



Better health, better futures

Experiences of people with palliative and end-of-life care needs “out-of-hours”

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Unscheduled care during the last year of life in Scotland: mixed method study

- Cohort study of all people who died in Scotland in 2016.
- Linked datasets covering 5 unscheduled healthcare services*



- Interviews with patients, bereaved carers and professionals about their experiences

*Unscheduled care = all urgent/unplanned care in-hours and out-of-hours (OOH)

Who needs unscheduled care during the last year of life in Scotland?

- 56,407 people died in Scotland in 2016.
- 91.7% had a long term condition as cause of death.

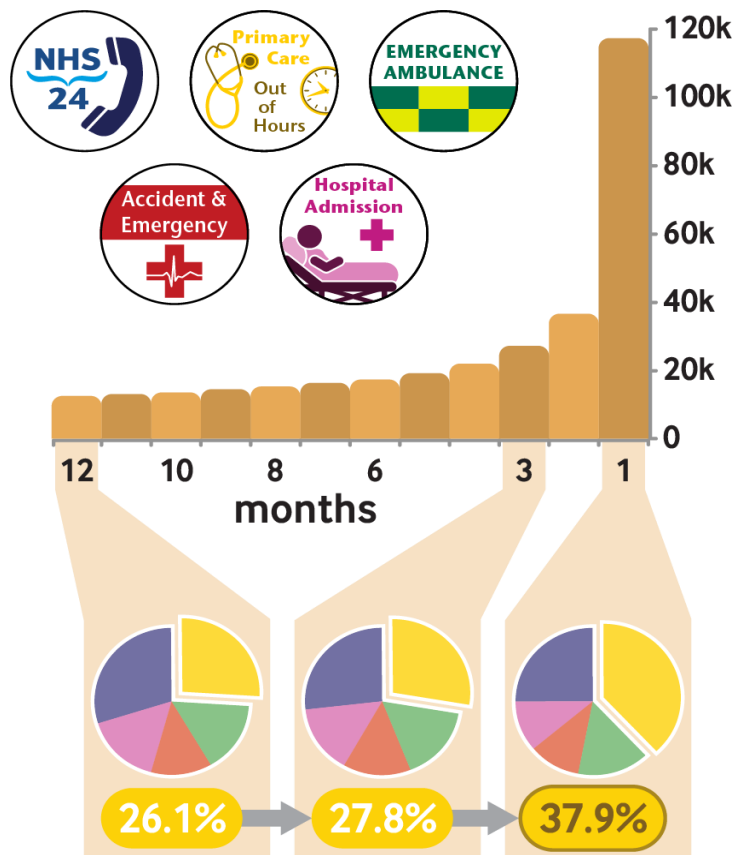


Table 1. Death in adults (18+) by underlying cause of death in Scotland 2016 (N=56,407)

Underlying cause of death	Number	%
1 Cancer	15,902	28.2
2 Organ failure	21,244	37.7
3 Frailty	14,023	24.9
4 Various	2,271	4.0
5 External	2,967	5.3
Total	56,407	100.0

Derived from ICD10 codes of underlying cause of death

What help do people seek?



Proportion of care delivered by
Primary Care OOH

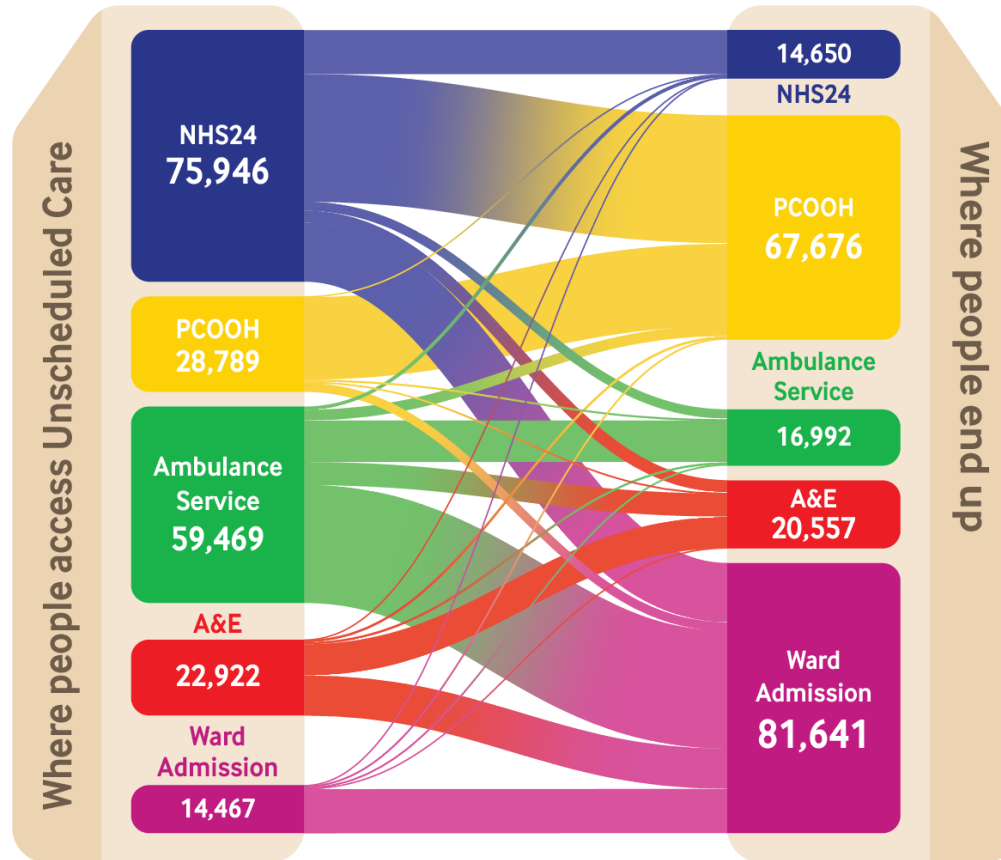
- Final month or two of life – much more service use.
- Primary Care out-of-hours delivers more care closer to death.
- Even before Covid-19, people used community unscheduled care even more in the last month of life.

Who did we talk with?

- Bereaved carers (6)
- Current service users and their family carers (37)
- GPs (8)



People's initial choices determine outcomes



“If I phone an ambulance, they’re duty bound to take you to hospital, but I didn’t want to go....”

What did people say about getting help?

Some people managed a complicated system well.

"I have a special helpline..."

"We've done it before so we know..."

Many were confused and just wanted help quickly.



What did people say about care OOH?

- Not waiting for help
 - Right to speak
- Legitimate problem
 - Best place of care



What matters to people?

The number one priority for people living at home with palliative and end of life care needs (PeoLC) is coordinated care 24/7.

"It should be a seven day a week, twenty-four hour service, because people don't stop being sick, or having falls, or whatever just because it's seven o'clock at night.....

What is happening?

- Public information campaigns - how to use services including NHS 24 and ambulances.
- Healthcare Improvement Scotland (HIS) - ACP toolkit:
<https://ihub.scot/acp>
- NHS Inform - updated public information on ACP:
www.nhsinform.scot/acp
- **RESPECT** emergency treatment and care planning
- Paramedic training for ambulance staff



Anticipatory care planning: *thinking ahead and planning for changes my health & care.*



<https://www.youtube.com/watch?v=hXoQn-VicMQ>

More Information

Original Article



Integrating lived experiences of out-of-hours health services for people with palliative and end-of-life care needs with national datasets for people dying in Scotland in 2016: A mixed methods, multi-stage design

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