

People on the Margins

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Learning Outcomes

- State the national picture
- Identify the challenges for engaging with the 'seldom heard'
- Identify the challenges/barriers in your own organisation

What do you think when you hear these terms?

- **Hard to reach**
- **People on the Margins**
- **Seldom Heard**

Who are they?



Engagement may not be straightforward

- ‘Seldom heard’ is a term used to describe groups who may experience barriers to accessing services or are under-represented in healthcare decision making.
- Rural communities
- black and minority ethnic (BME) groups
- gypsies and travellers
- lesbian, gay, bisexual and transgender
- asylum seekers and refugees
- young carers
- Teenagers
- people with mental health issues
- people with a learning disability
- Prisoners
- Homeless
- Over 75
- Dementia

Marie Curie (2015)

- Found some people who would benefit from palliative care do not receive any at all, either from specialist palliative care or generalists....

In 2014 National survey of Bereaved People found

- 21% hospitals offered 7 days SPC service majority offering 5 days a week, 2% offered 24/7 service

Inequalities and variation in EOLC: our questions



1. What are the **barriers** to people from some groups getting good care at the end of life?
 - People with a diagnosis other than cancer
 - Older people (over 75)
 - People with dementia
 - People from BAME groups
 - Other groups of people who may have specific needs: people with learning disabilities, people with mental health needs, LGBT people, people who are homeless, prisoners, travellers and Gypsies.
2. What **good practice** can others learn from at local level?
3. What **action** can national and local stakeholders take in the next five years to address inequalities?

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A new National Commitment



www.ncpc.org.uk

THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE



*Let's talk
about it*

“Our commitment is that every person nearing the end of their life should receive attentive, high quality, compassionate care, so that their pain is eased, their spirits lifted and their wishes for their closing weeks, days and hours are respected”

Ben Gummer MP

**Parliamentary Under-Secretary of State
for Care Quality**

www.dyingmatters.org

Did you know.....

‘People from the most deprived areas who die from cancer each year have 15,000 more emergency hospital visits in the final year of life compared with those from the least deprived areas ‘

Public Health England (2017)

Sleeman (2015)



Literature Review access not happening due to

- lack of
- lack of
- Previous
- lack of
- family/religious values

Inequality of Provision



Inequity

what are other
words for
inequity?

unfairness, injustice, wrong,
unjustness, partiality,
iniquity, discrimination, bias,
prejudice, one-sidedness



What are the Challenges for engaging...



"We need to understand people's needs and priorities, and shouldn't make assumptions about anyone... We are failing as a society if anyone suffers needlessly in their final weeks, days and hours."

- Claire Henry, MBE, Chief Executive of National Council for Palliative Care & Dying Matters Coalition

A different ending:

Addressing inequalities in end of life care

#DifferentEnding

www.cqc.org.uk/differentending

Identify challenges for your organisation



Conclusion

- We know more people would benefit from palliative care. Research is required as we still do not know from evidence which model is best.
- Given increasing demands we need to focus on improving care in the most cost effective way.
- What actions will we take to avoid these inequalities in access?

References

National Cancer Registration and Analysis Service, Public Health England and Macmillan Cancer Support. 2017. Macmillan-NCRAS End of Life Emergency Visits Workbook.

- www.ncin.org.uk/about_ncin/releases
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