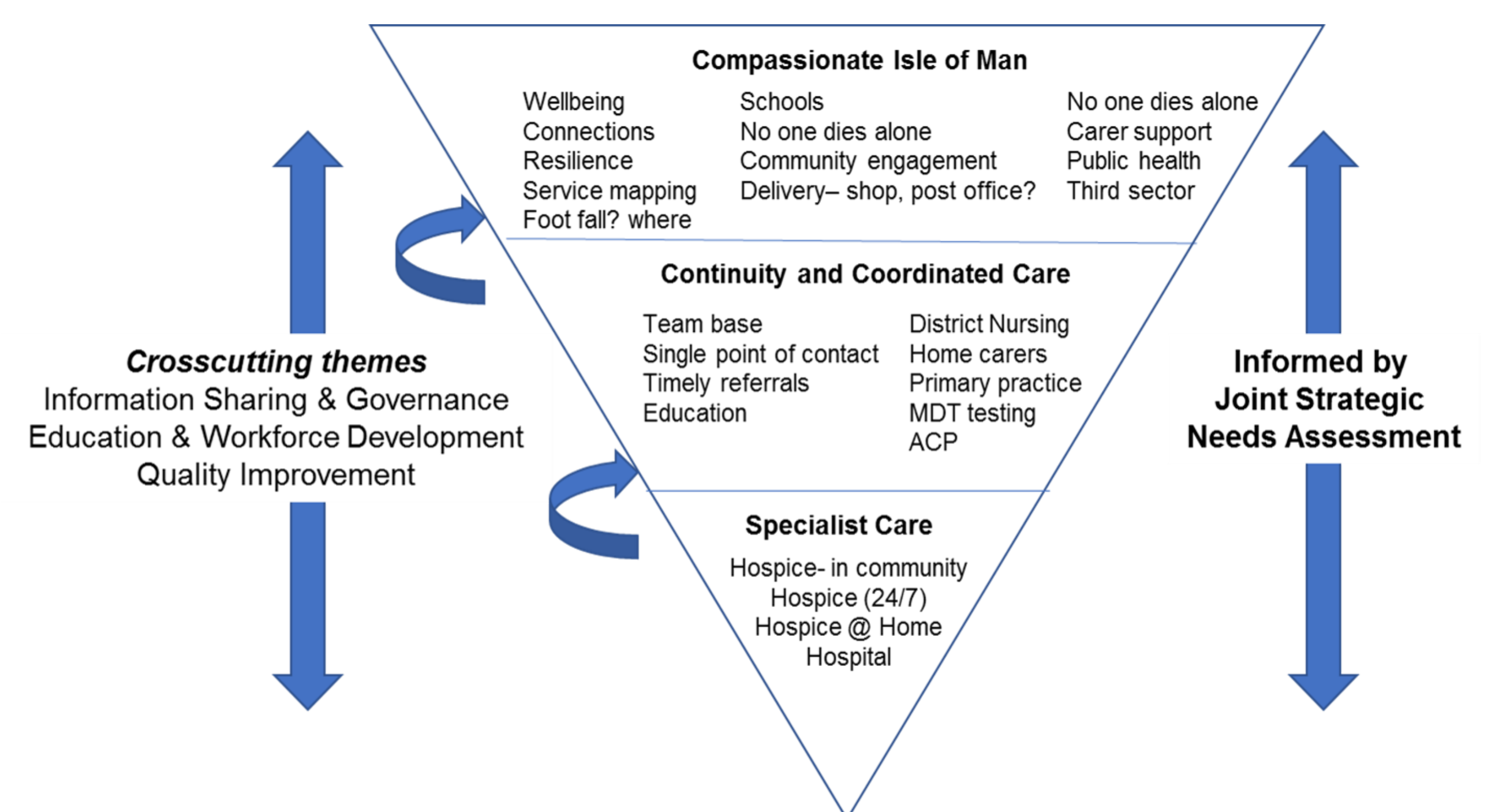


Figure 2. Work streams and enabling activities for the development of the Isle of Man Strategy for Integrated Palliative and End of Life Care

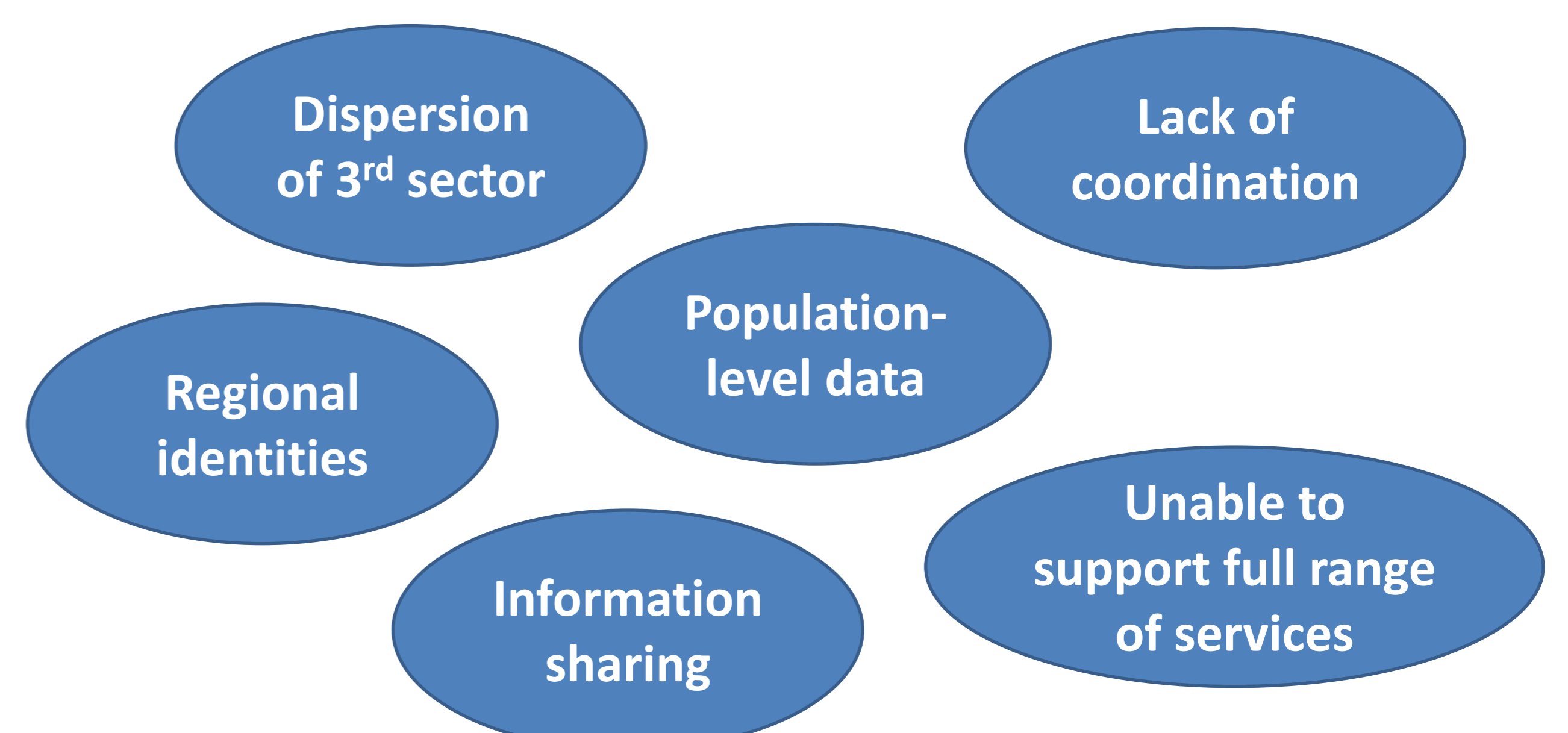
What matters to the Isle of Man public?

- ❖ **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