# A Human Rights based approach for Palliative Care:
## *Towards Solutions for Public Health Palliative Care*

**3rd International Research Seminar**
**AIIHPC and EAPC Reference Group on**
**Public Health and Palliative Care**

EAPC VZW Reference Group
Public Health & Palliative Care

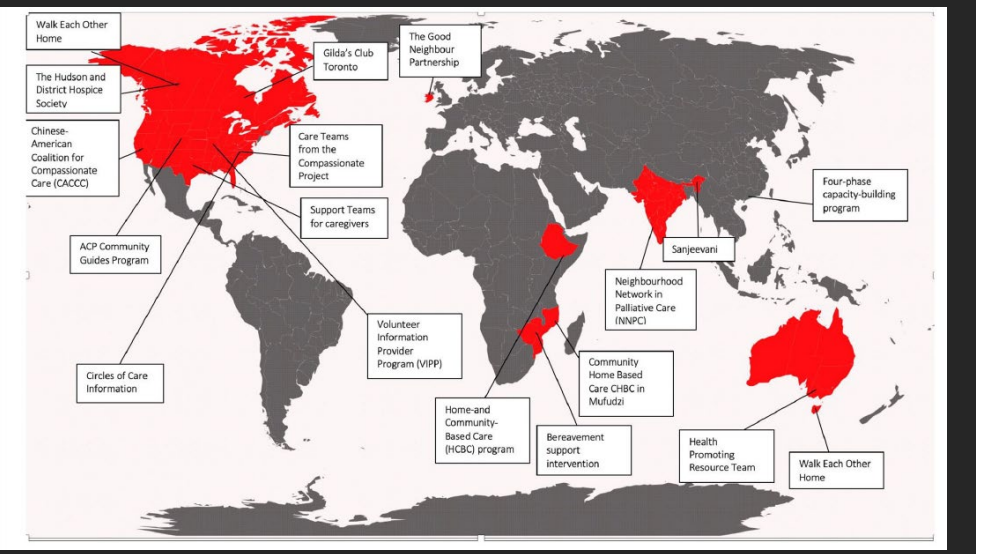
AIIHPC
All Ireland Institute of Hospice and Palliative Care

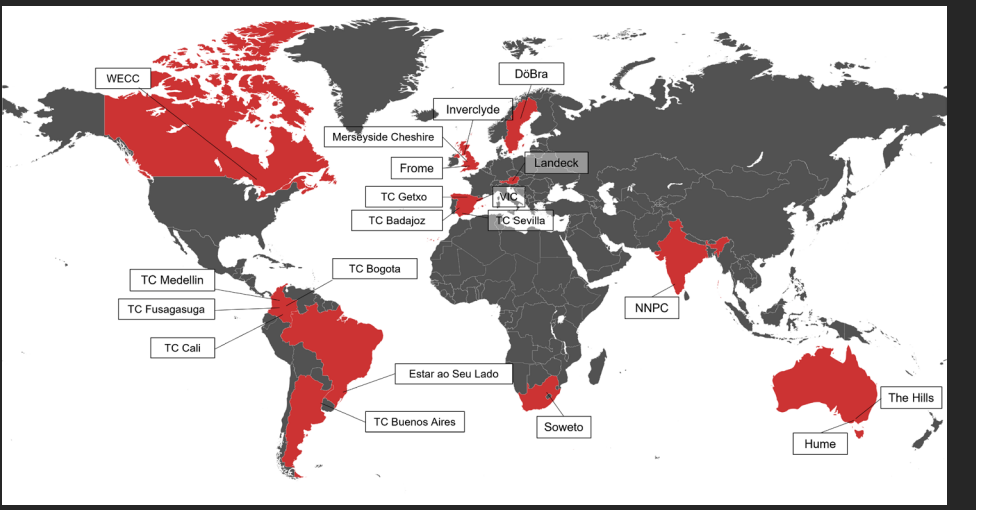
**#EAPCpublichealth**

# Looking forward

EXPLORING THE PRIORITIES FOR PUBLIC HEALTH PALLIATIVE CARE RESEARCH IN THE COMING DECADE

Steven Vanderstichelen, Carol Tishelman, Agnes van der Heide, Sonja McIlfatrick, Libby Sallnow, Luc Deliens, Joachim Cohen.




Two streams of research

1) Traditional public health approaches (i.e., surveillance sciences)

2) "New" public health approaches (i.e., practice methodologies)

Renewed and increasing interest in public health at the end of life

Fig top: D'Eer et al. (2022) Civic engagement in serious illness, death, and loss: A systematic mixed-methods review. Palliative Medicine. Mar 14, doi: 10.1177/02692163221077850
Fig bottom: Quintiens et al. Area-Based Compassionate Communities: a systematic integrative review of existing initiatives worldwide. Pal Med 2022, Vol. 36(3). DOI:

# Research question

What research topics should be prioritised in PHPC research over the next 10 years based on their appropriateness, relevance, feasibility and potential impact?

1. Go to wooclap.com
2. Enter the event code in the top banner

Event code
OBTJAQ

1. Send @OBTJAQ to 0460 200 711
2. You can participate

# What should we prioritise?

# Where do the priorities lie?

High priority

- equity, access and power,
- integrated palliative care
- care capacity and autonomy
- Community involvement
- Methodological and conceptual development

Disagreement about

- Methodological innovation and development
- Settings-based approaches
- Conceptual distinctions

# Methods

EUROPEAN, MIXED METHOD ONLINE DELPHI STUDY

IDEA GENERATION

RANKING EXERCISE DIGITAL SURVEY QUESTIONNAIRE

SNOWBALL SAMPLING METHOD

LIST OF 80 EXPERTS FROM 16 COUNTRIES

# Ranking criteria

| Criterion | Main question | Operationalisation | Scoring |
|---|---|---|---|
| Appropriateness | Should we do it? | It is ethically right to pursue this research option. | 5-point Likert scale (strongly disagree – disagree – neutral – agree – strongly agree) |
| Relevance | Why should we do it? | This research option would help bridge current knowledge gaps in public health palliative care. | |
| Feasibility | Can we do it? | We have the means (technology, infrastructure, funds, scientific methods) to pursue this research option. | |
| Impact | What do the stakeholders get out of it? | Pursuing this research option would produce findings, insight or impact that would benefit people in Europe. | |

# Research Priority Score (RPS) & Average Expert Agreement (AEA)

$$RPS = \frac{(Appropriateness\ score)+(Relevance\ score)+(Feasibility\ score)+(Impact\ score)}{4}$$

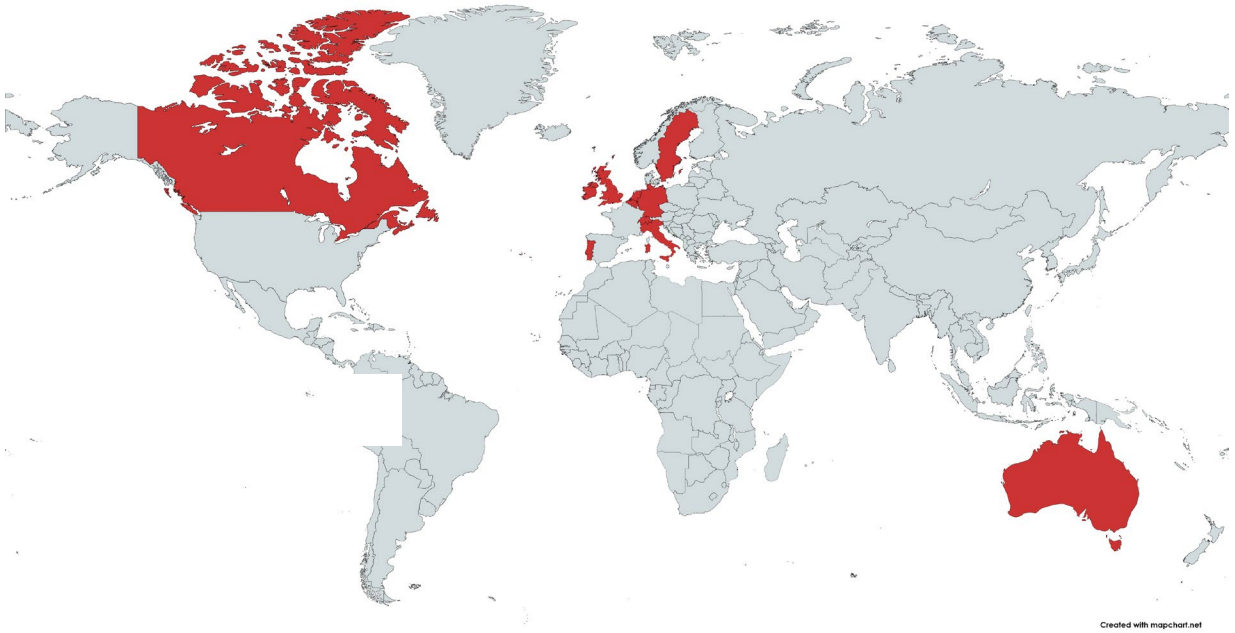
$$mean\ RPS = \frac{RPS}{N}$$

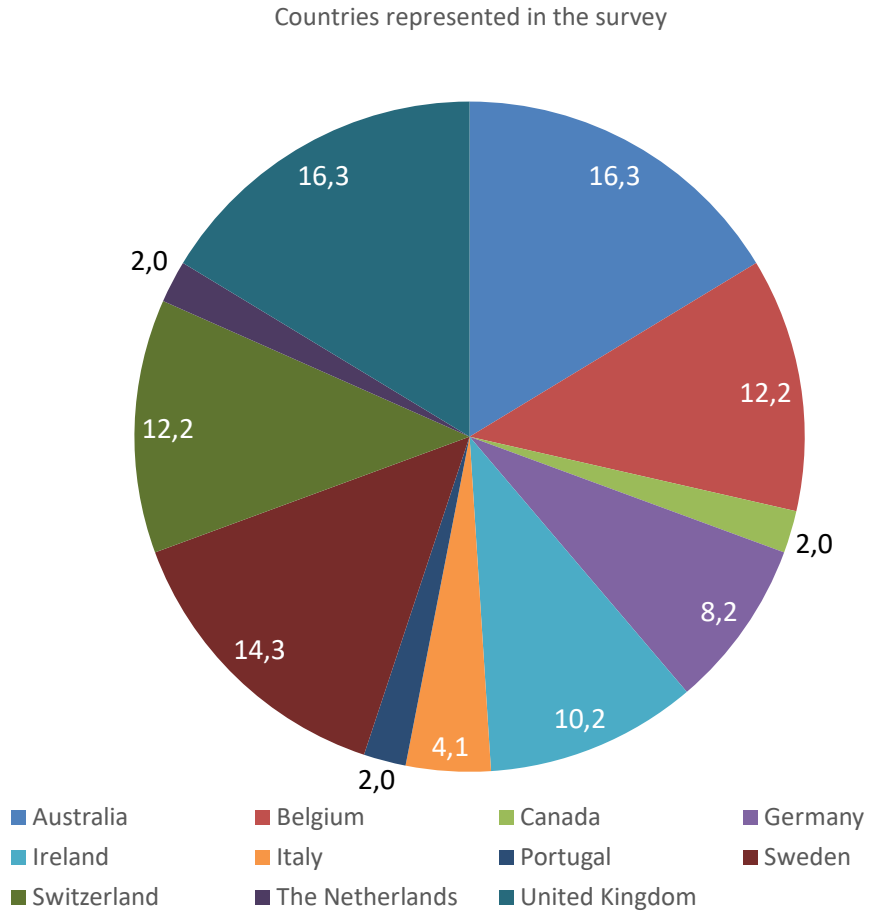
Scoring: 1.0 – 2.5 = low priority; 2.6 – 3.5 = uncertain; 3.6 – 5.0 = high priority.

$$AEA = \frac{1}{4}\sum_{q=1}^{4} \frac{N(scorers\ who\ provided\ most\ frequent\ response)}{N\ (scorers)}$$

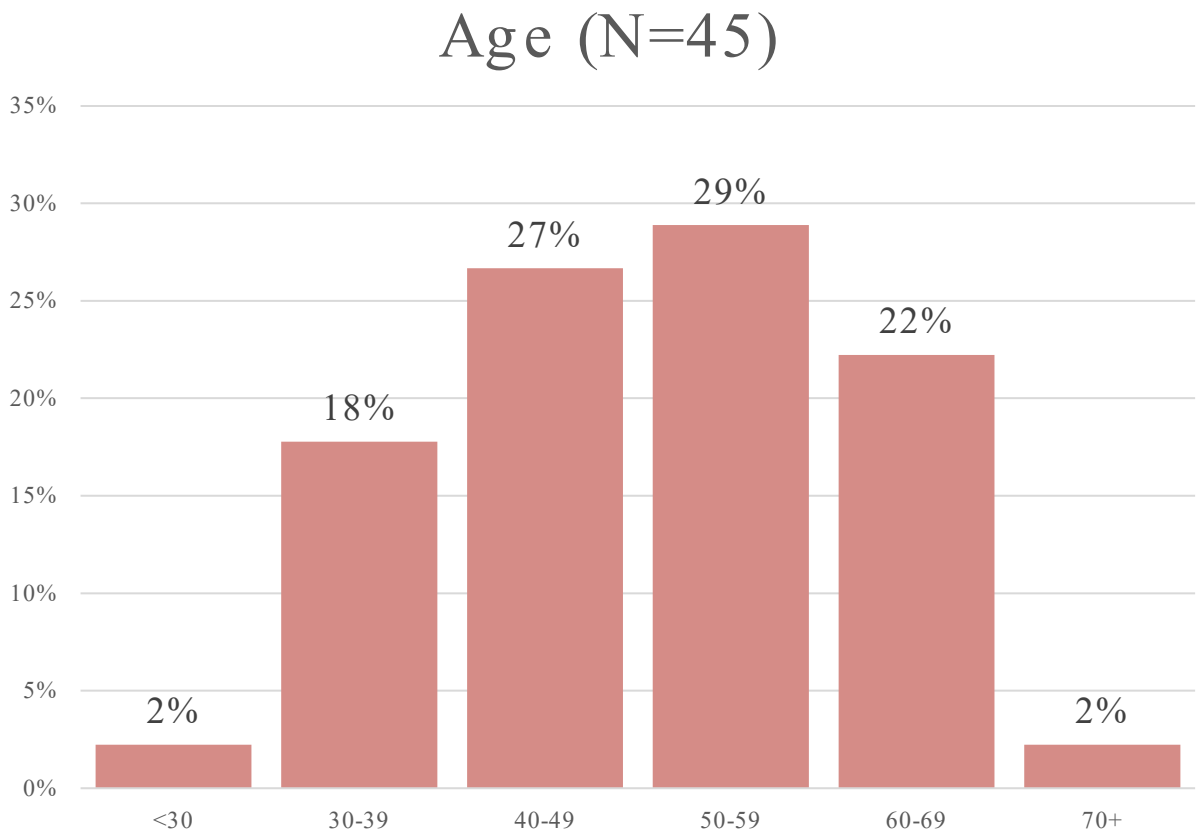
Scoring: ≤29% = disagreement; 30% - 69% = uncertainty; ≥70% = agreement

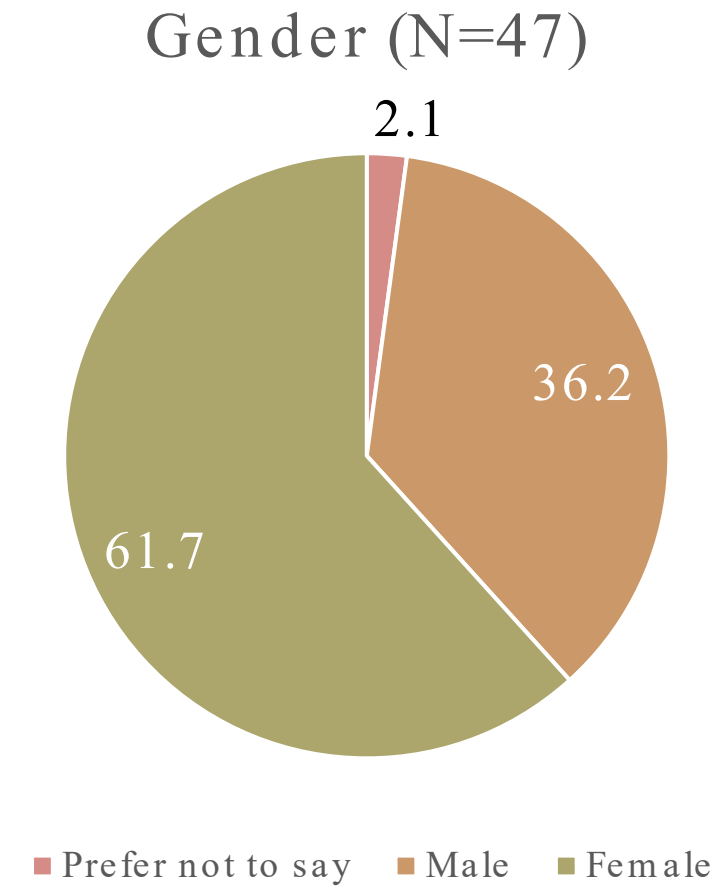
# Results round 1 (N=49)



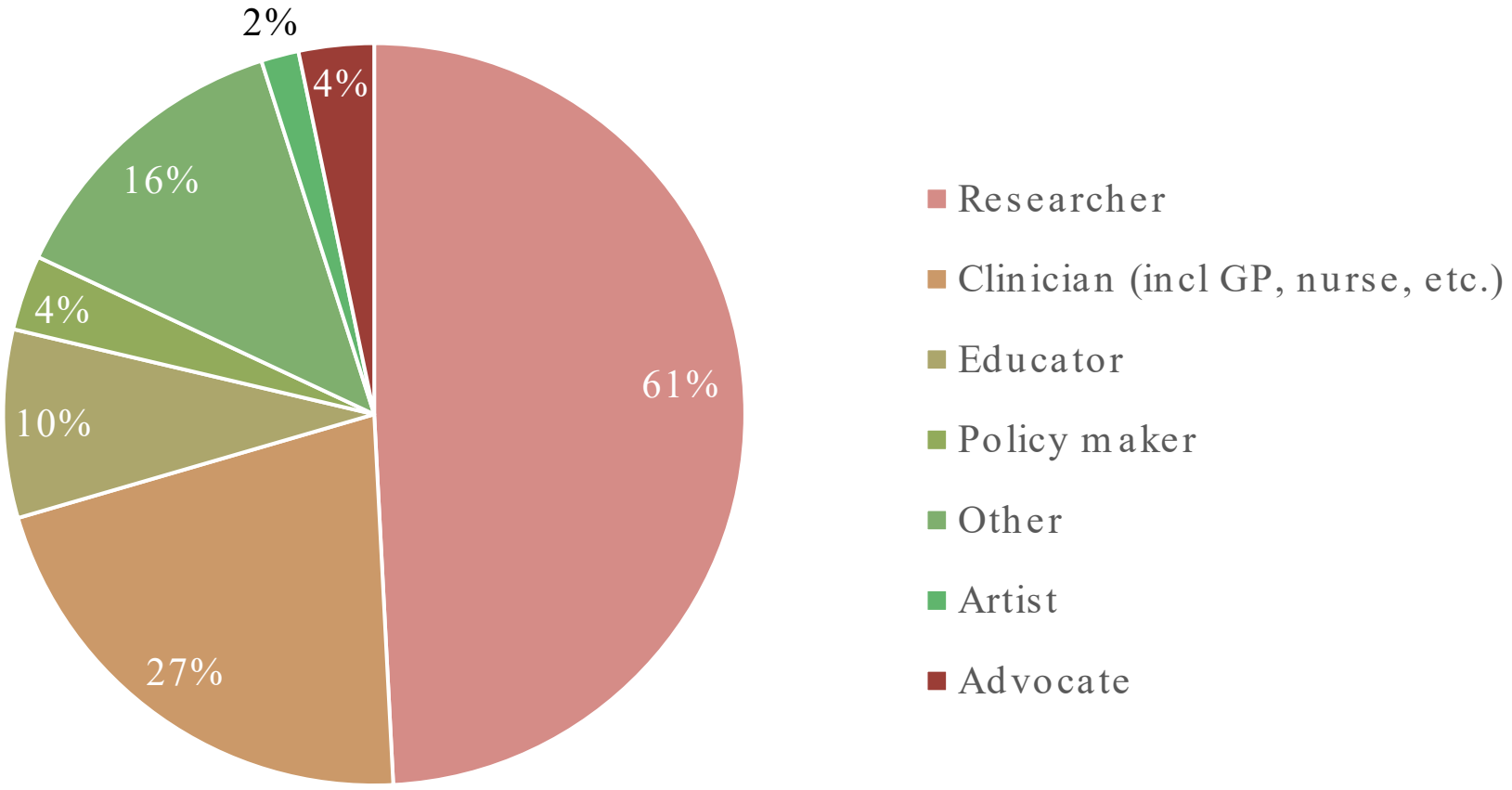



# Results round 1 (N=65)



# Results round 1 (N=49) – PHPC background



# Preliminary top 10 priorities

| Nr | Items | AEA | RPS |
|---|---|---|---|
| 25 | Represent and involve older people with care needs and their caregivers in palliative care research | 88% | 4,50 |
| 2 | Research barriers and facilitators to access to palliative care services for vulnerable and disadvantaged citizens (including but not limited to rural, refugee, homeless, disenfranchised populations) | 92% | 4,44 |
| 1 | Investigate and develop methods for involving disenfranchised, underserved and vulnerable populations in PHPC research. | 90% | 4,42 |
| 12 | Investigate the integration of, and dynamics between social and healthcare systems in palliative care | 87% | 4,35 |
| 13 | Further develop the evidence base for 'integrated' palliative care | 80% | 4,34 |
| 10 | Investigate the factors and mechanisms that may contribute to inequity through palliative care research | 85% | 4,31 |
| 34 | Investigate the societal value of public engagement with the topic of death and dying. | 79% | 4,21 |
| 7 | Determine how to support and help retain the autonomy of people with PC needs and their care networks | 81% | 4,20 |
| 3 | Investigate the factors that influence access to palliative care in rural or isolated areas | 83% | 4,14 |
| 39 | Explore the effects of community involvement on wellbeing in EoL situations | 81% | 4,11 |

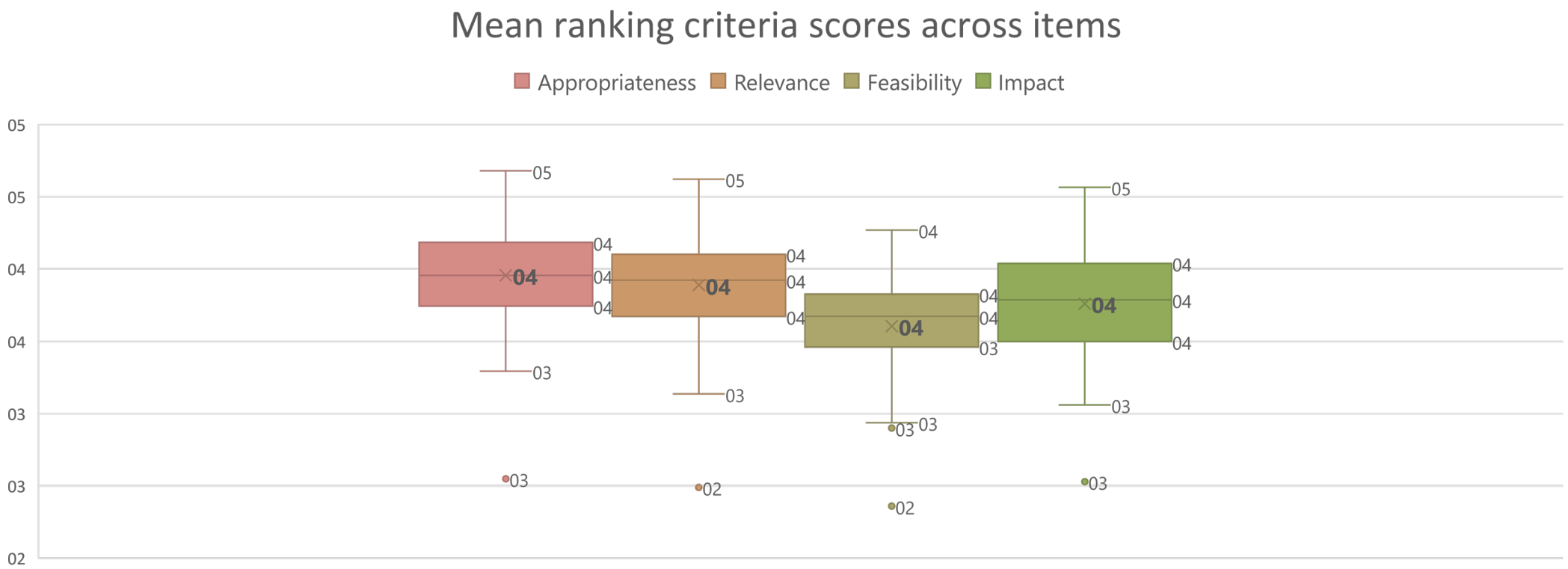
# Results round 1: RPS & AEA

| Average Expert Agreement | | Research Priority Score | |
|---|---|---|---|
| Agreement (≥70%) | 37 | High priority (3.6-5) | 50 |
| Uncertain (30% - 69%) | 25 | Uncertain (2.6-3.5) | 11 |
| Disagreement (<30%) | 0 | Low priority (1-2.5) | 1 |
| Total | 62 | Total | 62 |

# Uncertainty: 10 items with lowest AEA

| Nr. | Item | AEA | RPS |
|---|---|---|---|
| 32 | Investigate the strengths and limitations in Kastenbaum's death system model for understanding PHPC initiatives and their effects/impact. | 37% | 2,48 |
| 55 | Assessment of palliative care needs in patients with comorbidities and how they are being satisfied | 42% | 3,16 |
| 49 | Develop methodologies to study intersectoral partnerships in palliative care | 49% | 3,28 |
| 62 | Clarify conceptual distinctions between public health palliative care, health promoting palliative care and compassionate communities | 50% | 3,38 |
| 35 | Develop a model of liminal spaces and moments in which death knowledge and education are relevant for citizens (E.g. people who become parents, who just signed a mortgage, who are getting a life insurance, etc.) | 52% | 3,15 |
| 58 | Develop the concept of 'uncertainty' as an aspect of illness and care in PHPC research | 52% | 3,35 |
| 46 | Investigate how physical surroundings create and foster social connections in Palliative and End-of-Life Care situations | 55% | 3,40 |
| 9 | Develop a theory or framework of intersectionality of vulnerability in PC and EOL care | 59% | 3,45 |
| 23 | Develop a conceptual and practical framework for ‘social prescribing’ in PC and EOLC | 60% | 3,47 |
| 54 | Critically reappraise or reconceptualise the hierarchy of medicine to demonstrate the value of PHPC research. | 60% | 3,61 |

# Mean criterion scores across items


Mean ranking criteria scores across items
Appropriateness
Relevance
Feasibility
Impact
05
05
04
04
04
03
02
04
04
04

# Qualitative feedback on items was decisive

- 1 item removed due to low priority (RPS <2.5):
  - Item 32: Investigate the strengths and limitations in Kastenbaum's death system model for understanding PHPC initiatives and their effects/impact.
- 17 items removed due to redundancy, formulation too vague or leading
- 27 items rephrased to remove jargon, add specificity, and expand or narrow down their scope
- 1 item added due to splitting an item into two

# Next steps

## Increased sensitivity of the instrument

Expanding Likert scale from 5 to 8 points

Removing neutral middle point

## Randomised items in the questionnaire

Remove bias due to fatigue (e.g., careless rating of later items in the list or higher number of missings)

## Round 2 sent out

Analysis (Jan – Feb 2024)

Reporting (Ca. May 2024 (EAPC2024))

EAPC White paper (submission May-June 2024)

# EAPC Reference Group on Public Health & Palliative Care

HTTPS://WWW.EAPCNET.EU/EAPC-GROUPS/REFERENCE/PUBLIC-HEALTH/

Steering committee
Prof. Luc Deliens (BE) - Chair
Prof. Joachim Cohen (BE) – Co-Chair
Dr. Steven Vanderstichelen (BE) – Secretary

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Dr. Marie-Charlotte Bouësseau (FR)
Prof. Allan Kellehear (UK)
Prof. Sonja McIlfatrick (NI)
Prof. John Rosenberg (AUS)
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University of BRISTOL

Palliative and End of Life Care Research Group
Bristol Medical School

# Using routine data to understand inequity: A cross-sector project in a coastal community

Dr Lucy Selman, Associate Professor of Palliative & End of Life Care, University of Bristol

16 Nov 2023

@WsM_Community
@PEoLCSW

bristol.ac.uk

UKRI Arts and Humanities Research Council

Centre for Academic Primary Care

About

Research

Information for GP teachers

Courses and programmes

Public involvement and engagement

# Researchers partner with local communities to tackle health inequalities across the UK

*8 November 2022*

A new wave of research projects, including a consortium-building initiative led by the University of Bristol, has been announced to investigate the role of community assets such as parks, galleries and creative organisations in improving health outcomes.

View of promenade Weston-super-Mare



UKRI Arts and Humanities Research Council

## WsM Community Network Project

❖ **Aim:** to create a network that unites health and social care workers, people providing community assets, academics, and people with lived experience to work together to reduce health inequities in Weston and the North Somerset region.

❖ **Our focus** is on inequities related to end-of-life care, bereavement support, social isolation and loneliness.

- Initially a 9-month project, funded by the Arts and Humanities Research Council (Nov 2022-July 2023)

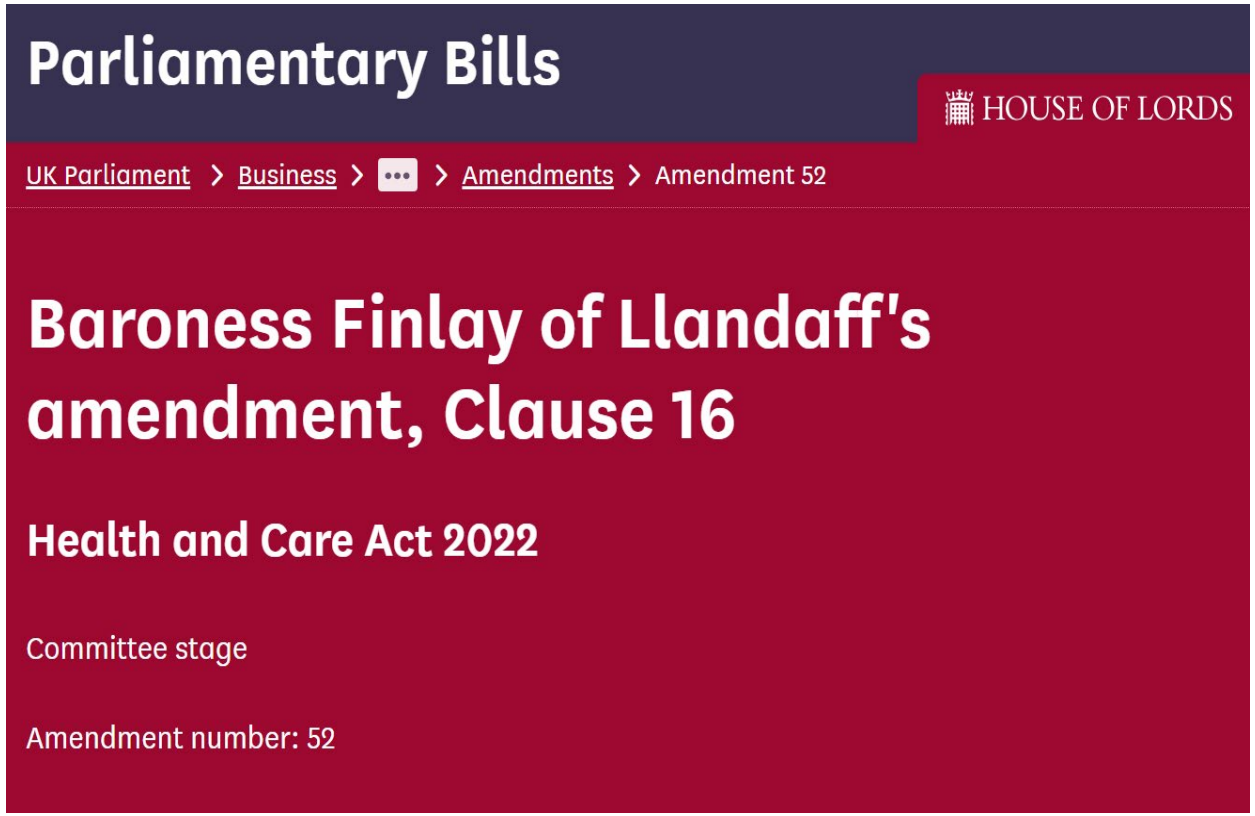
## The opportunity

- Transition to Integrated Care Systems in July 2022 - “Healthier Together” ICS covers Bristol, North Somerset and South Gloucestershire (1.1 million)

- Now legally required to work ‘with people, as well as for people’ – recognition of the potential benefits of **better integration** between NHS, local councils, voluntary, community and social enterprise (VCSE) sector and others

## Health and Care Act 2022

- Essential for the ICS to demonstrate the Health and Care Bill requirements around universal access to specialist palliative care for all, across care settings



## Network collaborators (and more!)

ARTS & HEALTH SOUTH WEST

RENS
Race Equality North Somerset

NHS University Hospitals Bristol and Weston NHS Foundation Trust

ARTS AND CULTURE

PIER HEALTH GROUP

VOLUNTARY ACTION NORTH SOMERSET

Weston Hospicecare

CULTURE WESTON

North Somerset Council

IPC

HOW
HUMANS OF WESTON

wesport
INSPIRING ACTIVE LIVES

aw VSC

Vision North Somerset

University of BRISTOL

Public Health England

National End of Life Care Intelligence Network

NHS University Hospitals Bristol and Weston NHS Foundation Trust

Healthier Together
**Improving health and care** in Bristol, North Somerset and South Gloucestershire

Community Network Meetings (December, February, June, September…)

Mapping available data, creating an open access dashboard

Mapping assets and resources → community directory

Community linkage and support

Reviewing arts evaluation data (last 5 years), interviews

Understanding the WsM ecosystem, cross-sector working & coproduction

**Aims**

Within 9 months:

1. Create an interactive dashboard that stakeholders can use to describe mortality statistics and the impact of disadvantage
2. Explore what we know about local access to palliative and end-of-life care and bereavement support
3. Understand current limitations in the data and generate recommendations

**Methods**

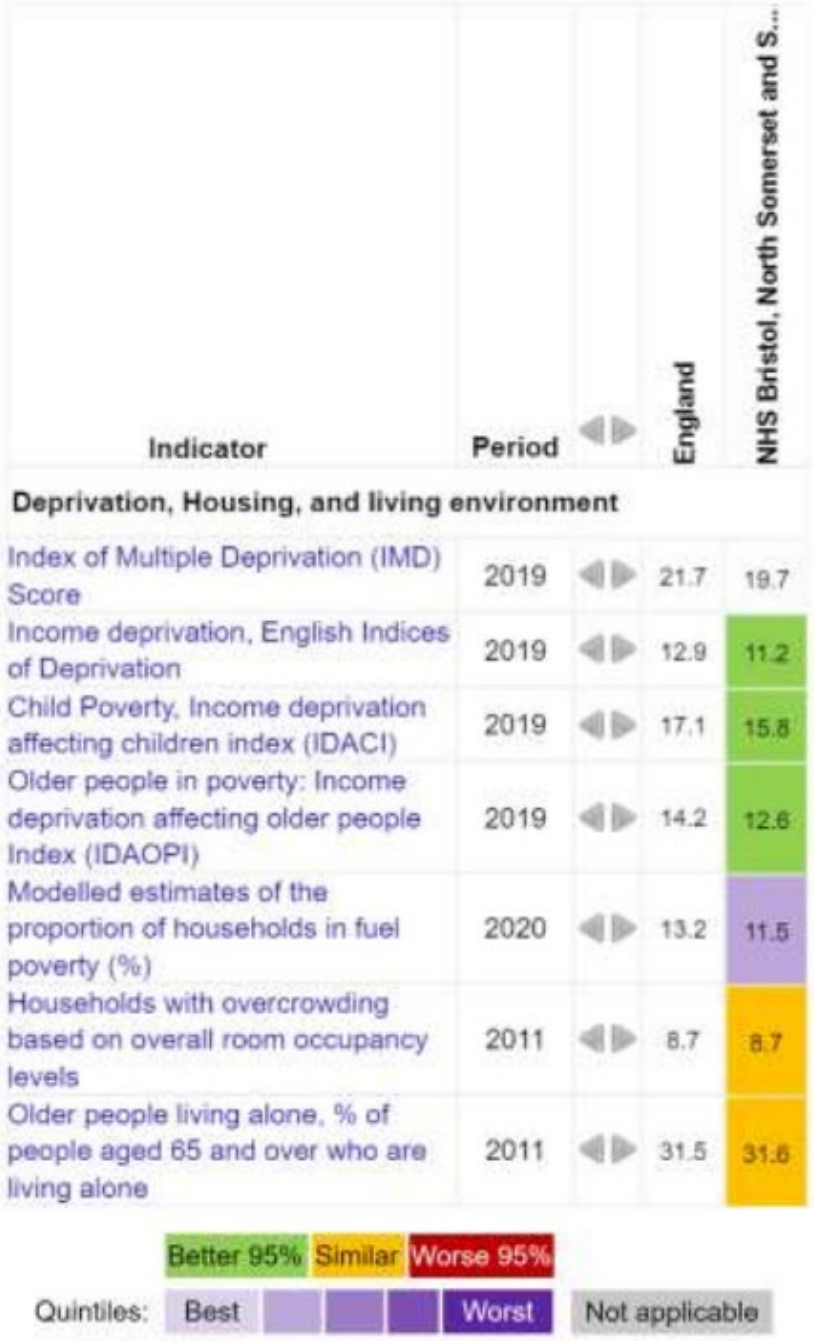
- Data asset mapping – public data sources, routine health and social care databases
- Gap analysis: consider what we are missing
- Identify what priority questions we can answer
- Make recommendations

## Public data sources

- Size of geographical region is key
- Region is relatively affluent, but North Somerset has the third-highest **income inequality** in England
  - nine neighbourhoods (all in Weston-super-Mare, WsM) amongst the most deprived 10% nationally
- WsM: seaside town with an older demographic, pockets of significant, worsening deprivation, high levels of mental health and addiction problems

**Weston-super-Mare**

- 64% of people registered with a Weston Town GP have a long-term health condition
- Worse health in older people, men, ethnic minority groups, lower social classes and people from socio-economically deprived areas
- Known barriers accessing end-of-life care and bereavement support
  - lack of awareness of available services, discomfort asking for help, discrimination, or a lack of appropriate services
- More likely to experience poorer quality care and be socially isolated and lonely – common consequences of serious illness, caregiving and bereavement and major outcome determinants



| Indicator | Period | | England | NHS Bristol, North Somerset and S... |
|---|---|---|---|---|
| **Deprivation, Housing, and living environment** | | | | |
| Index of Multiple Deprivation (IMD) Score | 2019 | | 21.7 | 19.7 |
| Income deprivation, English Indices of Deprivation | 2019 | | 12.9 | 11.2 |
| Child Poverty, Income deprivation affecting children index (IDACI) | 2019 | | 17.1 | 15.8 |
| Older people in poverty: Income deprivation affecting older people Index (IDAOPI) | 2019 | | 14.2 | 12.6 |
| Modelled estimates of the proportion of households in fuel poverty (%) | 2020 | | 13.2 | 11.5 |
| Households with overcrowding based on overall room occupancy levels | 2011 | | 8.7 | 8.7 |
| Older people living alone, % of people aged 65 and over who are living alone | 2011 | | 31.5 | 31.6 |



**Existing data**

- ICS data packs: [OHID Data packs - Palliative and End of Life Care Network - FutureNHS Collaboration Platform]
- Fingertips: https://fingertips.phe.org.uk/profile/end-of-life

Challenge: Data is not fine-grained enough

**Routine health & social care data**

- End of life and bereavement identifiers not routinely captured in most health and social care databases
- End of life register poorly completed, biased towards cancer diagnoses
- No systematic, routine identification of those who have been bereaved in health or social care databases
- GP bereavement code poorly used
- The Integrated Care Board (ICB) system-wide dataset includes GPs and hospitals, but access is time-consuming



Challenge: the data is not collected, hard to obtain

# Data sources used

| Provider | Dataset |
|---|---|
| Care Quality Commission (CQC) | Care homes |
| Department for Work and Pensions (DWP) | Attendance Allowance: Cases in Payment |
| | Bereavement Benefit |
| | Bereavement Support Payment: Claims in Payment |
| | Disability Living Allowance: Cases in Payment |
| | Personal Independence Payment: Cases with Entitlement |
| GOV.UK | Permanent exclusions and suspensions - school level |
| Ministry of Housing, Communities and Local Government | English indices of deprivation |
| Ministry of Justice | Lasting Power of Attorney |
| Office for Health Improvement and Disparities (OHID) | Local Health - Small Area Public Health Data |
| | Mental Health and Wellbeing Joint Strategic Needs Assessment |
| | Mortality Profile |
| | National General Practice Profile |
| | Palliative and End of Life Care Profile |
| | Segment Tool |
| Office for National Statistics (ONS) | Death registrations |
| | Census – Disability, Ethnic group, Gender identity, General health, Household composition, Household language, Household size, Legal partnership status, Migrant indicator, Provision of unpaid care, Religion, Sexual orientation |
| | Mid-year population estimates |
| | Prediction of the prevalence of loneliness for those aged 65 and over |
| Voluntary Action North Somerset (VANS) | VANS Support Directory |
| Weston Hospicecare | Referrals for North Somerset residents |

**Answerable questions**

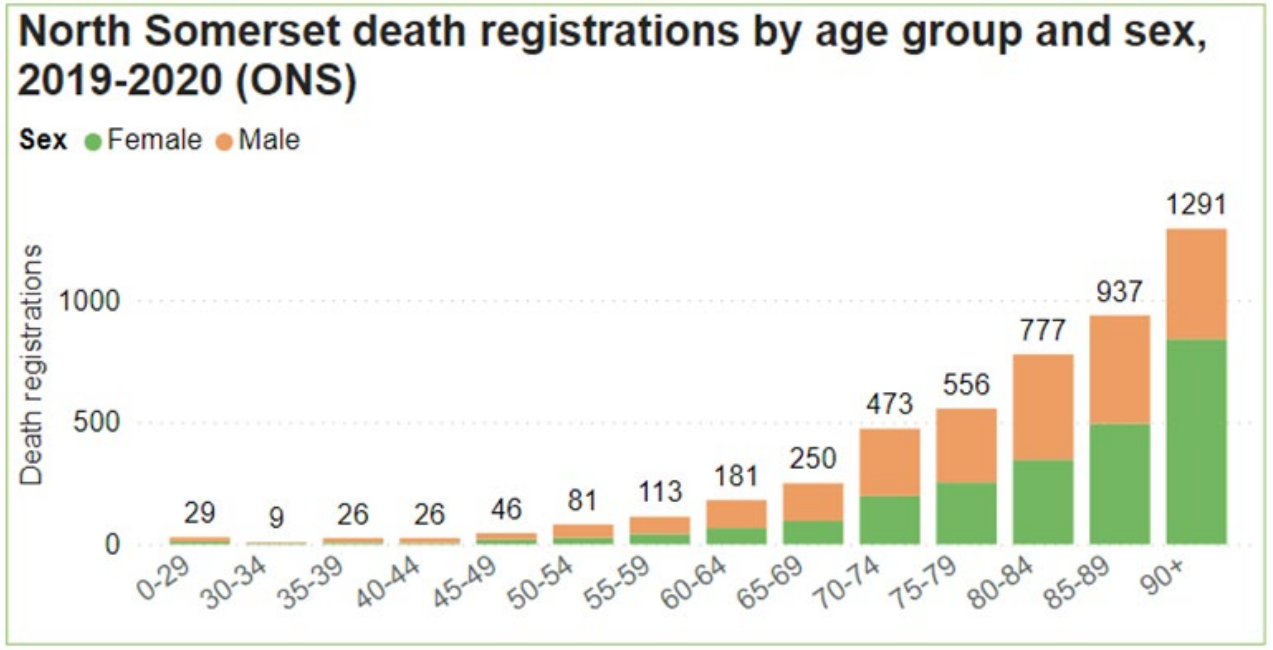
- How many people die each year in North Somerset?
- What are the age and sex characteristics of people who die?
- Where in North Somerset did people who died reside?
- Where do people die?
- What did they die of?

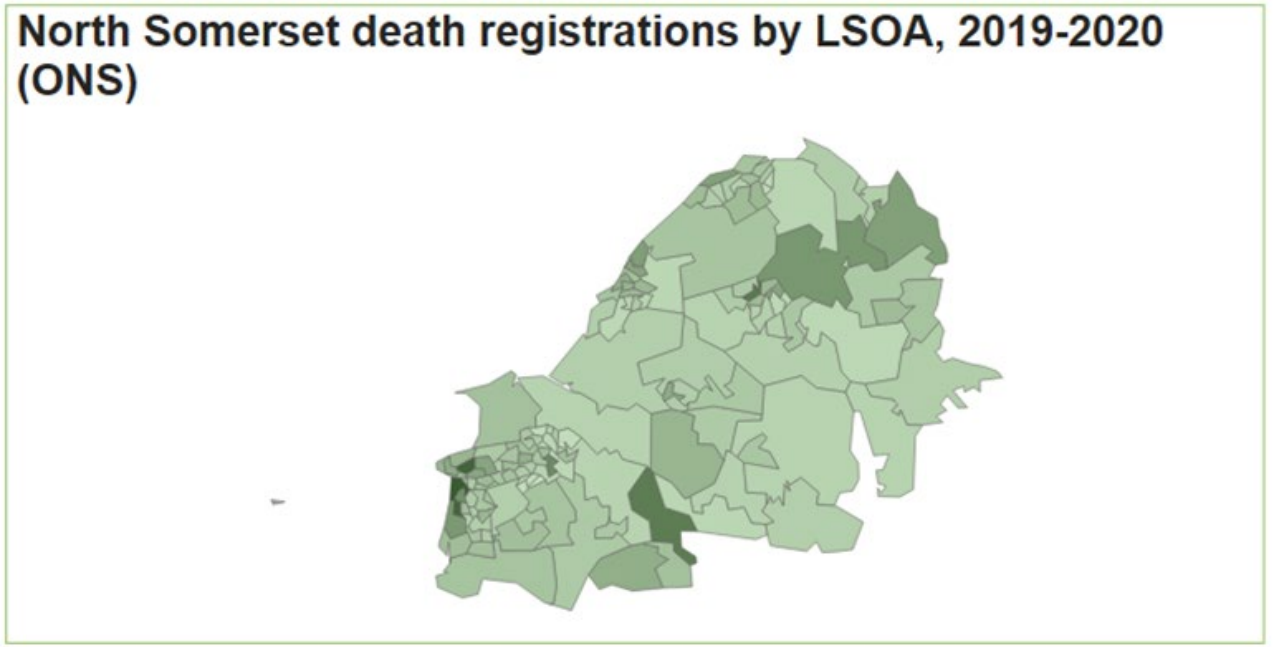
- Wherever possible, data was matched to Lower-layer Super Output Areas (LSOAs).
- LSOAs linked with the Index of Multiple Deprivation (IMD) 2019

➢Highlight differences for residents living in the most deprived areas (decile 1) and the least deprived areas (decile 10)

**Deaths**

- C.2,500 deaths registered each year
- Where do people die?
  - Hospital (38%), care home (31%), home (25%), hospice (4%), other (2%)
- Death registration rate in the most deprived areas of North Somerset (15.21 per 1,000 population) is **double** that seen in the least deprived areas (7.73 per 1,000)



# North Somerset Profile - comparison of the most and least deprived IMD 2019 deciles (decile 1 and decile 10)

Navigation

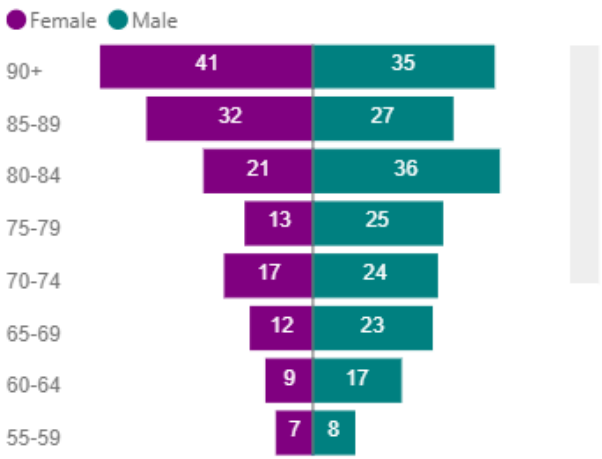
Data sources: ONS - Death registrations 2019 and 2020, Mid-2020 population estimates, Census 2021

Deaths per 1,000 = number of deaths registered per annum per 1,000 population. Rate calculated using mid-year population estimate for year death registered.

Death Registration Year

All

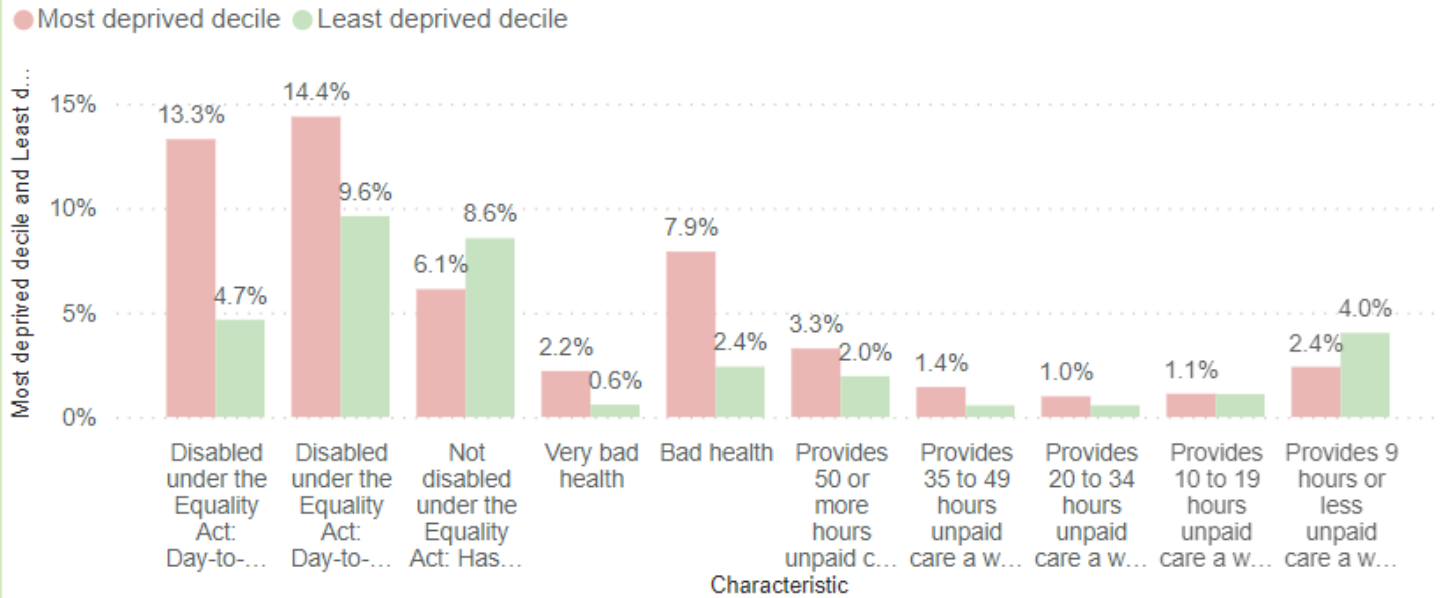
## Most deprived: Death registrations by age group and sex



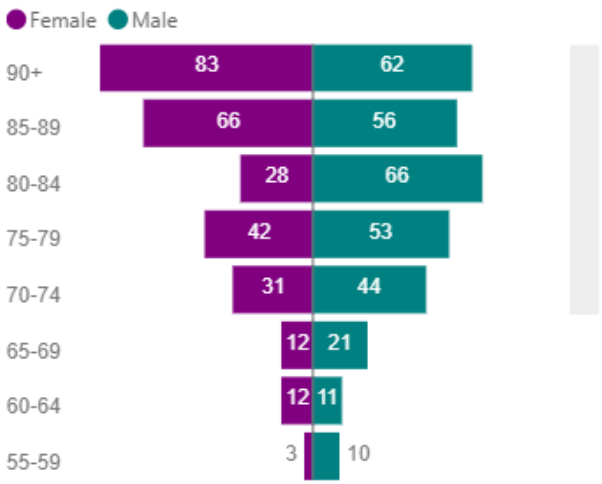

## Deaths per annum per 1,000 population

| Age Group | Female | Male | Total |
|---|---|---|---|
| 90+ | 264.52 | 426.83 | 320.68 |
| 85-89 | 103.23 | 177.63 | 127.71 |
| 80-84 | 60.69 | 141.18 | 94.84 |
| 75-79 | 34.30 | 73.10 | 52.70 |
| 70-74 | 27.78 | 45.54 | 36.00 |
| 65-69 | 19.87 | 38.92 | 29.29 |
| 60-64 | 14.38 | 28.57 | 21.29 |
| 55-59 | 7.64 | 11.07 | 9.15 |
| 50-54 | 8.01 | 5.68 | 6.91 |
| 45-49 | 2.67 | 5.01 | 3.87 |
| 40-44 | 0.00 | 8.53 | 4.26 |
| 35-39 | 0.00 | 2.62 | 1.24 |
| 30-34 | 0.00 | 2.13 | 1.08 |
| 0-29 | 0.42 | 0.42 | 0.42 |
| Total | 12.73 | 17.86 | 15.21 |

## Most deprived decile and Least deprived decile by Characteristic




## Least deprived: Death registrations by age group and sex




## Deaths per annum per 1,000 population

| Age Group | Female | Male | Total |
|---|---|---|---|
| 90+ | 149.82 | 178.16 | 160.75 |
| 85-89 | 72.13 | 87.36 | 78.41 |
| 80-84 | 20.09 | 49.07 | 34.32 |
| 75-79 | 19.38 | 24.80 | 22.07 |
| 70-74 | 10.37 | 15.80 | 12.99 |
| 65-69 | 4.60 | 9.30 | 6.78 |
| 60-64 | 4.52 | 4.42 | 4.47 |
| 55-59 | 1.03 | 3.29 | 2.19 |
| 50-54 | 0.69 | 3.74 | 2.22 |
| 45-49 | 0.00 | 0.33 | 0.17 |
| 40-44 | 0.71 | 0.78 | 0.75 |
| 35-39 | 1.24 | 0.91 | 1.08 |
| 30-34 | 0.00 | 0.00 | 0.00 |
| 0-29 | 0.09 | 0.15 | 0.12 |
| Total | 7.03 | 8.43 | 7.73 |

## Most deprived decile population

12478
Population estimate

51.6%
Females %

48.4%
Males %

2172
65 years and over

17.4%
% 65 years and over

380
Deaths (selected year(s))

15.21
Deaths per 1,000

## Least deprived decile population

40507
Population estimate

50.0%
Females %

50.0%
Males %

10127
65 years and over

25.0%
% 65 years and over

626
Deaths (selected year(s))

7.73
Deaths per 1,000

# North Somerset Profile - life expectancy gap between the most and least deprived quintiles

Navigation

Data sources: OHID Segment Tool

OHID state that data are calculated using 2011 Census based mid-year population estimates and that data will be updated when 2021 Census based population data for small areas are released in late 2023. Percentages may not sum to 100 due to rounding. Pooled death registration data for 2020 and 2021. Based on Index of Multiple Deprivation 2019

## Life expectancy (years)

| Geography | Female | Male |
|---|---|---|
| England | 82.7 | 78.7 |
| North Somerset | 84.0 | 80.4 |
| North Somerset least deprived quintile | 86.8 | 83.4 |
| North Somerset most deprived quintile | 80.4 | 75.6 |

## Gap (years) - North Somerset (NS) vs England

-1.3
Female

-1.7
Male

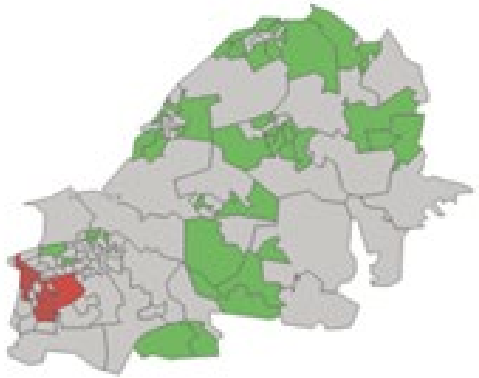
## Gap (years) - Least vs most deprived quintile in NS

6.4
Female

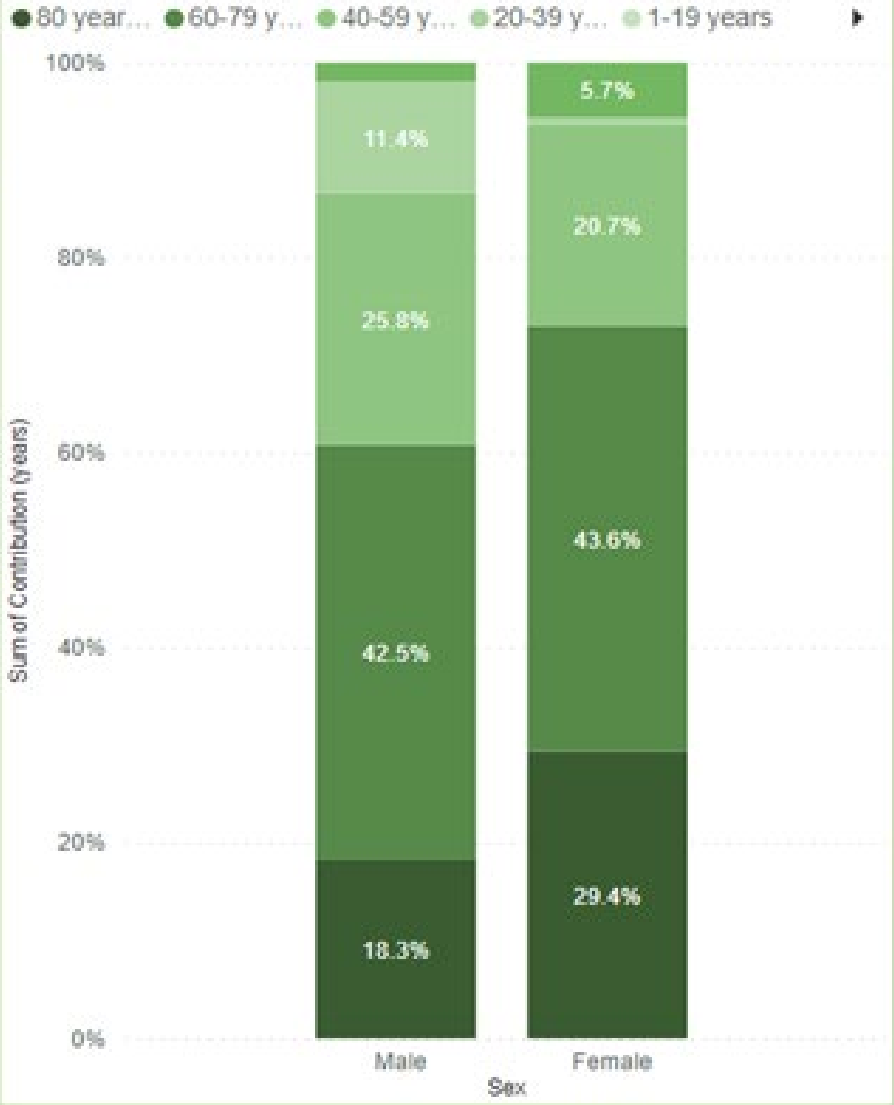
7.8
Male

## Most and least deprived quintiles (IMD 2019)

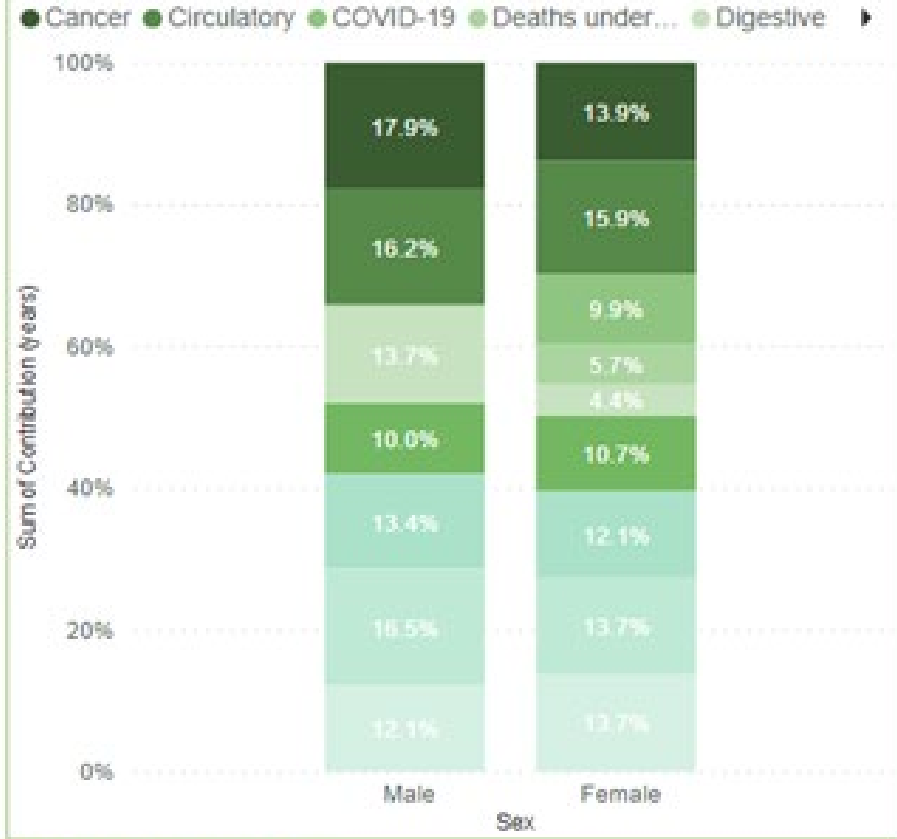
Decile ● 1 ● 2 ● 9 ● 10



## Breakdown of the life expectancy gap between the most and least deprived quintiles of North Somerset by age group, 2020 to 2021




## Breakdown of the life expectancy gap between the most and least deprived quintiles of North Somerset by cause of death, 2020 to 2021




## Number of excess deaths

| Cause of death category and sub category | Female | Male | Total |
|---|---|---|---|
| ⊞ Mental and behavioural | 54 | 54 | 108 |
| ⊞ Other | 66 | 38 | 104 |
| ⊞ Circulatory | 39 | 48 | 87 |
| ⊞ Respiratory | 45 | 40 | 85 |
| **Total** | **275** | **282** | **557** |

# North Somerset Profile - Prediction of the prevalence of loneliness for those aged 65 and over

Navigation

Data sources: ONS

Areas with a value closer to 0 (darker green) predict a greater prevalence of loneliness amongst those aged 65 and over and living in households compared to areas with a value further away from 0 (lighter green). The prediction values are based on analysis by Age UK and then applied to Census 2011 data by ONS.

Select one deprivation domain below (select deciles -->)

Index of Multiple Deprivation (IMD) Decile

1 10

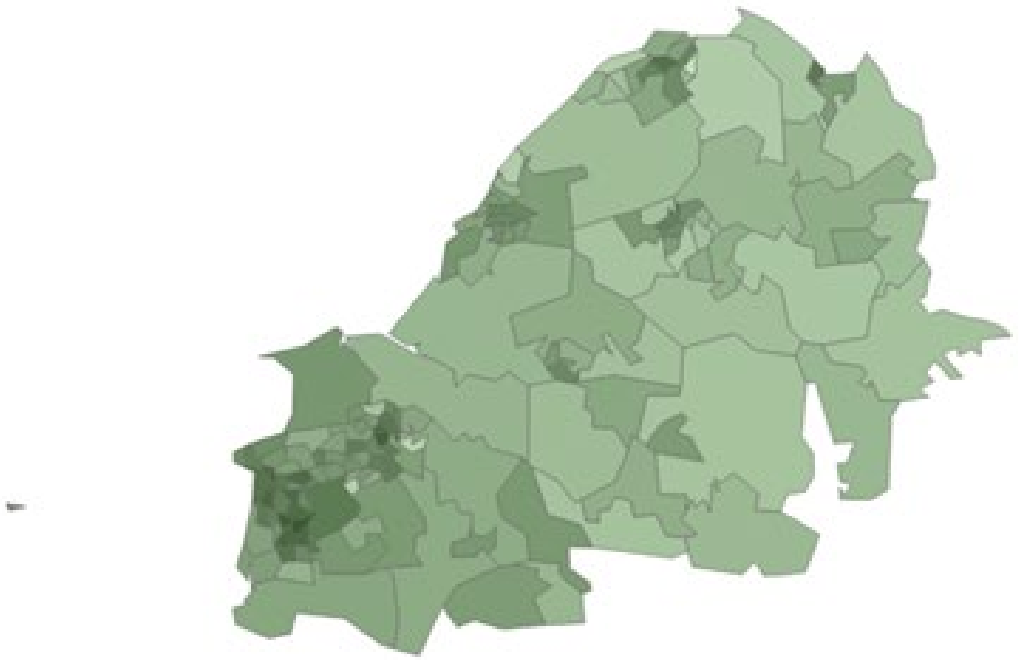
Greater prevalence of loneliness compared to North Somerset ave...

All

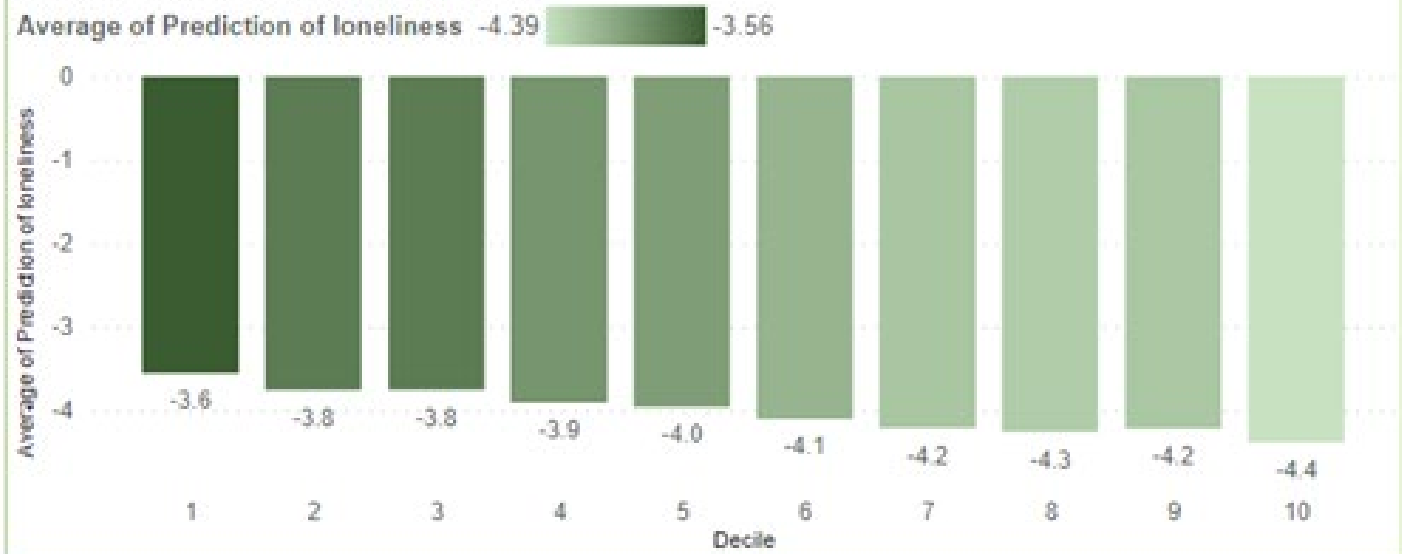
Prediction of the prevalence of loneliness for those aged 65 and over in North Somerset

-4.13

Prediction of loneliness and LSOA Name (2011) by LSOA Code (2011)



Average of Prediction of loneliness by Decile

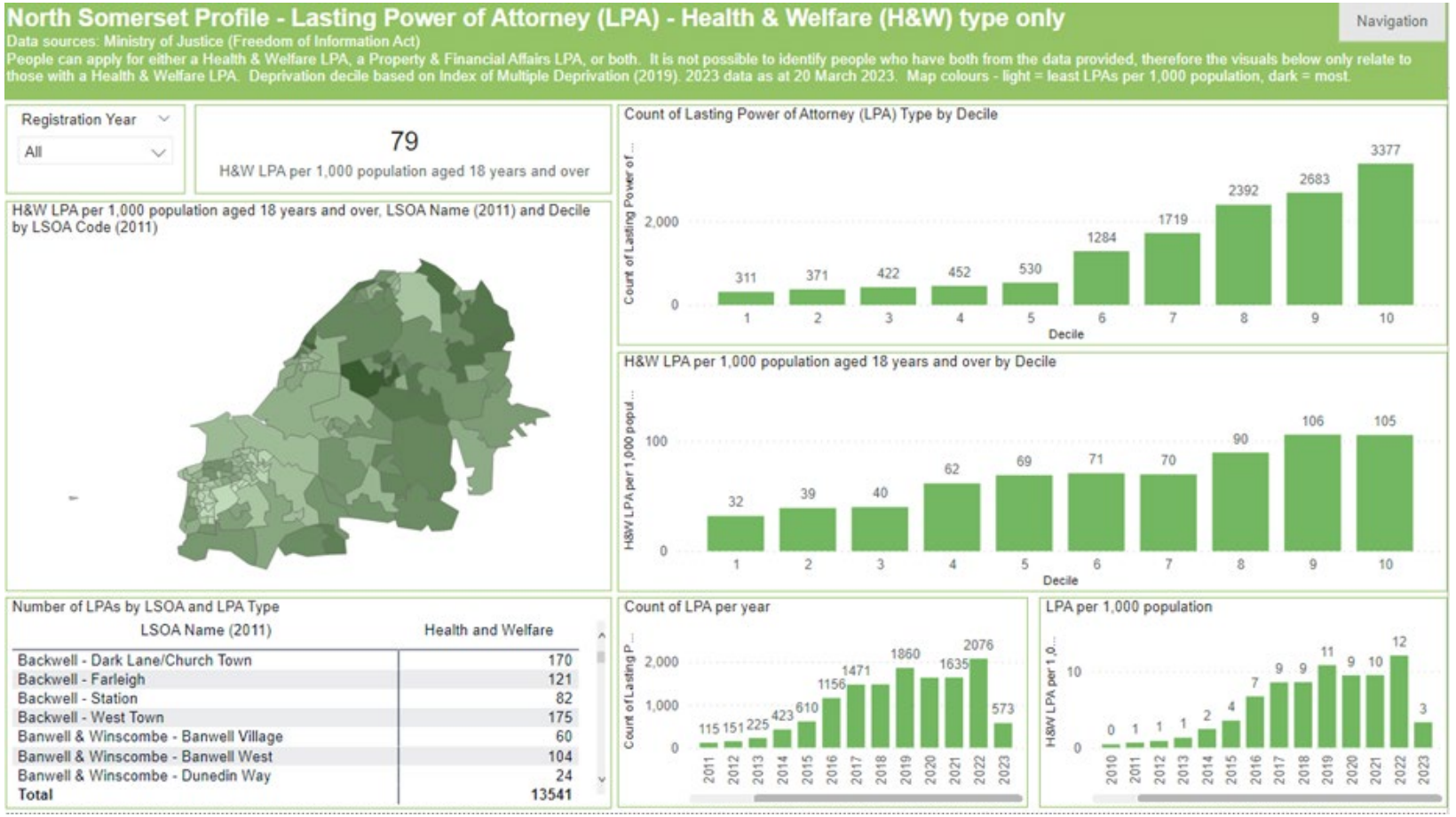



| LSOA Name (2011) | Decile | Prediction of loneliness | Greater than NS average? |
|---|---|---|---|
| WsM Central - Alfred Street | 1 | -3.46 | Yes |
| WsM Central - Grand Pier | 1 | -3.69 | Yes |
| WsM South - Argyle Avenue | 1 | -3.45 | Yes |
| WsM South - Byron Road | 1 | -3.40 | Yes |
| WsM South - Loxton Road | 1 | -3.69 | Yes |
| WsM South - Marchfields Way | 1 | -3.60 | Yes |
| WsM South - Windwhistle | 1 | -3.56 | Yes |
| WsM West - Victoria Quadrant | 1 | -3.61 | Yes |
| WsM Central - Ellenborough Park | 2 | -3.55 | Yes |
| WsM Central - Stafford Road | 2 | -3.75 | Yes |
| WsM Clarence & Uphill - Clarence Park | 2 | -3.75 | Yes |

## Using proxy measures

- People in the least deprived areas are more likely to have a health and welfare LPA for when they no longer have the mental capacity to make decisions

➢People living in these areas may have improved EOLC experiences



**Gap analysis**

- We lack a complete list of those who are receiving palliative and end of life care, and of those who have been bereaved, so we are unable to assess:
  - If access to palliative and end of life care and bereavement services is equal for all residents
  - Quality and impact of palliative and end of life care and bereavement services provided

- Where data is available, it is often not for the same time period or geography.
- E.g. we have death registrations by place of death for the period 2020 – 2022, however, death registrations based on the deceased's address are currently available for 2019 – 2020

**Recommendations**

- Collection of essential quality metrics and more robust ways of identifying eligible populations is key
- Need for coordinated work across sectors to measure timely, equitable, quality care for those towards the EOL or bereaved
- Routine indicators to measure quality of palliative and end of life care and holistic needs
- Medical examiner – unique opportunity to capture feedback from recently bereaved relatives and from case note reviews of patients who have died?
- Opportunities of GOV.UK Tell Us Once service?

**What next?**

- More questions to answer…
- System wide dataset will include key indicators across the health and social care sector – permission to use the new resource is underway
- Dissemination across our local network and with ICS partners

- How do we address barriers to equitable end of life experiences?
- What is the impact of social prescribing in the last year of life/bereaved?
- What is the role of GPs, medical examiners, community connectors and funeral directors to sign-post to assets?
- What do we know about diverse experiences of palliative and end of life care and bereavement in Weston-super-Mare: case studies in historically marginalised populations?
- How can we best identify those bereaved to trigger community connectors/availability of support?
- How can we routinely identify those isolated because of bereavement or who are in the last year of life?
- How can we best measure the morbidity associated with bereavement?

# Introducing a new Mortality Dashboard for North Somerset

## Webinar: 5 October 10-11am

Join us to find out more the new local **digital dashboard** on mortality, deprivation, end-of-life care and bereavement support, created by North Somerset Council in collaboration with the University of Bristol, Weston Hospicecare & Voluntary Action North Somerset (VANS)

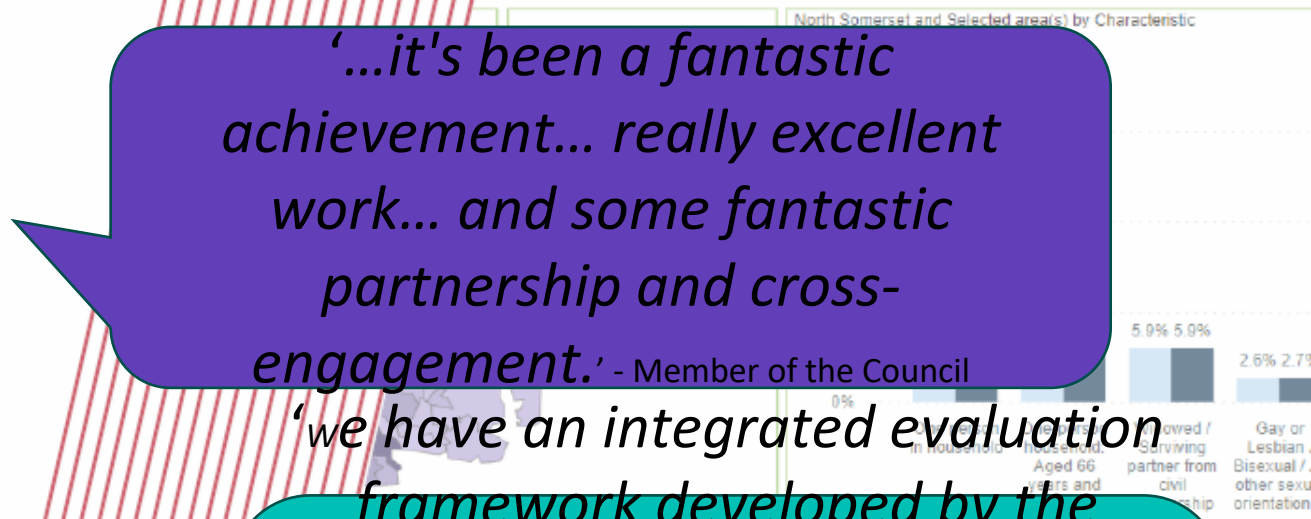
**Speakers:** Dr Charlotte Chamberlain (University of Bristol), Donna Davies & Nicola O'Driscoll (North Somerset Council), Sue Stone (VANS)

**Open to all – register** here
For more information, contact a.malpass@bristol.ac.uk

University of BRISTOL

North Somerset Council

VOLUNTARY ACTION NORTH SOMERSET




*'...it's been a fantastic achievement... really excellent work... and some fantastic partnership and cross-engagement.'* - Member of the Council

*'we have an integrated evaluation framework developed by the partners and a theory of change that we're going to test... this resource is just going to be wholly helpful for in starting to think about what we've got and what we're missing.'* - Locality partnership lead at the ICB

Healthier Together
Improving health and care in Bristol, North Somerset and South Gloucestershire

Weston-super-Mare Community Network for Health Inequities

Palliative and End of Life Care Research Group

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8th Public Health Palliative Care International Conference

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PHPCI Public Health Palliative Care International

EAPC Reference Group Public Health & Palliative Care

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