

Needs Assessment for Person-Centred palliative and end of life care in the Isle of Man

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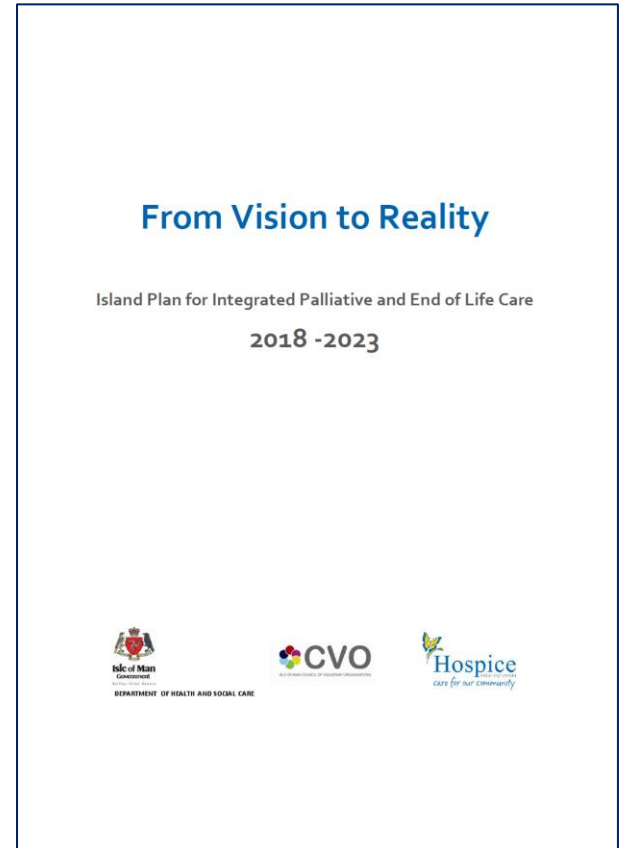
ICIC 2020



An Island Plan for integrated palliative and end of life care



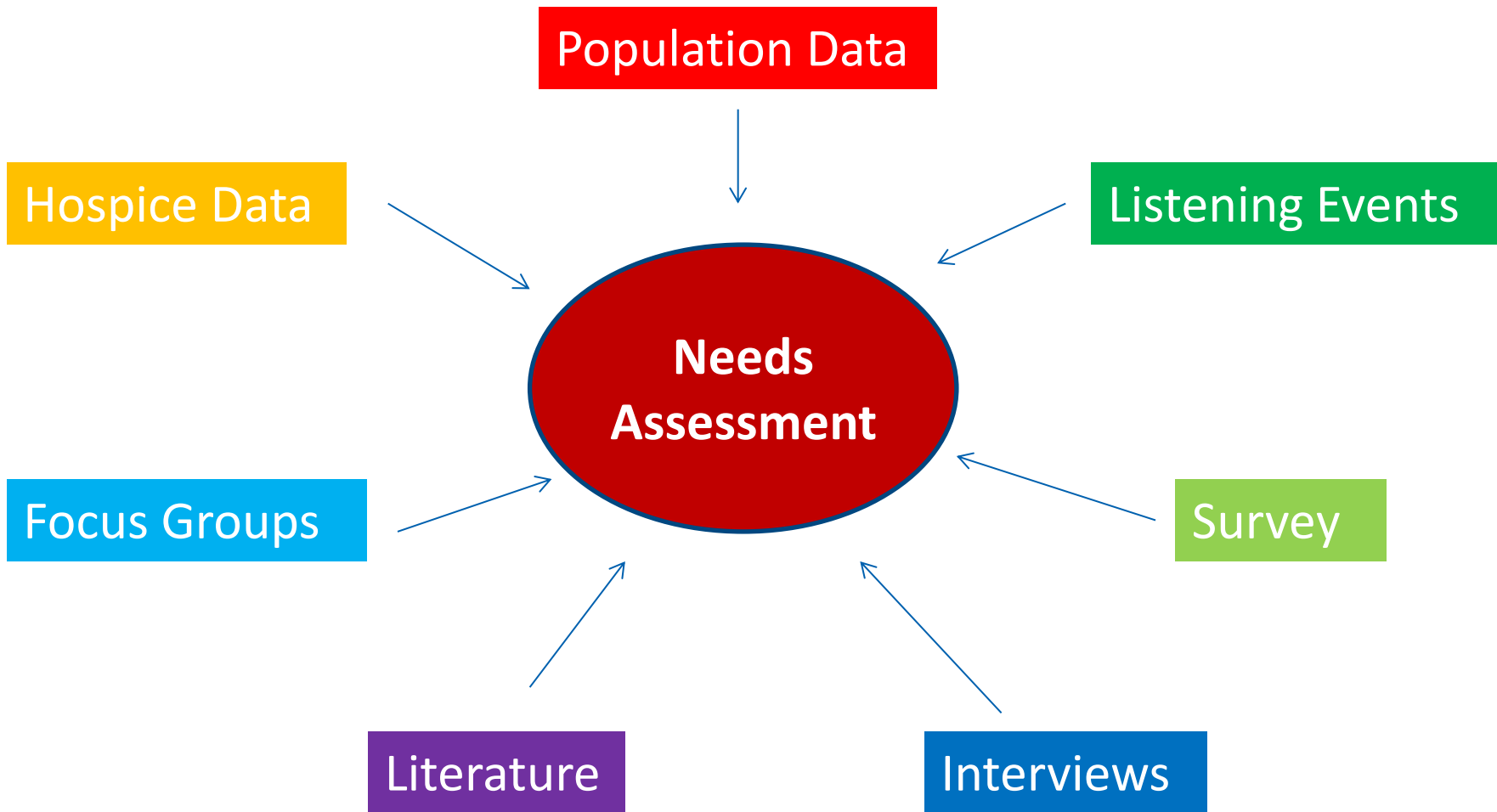
- Caring for people in the last phase of life is challenging
- Extending support to as many as possible will stretch limited resources
- Plan needed to ensure this is done fairly and maximises population benefit



Situation in 2018

- Ageing population
- Increasing referrals to Hospice
- Uncertain level of need among population
- Requirement for evidence, but lack of data, from which to develop Island Plan
- Creation of Strategic Partnership Steering Group (SPSG)
- Needs assessment is SPSG Workstream 1

Mixed methods were used



Questions for the needs assessment

- What services are currently available for palliative and end of life care?
- How many people on the Island could benefit?
- Who is Hospice helping at present?
- What do people want from these services?
- What is currently working well and not so well?
- How close are we to delivering appropriate care and what remains to be done?

Methods: quantitative data

- Death registry data from 2013-2018
 - 4 categories of benefit from palliative care: cancer, organ failure, neurodegenerative, dementia/frailty
 - Usual address and place of death

CAUSE OF DEATH

The condition thought to be the 'Underlying Cause of Death' should appear in the lowest completed line of Part 1

PART 1

(a) Disease or condition directly leading to death:

(b) Other disease or condition, if any, leading to (a)

(c) Other disease or condition, if any, leading to (b)

PART 2

Other significant conditions CONTRIBUTING TO THE DEATH

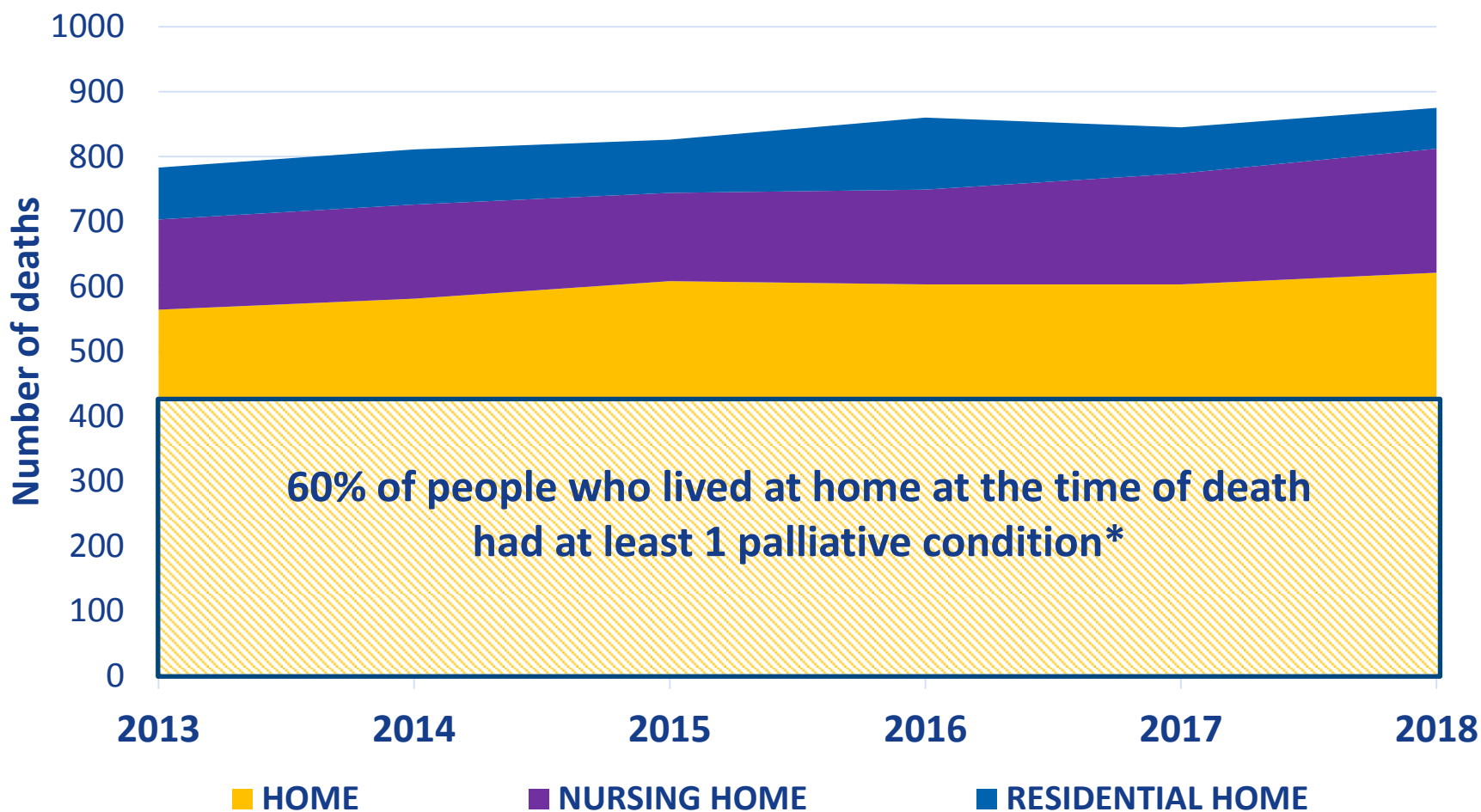
but not related to the disease or condition causing it.

Methods: qualitative data

- Interviews with health services and Third Sector professionals and volunteers (60) and patients/carers (12)
- Recorded, transcribed and analysed for main themes

Some findings: Carers

Where did people live when they died?

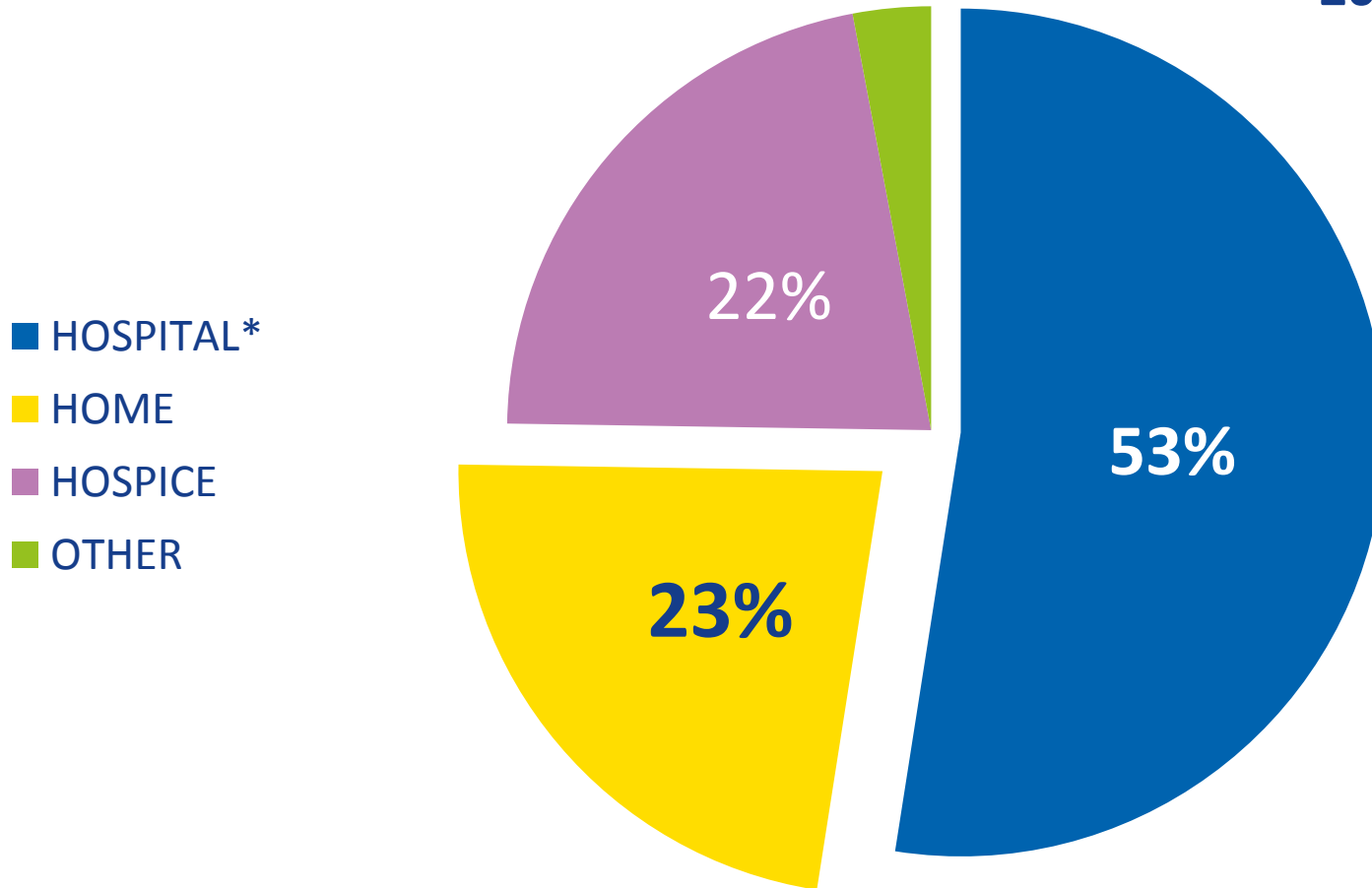


*Condition from one of the four groups: cancer, neurodegenerative, organ failure, dementia/frailty

Where do people living at home die?



2013-2018



*Hospital includes deaths at acute care hospital 50% and community cottage hospital 3%

Main themes from qualitative data

1. Carers as co-workers
2. Needs of carers as individuals
3. Gaps in services and support

Theme 1: Carer as co-worker

*“I appreciate I couldn’t survive without
her (carer)”*

-Patient

Carers provide and coordinate care...

- Provide hands-on care
- Devise systems to keep track of complexity of care
- Can identify areas where duplication can be reduced
- Identify symptoms requiring urgent care
- Keep track of medications and can identify errors
- Alert providers when exams or procedures need to follow a sequence to fit in with other care
- Follow-up on appointments
- Learn through experience

...but they are not recognised by the system



- Difficulties making appointments and discussing care

“The problem is that they won’t speak to me if (patient) is not there to say it is okay. I had to phone him, to phone them, to say they could speak to me.” - Carer

“We’ve learnt... that appointments get forgotten and they don’t always get made... I always have a back-up that if we’ve not received an appointment, I will phone up.” - Carer

- Consent processes not clear and are laborious

Elements that would help as a co-worker

- Training on what requires urgent attention
 - “It would be nice to know what can go wrong and what you need to treat urgently and what can wait.” - Carer*
- Ability to make appointments on behalf of patient
- Better communication between professionals
 - “I think what it is between the surgery and the chemist is they have a fight going on about who is responsible... one blames the other every time.” – Carer*
- A professional to help navigate the care system is invaluable

Inclusion of carers in care is needed

- Families feel excluded from decisions about care

“I don’t dispute that they are all clever people (clinicians), they know their job. It’s just that it’s not working. Each doctor is only seeing it from their point of view.” –Patient

“You feel almost like you’re being swept along in a tidal wave because you’re out of control... being involved and included in the process of discussion is helpful.” - Carer

Appropriate communication at different times and levels



- Inappropriate communication of difficult news
 - “I got a phone call... while I stood at IKEA... he (consultant) said... ‘It’s terminal, It’s grade 4. It’s nasty. And could you please let your family know.’” – Carer*
- Medical professionals make assumptions based on carer’s professional background
- Missing the ‘big picture’
 - “You are trying to piece all these little bits of jigsaw together instead of having the whole picture.” - Carer*

Theme 2: Needs of carers as individuals

“I’m not so much a wife anymore. I’m more a carer.”

- Carer

Caring impacts on mental health

- Change in role from partner to carer
- Accepting that help is needed can be difficult
 - “I felt that I was failing if I need help” – Carer
- Feelings of guilt for needing support
 - “A lot of carers feel guilt that they don’t have the physical strength to care” - Carer
- Accessing help is not always easy
 - “He (patient) doesn’t know I’m going to counselling because I just thought it might add to his feeling that you know, he’s put more on” – Carer*

Carers need physical, social, financial and emotional support



- *“Nobody can do a lot of the things that I do”*
- Respite provides “strength to carry on”
- Caring is a full-time job and carers get inadequate financial assistance

“She’s (carer) had to give up work. She could have been earning three times that... I feel my hands are tied because I can’t do more.” - Patient

- Carers are often living with conditions of their own
- Connections outside the caring role are vital
- Peer support could be beneficial

Theme 3: Gaps in services

“Obviously carers needs get overlooked and if you’re not careful, the carer turns into the cared-for”

- Professional

Support for carers is needed

- Carers don't recognise they are carers or may be afraid to ask for help
- Carer assessments need to become routine care
- Insufficient respite care
- Lack of clarity on who to contact
- Help navigating system

What would help? (Professionals' view)

- Out of hours service in community is lacking to support home care
- A rapid response team is needed to deal with emergencies
 - ✓ These could avoid some people being admitted to hospital in their last few days
- Better respite services would help keep people out of long term care
- Overnight care and financial assistance

Conclusions

- The majority of people who die with a palliative condition live at home (not a care home)
- Most will likely require support from an informal carer
- Carers need to be recognised as co-workers in an integrated care framework AND as individuals
- Identification, recognition and support for carers is essential to provision of care in the community
- Carers are an integral part of delivering person-centred integrated care



Thank you

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