

What matters at the end of life?

Results from community listening events on the Isle of Man



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Background

Hospice Isle of Man (IOM) conducted a series of community listening events to thank the community for 35 years of support and to inform Hospice strategy for the next 5 years.

Aims: 1) To understand what the public knows about Hospice and learn about their experience. 2) To find out what matters most when confronted with end of life. 3) To ask how Hospice can best serve the Isle of Man

Methods

- Hospice staff arranged a series of listening events at 7 locations across the Island.
- Venues included supermarkets, coffee mornings and lunches held at local churches.
- Members of the public were approached and were asked the following questions:

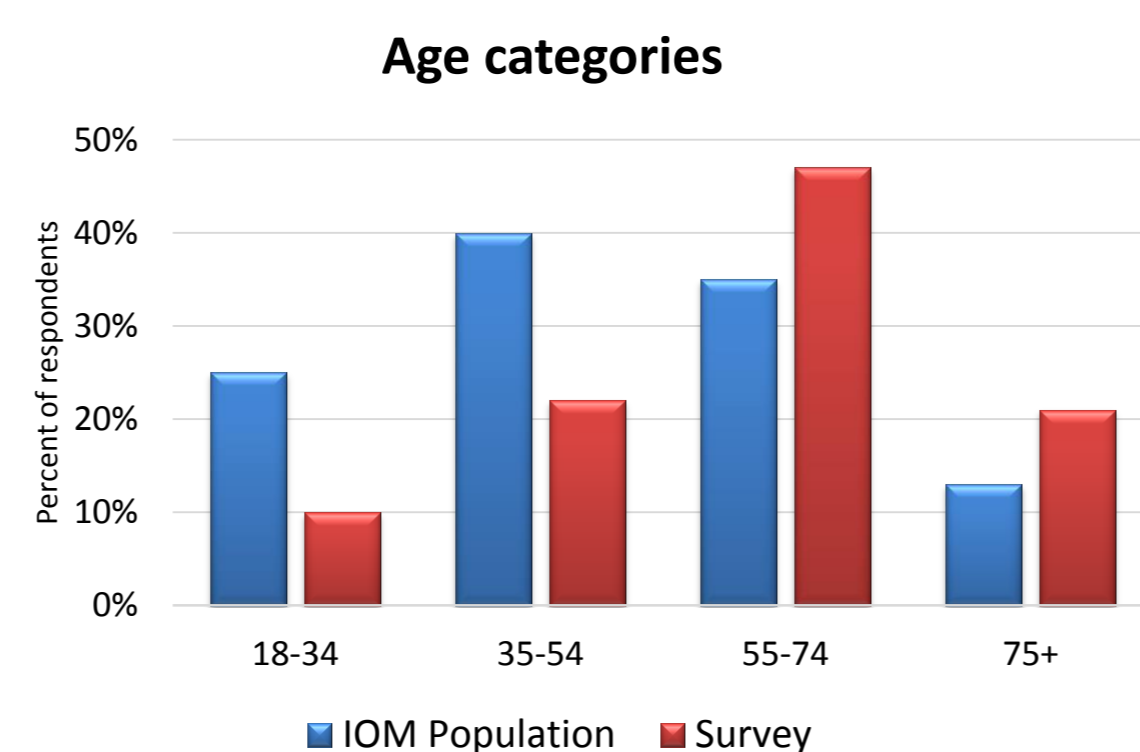
1. *What do you know about Hospice?*
2. *If you or your family had to use Hospice services, what would matter to you?*
3. *How do you think Hospice can best serve the community over the next 5 years?*



Results

Total Respondents, n = 278

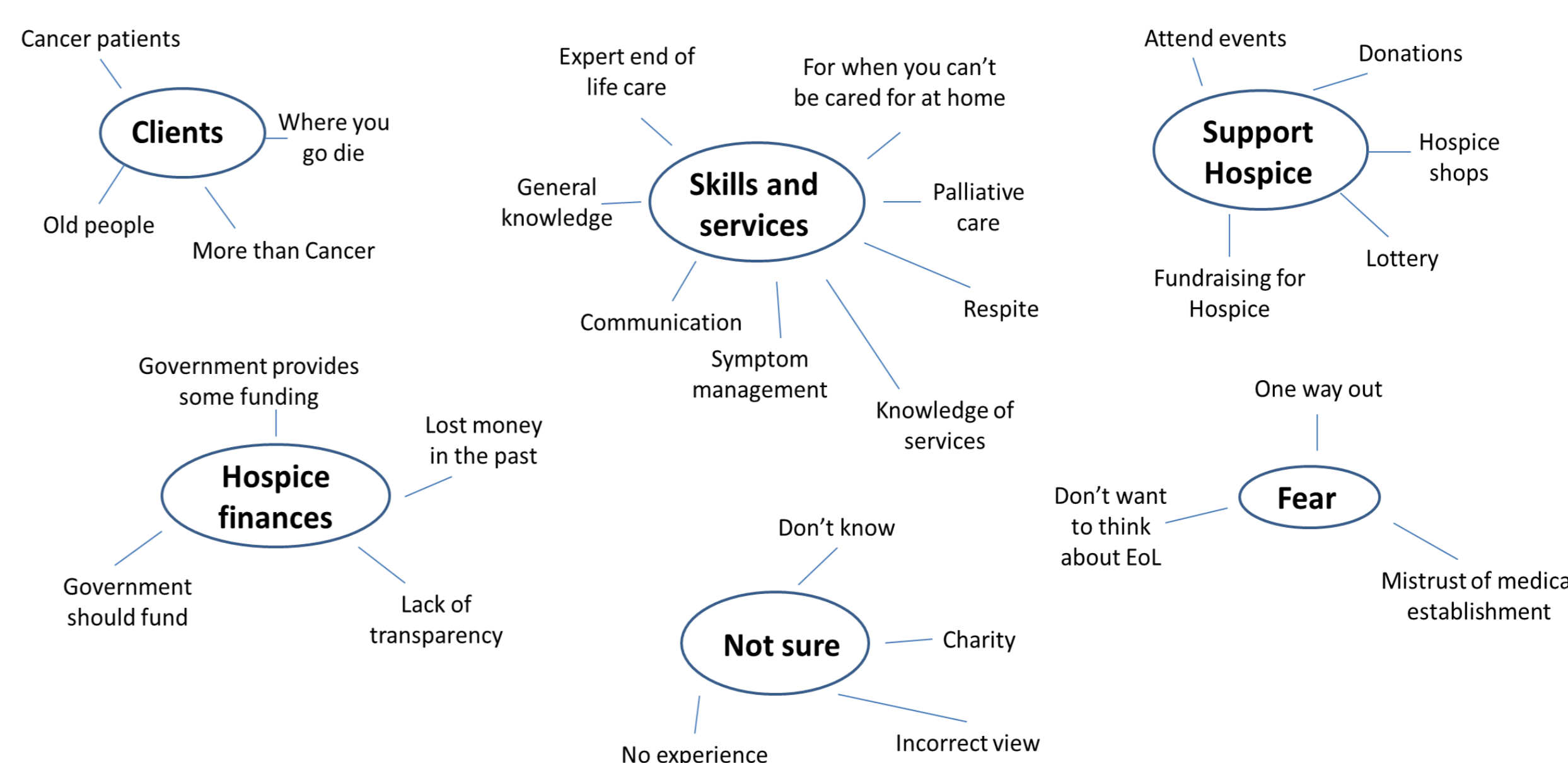
- Females = 63%
- Users (self or close relative) = 32%
- Professionals / volunteers = 8%
- General awareness of Hospice = 74%
- Awareness of 4+ services = 5%



2. What matters to you?

- ❖ **Effective care** – Holistic, knowledgeable staff, continuity, quality of care regardless of location, symptom management, 24/7 service, communication, respite, comfort
- ❖ **Person-centred care** – Dignity, preferred place of care, make the most of time left, spiritual care, “the small details”, kindness, trust, personalised attention, complementary therapies, convenient location
- ❖ **Equity** – Specialist care available for all who need it regardless of disease or background
- ❖ **Environment** – ‘home from home’, calm, peaceful, open access for family
- ❖ **Sustainability** – ‘Available when I need it’, funding, staff well-being, size of facilities
- ❖ **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
- ❖ **Communication** - Honesty, to be kept informed

1. What do you know about Hospice?



“The Isle of Man would be lost without it [Hospice].”

“I want to be treated like I wasn't a dying person, make the most of time I'd have left.”

3. How can Hospice best serve you?

Raise Awareness

Improve Access

Secure Funding

Improve Transparency

Work with others

Support the Community

Conclusions

- ❖ The Isle of Man public is generally aware of Hospice but had little knowledge of the range of services offered. There were a number of misconceptions including the idea that Hospice only served cancer patients or that the only reason to go to Hospice is to die. Comments relating to care, its quality and effectiveness were the most commonly mentioned. Hospice can best serve the community by raising awareness of services, death and dying, supporting all members of the community and by ensuring its sustainability.