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
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The recognition, assessment & perceptions of total pain in people with profound intellectual disabilities - A mixed methods systematic review

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- This study represents one phase of a larger study exploring pain in people with profound intellectual disabilities

- Supervised by: Dr. Mary Nevin & Professor Kate Irving

- For more information contact Maeve Goodall; maeve.goodall2@mail.dcu.ie

Concept of ‘Total Pain’

Physical

Psychological

Emotional

Spiritual

Social

Background

- People with profound intellectual disabilities – non-verbal, high prevalence of multi-morbidities, fully reliant for activities of daily living, individual.

- Pain as a multi-faceted experience (Davis, 2000; Cassell, 2004; Saunders, 1954).
- **The absence of verbal reports of pain does not negate the possibility of the presence of pain (IASP, 2020).**

- Historical belief of people with intellectual disabilities having higher pain thresholds (Symons et al., 2008).

- Over 76.19% of health care professionals expressed challenges in recognising and assessing pain in the person with profound intellectual disabilities causing serious, painful conditions to go untreated (Millard *et al.,* 2019).

Aims

* Synthesise current research in the recognition, assessment & perceptions of all facets of pain in people with profound intellectual disabilities
* Gain an understanding of current practices
* Highlight areas for future research

Mixed methods review

Five databases were searched

Cinahl, PsycInfo, Scopus, Medline,

Web of Science

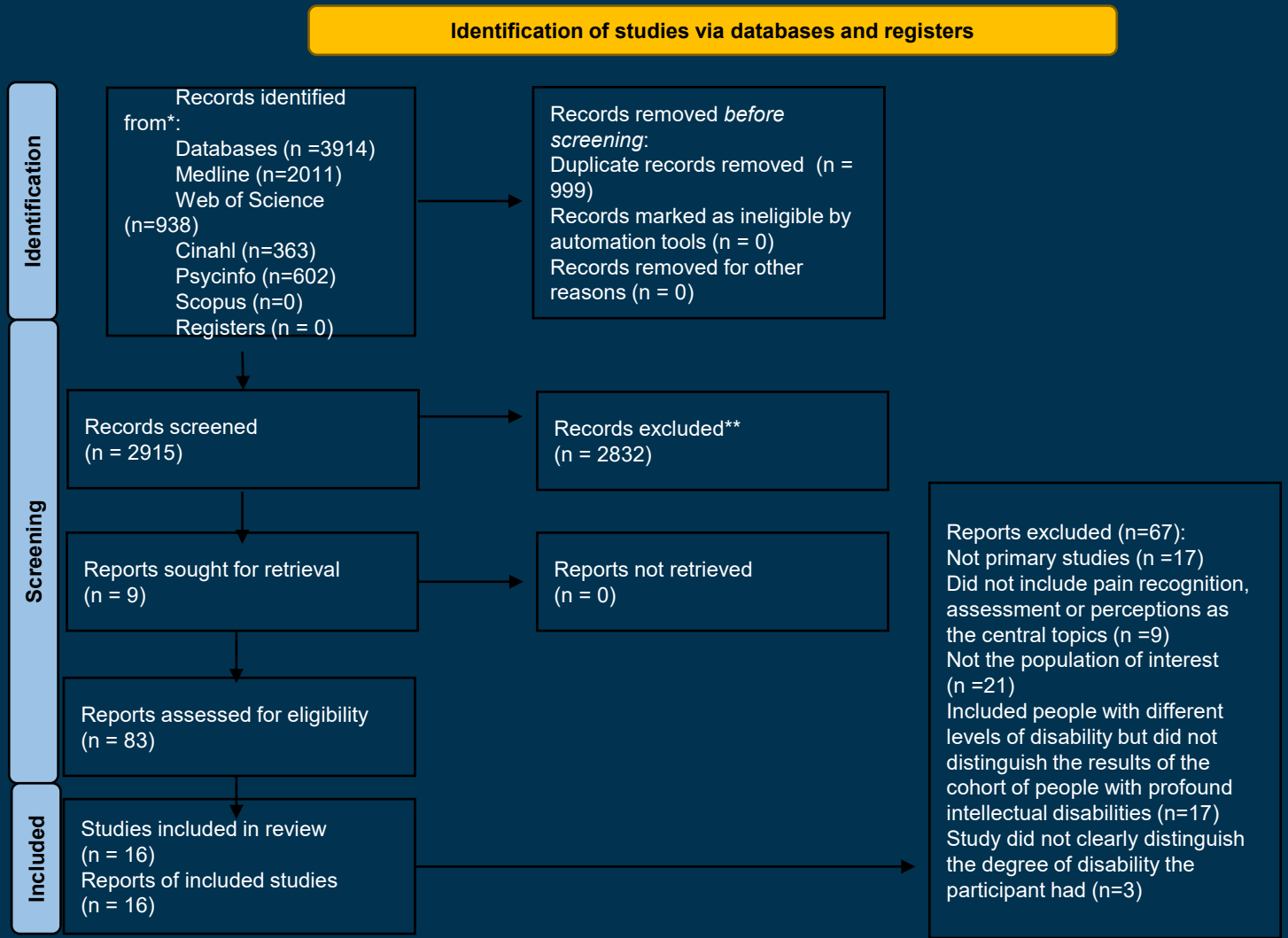
Inclusion/Exclusion Criteria

Inclusion Criteria

* Studies including pain recognition, assessment or perceptions as the central topics.
* Studies including people with profound intellectual disabilities as participants.
* Studies including carers of people with profound intellectual disabilities.
* Research based in all settings.
* All study methodologies including quantitative, qualitative and mixed methods studies of any design.

Exclusion Criteria

* If the study was not a primary study such as a systemic review or scoping review.
* If the study did not include pain recognition, assessment or perceptions as the central topics.
* If the study did not clearly distinguish the degree of disability a participant had.
* If the study included people with different levels of disability but did not clearly distinguish the results for the cohort of people with a profound intellectual disabilities.


Identification of studies via databases and registers
Identification
Records identified from*:
Databases (n =3914)
Medline (n=2011)
Web of Science (n=938)
Cinahl (n=363)
Psycinfo (n=602)
Scopus (n=0)
Registers (n = 0)
Records removed *before screening*:
Duplicate records removed (n = 999)
Records marked as ineligible by automation tools (n = 0)
Records removed for other reasons (n = 0)
Screening
Records screened
(n = 2915)
Records excluded**
(n = 2832)
Reports sought for retrieval
(n = 9)
Reports not retrieved
(n = 0)
Reports assessed for eligibility
(n = 83)
Reports excluded (n=67):
Not primary studies (n =17)
Did not include pain recognition, assessment or perceptions as the central topics (n =9)
Not the population of interest (n =21)
Included people with different levels of disability but did not distinguish the results of the cohort of people with profound intellectual disabilities (n=17)
Study did not clearly distinguish the degree of disability the participant had (n=3)
Included
Studies included in review
(n = 16)
Reports of included studies
(n = 16)

Methodologies

13 Quantitative studies

2 Qualitative studies

1 mixed methods study

Mixed Methods Appraisal Tool Hong *et al.* (2018)

Quantitative Criteria:	
A1.	Is the sampling strategy relevant to address the research question?
A2.	Is the sample representative of the target population?
A3.	Are the measurements appropriate?
A4.	Is the risk of nonresponse bias low?
A5.	Is the statistical analysis appropriate to answer the research question?
Qualitative Criteria:	
B1.	Is the qualitative approach appropriate to answer the research question?
B2.	Are the qualitative data collection methods adequate to address the research question?
B3.	Are the findings adequately derived from the data?
B4.	Is the interpretation of results sufficiently substantiated by data?
B5.	Is there coherence between qualitative data sources, collection, analysis and interpretation?
Mixed Methods Criteria:	
C1.	Is there an adequate rationale for using a mixed methods design to address the research question?
C2.	Are the different components of the study effectively integrated to answer the research question?
C3.	Are the outputs of the integration of qualitative and quantitative componants adequately interpreted?
C4.	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?
C5.	Do the different componants of the study adhere to the quality criteria of each tradition of the methods involved?

Included Study	Quality Criteria Met	No. of Criteria Met
Breau et al. (2003)	A1, A2, A3, A4, A5	5
Courtemanche et al. (2012)	A2, A3, A4, A5	4
Genik et al. (2017)	A1, A2, A3, A4, A5	5
Icht et al. (2021)	A1, A2, A3, A5	4
Kildal et al. (2021)	A1, A2, A3, A4, A5	5
Lotan et al. (2009)	A1, A2, A3, A4, A5	5
Lotan (2010)	A1, A2, A3, A4, A5	5
Lotan (2013)	A1, A2, A3, A4, A5	5
McGrath et al. (1998)	B2, B3, B4, B5	4
Petigas & Newman (2021)	A1, A2, A3, A4, A5	5
Parker & Belew (2013)	B1, B2, B3, B4, B5	5
Phan et al. (2004)	A1, A2, A3, A4, A5	5
Solodiuk (2013)	C1, C2, C3, C4, C5	5
van Der Putten & Vlascamp (2011)	A1, A2, A3, A4, A5	5
Zanchi et al. (2017)	A1, A2, A3, A4, A5	5
Zwakhalen et al. (2003)	A1, A2, A3, A4, A5	5

(Hong *et al.* 2018)

Convergent qualitative design

(Pluye & Hong, 2014)

Results

Themes

1. Absent Voices
2. Reductionist Assessment
3. Pain Intensity
4. Sharing of Expertise

Physical pain was the only form of pain researched in the included studies

Eight Tools Included in the Studies

Lotan et al. (2009) **Non-Communicating Adult Pain Checklist – Revised (NCAPC-R)**

Lotan et al. (2010) **Non-Communicating Adult Pain Checklist (NCAPC)**

Lotan et al. (2013) **Non-Communicating Adult Pain Checklist & Pain and Discomfort Scale (PADS)**

McGrath et al. (2008) **Pain Checklist**

Parker & Belew (2013) **Tailored Observational Pain Screen (TOPS)**

Phan et al. (2005) **Pain and Discomfort Scale (PADS)**

van der Putten & Vlaskamp (2011) **Pain Behaviour Checklist (PBC)**

* Zanchi et al. (2017) **Italian version of the Non Communicating Childrens Pain Checklist-Revised (I-NCCPC-PV)**

Solodiuk et al. (2010) **Individualized Numeric Rating Scale (INRS)**

Conclusion

Complex phenomenon

Directions for future research:

- 1. All aspects of pain need to be explored
- 2. Methods of assessment – Individualised
- 3. Inclusion of pain intensity
- 4. Sharing of knowledge

Informed a Qualitative, Appreciative Inquiry Study

Investigating how nurses can improve upon total pain recognition and assessment in people with profound intellectual disabilities.

Individual & Focus group interviews with 8 co-researchers through the four stages of Appreciate Inquiry – Discovery, dream, design, destiny.

Creation of a holistic pain awareness campaign

Development of a holistic pain recognition tool and assessment guide for people with profound intellectual disabilities

Publications to follow

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Grazie
Thank you
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DCU

Ollscoil Chathair
Bhaile Átha Cliath
Dublin City University

PRIDE in Death: An LGBTQI+ Death Café

Paula Pinto Araya
Programme Manager for Policy and Engagement
All Ireland Institute of Hospice and Palliative Care

How it came to be:

- Palliative care a misunderstood concept
- Week to promote conversations around advance care planning, death, dying and bereavement
- 43% of people agree that if they had to have palliative care, they do not have enough information to make those decisions or have those conversations.

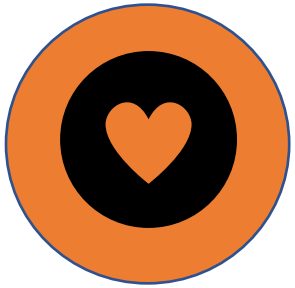
Importance of partnership and collaboration

- LGBT+ Ireland (James O’Hagan)
- Irish Hospice Foundation (Valerie Smith)
- All Ireland Institute of Hospice and Palliative Care (Paula Pinto)

46% live alone

48% discussed final wishes

31% feel lonelier as they age



43% are single

42% poor quality service due to LGBTQI+ identity

Stonewall's 'Lesbian, Gay, and Bisexual People in Later Life' study (2011)

Let’s have a community focused conversation!

Proud to be the first ‘out’ generation, now they would be the first ‘out’ generation to become older people.

Advance Care Planning evidence is compelling

Shared understanding and decision-making (Gott et al 2011)

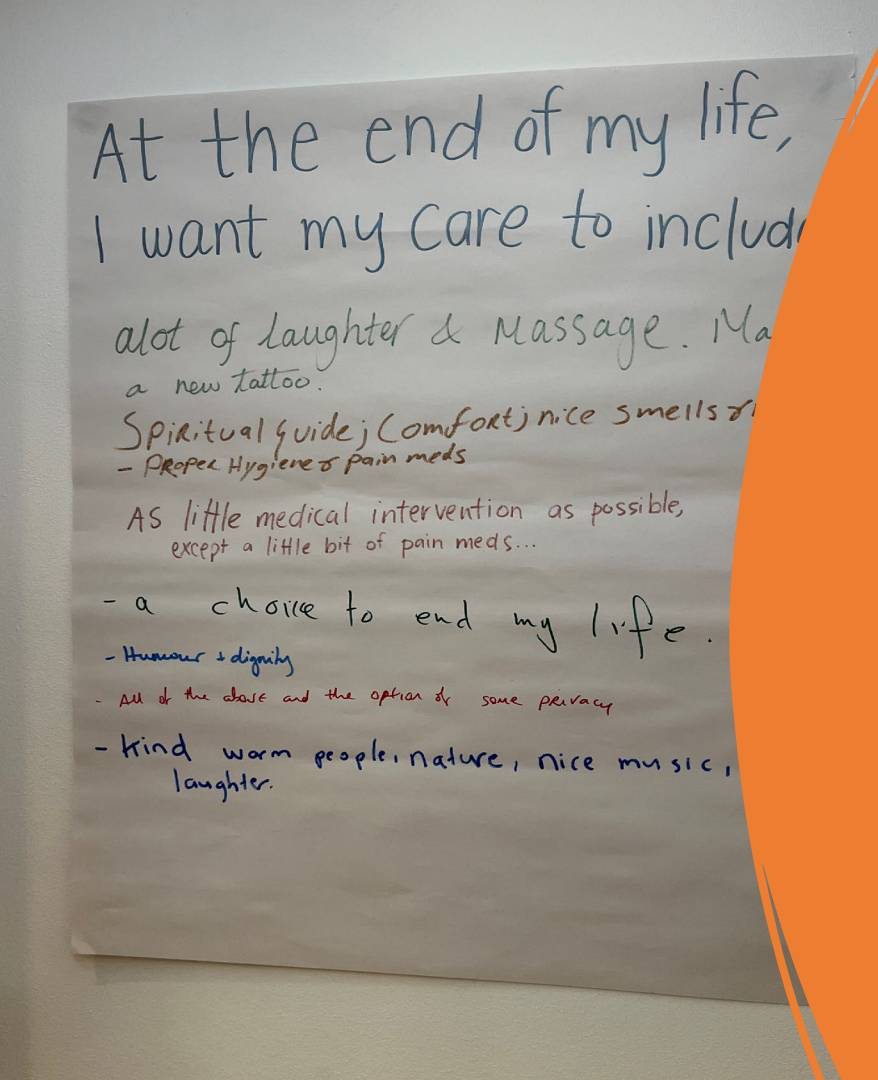
Improved quality of life (Schichtel et al 2019)

Enhanced hope (Davison 2006)

Lower readmissio nand ICU rates (Song et al, 2006)

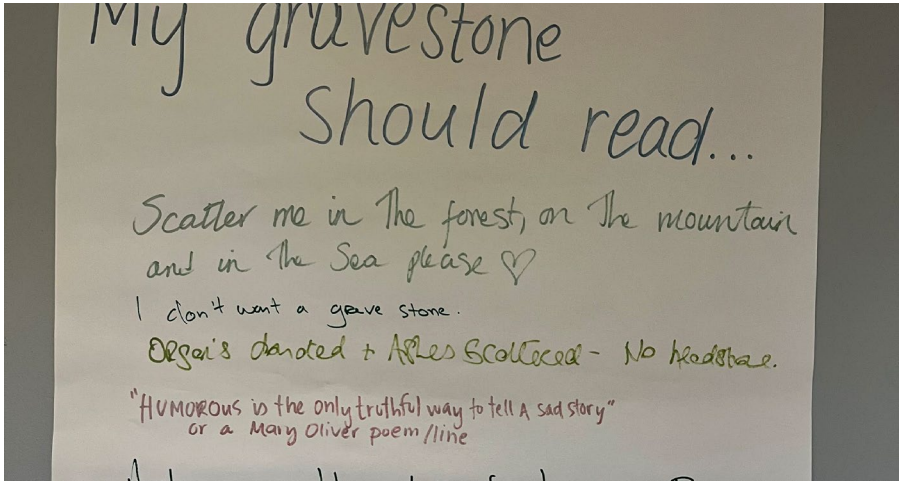
Sense of control (Lyon 2007)

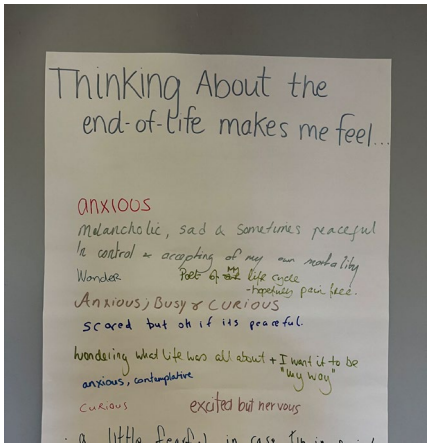
A voice at the end of life (Hanratty et al 2014)

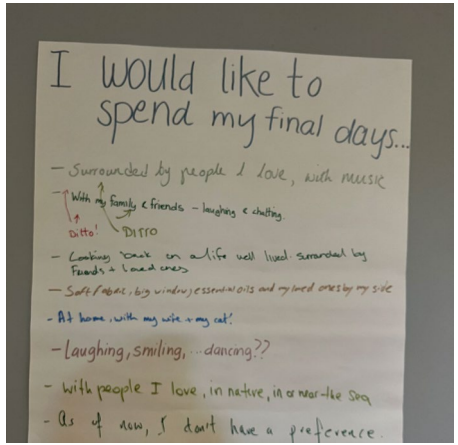


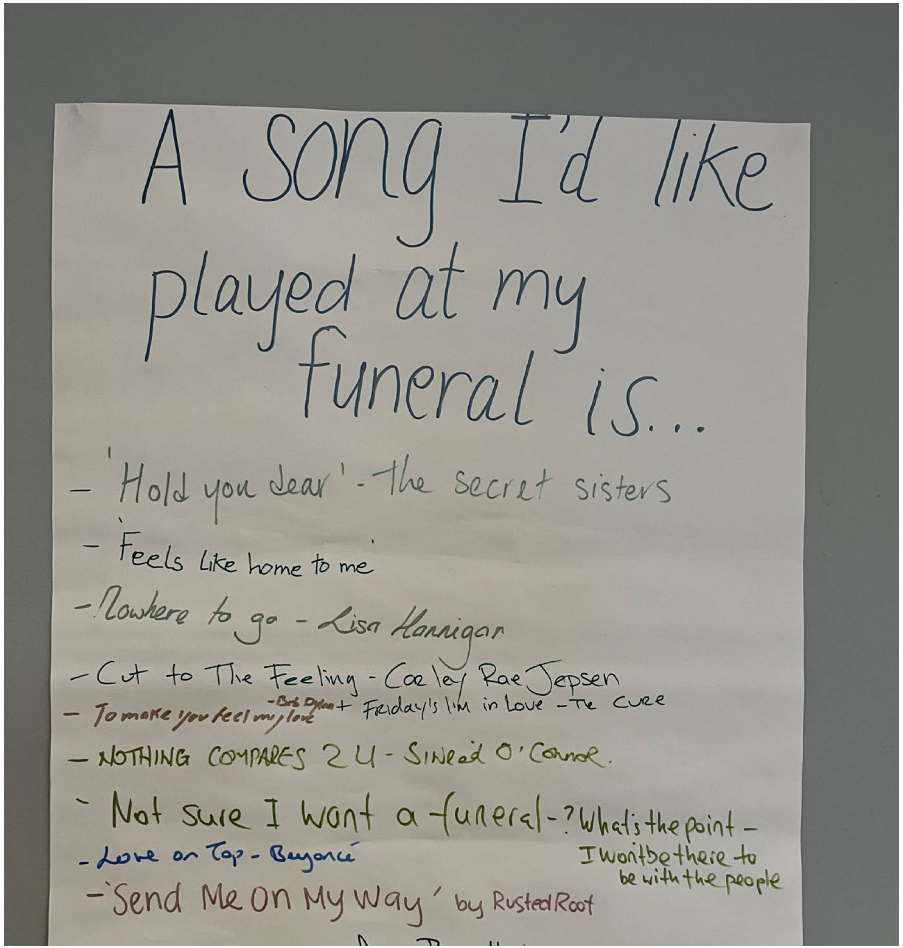
Planning: Structured Facilitation

- Videos and stories to respond to
- Structured questions
- Small group breakouts
- Interactive elements
- Conclusion


My gravestone should read...
Scatter me in the forest, on the mountain and in the Sea please ♡
I don't want a grave stone.
Organs donated + Ashes Scattered - No headstone.
"HUMOROUS is the only truthful way to tell A sad story"
or a Mary Oliver poem/line


Thinking About the end-of-life makes me feel...
ANXIOUS
Melancholic, sad & sometimes peaceful
In control & accepting of my own mortality
Wonder
Part of life cycle
Hopefully pain free.
Anxious, Busy & CURIOUS
scared but ok if its peaceful.
wondering what life was all about + I want it to be "my way"
anxious, contemplative
CURIOUS
excited but nervous


I would like to spend my final days...
- Surrounded by people I love, with music
- With my family & friends - laughing & chatting
Ditto!
DITTO
- Looking back on a life well lived surrounded by Friends + Loved ones
- Soft fabric, big windows, essential oils and my loved ones by my side
- At home, with my wife + my cat.
- Laughing, Smiling, ...dancing??
- With people I love, in nature, in or near the Sea
- As of now, I don't have a preference.


A Song I'd like played at my funeral is...
- 'Hold you dear' - The secret sisters
- 'Feels like home to me'
- Nowhere to go - Lisa Hannigan
- Cut to The Feeling - Carly Rae Jepsen
- To make you feel my love - Bob Dylan + Friday's I'm in Love - The Cure
- NOTHING COMPARES 2 U - Sinead O'Connor.
- Not sure I want a funeral - ? What's the point - I won't be there to be with the people
- Love on Top - Beyoncé
- 'Send Me on My Way' by Rusted Root

Welcoming Environment

Response was Overwhelmingly Positive

What we anticipated

- People afraid or anxious
- Need to fill time
- More men than women and nonbinary people
- Older people
- Primarily white Irish

What happened

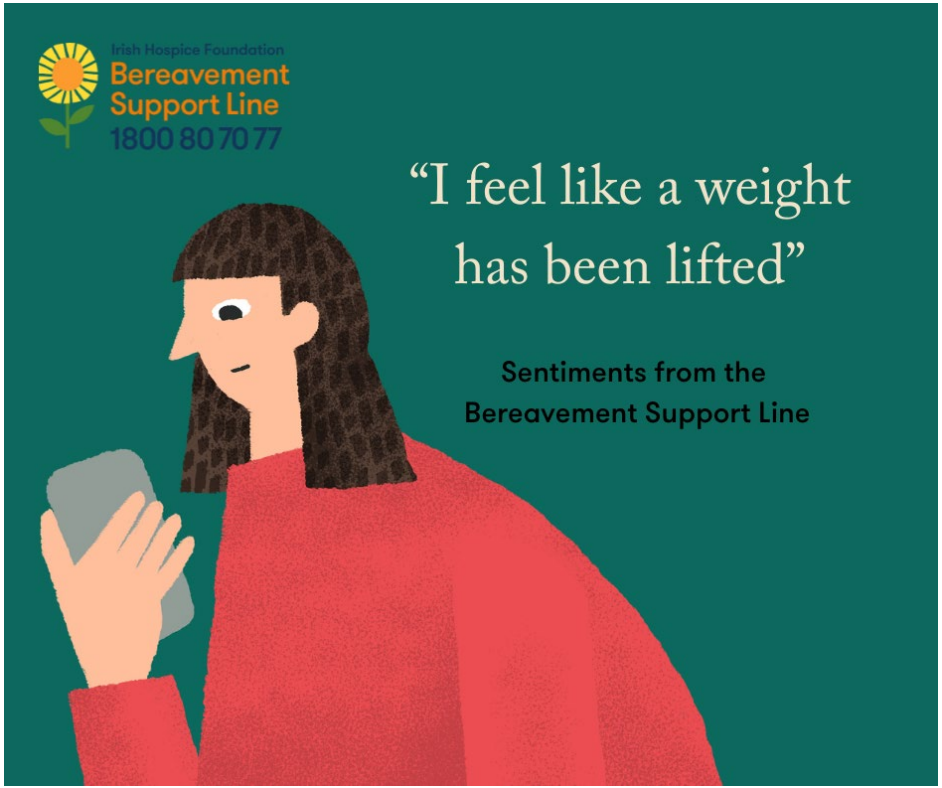
- People engaged and talkative
- Went over time
- Gender diversity
- Age diversity
- Primarily white Irish

Main Takeaways

- Bereavement Support
- Intergenerational Networks
- LGBTQI+ End of Life Reference Group
- “Pearly Gate-Keeping”
- LGBTQIA+ Nursing Homes
- More events

Bereavement Support

- Specific LGBTQIA+ Bereavement Supports do not exist
- LGBTQIA+ people suffer from ambiguous and complicated grief due to a variety of issues specific to being LGBTQIA+
- E.g. partnership between IHF's Bereavement Support Line training, and LGBT Ireland training



Intergenerational Networks

“I feel shame about aging, will I be seen as a lost cause with nowhere else to go?”

- Assumption that the desire was 1-way
- Found it to be reciprocal
- Few if any places exist to connect
- Few places tend to be pubs, but limited there as well

LGBTQI+ End of Life Reference Group

Resources for members of public

Resources for healthcare staff

“Pearly Gate-Keeping”

“We often see that the queer family is shunted aside”

- Creative engagement around end of life conversations
- Creativity for funeral planning outside of religious rituals
- Creative outlet and creativity for ease of communication

LGBTQI+ Nursing Homes

- Specific LGBTQIA+ Nursing Homes
- A place to be keep identity intact
- A place to make own traditions
- A safe space

Adamant About Ongoing Events: developing a sustainable model

Takeaways

- Honest conversations to inform people centred care

- Right partnerships, working with gateway organisations

- Sustainable growth