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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Psychometric validation of the Death Literacy Index and benchmarking of levels of death literacy in the UK

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With kind thanks for bursary to attend conference

Death Literacy

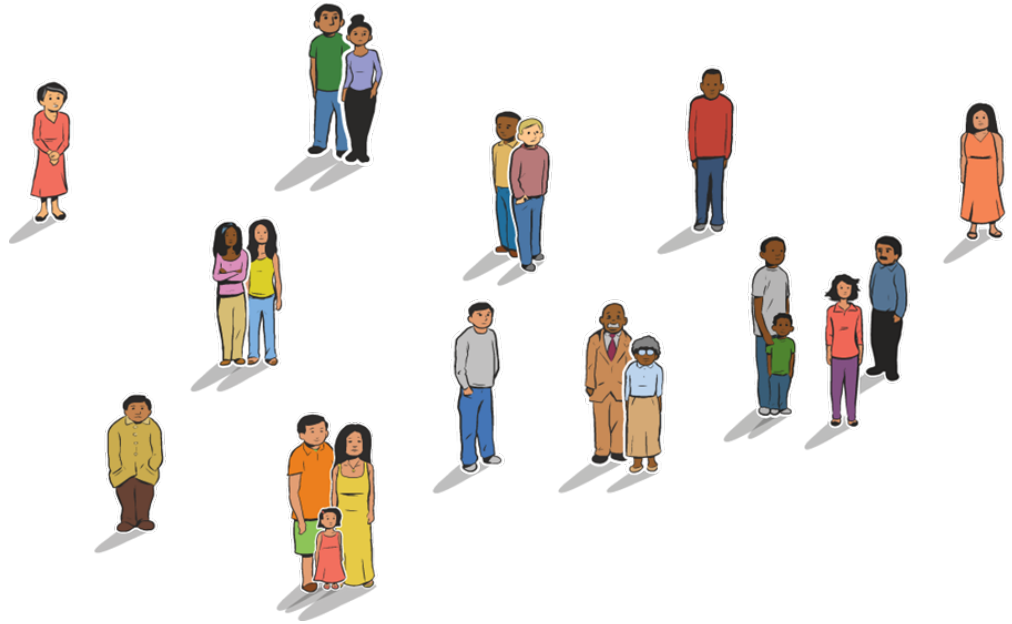
"a set of knowledge and skills that make it possible to…understand and act upon end-of-life and death care options" (Noonan et al., 2016)

The need for a way to measure ‘Death Literacy’

Increasing focus on new public health palliative care approaches

- For community-based interventions, how do we know what to target? How do we evaluate success?

- Limited research evidence of impact from public health approaches (Durmont et al, 2022; Sallnow et al, 2016)



Existing measures are often; too narrow (e.g., focused on one problem), concerned with measuring affective states, not focused on community

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DEATH LITERACY INDEX: A REPORT ON ITS DEVELOPMENT AND IMPLEMENTATION

WESTERN SYDNEY UNIVERSITY · THE GROUNDSWELL PROJECT · THE WICKING TRUST · LA TROBE UNIVERSITY · USC

The Death Literacy Index (DLI; Leonard et al, 2020)

- 29 item measure, 4 subscales
- Aims to help i) determine current levels of death literacy at a population/local level, and ii) measure the impact of community interventions
- Can be used by researchers and community practitioners
- Example item-

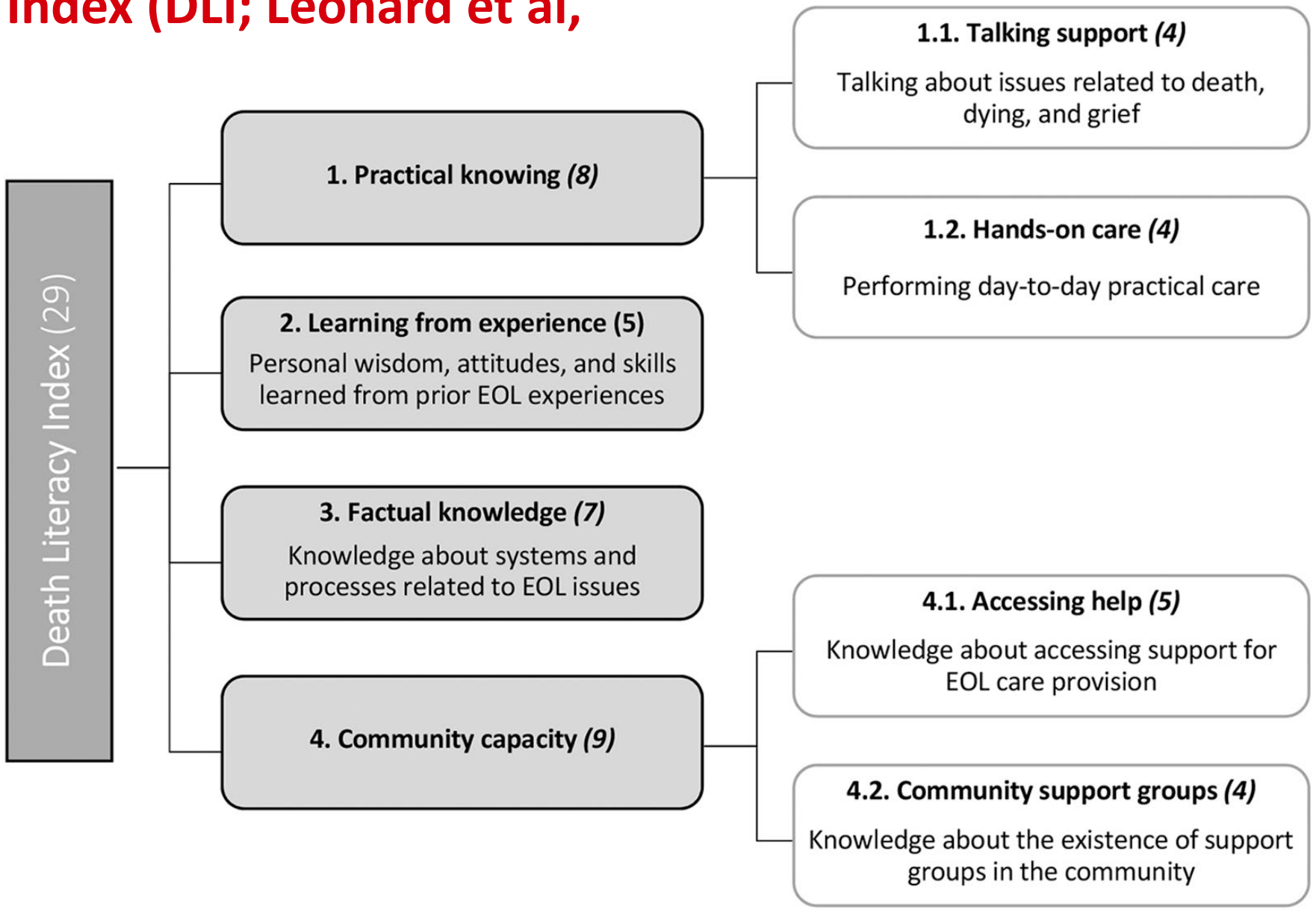
PRACTICAL KNOWLEDGE (2 Subscales)

Talking support (1)

PLEASE RATE HOW DIFFICULT OR EASY YOU WOULD FIND THE FOLLOWING TALKING SUPPORT (on a scale of 1-5 between *Not at all able* to *Very able*)

1. Talk about death, dying or grieving to a close friend
2. Talk about death, dying or grieving to a child
3. Talk to a newly bereaved person about their loss
4. Talk to a GP about support at home or in their place of care for a dying person

The Death Literacy Index (DLI; Leonard et al, 2020)



Notes: EOL=end-of-life

Acknowledgement- Johansson et al, 2022 for figure

Methods

Aim:

- To examine the psychometric properties of the Death Literacy Index in a UK population-level sample (dimensionality, construct validity, internal consistency, and interpretability) and to provide a benchmark of DLI and subscale scores for the UK, and to examine demographic variability in scores.

Methods

- A cross-sectional online survey with data collected between October & November 2020
- A representative of UK adults (n=394) recruited via Prolific (based on age, gender & ethnicity of 2011 Census)
- Measures included the DLI, alongside several measures to assess construct validity
  - Convergent validity- death competency (Coping with Death Scale; Bugen et al, 1984), items on objectives knowledge and actions regarding discussion of death & dying
  - Discriminate validity- loneliness (Short Revised UCLA Loneliness Scale; Hughes et al, 2004)

- CFA used to assess dimensionality, one additional item tested alongside original model (*I know the contribution the funeral home staff can make at end of life*'), construct validity assessed via correlations/ANOVA

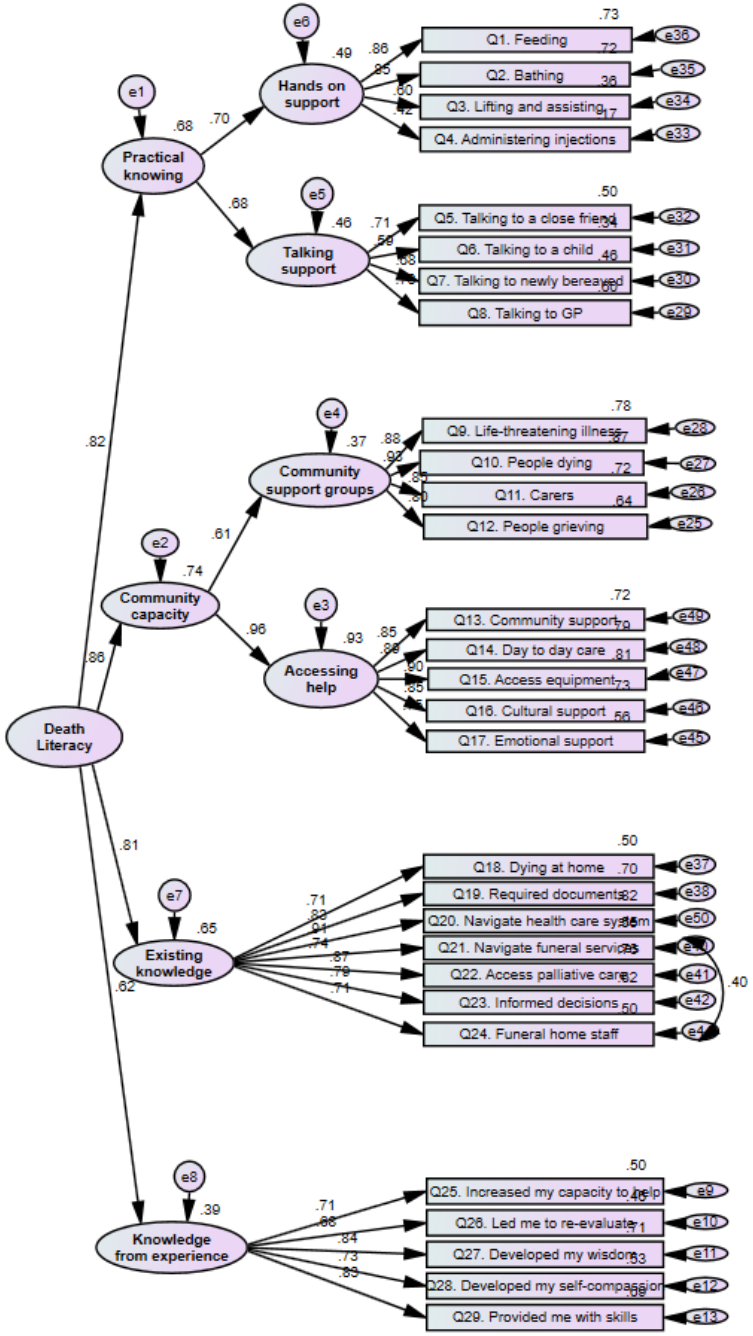
Validation of the DLI

Dimensionality

χ^2 (368)=812.83, p<0.001, Bollen-Stine bootstrap p =0.004, Q=.2.21, CFI= 0.94, RMSEA= .07 (90% CI, .050-.061), SRMR=.07.

Internal consistency

The Cronbach's alpha for each subscale were between α= .76 and α=.93, with the Omega coefficient between ω = .78 and ω = .93. The total scale reported α= .935 and ω =.933, evidencing good overall consistency.



Validation of the DLI

Convergent validity

- Expected significant, positive associations between the subscales/DLI total and…
  - objective knowledge of the death system (small effect sizes, r=0.13-0.23)
  - death competence (moderate effect sizes, r=0.40-0.66)
  - actions relating to discussing death and dying – community (small effect sizes, r=0.24-0.39)
  - actions relating to discussing death and dying- family (small effect sizes, r=0.24-0.45)

Discriminate validity

- Expected significant, negative associations between the subscales/DLI total and…
  - Loneliness (small effect sizes, r=-0.10- -0.17)

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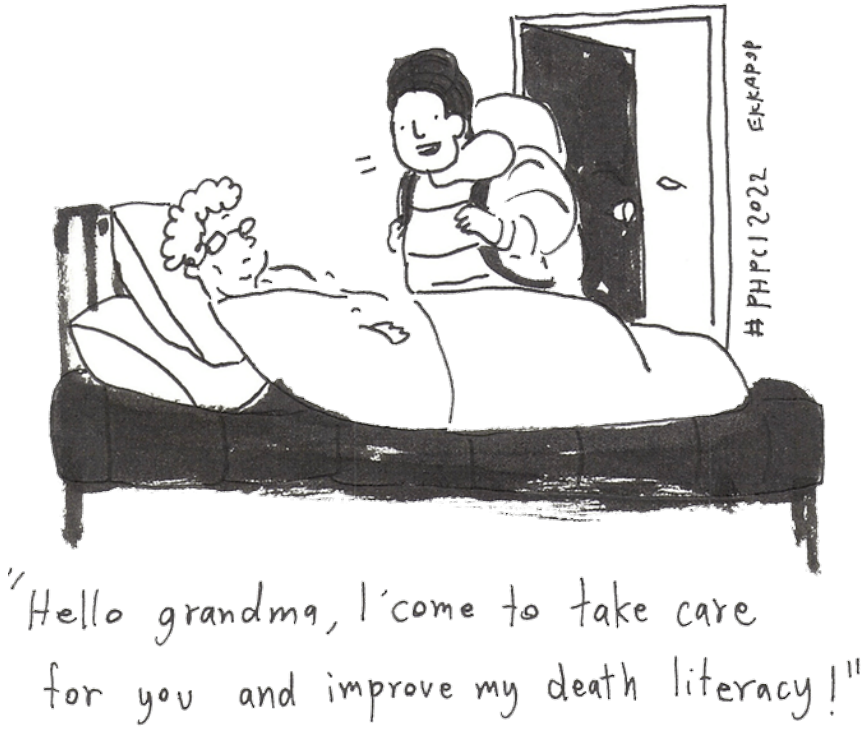
Validation of the DLI



Known groups validity

- Expected significantly higher mean scores on DLI subscales/DLI total between 'expert' and 'non-expert' groups, for example-
  - Work/have worked with people at end of life, including volunteering (medium-large effect sizes, Eta sq. 0.07-0.20)
  - Bereaved carer/family member/partner/spouse/friend of someone who has died in the last 2 years (small-large effect sizes, Eta sq. 0.02-0.14)
  - Carer/family member/partner/spouse/friend of someone who is thought to be in the last few years of their life (no significant differences on hands on support, community support groups & accessing help)

Validation of the DLI

Interpretability

The participant's total score on each subscale represented the total possible range for all subscales. There was no evidence of floor or ceiling effects on most subscales or total scale, except for 'Factual Knowledge'

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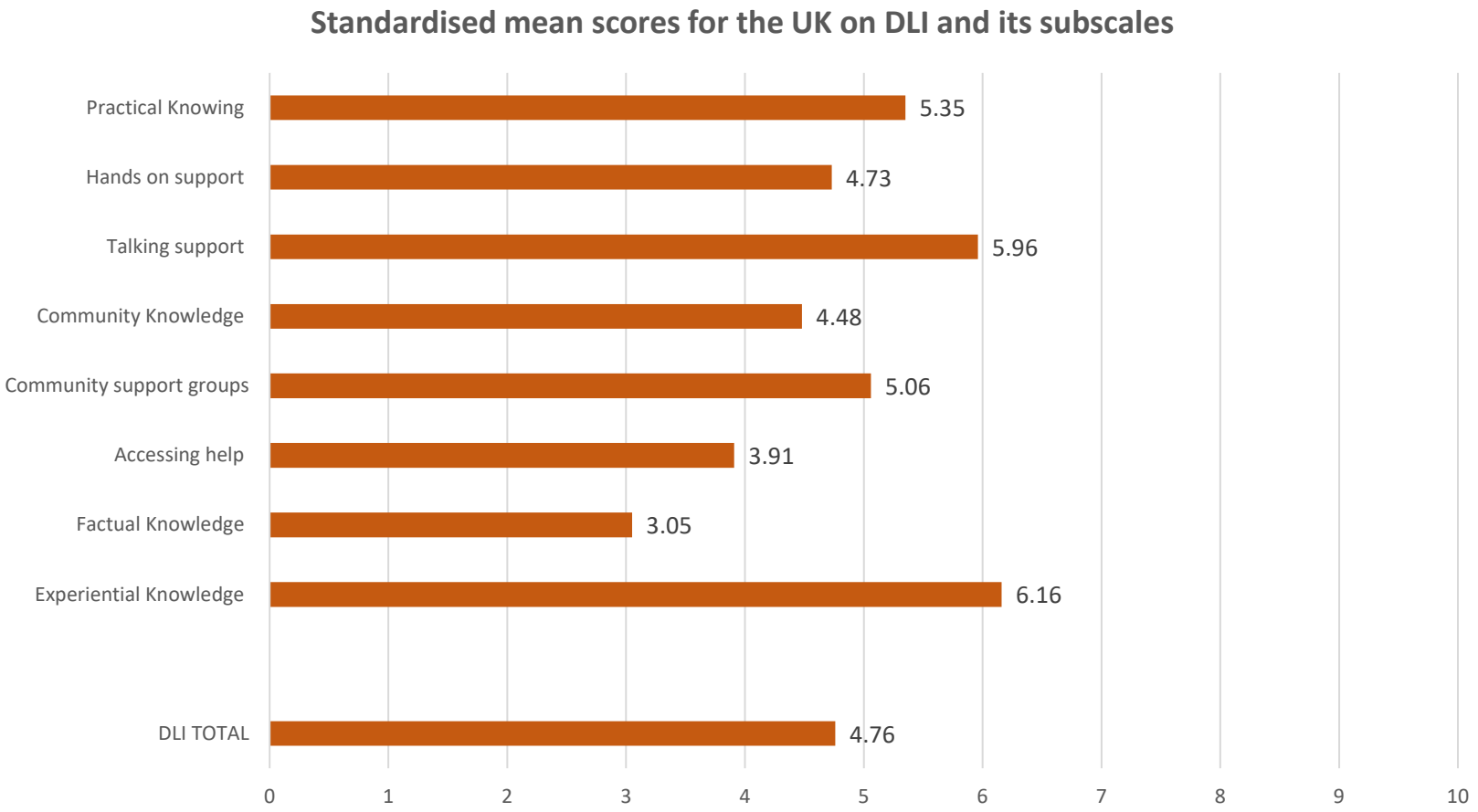
UK benchmarks on the DLI



Socio-demographic variables predicting higher levels of death literacy –

- Older age
- Rural Location
- Having children
- Chronic physical health condition
- Religious or spiritual background

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Conclusions

- The Death Literacy Index (DLI) appears to be a valid and reliable measure of death literacy for use in the UK population – with one substituted item

- In the UK, individuals have comparatively high levels of learning through experience and have an ability to talk about death and dying. Areas to strengthen capacity include knowing how to access help and factual knowledge around death and dying

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Next Steps

frontiers | Frontiers in Public Health

TYPE Original Research
PUBLISHED 11 May 2023
DOI 10.3389/fpubh.2023.1140475

Check for updates

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RECEIVED 09 January 2023
ACCEPTED 14 April 2023
PUBLISHED 11 May 2023

CITATION
Che SL, Li X, Zhu M and Ng WI (2023) The Death Literacy Index: translation, cultural adaptation, and validation of the Chinese version. *Front. Public Health* 11:1140475. doi: 10.3389/fpubh.2023.1140475

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The Death Literacy Index: translation, cultural adaptation, and validation of the Chinese version

Sok Leng Che[1], Xiang Li[2], Mingxia Zhu[2] and Wai I Ng[2]*

[1]Nursing and Health Education Research Centre, Kiang Wu Nursing College of Macau, Macao SAR, China, [2]Education Department, Kiang Wu Nursing College of Macau, Macao SAR, China

Objective: Applying public health approaches to address palliative care allows for a broader perspective. The Death Literacy Index (DLI) is a novel instrument designed to assess the knowledge and skills required to access, comprehend, and make informed decisions regarding end-of-life care. Translation of the DLI could strengthen the capacity to build desirable services and policies regarding dying and death. It could also help to identify the barriers to services and future advocacy efforts.

Methods: The DLI was forward translated into Chinese and backward translated through two panels. Two rounds of cognitive interviews and a pilot test were conducted before the survey. A sample of 3,221 participants was recruited via an online survey in five cities in southern China (Guangzhou, Zhuhai, Jiangmen, Hong Kong and Macao) to evaluate the factor structure, validity and reliability of the translated DLI. Additionally, multi-group confirmatory factor analyses (MGCFA) were performed to examine measurement invariance across genders and the experiences of parental death.

Results: Exploratory factor analysis showed a six-factor structure for the translated DLI, and confirmatory factor analysis confirmed the structure. The overall scale and subscales had high internal consistency and satisfactory validity. The results from MGCFA showed that death literacy was adequately invariant for different genders and experiences of parental death.

Conclusion: The Chinese DLI is a reliable and valid instrument for measuring death literacy among people in southern China, and therefore can be used for both research and community practice.

KEYWORDS

death literacy, Death Literacy Index, validity, reliability, factor analysis

OMEGA - Journal of Death and Dying
OnlineFirst, December 12, 2022
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https://doi.org/10.1177/00302228221144672

SAGE journals

Original Manuscript

Validity and Reliability of the Turkish Version of the Death Literacy Index

Vahide Semerci[1], Ebru Sönmez Sari[1], and Ahmet Seven [2]

Abstract
Death literacy is defined as a set of knowledge and skills that make it possible to gain access to, understand, and act upon end-of-life and death care options. This study was conducted to test the validity and reliability of the 29-item original version of the Death Literacy Index (DLI) in Turkish society. The scale was applied on a sample of 436 Turkish adults determined using the snowball sampling method. Explanatory and confirmatory factor analyses were performed. The scale consisted of 6 subscales. The test-retest analysis of this study showed a strong and highly significant positive correlation between overall DLI (.98) and its subscales (.73–.98). The total Cronbach's alpha reliability coefficient of DLI was found to be .90. It was observed that the Turkish version of DLI was a valid and reliable tool and suitable for use in Turkish society.

Keywords
end-of-life care, death literacy index, reliability, validity, culture, Turkey

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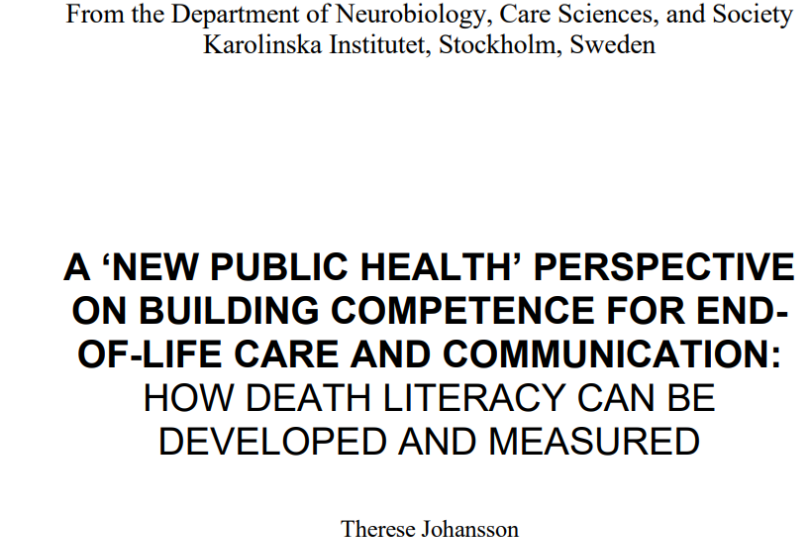


From the Department of Neurobiology, Care Sciences, and Society
Karolinska Institutet, Stockholm, Sweden

A 'NEW PUBLIC HEALTH' PERSPECTIVE ON BUILDING COMPETENCE FOR END-OF-LIFE CARE AND COMMUNICATION:
HOW DEATH LITERACY CAN BE DEVELOPED AND MEASURED

Therese Johansson

Currently, QUB & AIIHPC PhD researcher Stephanie Crawford is working to validate the DLI for use in Ireland…

QUEEN'S UNIVERSITY BELFAST

Thank you!

Original DLI, including guidance on use (via Death Literacy Institute Website)

Validation of UK version

Graham-Wisener *et al. BMC Palliative Care* (2022) 21:145
https://doi.org/10.1186/s12904-022-01032-0

BMC Palliative Care

RESEARCH Open Access

Psychometric validation of the death literacy index and benchmarking of death literacy level in a representative uk population sample

Lisa Graham-Wisener[1*], Paul Toner[1], Rosemary Leonard[2] and Jenny M. Groarke[1,3]

Abstract

Background: Death literacy includes the knowledge and skills that people need to gain access to, ur and make informed choices about end of life and death care options. The Death Literacy Index (DLI) c determine levels of death literacy across multiple contexts, including at a community/national level, a the outcome of public health interventions. As the first measure of death literacy, the DLI has potentia advance public health approaches to palliative care. The current study aimed to provide the first asses psychometric properties of the DLI in the UK, alongside population-level benchmarks.

Methods: A large nationally representative sample of 399 participants, stratified by age, gender and prospectively recruited via an online panel. The factor structure of the 29-item DLI was investigated us tory factor analysis. Internal consistency of subscales was assessed alongside interpretability. Hypothe tions with theoretically related/unrelated constructs were examined to assess convergent and discrim Descriptive statistics were used to provide scaled mean scores on the DLI.

Results: Confirmatory factor analysis supported the original higher-order 8 factor structure, with the model including one substituted item developed specifically for UK respondents. The subscales repor consistency. Good convergent and discriminant validity was evidenced in relation to objective knowl death system, death competency, actions relating to death and dying in the community and loneline groups validity was achieved with respondents with professional/lived experience of end-of-life care levels of death literacy. There was little socio-demographic variability in DLI scores. Scaled population- scores were near the mid-point of DLI subscale/total, with comparatively high levels of experiential kn the ability to talk about death and dying.

Conclusions: Psychometric evaluations suggest the DLI is a reliable and valid measure of death litera UK, with population level benchmarks suggesting the UK population could strengthen capacity in fac and accessing help. International validation of the DLI represents a significant advancement in outcor ment for public health approaches to palliative care.

Pre-registration: https://osf.io/fwxkh/

University of BRISTOL

Palliative and End of Life Care Research Group
Bristol Medical School

Building death and grief literacy in a coastal town: Good Grief Weston

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

17 Nov 2023

@WsM_Community
@PEoLCSW

bristol.ac.uk

UKRI Arts and Humanities Research Council

GOOD GRIEF WESTON
A FESTIVAL OF LOVE + LOSS

Background

- Festivals can play an important role in improving death and grief literacy, enabling members of the public to engage with these often-sensitive topics

- Good Grief Weston festival was co-designed and delivered with the community by Weston-super-Mare Community Network for Health Inequities – building on Good Grief Festival (goodgrieffest.com)

- Delivery was led by Culture Weston [now Super Culture]

- The festival was held over 8 days in May 2023 in Weston-super-Mare, a coastal town in Southwest England with high levels of socio-economic disadvantage but rich community assets

Selman et al. 2023. *Engaging and supporting the public on the topic of grief and bereavement: an evaluation of Good Grief Festival.* Pall Care Soc Prac

Weston-super-Mare Community Network for Health Inequities

Community linkage and support

Mapping assets and resources → community directory

Reviewing arts evaluation data (last 5 years), interviews

Understanding the local ecosystem, cross-sector working & coproduction

GOOD GRIEF WESTON
A FESTIVAL OF LOVE + LOSS

Mapping data collected by health & social care & Local Authority

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

bristol.ac.uk

Poster campaign

Programme

See:
https://superculture.org.uk/projects/good-grief-weston/

bristol.ac.uk

WHAT'S ON

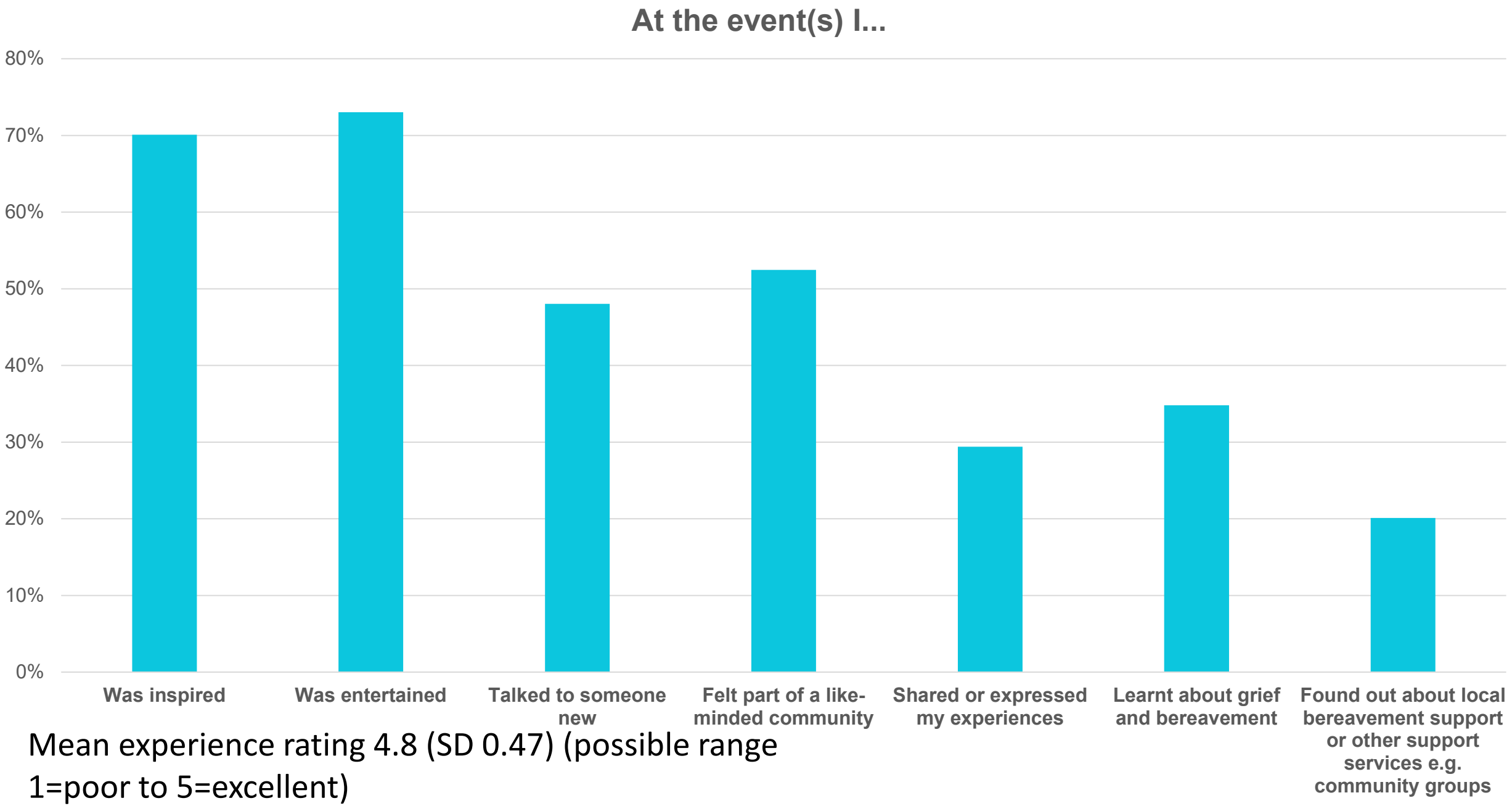
MON 1	**Grief Moves by The Fandangoe Kid and The Loss Project** A 'Grief Rave' on the high street! Bring a song you would like to play as an act of remembrance.
	Moving Through Life: Yoga with Morven Hamilton A supportive yoga session for all women.
	Aftersun Searing memoir of a father-daughter holiday. Dr Jimmy Hay (University of Bristol) will lead a post-film discussion on grief and memory.
TUE 2	**Grief by the Seaside: a double-bill of Tattoos and Bingo with Dr John Troyer and YARA + DAVINA** A talk on the fascinating art of memorial tattoos, followed by Death Euphemism Bingo.
	Four Seasons workshop for under 5s and carers A theatrical introduction to the cycle of life.
WED 3	**In conversation with Michael Rosen** One of Britain's best loved writers and poets, on life, loss and literature.
	Memories Shared: A Reminiscence Session Digitised historic images evoke times passed.
	Weston Re-Makes It Join the regular Weston stitchers to create your own personal piece using fabric which is special to you.
	Forget-Me-Not Create your own memorial flower, part of a large-scale community arts project.
THUR 4	**Theatre Orchard Youth Theatre** Premiere performances on life, death & memory.
	Milton Road Requiem Samir Savant from St Georges Bristol and the Fitzhardinge Consort choir explore musical representations of grief from across the ages.
	No Barriers Here, with Weston Hospicecare Use arts & crafts to gently unlock conversations about end of life.
	Arts + Crafts outdoors Illuminate fond memories in this al fresco lantern-making session.
	The Reader Be part of a friendly group reading a book aloud and discussing it together.
FRI 5	**An evening with Kathryn Williams** Music and musings from renowned singer-songwriter.
	Bereaved Men's Cookery Group Be supported and inspired to cook healthy, cost-effective meals.
	The Reader Be part of a friendly group reading a book aloud and discussing it together.
	Bereavement Cafe Tea, coffee, cake and chat.
SAT 6	**Grief Kid exhibition plus tea, chat and art** Unique illustrations on the feelings of grief.
	Seeds of Memories An uplifting show packed to the brim with puppetry and poetry.
	Pottering Through Lose yourself in clay! Create a memorial tile for a legacy artwork for the town.
	Relaxing and Restorative Yoga with Do Yoga Breathe out, meditate and gently move.
SUN 7	**Woodspring Tales – The Write Box and Marianne McAleer** Reflective arts walk through Sand Bay.
	Double bill: Everything You Wanted to Know About Death, Dying and Grief but Never Had the Chance to Ask One-woman show, panel discussion and Q&A.
	Super Synchro demo and workshop Meet Weston's new synchro swimming group, and join in!
	The Griefmobile – Zoe Papadopoulou 1970s fiat ambulance transformed into touring grief archive
MON 8	**Grief at Grove Park** Opening Ceremony with Rupert Callender; The Guy in the Luggage Rack aerial comedy; House of Figs; Marvin Muoneke; The Poetry Machine; Forget-Me-Not installation; arts & crafts. Plus Weston Hospicecare, Pete's Dragons & Global Kitchen.

Evaluation

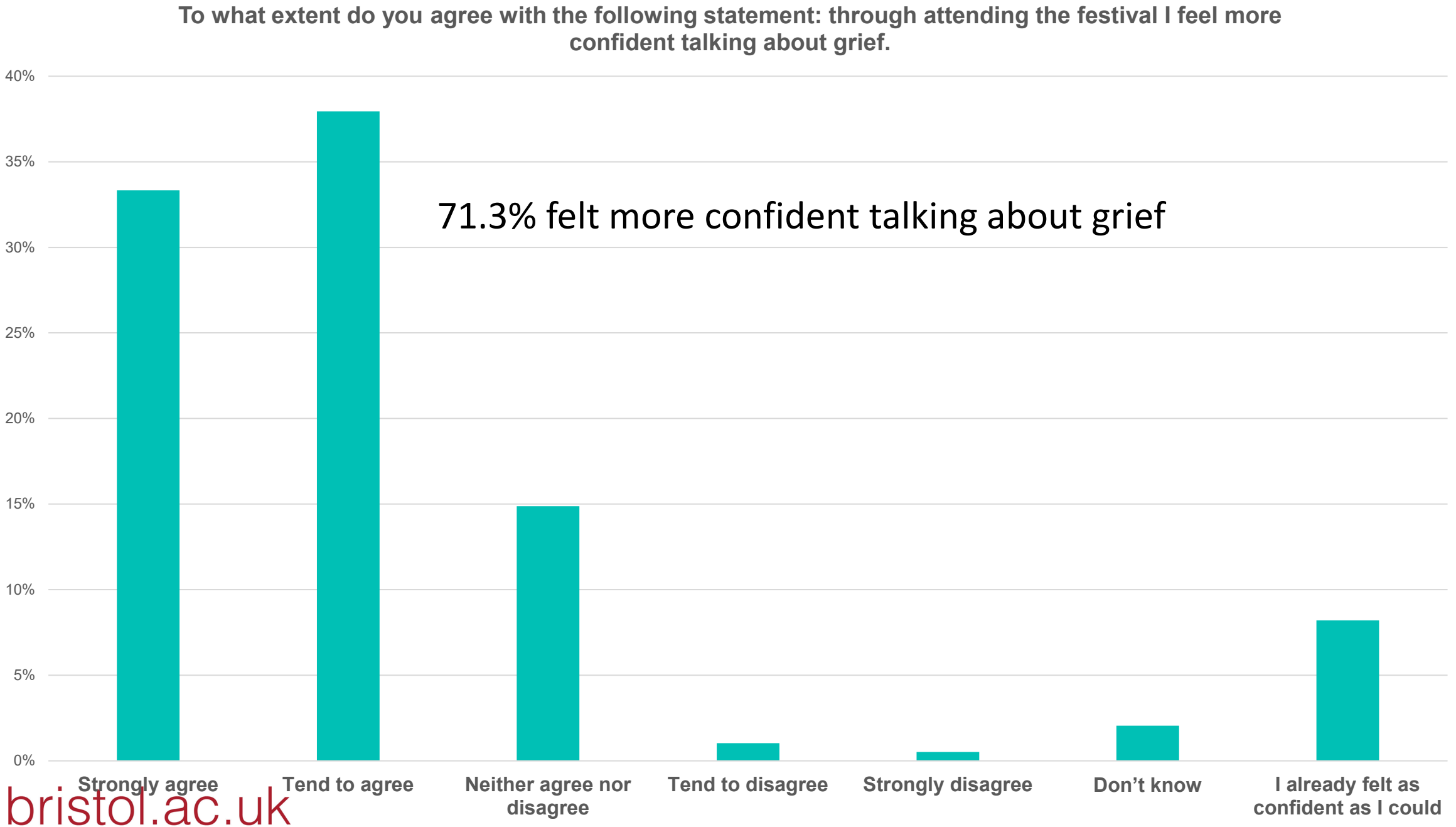
- **Aim:** To evaluate the reach and impact of Good Grief Weston and gather data to inform future festivals
- **Methods:** Mixed methods evaluation (survey and focus groups)
  - Online and paper surveys assessing participants' characteristics and experiences were administrated during and after the festival
  - Survey participants who indicated their willingness to participate invited to attend a focus group
  - Focus groups were recorded, transcribed and analysed using thematic analysis
  - Data were collected by trained community co-researchers

Participants

- Approximately 3000 people attended the festival across 8 days
- **Survey participants**
  - 204 completed surveys
  - 64% from women
  - Age range ≤15 to ≥75 years (mean 52 years)
  - 88% identified as white
  - 15% deaf, disabled/with a chronic condition
  - 19% neurodivergent
  - 9% gay, bisexual or queer
- Two focus groups were conducted (n=8 participants, all women), lasting c.1.5 hours



Mean experience rating 4.8 (SD 0.47) (possible range 1=poor to 5=excellent)


To what extent do you agree with the following statement: through attending the festival I feel more confident talking about grief.
40%
35%
30%
25%
20%
15%
10%
5%
0%
71.3% felt more confident talking about grief
Strongly agree
Tend to agree
Neither agree nor disagree
Tend to disagree
Strongly disagree
Don't know
I already felt as confident as I could

Reasons for attending

- Previous positive experience of online festival

- To engage with unresolved grief, dedicate time for healing

In the two or three years before lockdown I lost both parents and my brother and in the sort of scurry to well sort out funerals and all sorts of legal stuff and then lockdown I haven't dwelt, well I just haven't thought about it at all really and then suddenly I thought grief, oh grief, gosh, what happened to my grief?... It was like, I felt like my soul needed it... I'd denied something and I just needed to be there. Yeah. – FG5

“A forgotten about place”

- Surprise and delight, pride
- Role of festival, arts and culture in regeneration and tackling inequalities

I actually couldn’t believe it when I saw that it was the first live Good Grief events were going to be in Weston of all places! – FG7

Things like this just never happen in Weston. It's such a forgotten about place so, yeah, I think it's really important for things like this to happen here because other places get prioritised… it showed what Weston can be like. – FG1

Such a great idea for Weston and community, bringing life back into this town I loved as a child :) for our next generation. 09858

Value of co-production

What a wonderful initiative. It has really encouraged community-building and local spirit. 02199

But it was also that collaboration, how it didn't feel like Bristol University was swamping into Weston. It felt like it used the community centres and the community hubs to grow the festival out of it. – FG3

Obviously some of the big people, like Michael Rosen, they came from other places, but lots of people were home grown, from here. – FGfac

Diversity of the programme

When I looked at the programme I thought, well this is great because there's something here for everybody… there are different ways that you can react, in a way that you feel keeps you safe but also keeps you informed. – FG4

I thought the curated line up of events was brilliantly varied and interesting, and although emotional, not too 'heavy'. I also really valued being able to pay for tickets on a sliding scale, so thank you for enabling that. – Survey 80859

I thought blimey that's a pretty full-on programme. That could be really overwhelming for some people but then I thought not everybody's gonna go to all of it and they'll be drawn to whatever they're drawn to. – FG8

Connecting, inspiring

It's so good and makes people feel they are not alone and there is a community of people who understand. Love these events. Survey 67892

Thank you. It's an amazing to be part of this and to book other events during this week. It's nice to feel a sense of belonging with others who have also experienced grief. Survey 30668

Funny enough I found that it was actually inspiring and feel uplifted - probably because of accepting it's all part of normality. PC35

Expression and processing of grief

- Creative, deep, freeing, enlightening, restorative – sometimes painful

I think I felt it was really sort of healing, you know, being with different people and the conversations we had. It was (-) not sombre but it was just (-) it felt really special. – FG3

It's beautiful to be able to shed a tear with someone without feeling silly or ashamed, sharing a felling, which is very personal, but also very shared and familiar. I hope this happens every year. Survey 02944

Quite exposing. Raked up a lot of memories which was painful. Survey 84183

People to listen

- Trained ‘listening post’ volunteers needed and appreciated

It was just a little concern I had, as an art therapist, that bringing these things to people sometimes who might come in off the street and producing creative stuff and erm or music, how powerful it could be, and there were listening people and, well, I was one of them at one, well, I think there could have been more listening people because I just think if somebody was really upset and triggered and somebody else was with that person they may feel like not waiting around or they may feel oh I can’t interrupt. – FG6

Safety, inclusivity

It was really safe and inclusive and I was really trying to get somebody to come to the synchronised swimming and then the people were 'no, no, we'll watch, we'll watch' and then it was just like 'well, no, I'm going to do it' and again the group from ((town)) was so lovely and so inclusive. It was just (-) you couldn't stop smiling. It was just really lovely. Really, really lovely."- FG3

Then when I went to ((X venue)) it was so accessible. It was great. Like they just let [relative with Alzheimer's] – because she's in a wheelchair – and that great singer was there, the gentleman, and then the two ladies from [xxx], they were amazing, so that was really lovely. – FG2

Barriers to engaging

- Booking events might be a psychological barrier
- Clashes with work
- Timing over public holidays *increased* participation
- Alcohol consumption

And that was the same with the swimming, wasn't it? It's like more the merrier. It's going to happen, come if you [want] and that feels (-) that's a really lovely way to be, because you can think 'oh, well, I can still go' – FG3

If you're really having trouble grieving, you wouldn't be able to get your head round booking all these things – FG8

Suggestions

- Tag line/framing
- Events to *remember and celebrate*, events in parks e.g. outdoor theatre
- A festival hub space e.g. marquee; decorations
- Opportunities to debrief e.g. after the film screening
- A teenage hub – representation, gaming, music
- Online GGF events also valued

A few friends of mine said, oh, coz it said 'shame it didn't have love loss and celebrating life' because I think some people were not put off but thought it would be too sad. – FG2

If it's going to be a festival for the whole week, just brighten up the town with things, not just posters – massive sunflowers that are made out of art that are in the high street just dotted around. – FG2

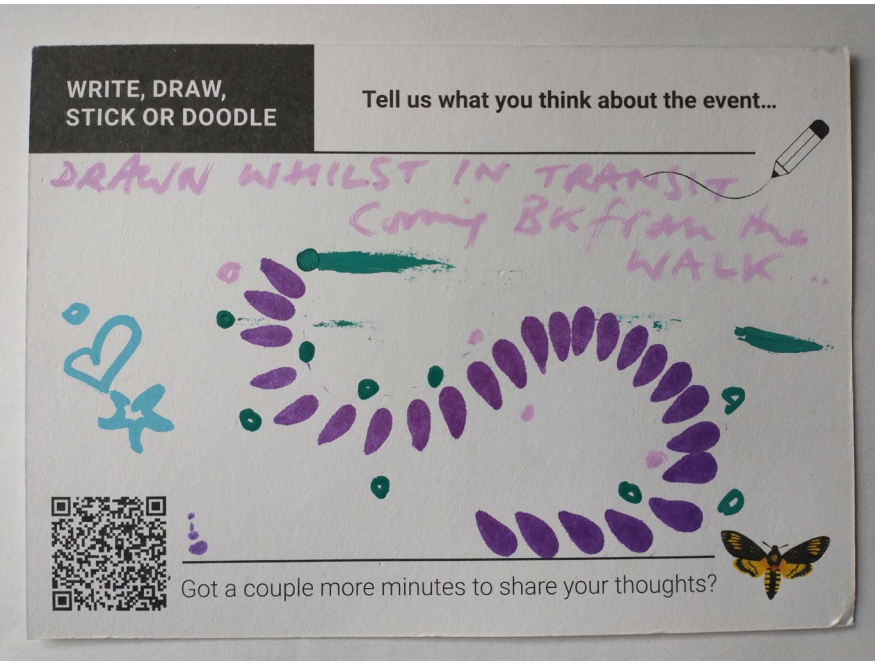
Including men

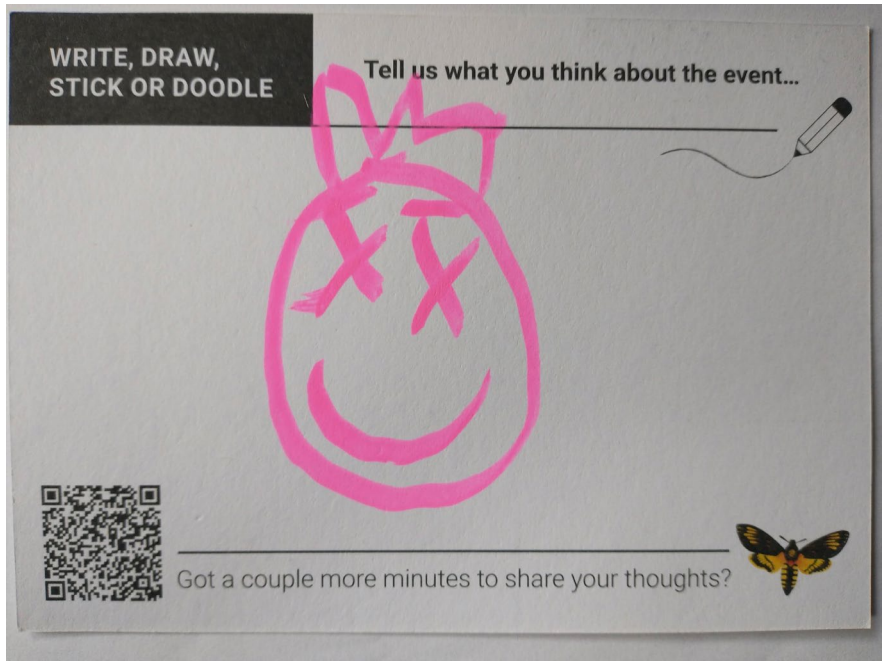
Specific events targeted men e.g. bereaved men's cooking workshop, allotment session

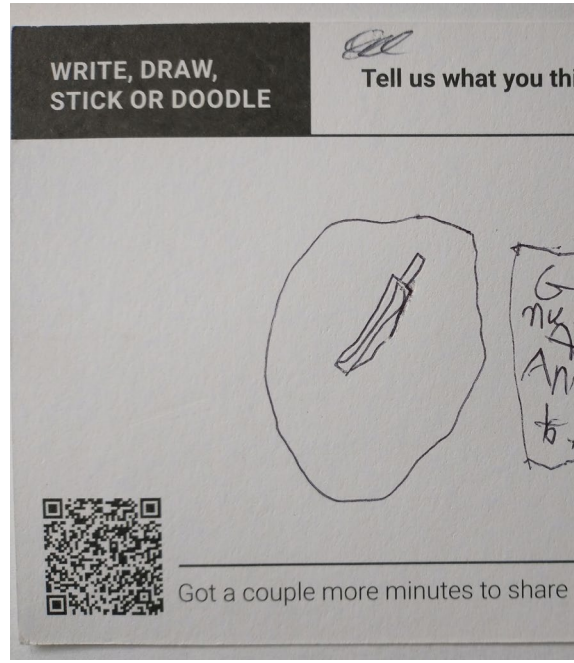
So, with the men's one, like the men's cooking, he was working, but he did all the yoga ones. He was like 'oh, I'll go to the yoga ones'… But my partner said 'but it will all be women' [at the art event] so it was like 'oh, I don't think I'll go'. FG2

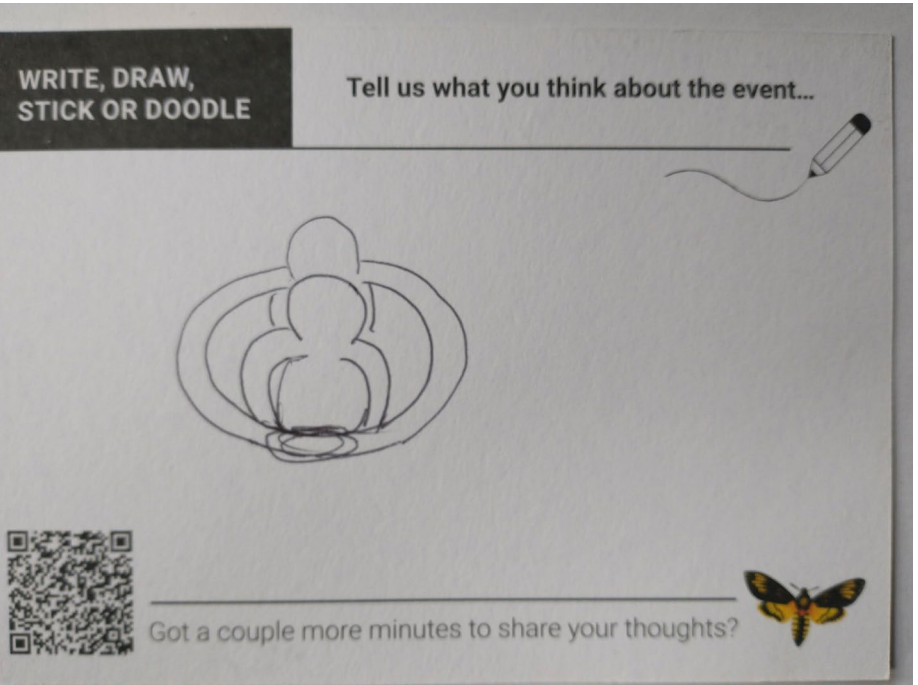
Suggestions: sport, ambassadors for young men, activities e.g.

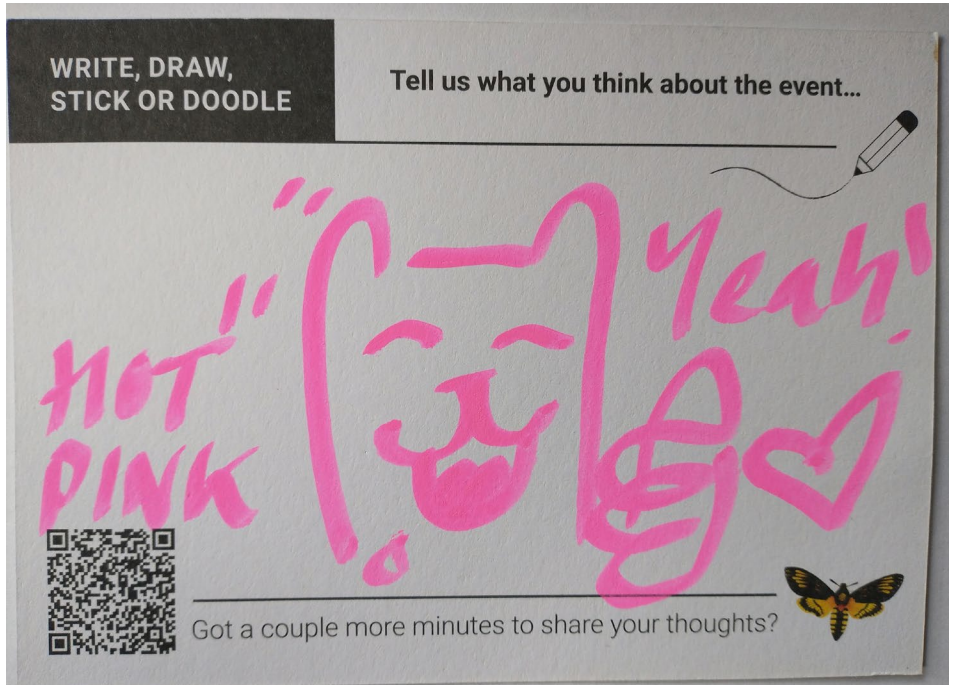
I wondered if you could have like a man's workshop where they make bird tables or something out of wood and you advertise it like they're coming to make something and they wouldn't even realise and they just get chatting to each other. – FG8

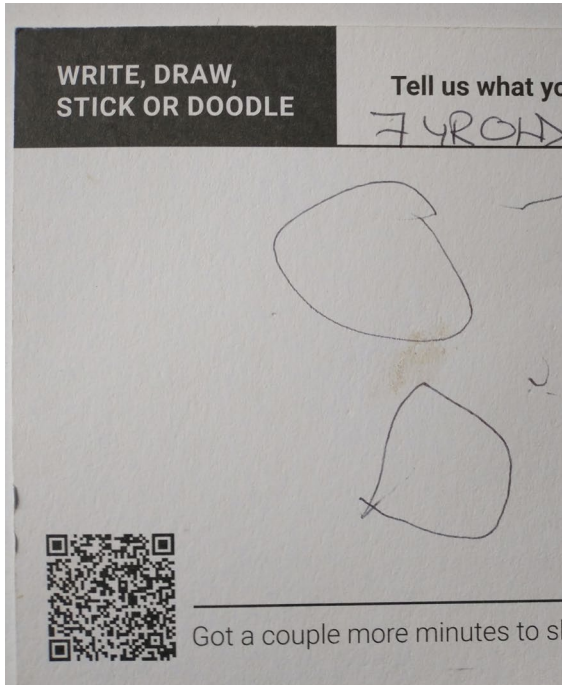

WRITE, DRAW, STICK OR DOODLE
Tell us what you think about the event...
DRAWN WHILST IN TRANSIT
Got a couple more minutes to share your thoughts?


WRITE, DRAW, STICK OR DOODLE
Tell us what you think about the event...
Got a couple more minutes to share your thoughts?


WRITE, DRAW, STICK OR DOODLE
Got a couple more minutes to share


WRITE, DRAW, STICK OR DOODLE
Tell us what you think about the event...
Got a couple more minutes to share your thoughts?


WRITE, DRAW, STICK OR DOODLE
Tell us what you think about the event...
HOT PINK
Yeah!
Got a couple more minutes to share your thoughts?


WRITE, DRAW, STICK OR DOODLE
Got a couple more minutes to s

Reflections

- Positive engagement and experiences; important guidance for future work
- Festival helpful for:
  - raising awareness, confidence in discussing grief
  - bringing communities together
  - providing something for everyone
- Need to meet people where they are, not where you think they should be
- Think creatively about evaluation

Martin et al. 2022. How are public engagement health festivals evaluated? A systematic review with narrative synthesis. PLoS One.

Arts and Humanities Research Council

Palliative and End of Life Care Research Group

Acknowledgements

- The people of Weston who came together, participated and shared their views
- Community co-researchers: Karen Lee, Lin Toulcher, Polly Maxwell, Nina Thomas-Bennett, Mark Bradshaw, Becky Condron
- Study team and collaborators: James Robb, Alice Malpass, Olly Clabburn, Alison Bamford, Rachel Hare, Lesel Dawson, Fiona Matthews
- Funder: AHRC

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