

# The Departure Lounge

## 11th May - 7th June 2019

### Evaluation Report

*...the people of Lewisham are lovely, engaging and curious. This gives me hope that this taboo topic can be brought out into the open so that people tell others of their wishes and have a positive experience at the end of their lives*

(Guide, End of Project Survey)

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# 1. Executive Summary

This document reports the findings from the evaluation of The Departure Lounge (TDL) against its objectives. TDL was a staffed pop-up installation in Lewisham Shopping Centre, created by the Academy of Medical Sciences (AMS) with designers The Liminal Space, to build awareness and encourage people to talk about death, dying and end of life care (EOLC). A mixed-methods evaluation was conducted to understand the impact of the installation on its audiences and included a digital survey embedded in the installation, in depth pre- and post-visit interviews, observations, feedback from Hosts through the daily record and an end of project survey, feedback from Guides through daily reflections and an end of project survey. This document sits alongside a second report which explores the project team's learning.

The Departure Lounge occupied an empty retail space in Lewisham Shopping Centre from 11<sup>th</sup> May to 7<sup>th</sup> June 2019 – it was open Tuesday to Sunday each week. Over 2,500 visitors crossed the threshold into the shop during its 24-day run, with many more noticing it as they passed by. On discovering what TDL was about, some felt anxious or even disgusted – not wanting to talk about death – but many were curious or keen to engage. They read or listened to the content, wrote down their experiences or thoughts and talked with Hosts or Guides.

Visitors were positive about their experience and thought that TDL provided an important service to the community. They recognised that it is important to overcome the taboo and talk about death; that emotions and cultural norms make death difficult to discuss or even to think about; and that it's important to prepare for end of life by letting loved ones know your wishes. For some visitors, TDL bore witness to their experiences of death and dying and even provided solace to those living with EOLC dilemmas and grief.

## **The audience**

TDL was visited by people of different ages – older and younger adults, some families and teens. The majority were adults, including large numbers of older adults (65+ years). Some visitors had found out about TDL through the wide-reaching media coverage and purposefully visited. Many others came across it while in the shopping centre, intrigued to know what the new pop-up shop was ("Is it a luggage shop?"). More women seemed to visit than men (60% female). Approximately 60% of visitors were local (living, working or studying in Lewisham) and their ethnicity and religion reflected the local community: approximately 50% were of BAME heritage; most had no religion, those with religion were mostly of a Christian denomination. The strategy of siting the installation in a shopping centre meant people encountered it in their everyday lives and consequently TDL's audience reflected the diverse, local population – a broader demographic than might be expected to an exhibition in a conventional London museum or gallery space.

## **Visitors' engagement with the installation**

Most visitors stayed between 1 and 10 minutes in TDL although dwell times ranged from under a minute to well over an hour. Visitors liked the calm, welcoming atmosphere. The content was grazable and distributed in bite-sized pieces inviting self-navigation and making it intellectually accessible. Visitors appreciated the 'it's a journey' metaphor – which made the content more approachable – and they responded positively to the personal stories which made the content relatable. Visitors found talking to the Guides and Hosts who staffed the space impactful for the information and advice they provided and especially for the listening ear and emotional support they offered.

Visitors' experience in TDL often seemed to follow a journey: they were curious about the installation and quickly immersed in it; the content acted as a trigger, opening up existing thoughts and memories; and for those that find death difficult to think about or for whom it's far from top of mind it was found to be a safe

space to discuss the subject. Thoughts were emotionally impactful, and the content led to a realisation (or reaffirmed) that thinking about death and EOLC is important and that there are choices that need making.

### **Emotional impact**

TDL is a space where unusually open conversations about life, death, loss and family occurred. It is a significant achievement for an exhibition to provoke such reflection and such an emotional connection in visitors. The design and staffing created a comfortable, “permission-giving” space. Whilst TDL’s content can be “saddening”, visitors appreciated the warm welcome and the non-morbid tone. Those that gave it time connected with the subject matter at a “deep” level and many felt reflective, moved, “enlightened”, and safe. A small minority were distressed or even angered by the topic being raised at all. Personal stories and conversations with Hosts or Guides were key in easing past the initial hesitancy that many visitors displayed.

There was a notable contrast in the responses to TDL in those with or without personal experience of bereavement. The former often found themselves revisiting and sharing their loss and grief or looking for support in TDL. They appreciated being able to share their story but not all found the answers they were looking for. Those with little experience of death tended to consider it in more abstract terms and thought less about EOLC.

The Guides witnessed a striking range of emotions – from anger and distress to anxiety, grief, reflection and relief – and their role included dealing with intense, sometimes challenging, situations including hearing from people with terminal diagnoses, recent bereavements and complex grief. TDL’s private booth played an important role in supporting some of these individuals.

### **Empowerment and choice**

Following a visit to TDL – and with the importance of the subject top of mind – many people showed awareness that they have agency and choice around end of life issues with some visitors resolving to take action. Visiting may have provided the impetus and motivation they needed. Many visitors said they would use the installation itself, or elements of it, as tools to scaffold difficult conversations they felt they needed to have with family or friends.

However, although the experience provided impetus to take action (or at least the resolve to do so), intentions were often expressed cautiously, suggesting a lack of clarity in exactly what the next steps would be, or a hesitancy in addressing this with family. Many talked about “making provision” or referred to after-death activity such as making wills or funerals wishes with no knowledge of how to make a will. There was also little or no discussion of EOLC options.

Notably, as with the emotional impact of visiting TDL, visitors’ empowerment and future actions seemed to be shaped by personal experience. Those *with* experience of bereavement or EOLC seemed more familiar and comfortable with the terminology and concepts, more likely to raise such issues, to know what to ask or to describe actions they intended to take. By contrast, those *without* prior experience seemed more likely to simply say “this has given me lots to think about”, to defer taking action, to be less specific about what action they might take or to talk about ‘after death’ actions.

### **Awareness of research around death and dying**

Visitors’ awareness of health research and innovation around death and dying, where it did occur, mostly focused on statistics mentioned in the installation such as increase in age at death and causes of death in men and women. Whilst these were impactful for some, they were appreciated less than the personal stories and this content was given relatively low prominence in the displays and in the Guides information-sharing with visitors. Although visitors did not leave with an understanding of this research, they did leave with a realisation that they have an active role in decisions about care and dying. It seems they might be

prepared to have conversations about care and dying with their doctor or future medical/care professionals, or at least be aware that they can.

### **Impact on the Guides**

Most Guides were involved in the project because they were motivated to engage the public with the topic – many wanted to encourage people to do advance planning, or support people to overcome the fear of talking about death. While already experienced in working in death and dying with the public, the majority of Guides felt they had learned from their experience in TDL, saying they had learned more about the process of helping people talk about death or dying, they had learned from the experience of talking with a diverse audience and also learned from working alongside other Guides and the Hosts.

25 out of 31 Guides said their work in TDL would impact on their professional practice – by getting involved in other public engagement events, using the resources and ideas with other communities, informing their interactions with patients and when teaching. Others mentioned having a better understanding of palliative care, informing research directions, the importance of having conversations with patients early, and feeling “reinvigorated” for their work.

### **Website visitors**

2,505 users visited TDL’s website between May 10th and June 24th 2019, peaking within days of the installation’s launch. A close correlation between higher web traffic and the period when TDL was open in Lewisham suggests that people who heard about or visited TDL were amongst those visiting online. Most of the 2% of online visitors who completed the website’s pop up survey, said that they were already confident talking about death and dying suggesting a number of web visitors, or at least survey respondents, may have a professional interest in TDL (such as health care professionals, Death Café organisers) or already had some experience of death or EOLC. The website was not obviously signposted in TDL.

### **Event participants**

One off-site event, ‘Dead Beats’, was held in a pub in nearby Blackheath. This free event was hosted by comedians and billed as ‘What music do you want at your funeral?’. The event targeted, and reached, a more science-engaged audience than TDL. It was attended by 25 people who were mostly female, White and aged 35-44, and approximately half of whom were local.

The event was well received by its audience, most rating it excellent. However, when asked ‘What might you talk about to the people you love or future medical carers, that you hadn’t considered before today’ responses were mixed, suggesting the event did not directly deliver on the project’s objectives beyond feeling comfortable talking about death and dying.

### **What could be improved**

Very few suggestions for improvement to the physical space were made by visitors, Guides or Hosts. A handful of comments suggested improvements could be made to improve physical access for the broadest possible audience, particularly in terms of visual access and provision for the deaf and hard of hearing. The frequency of ‘What is this?’ exchanges between visitors and the Hosts/Guides also suggests that more might have been done to communicate the topic and purpose of the installation to passers-by and to distinguish the nature of TDL’s offer from the retail units it was surrounded by.

The experience provided impetus and resolve to take action but not all visitors were clear on what action to take, saying vaguely that they “will make provision”. A more explicit roadmap of the options available and what people could do next could have provided a scaffold for their next steps, perhaps via physical elements within the installation, messaging provided by Guides or signposted resources on the website.

And finally, more might have been done to prioritise messaging about health research and innovation in EOLC. This content could have been given more prominence and 'real estate' within the installation. And Guides could have been explicitly briefed to share this information with visitors. However, visitors responded very positively to personal stories so it's quite possible that making such an adjustment, whilst it would have supported one project objective, might inadvertently undermine the high levels of engagement achieved by TDL.

## **About the evaluators**

### ***Emily Scott-Dearing***

Emily Scott-Dearing was a biomedical research scientist before joining the Science Museum, where she worked for 16 years. There she led teams to deliver an array of permanent galleries, temporary exhibitions, events programmes, festivals and digital content, in roles including Head of Exhibitions & Programmes and Lead Curator for the Medicine Galleries Project. She now works independently as a content, interpretation and public engagement consultant. She has recently curated exhibitions for the Wellcome Collection and The Francis Crick Institute.

### ***Emma Pegram***

Emma Pegram has worked in education in schools and out-of-school contexts for the past 20 years. Much of her expertise was developed at the Natural History Museum, London, where she was the Learning Research and Evaluation Manager responsible for evaluating the impact of the Museum's programmes, events and exhibitions on their audiences. Now as a freelancer, Emma uses her experience to help museum learning and science communication professionals learn from evaluation to create better learning experiences for their audiences. Recent clients include The Francis Crick Institute, Royal Botanic Gardens Kew and the National Trust.

## 2. Introduction

To deliver on its strategic challenge ‘to become the exemplar of a modern scientific academy’ – diverse, trusted, dynamic, relevant and accessible – the Academy worked with design agency The Liminal Space to create the Departure Lounge, to engage the public with the important but often neglected health topic of death and dying. The project was supported by The Health Foundation and Wellcome as well as a core grant the Academy received from the Government Department for Business, Energy & Industrial Strategy. The UK will soon be faced with a sharp increase in the number of deaths each year as a consequence of an aging population and more people living into extreme old. At present ‘death literacy’ (understanding the physiology of dying prevents hospital admissions, and knowledge that earlier contact with palliative interventions improves quality of life and pain management) and the ability to engage with the topic is low amongst the public and in particular with lower socioeconomic groups who may be less informed about their choices and who often experience poor healthcare outcomes. The Departure Lounge, therefore, aimed to facilitate exchanges between the public and researchers/health care professional to consider or share views on what death means to them, and how research/the health service can support a ‘good death’. It did this by creating an immersive installation in an empty shop in Lewisham Shopping Centre which was open from 11th May to 7th June 2019, developing an accompanying website version of the content and delivering a public event. The shopping centre location was chosen to enable a broad demographic to encounter TDL, particularly people of different ethnicities and those of lower socioeconomic backgrounds. As well as the public facing aspects of the project, there was a programme of policy activity, involving stakeholders, researchers, policy makers and including a Policy Catalysis Workshop, ensuring the learnings from the public engagement project could be fed into policy activity. The policy work is reported separately by Ipsos MORI<sup>1</sup>.

### Project Vision

To create physical/digital spaces that empower participants to plan a ‘good death’, where people typically disconnected from science engage with research and researchers participate in a broader social conversation to inform their work.

### Aims of project

- Provide opportunities for researchers to talk meaningfully with publics about their work and contribute to better people-centred health research.
- Facilitate wide-ranging intergenerational exchanges about death and dying, empowering people to make plans/explore choices.
- Increase public awareness of health research and innovation around death, dying and the ageing population.
- Enable public debate to drive policy discussions on death and dying.

### Target audiences

- Public – ethnically diverse to cover a range of cultural attitudes to death and dying, lower-income (equating to lower health outcomes), local to high street exhibition venue. All ages (including intergenerational conversations) 1,500 in store, 250 at events
- Researchers
- Stakeholders, particularly policy-makers<sup>2</sup>
- Project Team<sup>3</sup>

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<sup>1</sup> Ipsos Mori (2020). The Departure Lounge, Public attitudes to death and dying - Research report <https://acmedsci.ac.uk/file-download/25349242>

<sup>2</sup> outside the scope of this evaluation

<sup>3</sup> The learning of the project team is reported separately

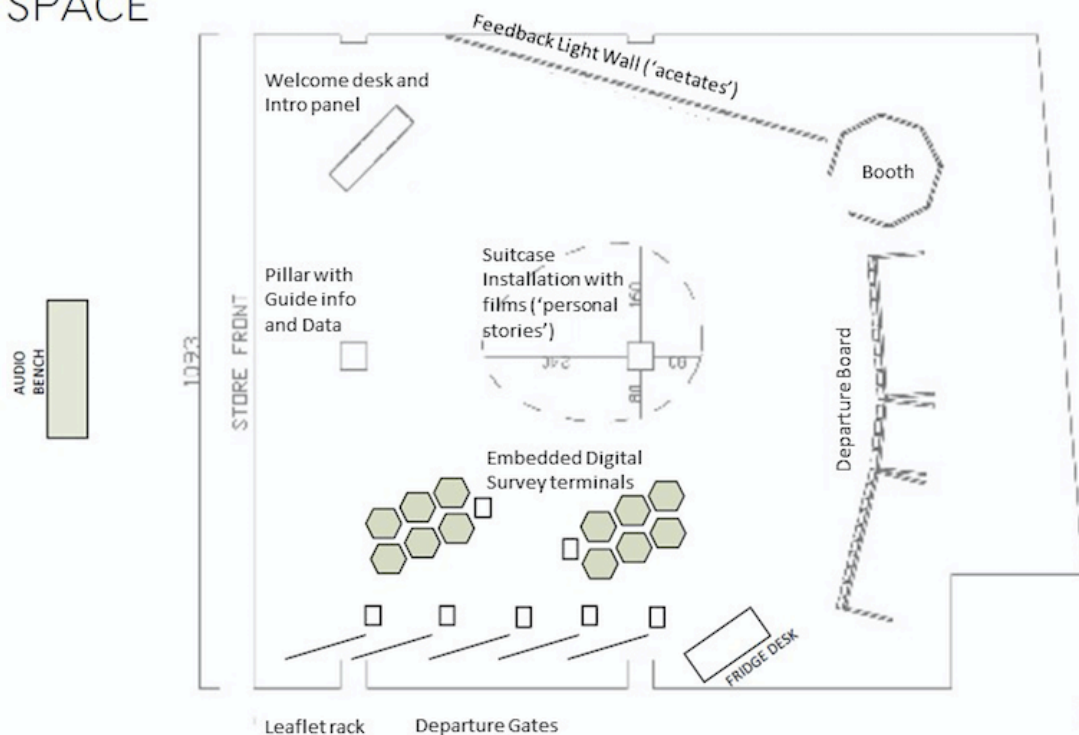


## Description of the Departure Lounge

TDL occupied an empty shop in Lewisham Shopping Centre. It was in a busy thoroughfare with a popular phone shop opposite. The shop front was open: two large windows contained a number of eye-catching, travel-style posters about death euphemisms such as ‘kicked the bucket’ and ‘popped your clogs’ – and an open doorway.



## THE SPACE



The lighting was soft, highlighted with neon and this, alongside a soundscape, created a calming atmosphere in the shop – a contrast to the busy thoroughfare and pop music of the shopping centre. The front face of a pillar at the entrance of the shop stated: ‘The Departure Lounge. Talk to one of our guides in the space today. Pick up a brochure to discover who else will be in The Departure Lounge. Because talking about death makes life easier.’ The names and professional roles of the Guides on duty that day were also displayed on the front of the pillar with statistics about death rates printed on the remaining three sides.

Within the space information was delivered in bite-sized pieces (i.e. no long text panels) on an installation of suitcases and at the ‘Departures Board’, a wall-mounted display at the back of the space. The suitcases contained personal stories printed on suitcases and luggage labels, through evocative films and a soundscape; the ‘Departures Board’ comprised a series of small boxes, some of which could be opened, containing short pieces of information from health care professionals or facts and statistics about death and end of life care. Some were printed on tickets, or other travel-related paraphernalia, or presented as audio relayed via telephone receivers. Other information was provided on leaflets and postcards available at a desk near the entrance or on plinths in the ‘Departure Gate’ area. The ‘Departure Gate’ area also had seating and two low-level plinths containing touch screens which housed the Embedded Digital Survey, to one side was a fridge with bottles of lemonade which could be taken by visitors. The labels on the lemonade bottles prompted discussion about death and dying such as ‘What would your final words be?’. A light wall along one side lent a soft glow, with acetates hung on it displaying personal experiences or wishes for your last journey contributed by visitors. A curtained booth was available in one corner for those requiring privacy. Floor stickers (yellow vinyl arrow lines) containing prompt questions such as ‘I want the end of my life to be...?’ loosely connected the various elements of the installation to encourage movement between areas.

On the bench outside the shop sat a yellow ‘emergency’ phone which played audio also found on the phones in TDL. Further stickers across the floor connected the phone to the shop, and digital advertising boards

throughout the shopping centre showed a TDL advert based on the window posters for the first two weeks of opening.

The installation was staffed by 2 Hosts and at least 2 Guides at any one time. The Hosts had acting and retail backgrounds and managed the daily operations of the shop. They also welcomed visitors, engaged in conversations about death and EOLC, supported the Guides and ensured there was continuity in the experience each day. The Guides generally each did two shifts in TDL (often on consecutive days). All had experience of talking with the public about death and dying through their professional or voluntary work. They came from different parts of the country and ranged in career stage from early stage researchers to retired nurses. Some worked in academia, many in the health care service, others as doulas or death cafe organisers. Hosts and Guides received a comprehensive day of training as well as a number of online resources and other support from AMS. Those who spent more than three days in the shop (predominantly Hosts and AMS staff) were offered a post-project Decompression Session with a trained psychiatrist, in acknowledgement of the toll their work discussing death and supporting the grieving in TDL might take.

The Departure Lounge was open on Tuesdays to Sundays. It was drop in – visitors did not need to book – however, the AMS also invited specific groups from the community to attend at pre-arranged times for an introductory talk and then to experience the installation.

This report covers the evaluation of TDL installation in Lewisham Shopping Centre, the associated website and public event. It begins with the evaluation aims and description of evaluation methods used and then moves on to detail the findings. The findings are broadly structured around the aims, beginning with a description of the visitors and their experience in TDL and then focusing on the outcomes achieved. The report also covers the impact of the experience on the Guides, findings from the web survey and event feedback form. It concludes with a discussion of the main achievements of TDL and learnings for the AMS's future public engagement programme.

### 3. Evaluation aims and objectives

The evaluation was planned to demonstrate the performance of the project against its aims and objectives by providing evidence on:

- Engaging with an ethnically diverse and lower socio-economic status audience (as a correlate of people with poorer health outcomes) – collecting data on participant demographics including age, gender, ethnicity, disability and socio-economic status.
- How intergenerational groups engage with the subject<sup>4</sup>
- Participant learning – changes in 'death literacy' (understanding, attitude, potential future behaviour) – that demonstrates empowerment to make plans/explore choices about death and dying.
- Awareness amongst participants of health research and innovation around death, dying and the ageing population.
- Emotional impact on participants
- Participant enjoyment of the experience – what factors contribute to this or not?
- Researcher learning – impact on engaging the public with their research; how does this project contribute to better people-centred health research?

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<sup>4</sup> This was not explored in detail as the intergenerational audience did not become a target audience for TDL

## 4. Evaluation approach and methods

### 4.1 Embedded Digital Survey

A digital survey on an iPad was embedded on two plinths in the Departure Gate area of TDL. It was intended for visitors to encounter it as part of their experience, rather than as stand-alone 'evaluation feedback'. It contained three open ended questions to encourage visitors to reflect on their experience as well as questions to capture demographic characteristics (Appendix 1). Visitors could self-select to complete the survey or were encouraged to by Guides and Hosts. Where visitors had difficulty reading or physically using the touch screens (the font was small, and the iPads had a delay) Guides and Hosts typed in their responses. Sometimes Guides and Hosts encouraged visitors to complete the digital survey after they had taken part in a scripted Ipsos MORI interview which some visitors were invited to participate in during their visit. A total of 148 completed surveys were received. (The demographics of Embedded Survey Respondents referenced in this report can be found in Appendix 2.)

### 4.2 Pre and Post Visitor Interviews

These interviews were intended to give richer, qualitative insight from adult visitors to TDL in relation to the project's objectives. Due to the sensitivity of the content, interviewees were recruited beforehand rather than approached in the installation. A 5 minute pre-visit interview took place in a cafe near TDL. Interviewees then visited TDL at their own pace, and once they were ready, follow up interviews took place again in the café (see Appendix 3 for interview schedule). Follow up interviews lasted between 20 and 40 minutes. Interviews were audio recorded and transcribed and responses were categorised and analysed looking for themes and patterns in relation to the objectives listed above.

Recruitment was aimed at local audiences (although some came from further afield) via an online notice on Lewisham Shopping Centre's website, leaflets in the local library, medical centres and supermarket community notice boards, through community groups who had booked in to visit TDL, through a student representative at Goldsmiths, University of London and through Twitter. Interviews occurred during weekdays, at weekends and in the half term holiday. Some interviews took place with individuals, others in pairs (usually with a friend of similar age).

Twenty visitors were interviewed, their details are provided below.

Date		Demographics	Local?	Notes
Wed 15 <sup>th</sup> May	Interviewee 1	Female, Late 20s, Mixed British	Yes	Mother died 7 years ago, Grandmother's husband is dying
Sat 18 <sup>th</sup>	Interviewee 2	Female, 40s, Black British	Yes	Sister died 7 years ago, elderly mother, mother's husband is dying. She was the aunt to Interviewee 1
	Interviewee 3	Male, late 40s, Black British	Yes	Family spans from his grandparents to his grandchildren, considers seeking help with father's EOLC as failure

Tues 21 <sup>st</sup>	Interviewee 4	Female, 60s, White British	Yes	Had visited a few days earlier and wanted to give her response to TDL. Much experience of death/EOLC.
	Interviewees 5&6	Female 20s, Male 20s, White British & European	Yes	A couple. Little experience of death/EOLC although the male's dog had died recently.
Thurs 23 <sup>rd</sup>	Interviewee 7	Female, 80s, White British	No	Member of the Lewisham Pensioners Forum. Much experience of death/EOLC. Prepared for her own death.
	Interviewee 8	Female, 80s, Black African	Yes	Member of the Lewisham Pensioners Forum. Much experience of death/EOLC, Supports Death Matters. Prepared for her own death.
Wed 29 <sup>th</sup>	Interviewee 9	Female, 20s, South East Asian	No	Little experience of death/EOLC.
Sat 1 <sup>st</sup> June	Interviewee 10	Male, early 20s, White British	No	Grandmother at EOL. Disagrees with his parents' approach to her care.
Wed 5 <sup>th</sup>	Interviewees 11&12	2 Females, 20s, White British & American	Yes	Goldsmiths students, 2 friends. Little experience of death/EOLC.
	Interviewees 13&14	1 Female, 1 Male, 20s, White British	Yes	Goldsmiths students, 2 friends. One had little experience of death/EOLC. The male had a friend at school whose brother died at 21 years.
	Interviewees 15&16	2 Males, 20s, White British & Irish	Yes	Goldsmiths students, 2 friends. One had little experience of death/EOLC. The other has a grandmother with late stage dementia.
Thurs 6 <sup>th</sup>	Interviewee 17	1 Female, 50s, Black Caribbean	No	Father is in his 90s, she finds it difficult to talk to him about his wishes.
Fri 7 <sup>th</sup>	Interviewee 18	Female, 20s, Black British	Yes	Grandfather at EOL and has experienced other family bereavements but says she "doesn't really think about death".
	Interviewee 19	Female, 50s, Indian	No	Much experience of death/EOLC. Living with complex grief from recent bereavements. No children, so concerned about her own EOLC/ will.
	Interviewee 20	Male, 30s, Black British	Yes	Little experience of death/ EOLC. Uncomfortable connecting the topic to his own life/ mortality.

Table 1. Departure Lounge Interviewees

### 4.3 Observations and dwell times

Visitors' behaviour in the installation were observed. Dwell times, who people visited with and observable demographics of visitors were noted. The reactions of passers-by to TDL was also observed. Observations and dwell times were recorded on 9 days and included weekdays, weekends and half term as well as at different times of day.

166 dwell times were recorded, and the demographics and behaviours of over 360 individuals were noted.

### 4.4 Guide End of Day Reflections

At the end of each day Guides were asked to complete a paper form reflecting on their experience and noting the kinds of interactions they had with visitors (Appendix 4). As figures were recorded post hoc, data provided by the Guides are necessarily estimates rather than exact. The evaluators also informally interviewed Guides on their experiences and interactions on the 9 days they visited TDL.

69 Guide End of Day reflections were completed.

### 4.5 Host Daily Record

At the end of each day the Hosts completed a digital survey capturing visitor numbers, who people visited with, behaviours in the installation, and notable feedback from visitors that day (Appendix 5). The Hosts used clickers to record the number of younger (18-45) and older (46+) adults (ages were judged by the Hosts). The number of under 18s were estimated at the end of each day. The evaluators also informally interviewed Hosts on their experiences and interactions on the 9 days they visited TDL.

24 Hosts Daily Record were completed - one for each day of opening.

### 4.6 Guide End of Project Survey

After their final session in TDL, Guides were sent a digital survey to record their motivations for taking part, feedback on their experiences and whether these might impact on their professional or volunteer work (Appendix 6).

30 out of 34 Guides completed this survey.

### 4.7 Host End of Project Survey

Once TDL had closed, the Hosts were sent a digital survey to reflect on their experience, record any further observations on how visitors behaved in the installation and how non-visitors reacted to it (Appendix 7).

2 out of 3 Host End of Project surveys were completed.

### 4.8 Website pop up survey

A short multiple-choice pop up survey was added to the Departure Lounge website to capture online visitors' confidence in talking about death as well demographic data on age and gender (Appendix 8).

55 surveys were completed between 12 May 2019 (the day TDL launched in Lewisham and online) and 26 June 2019.

## 4.9 Event Feedback Form

On the evening of Thursday 16th May, an event titled ‘Dead beats’ was held at the Old Tigers Head pub, Blackheath, London. The event was planned to reach local, science or culture-interested adults, aged approximately 20-45, to give them an opportunity to talk about death in an informal and less emotionally-charged context. 25 people attended the event and a paper feedback form was used to capture what participants may now talk about as a result of attending, likelihood to visit TDL or the website and audience demographics (Appendix 9).

14 feedback forms were completed.

# 5. Findings

## The Departure Lounge pop up installation in Lewisham Shopping Centre

### 5.1. Audiences

The Departure Lounge exceeded the AMS’s expectations of number of visitors with 2,551 people visiting during its 24-day run (the expected target was 1,500). While visitors of all ages experienced the installation, the vast majority were adults and, of these, large numbers were older adults. More women seemed to visit than men. 50% of adults visited on their own and 31% with another adult of a similar age – with partners, other family members or friends. 60% of visitors appeared to be local, with ethnicities and religions reflecting much of the local community: approximately 50% were BAME, most had no religion, followed by those of Christian denominations. Approximately 17% of visitors had a lasting illness or disability that affected their daily life (although this figure likely underrepresents the proportion of visitors with disability). The findings show, therefore, that TDL succeeded in engaging a diverse audience in talking about death and dying – an audience that, while including those who might travel to visit an experience like this, also reflected the ethnically diverse, lower income population local to the shopping centre.

#### Number of visitors

A total of 2,551 people visited TDL during its 24-day run. Daily figures ranged from a peak of 157 on Saturday 11th May (the opening day) to 58 on Friday 24th May; the mode number being 100. Weekends were generally busier with an average number of 121 visitors per day, compared with 103 on weekdays (Tuesday to Friday) and 88 on weekdays during Half Term (28th-31st May).

Hosts noted that some visitors came on multiple days – some specifically to have conversations with other Guides, or to bring family or friends with them on subsequent visits.

#### Ages of visitors

Ages of visitors were captured through the Hosts counts, Embedded Digital Survey responses and evaluators’ observations. Unsurprisingly the majority of visitors were adults, with approximately 60% of these being older adults (45+ years). Observations suggested approximately 40% older adults were elderly (65+ years). (See Appendix 10 for ages of visitors collected through each evaluation method.)

Children (under 18s) visited TDL in much smaller numbers – it was not generally seen by visitors nor advertised as an experience for families. Those that did visit were just as likely to visit during weekdays (after school hours) than at weekends or at Half Term.

	No. visitors
Under 5 years	66
5-11 years	70
12-17 years	130
Younger adults (18-45)	901
Older adults (over 45 years)	1,384
<b>Total number of visitors</b>	<b>2,551</b>

Table 2. Number of visitors of different ages to TDL (Hosts clicker counts for adults and estimate of daily number of children. n=2,551)

### Gender

Observation data provided an indication of who visited. It suggests 60% of visitors to the installation were female.

	No. visitors
Females	216
Males	134

Table 3. Gender of visitors (Observations. n=350)

Hosts and Guides anecdotally reported that more women than men visited TDL. The Embedded Survey data was completed by far more women than men (108 women, 34 men, 1 describes gender another way, 3 Prefer not to say), partly a result of more women visiting the space but also because women are generally more likely to complete surveys of this kind.

### Intergenerational engagement

Hosts' Daily Record and evaluator observations provided data on whether people visited TDL on their own or with others. Data suggests the majority (50%) were adults visiting on their own, followed by adults visiting with other adults of a similar age (these might be with partners, other family members or pairs/groups of friends) (31%). Approximately 16% visited in intergenerational groups – adults with children (6%) or adults with older adults (10%). Few children visited unaccompanied by adults (3%), on occasion groups of teenagers visited together.

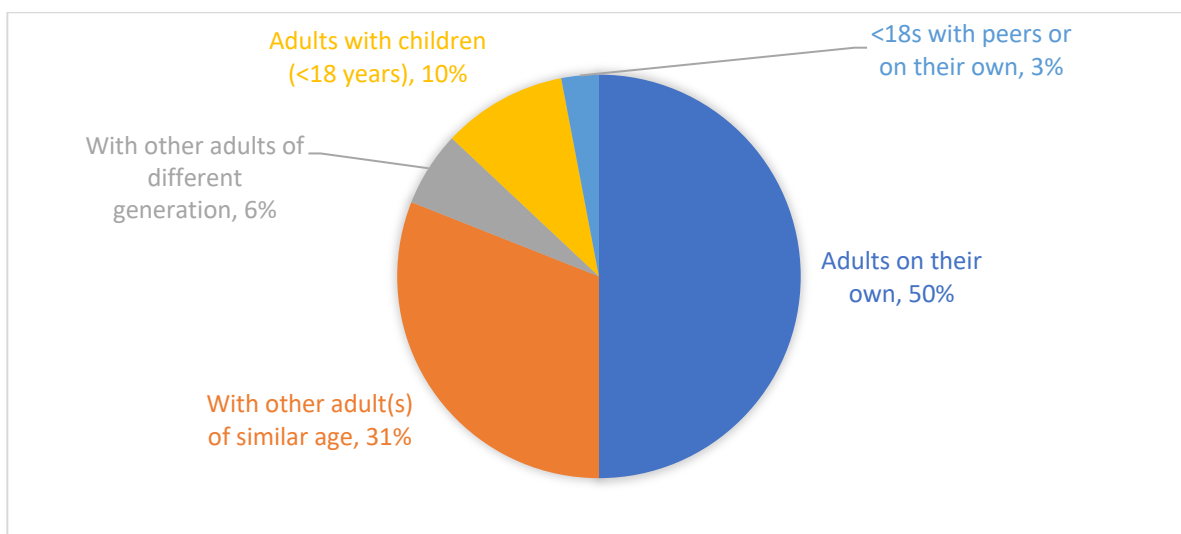


Fig 1. How people visited (Evaluator observations n= 362)



There is some observational data and feedback from Hosts and Guides that intergenerational groups visited TDL – a parent with a teenage child, an adult with an elderly parent for example – but as suggested by the how people visited data above, these were a small minority.

### Local

The Embedded Digital Survey provided data on whether respondents lived, worked or study in the Borough of Lewisham. It suggests approximately 60% of visitors may have been local to the shopping centre.

Do you live work or study in the Borough of Lewisham?	No. visitors
Yes	84
No	61

Table 4. Do you live, work or study in the Borough of Lewisham? (Embedded digital survey, n=145)

### Ethnicity

The Embedded Digital Survey provided data on respondents’ ethnicity (table 5). These were given in response to an open question and categorised as follows:

Asian or Asian British	7%
Black or Black British	24%
White	53%
Mixed/Multiple	5%
Other	9%
PNTS	1%

Table 5. Survey respondents’ ethnicities (Embedded Digital Survey n=139)

Observations of the ethnicity of visitors were also made and provided similar findings – that approximately 45-50% of TDL visitors were of Black or other ethnic minority heritage (table 6). Note, observational data was ascertained visually so we can’t be confident of this data – ethnicity is a complex and contested concept as well as socially constructed.

Asian or Asian British	9%
Black or Black British	35%
White	49%
Mixed/ Multiple	5%
Other	3%

Table 6. Visitors’ ethnicities (Observations n=363)

These figures are comparable to the Borough’s BAME population: White 57%, Black African 14%, Black Caribbean 12%, Black Other 6%, Indian 2%, Pakistani 1%, Bangladeshi 1%, Chinese 1%, Other Asian 3%, Other 3%<sup>5</sup>.

## Socio economic background

Socioeconomic data was not collected of TDL visitors. Instead the socioeconomic status of visitors was determined by information for the local population. In the overall Index of Multiple Deprivation<sup>6</sup>, Lewisham’s average score was 28.59, which puts Lewisham as the 48<sup>th</sup> most deprived of all 326 English Local Authorities (one being the most deprived) and within the 20% most deprived Local Authorities in England. Within the 18 wards of the borough, Lewisham Central has the 5<sup>th</sup> highest number of income deprived children.

Evaluation data suggests approximately 60% of TDL visitors were local. We conclude, therefore, that TDL reached a large proportion of people of lower income (equating to lower health options).

## Disability

The Embedded Digital Survey provided data on the number of respondents who reported having had a long-standing illness or disability that affects their daily life, suggesting 17% of visitors did. However, this is likely to under represent the proportion of people with disabilities who visited TDL given the large number of elderly visitors. Also, the iPad survey would have been difficult to access for some visitors (this was overcome to some extent by Guides and Hosts supporting visitors to complete the survey).

Longstanding illness or disability?	No. visitors
Yes	25
No	112
Prefer not to say	5
Don’t know	3

Table 7. Do you have a longstanding illness or disability that affects your day to day life? (Embedded Digital Survey, n=145)

## Religion

The Embedded Digital Survey provided data on respondents’ religion. These were given in response to an open question and categorised as follows:

Religion	No. visitors
None	62
Christian	45
(‘Christian’	25)
(Church of England	10)
(Catholic	6)
(Quaker	1)
(Unitarian	1)
(Holy Ghost Christian	1)

<sup>5</sup> 2015 Round Ethnic Group Populations Projections, GLA <https://data.gov.uk/dataset/17054e32-d200-453f-89bf-5f284d060936/2015-round-ethnic-group-projections>

<sup>6</sup> Indices of Multiple Deprivation 2015 [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/465791/English\\_Indices\\_of\\_Deprivation\\_2015\\_-\\_Statistical\\_Release.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/465791/English_Indices_of_Deprivation_2015_-_Statistical_Release.pdf)

(Jehovah's Witness	1)
Spiritual	8
Agnostic	5
Atheist	5
Muslim	1
Buddhist	1
Jewish	1
Humanist	1
Pagan	1
Other	6

Table 8. What faith, if any, do you practice? (Embedded Digital Survey n=136)

While people of different religious beliefs (and none) seemed willing to engage with TDL, the Embedded Digital Survey data suggests that of those visitors who describe themselves as religious, most were of a Christian denomination. The Embedded Digital Survey seems to have captured data from proportionally more visitors with no religion than is reflected in the religious background of the local population, although as with the local population, most with religion identified as Christian. (Over half of all Lewisham residents identify themselves as Christian (53%), followed by no religion (27%), Muslim (6%), Hindu (2%).<sup>7</sup>)

## 5.2 Engagement with the installation

While some visitors had found out about TDL through the media and purposefully visited, many came across it while in the shopping centre. The pop-up shop drew curiosity from passers-by intrigued to know what the new shop was (“Is it a luggage shop?”). Many entered and explored the content, contributed their experiences and/or talked to Guides and Hosts. However, on hearing TDL was an installation designed to encourage people to talk about death and dying others were less willing to engage, considering it “morbid” or not wanting to talk about death for fear of “talking it into existence”.

Dwell times ranged from under a minute to well over an hour with most people staying between 1 and 10 minutes. People who engaged in dialogue with Guides or Hosts stayed longer. Most Guides’ interactions were with adults (of all ages) visiting by themselves. Guides provided a listening ear to visitors’ own experiences and views, talked about the installation, provided advice and information, and discussed death and end of life care. Guides also administered the Ipsos MORI interview and talked to other death, health care and science communication professionals who visited.

Visitors appreciated the ‘it’s a journey’ metaphor of the design, they enjoyed the “calm” atmosphere created by the lighting, they thought staff were welcoming and knowledgeable, and the content designed to make the subject approachable. They said the most impactful aspects were talking to Guides and Hosts, hearing/reading personal stories including those contributed by other visitors (“people like me”), and the content in the Departure Board.

Visitors made very few suggestions for improvement to the physical space. Perhaps better signage outside the shop may have attracted more visitors. Physical access to the content was difficult for people with visual dyslexia and deaf and hard of hearing people. Hosts suggested including content in the installation on unexpected or violent deaths as there were requests for literature on topics such as miscarriages, suicide and knife crime. Support leaflets and resources from other charities and organisations on many of

<sup>7</sup> 2011 Census <https://www.ons.gov.uk/census/2011census>

these topics were available, but stored behind the exhibition to maintain brand consistency in the public facing areas.

### 5.2.1 Motivations of visitors

The Hosts recorded how visitors said they had found out about TDL. Many people had just come across it while visiting the shopping centre, others saw articles in the press or on television (“on the news”, Times, Guardian, Time Out were mentioned), or heard through family members or professional networks. Others came across it while in the shopping centre that day. The appearance of the intriguingly lit new shop and the headlines on the posters in the window drew people’s attention – about 50% of people passing would look towards TDL as they walked past, slow down to read posters or pause at the threshold for a moment and perhaps read the text on the front pillar. Of those who just came across it, many thought it was a luggage shop or selling flights or holidays; when they found out it was to encourage discussion about death and EOLC some were still uncertain and asked if it was selling insurance, funeral arrangements, “is it a cult?”. Many of these people stayed to find out more – often having a conversation with a Guide or Host and then taking away some leaflets – but a proportion also left; they did not want to talk about death. Those who purposefully visited, who already knew about TDL, came to find answers – many had specific questions or an experience they wanted to talk about. Some worked professionally in this area or in science communication and looked for inspiration.

*What’s this about?... You’re kidding! Look at those suitcases. I thought it was BA! It’s not in your face. This is better.* (Two women, 40s and 65+, overheard talking to a Host at the threshold)

*Had many varied conversations. Many people wanted to talk about past experiences of grief and bereavement, good and bad experiences. There were a few people who had come specifically to find the installation and took time to really read their way around the exhibit, these people would have quite considered questions and time for a good discussion. Quite a few people had a professional interest in the project. I had one chap who had some really specific questions about end of life drugs and syringe drivers that thankfully I could answer, he came in, asked those questions and left again, apparently satisfied.* (Guide, End of Project Survey)

### 5.2.2 Behaviours

#### ***Some thought it was not for them***

The subject was certainly a barrier for some. People thought talking about death or talking about it in a shopping centre was inappropriate, that it was “morbid” or “in poor taste”. Some people did not want to “speak it into existence”. Hosts reported that people would walk away, their eyes would “glaze over”. Some people said it was not suitable for children or upsetting for older people. The Hosts reported some people being quite angry about this and some passers-by were observed being quite vocal in their shock.

*Dad with kids. He is intrigued, reads the information in the windows, hesitates... Brings the kids over, asks “What’s it about?” A Guide explains. “OH!” He’s shocked. “They’re too young’. He leaves ushering the kids away but keeps looking back. Stops to tell his wife about it. His period of interest and investigation lasts several minutes.* (Observation)

*Woman in 30s with elderly mother in wheelchair. They slow down as they go past and read the posters. The younger woman is heard saying “Is that a joke?”. They go to the threshold and a Host explains what TDL is. The woman says, “I think that’s weird”* (Observation)

### Visitors behaviours in the installation

However, many people did cross the threshold, curious to find out more. Often, they would be drawn to the leaflets on the table to the left of the entrance, looking for information to understand what the pop-up shop was. Most were also greeted by Hosts or Guides. Some people then seemed to want to continue to talk to the Host or Guide, while others wanted to look around the installation in their own time (some might engage with a Host or Guide later). Those who wanted to experience more would wander around the luggage exhibit, read (and sometimes contribute to) the acetates at the Departure Window, dip into the content and listen to some phones on the Departures Board. The Hosts often offered free lemonade to draw people into the space (being immersed in the space rather than hovering at the threshold was more conducive to conversations about death), using the questions printed on the bottles as prompts for conversations. Some visitors would engage in longer conversations with Guides, sometimes using the seats in the Departure Gate area, occasionally being offered to use the booth if they became emotional and needed some privacy. Visitors who had spent a little time in the space were asked by Guides if they would take part in the Ipsos MORI interview and/or invited to give feedback on the Embedded Digital Surveys. The postcards and other literature were offered to support visitors' requests or interests. Sometimes visitors collected all of them.

*A mom and her daughter (~15), walked past and while the mom stopped the daughter was visibly anxious [...] but we were able to have a conversation about that to explore the daughter's ideas without being challenging or confrontational. The daughter noted that it was the emotions that came with death that were most intimidating to her and she was worried about letting those in before she had to. With her permission, I was able to give her a set of postcards to take away and look over with her mom. These tools felt like a good in-road for them both because they capture the important parts of living just as much as they do dying. The interaction stands out for me because I was so impressed with the daughter's ability to even engage with me let alone articulate her emotional concerns. What an amazing opportunity for both mom and daughter to have the space to start that conversation. (Guide, End of Project Survey)*

### Dwell times

Recorded dwell times show that people might visit TDL for less than one minute or would stay up to (and sometimes well over) an hour. Most people (46%) stayed in the installation between 1 and 10 minutes (see Figure 2 ), and of these 39 visitors stayed 1 to 3 minutes and 37 visitors stayed 4 to 10 minutes. The average length of time in TDL was 12.7 minutes.

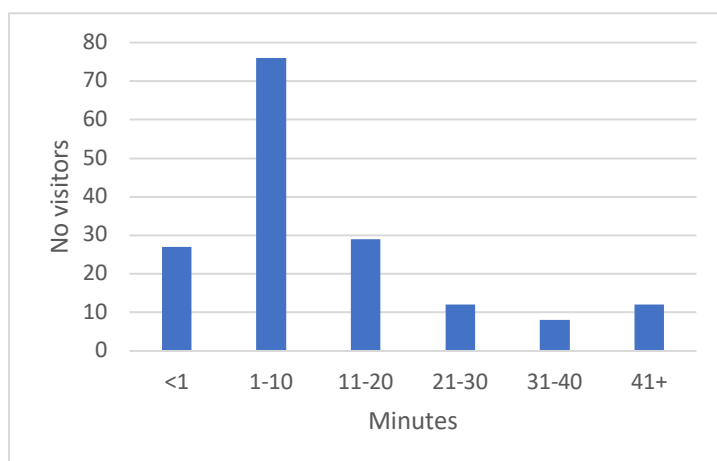


Fig 2. Dwell time of visitors who had crossed TDL's threshold (Observations n=166)

Observations showed the amount of time was characterised by different behaviours and activity in TDL.

Time spent	Observations
<1 minute	People try to work out what the place is and either don't find out, decide it's not for them, or plan to come back another time
1-3 minutes	Visitors take a quick look around the installation, pick up some leaflets and leave
4-10 minutes	As above but pausing at some information/exhibits. Might include a brief introduction or acknowledgement from a Guide or Host
11-20 minutes	Visitors browse around the installation, stopping at some information but not all. Some write their story/wishes on an acetate. Likely to include a short conversation with Guide/Host. Might include the Embedded Digital Survey and/or Ipsos MORI interview.
20+ minutes	Visitors engage in a longer talk with Guides/Host. Some do this and read/listen to other content, although some who stay longer just talk with Guides/Hosts. Some spend time on every aspect of the installation and go through every box on the Departure Board but most do just a few.

Table 9. Dwell times and typical behaviours (Observations)

### 5.2.3 Hosts' role

As well as supporting the Guides and managing the operations of the installation, the Hosts often greeted visitors and helped to set the tone of the visitor experience. They were approachable and friendly, with the right balance of compassion and good humour. The Hosts were the constant across the installation's run (while the Guides each did only a couple of shifts) sharing learnings from each day with new Guides, tips like: not 'pouncing' on people at the threshold but giving them a moment before talking to them, of bringing people into the space and away from the busyness/noise of the Shopping Centre where they might feel more comfortable engaging with the subject, inviting people to take a free lemonade and using the labels to start getting people to talk about death.

### 5.2.4 Guides' interactions

Visitors encountered Death and End of Life Care professionals in the installation – these were the Guides, two or three of whom were present in TDL each day. They greeted visitors and engaged them in talk about death. Guides reported that, on average, they interacted with around 15 visitors each day suggesting that far from all visitors will have engaged with a Guide during their visit.

Guides described that they were generally, but not exclusively, interacting with adults, both older (50+ years old) and younger (<50 years old). They also reported interacting with teens and children, but much less frequently. It was more common for Guides to interact with people who were visiting on their own.

% of guides' reports that mentioned speaking to...	
Adults aged 50+	65%
Adults aged <50 years old	62%
Teens/ children	26%

Table 10. Estimated proportions of visitors Guides talked to (Guides End of Day Reflections, n=69)

Observations from the Evaluators and Hosts supports the Guides' feedback. It seems older people, those with strong opinions, or with recent experience of death or EOLC seemed more willing to engage in conversations with the Guides.

The interactions with visitors that Guides recorded in their end-of-day reflections can be grouped into 6 types (Fig 3).

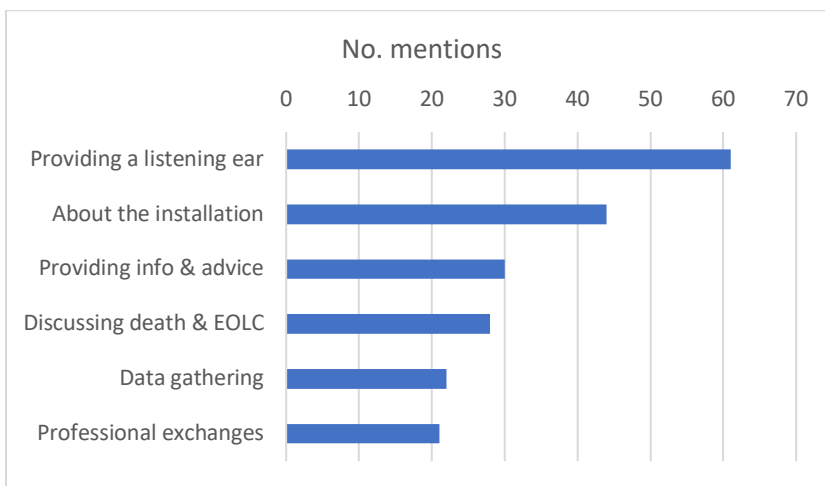


Fig 3. What types of interactions did you have? (Guide End of Day Reflections n= 206 comments from 69 reflections sheets)

The most frequent activities were providing a listening ear to visitors' own experiences and views (a striking 88% of the Guides' reports mentioned this type of interaction).

*[We mostly talked about] what was the exhibition about. Why were we doing this. Why we don't talk about death in our society. Some personal experiences about a relative who died or someone who was close to the end of life and didn't want to talk about death. How some cultures were less keen on talking about death. (Guide, End of Project Survey)*

*Had a disabled visitor (wheelchair bound with element of learning disability). She was clearly quite vulnerable and lonely. Had a long chat with her about her Mum who had died 23yrs ago the next day. The lady had only been in her teens when her Mum died but was still grieving quite acutely. She talked for a long time about her Mum and her life without her. Had strong beliefs about her Mum watching over her and being with her. Very moving, lovely to have the time to give her (at work, I don't often have the time to let people talking as freely as they'd like to). Felt she was glad of the opportunity to tell her story and be listened to. Really good experience. (Guide, End of Project Survey)*

21% of the interactions described by Guides involved fielding questions and having discussions about the installation itself. Two thirds of all Guides reports mentioned such activity, but this is likely to under-represent the frequency of such interactions; several Guides quantified this activity as making up more than two thirds or even 80-100% of their interactions. They said they were repeatedly asked "what is this?", "is it a shop?", "what's it about?" etc.

*It was mostly “what’s this then?” (Guide, End of Day Reflections)*

15% of the interactions described by the Guides in their end-of-day reflections involved them providing a service: advice or information. It seems some visitors had come to TDL specifically to request information or for advice. Where details were given, leading topics that visitors requested advice or info on were:

- Advanced directives/ Advance care plans/ Lasting power of attorney (10 mentions)
- Donating organs/their body to medical research (8)
- Options/ services for EOLC, including palliative and hospice care (7)
- Wills (5)
- Bereavement (5)
- Not specified (8)

*As soon as the shutter lifted on the first day, a lady came in with a list of questions. She had heard about the installation and wanted to talk about her concerns for her future care. She had witnessed what she considered to be poor care and decisions for her husband when he was dying and with her friends who were in hospital. It was so impactful because she seemed to mainly want to release her emotions about the experiences but also to proactively manage her own future. She embodied the notion of “empowerment”. She...seemed quite content when she left. (Guide, End of Project Survey)*

*One older gentleman specifically wanted to know how to donate his body to medical science. We were able to help provide information about this - good job done. He was very pleased. (Guide, End of Day Reflections)*

14% of the interactions described by Guides in their end of day reflections involved them engaging in discussions about death and EOLC. Where details were given, specific topics of discussion were:

- The difficulty/ importance of talking about death and EOLC (16 mentions)
- EOLC choices, plans or preparations (12)
- Funeral plans (8)

*Personal interests in exploring themes around death and dying. Most people expressed that this was a very important subject that needed to be explored. (Guide, End of Project Survey)*

11% of the interactions described by Guides involved them enabling data gathering, mostly via the Ipsos MORI survey but also helping people do the embedded evaluation on iPad (the Hosts and Guides took on this task when multiple visitors were noted to be finding the interface tricky to use).

10% of the interactions described by Guides involved a professional exchange, noting that the visitor expressed a professional interest in TDL (e.g. because they were a nurse, dementia carer, cemetery manager, Death Café organiser) or, noting that they (the Guide) told visitors about their own work/ research.

*I had an experience talking to a priest who explained she had difficulty talking to her clergy about dying and had come to look and see whether there was anything she could see that would help her. She said “Help them to be with who they are. Don’t decide for them or take over” (Guide, End of Project Survey)*

*Some asked how I coped doing my job [as a palliative care nurse] and one person wished to speak to me how they could progress in a career in palliative care (Guide, End of Project Survey)*



## 5.2.5 Aspects visitors enjoyed, or thought could be improved

### **What did visitors enjoy**

There were a number of elements that visitors particularly enjoyed. They were complimentary of the design, the metaphor, what the TDL had set out to achieve and that it had done this in a shopping centre in Lewisham.

Interviewees liked the atmosphere in the installation. They described it as “calm” with “warm lighting”. They thought it created the right atmosphere and matched the content.

*it's kind of got a happy feel to it because of the colour and the design. (Interviewee 9)*

*you can tell that there's been a lot of hard work to match up the, like, the gentle lull of it all and it's [...] it's not in your face and it's all quite, like, soothing and then you're reading about how all these deaths are gentle and soothing (Interviewee 12)*

They enjoyed the metaphor of the concept, saying it was “surprising” and “creative”. Some interviewees hadn't understood it straight away but enjoyed the moment when they realised. They thought it was a “clever trick” for the right reasons as they thought it helped to make the content approachable.

*Kind of catching them [the public] off guard like that could actually be a positive thing because...I don't actually think about stuff like this and it could actually help them 'cause maybe they know somebody who's terminally ill or they could relate to it. [...] There was one point where I was standing there thinking 'why did they use suitcases?' out of all the things and then I saw the departure sticker like when you go on holiday and I was like 'ooooh Departure lounge' [...] and I started putting little things together and the arrangement of the shop started making sense. But when you first go in there it's like 'is this to do with holidays or what is this?' It's a perfect location and how it's been presented is perfect because how it's been presented you don't know what it is so you've got to walk in and speak to somebody to find out and when you do find out its actually interesting information.” (Interviewee 18)*

They thought the design was excellent and the experience was well thought out – the interpretive devices were varied and the many voices used were appreciated.

*I really enjoyed it, the way it was professionally done especially from a design point of view – it entices a lot of people to go in and actually read and having the drawers makes people more interested in finding out because they have to grab things and view what's inside.” (Interviewee 10)*

*The one which is in the middle...with the suitcases, it was quite creative and nicely done. And the fact that it's been made a little participatory by asking people to write stuff down. I liked the idea of these water bottles very much in fact I picked up this one because 'what is a life well lived?'[...] I'll keep it in the fridge I think - as a reminder. (Interviewee 19)*

*It's so carefully thought out. The design is not so contemporary that it will put older people off. (Interviewee 17)*

Visitors also appreciated the sensitive treatment of the content and the objective positioning. Interviewees were asked before their visit what they might expect the installation to be like. When questioned afterwards, many were surprised that it wasn't at all morbid.

*it's really not daunting at all as well, it's really nice, it's welcoming and it's not as morbid as what anyone would think when they first hear about it, there's nothing morbid in there at all really.*  
(Interviewee 2)

*It was good because it wasn't trying to push a viewpoint or a particular opinion. It was quite open in telling the different experiences of different people* (Interviewee 10)

Visitors were asked through the Embedded Digital Survey, what aspects of TDL had most impacted them. Many respondents named parts of the experience: talking with staff, personal stories/ visitors' responses, the Departure Board or other content. A number mentioned the design itself (Table 11).

<b>Aspects of TDL survey respondents said were most impactful</b>	<b>No. mentions</b>
Talking with staff	30
Personal stories	15
Other visitors' responses (on acetates)	12
Departures Board	13
Specific content	8
Design/concept	15
The whole thing	4
The fact that it is in the shopping centre	3
"It's amazing"	2
The booth	1

Table 11. What aspect of the visit has had the most impact on you? (Embedded Digital Survey, n=139)

Most Embedded Digital Survey respondents said their encounter with the Guides, Hosts or "staff" had the most impact on them. They mentioned: being listened to, that the people working in TDL were empathetic, and supportive. Also mentioned was their dedication, enthusiasm, kindness and humour. Visitors had things explained to them and thought the Guides were knowledgeable and resourceful. They wrote about the value of having conversations in making them aware of end of life care and death choices or hearing different ideas to their own. Some valued talking about their own grief and of "opening up".

*Talking to the host, I've never been able to talk to anyone about these things and you are resourceful*  
(Embedded Survey Respondent 56)

*Chat with host has got me thinking, it's not something I talk about a lot, it's got me thinking more about the reality of death. How can I help other people who have an issue about it?* (Embedded Survey Respondent 40)

Related to this were 15 responses about personal stories having the most impact on them. Many survey respondents simply wrote "personal stories" in response to the question but some described content found on the luggage or in the Departure Board.

*Reading about what people have said to their loved ones as their death approaches, or what has been said to them. It has sort of given me permission to say the things I want to say* (Embedded Survey Respondent 63)

*The insights from people in the hospice and their thoughts.* (Embedded Survey Respondent 43)

Twelve others were more specific about "personal stories" – mentioning the personal stories left by other visitors on the acetates.

*Moved by the comments displayed by people that already visited the departure lounge. (Embedded Survey Respondent 28)*

*The post wall. I am surprised to see there are so many people thinking about this issue (Embedded Survey Respondent 91)*

Thirteen people specifically mentioned the Departure Board (or “little boxes”) as the aspect of the experience they found most impactful. Eight of these were mentions of the phones – the content and as an interpretation device.

*Helpline phone recordings from medical practitioners gave great comfort. (Embedded Survey Respondent 48)*

*The boxes at the back (Embedded Survey Respondent 53)*

Eight people mentioned other specific content they found impactful. This included: statistics x3 (life expectancy was mentioned by one), “the bit about legacy”, “pulling the plug and having to make decisions for someone who is unable to”, “information on palliative care”, “the relevance of food to life and death”, “comparing labour to death”.

Fifteen people thought aspects of the design, concept or interpretative approach were particularly impactful. They mentioned the appearance of the space, the colours, the metaphor, and the “open”, “positive”, “common sense” content.

*The overall set up/ exhibit is brilliant! Such a creative way to get people to broach the topic and normalise conversations about death and dying (Embedded Survey Respondent 138)*

*The idea of the departure lounge, the analogy of an airport is inspired, made it easy for me to enter and talk to the staff (Embedded Survey Respondent 123)*

Four people couldn’t single out a specific aspect they found most impactful – they liked “the whole thing”. Three liked the fact it was in a shopping centre, two responded “It’s amazing”, one person mentioned the booth.

*The booth I liked the privacy (Embedded Survey Respondent 55)*

*The fact that this conversation is taking place in a shopping centre (Embedded Survey Respondent 132)*

### ***What aspects of the installation could be improved (visitors’ perspective)***

While curiosity about a new shop in the shopping centre drew people in and engaged them in conversations about death that they perhaps didn’t expect to have that day, others may not have entered the installation because it was unclear from the outside what it was. The shop didn’t have a large sign above the doorway (like other nearby shops) or large title text on the windows or front pillar explaining what it was. We don’t have evidence of how many might have entered if they knew from the outside what TDL was, nor how many visitors may not have crossed the threshold if they had known, however, many people were observed pausing and looking curiously then walking on. Perhaps a sign or explanatory text at the entrance may have helped pique their curiosity.

Note: part way through the installation’s run, the text on the front pillar was rearranged to position the reference to talking about death at a more optimal reading height but this didn’t seem to make a significant difference to visitor numbers.

Other than those who had issue with the concept and did not enter, very few visitors suggested improvements with elements of the design. Some thought there wasn't enough lighting and it was too dark, a couple disliked the colour. A woman with visual dyslexia found black text on grey or yellow backgrounds hard to read. A Host reported that three deaf people (who visited together) could not access key aspects of the content: the Guide could not communicate with them and there was no printed transcript for the audio content accessed via phone handsets. They were frustrated that no provision had been made to enable access for them.

While some passers-by noticed the vinyls in the shopping centre drawing attention to the shop, very few people were observed listening to the audio on the 'emergency telephone' situated on the bench outside.

Some visitors came looking for specific things that may not have been provided by TDL. The hosts recorded some people thought TDL was missing information on unexpected or violent deaths. They mentioned: miscarriages, knife crime "given the history of the area", suicide. Nor was TDL able to fully support those with complex grief who were looking for resources or indeed answers.

### 5.3 Emotional impact on visitors

TDL's design and staffing created a comfortable, "permission-giving" space in which many visitors felt calm, reassured and more able to engage with the topic of death and EOLC. Whilst TDL's content could be "saddening", visitors appreciated the warm welcome and the non-morbid tone. Those that gave it time connected with the subject matter at a "deep" level and felt reflective, moved, "enlightened" and safe. Their awareness of death is raised. But a small minority were distressed or even angered by the topic being raised at all.

In this context, visitors connected with the topic most strongly through personal stories (especially at the Suitcases and on the Feedback Light Wall) which they found intimate and relatable. These stories and the Guides were key in easing past the initial hesitancy many visitors displayed. For many, the personal stories provided a way in to reflect on their own experiences of death and EOLC, triggering autobiographical memories, especially about family and loss. As one Host put it, "everybody has a story" to tell and both Host and Guides recognised that often people just wanted to be heard. Beyond the basic, but frequent, exchanges about what TDL was and why it was here, the Guides' major role was to bear witness to these personal stories and to provide emotional support as well as information and advice.

There was a notable contrast in the responses to TDL in those with or without personal experience of bereavement. The former often found themselves revisiting and sharing their loss and grief or looking for support in TDL. Many of these people appreciated being able to share their story but not all found the answers they were looking for. Those with little experience of death tended to consider it in more abstract terms and thought less about EOLC. In having the subject brought to top of mind, they connected it to their own experiences, recalling autobiographical memories or reflecting on their views of death or on their current family situation.

The Guides' role included dealing with intense, sometimes challenging, situations including hearing from people with terminal diagnoses, recent bereavements and complex grief. The Booth played an important role in supporting some of these individuals. Guides witnessed a striking range of emotions – from anger and distress to anxiety, grief, reflection and relief – using their training and giving much thought to how to best engage and support visitors as well as one another.

### 5.3.1 TDL provides a safe space

Interviewees found TDL to be a safe space in which to think about death, finding TDL reflective, “reassuring” and “trusting”. There were aspects of the design and the interpretation that they liked that seemed to contribute to this – the warm, soft lighting, the gentle soundscape, that a “positive attitude” was promoted, that they were greeted by staff in the space. They did not tend to perceive the visit as uncomfortable, nor morbid, although some found the visit “saddening”. One Guide described it as “a permission-giving space”.

*I expected it to be sadder, but there were lots of happy endings (Interviewee 5)*

*An 87 year old lady who had come on Monday to find it closed and made the effort to return specially. She really wanted to talk [...]. Made me realise again how few places make this sort of conversation possible. (Guide, End of project survey)*

Interviewee 17 appreciated the fact that everyone who entered TDL was acknowledged. She said this made her feel supported and that she was sharing the experience within the space with others. Given the content matter she felt it was important not to feel isolated.

But there were people who found the space less comfortable and related this to their own experience of death.

*A woman who'd experienced multiple family bereavements reflected: “[How do I] Feel?’ I don’t know – it’s not as if you come out very cheerful or happy or anything so... Yeah – that’s how it is. It’s something that should be done.” (Interviewee 19)*

*The noise of the dog, that was not good. [I] was reading something about the death and then I heard the noise from the dog almost at the same moment [...] and I realised because that is my only experience close to death [...] I was really sad about this. (Interviewee 6)*

Emotional impact was explored in the interviews. Interviewees were asked how they felt after visiting TDL. Many said the experience had immersed them in the subject and made them think. They felt “calm”. It had slowed them down and provided time for contemplation, heightening their “awareness of death, end of life and reality”.

*Quite a deep afternoon...one of the most introspective days I’ve had (Interviewee 16)*

*obviously ...we don’t really think about death much, I’ve probably made myself a bit like, I don’t know, like, it’s a bit of a sad topic, isn’t it? But at no point there I was upset [...] it’s a bit of a warming topic (Interviewee 5)*

### 5.3.2 Personal experiences provide a way in

By far most interviewees mentioned reading people’s personal experiences – both those written on the acetates by other visitors and those told on the suitcases – as the aspects of TDL that stood out to them. They were discussed with reference to how this content made them feel. Their comments suggest they found these were intimate and relatable, told by people like them (as opposed to experts). They found them moving, a helpful way in to reflect on their own experiences of death and end of life care. Several interviewees referred specifically to being moved by reading the thoughts and experiences of children (who had completed a number of acetates displayed on the Feedback Light Wall).

*When the kids write about...that's stands out... it's very personal just seeing the handwriting. When people were literally talking about seeing their loved ones... being at the bedside on someone's passing you just go there immediately. I went there, for sure. (Interviewee 20)*

*I think because I've gone through a few deaths in very quick succession they resonated a lot [the personal stories]. (Interviewee 19)*

*one story that I found quite moving and it was about a woman whose husband's died. She's talking about, like, ironing, it looked like she was wondering if it was, like, the last time she'd iron these clothes. I found that quite moving, reading that and then, yeah, you know, got to the point where she's ironing and it was, like, the suit that he was going to wear...(Interviewee 15)*

### **5.3.3 “Everybody has a story”**

The Hosts noted that “everybody has a story”. This is reinforced by interview data. As well as referring to personal stories they encountered in the space, interviewees would often also mention personal experiences of death of family or friends; the Departure Lounge, therefore, is eliciting personal, emotional connections. A visit triggered reflections on visitors’ own personal circumstances, leading them to share personal experiences of loss. This finding is supported by the large number of stories written by visitors on the acetates.

*I always find that people want to talk - their problem has been finding someone to listen. (Guide, end of project survey)*

*It's kind of poignant because my dad's 89 so he's in his last stages of life. (Interviewee 3)*

The findings from interviewees are echoed by the Guides in their end of day reflections, who found listening to personal stories particularly memorable. When asked to recount interactions that stood out for them, the types of interactions they described can be grouped as follows (Figure 4) – listening was one of these.

- Listening: Visitors need to be heard. Guides are bearing witness and providing a listening ear or space for visitors to reflect.
- Discussing: Visitors are discussing their ideas, plans and options around death and EOLC, including the challenges/ importance of talking about death & EOLC with family.
- Providing information: Visitors are seeking advice and information about death and EOLC.
- Providing impetus: Visitors are resolving to take action
- Enabling: Visitors are supported to talk about death & dying amongst themselves.
- In a small minority of cases, Guides also reported instances where they had been unable to help or engage visitors in need.

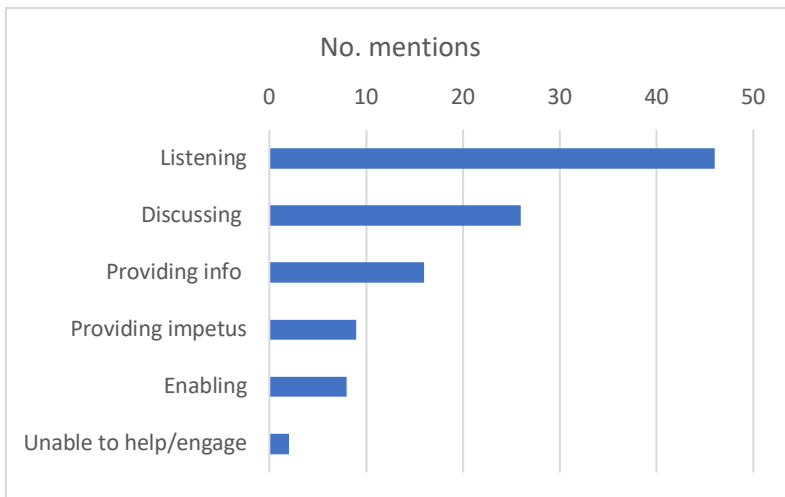


Fig 4. Tell us about something a visitor said or did in TDL today that stayed with you (Guide End of Day Reflections; n=107 comments from 69 reflections sheets)

Listening interactions involving bearing witness, providing a listening ear or space to reflect were recounted most frequently: approximately 40% of Guides comments reported these kinds of interactions with visitors. Guides noted that visitors needed to be heard.

*A woman talked about her experience of her mother's death...and feeling she didn't have a chance to prepare fully. This resonated with my own experience of my dad's death and I enjoyed talking to her about this. (Guide, End of Day Reflections)*

*"One interaction [stood out]: a 69 year old [...] who had emergency successful triple bypass surgery last year to save his life. Since then he's been wondering what the purpose of his life is and what he is "meant by God to achieve" between now and death [...] We talked about finding meaning in life (and in death). He's frightened to retire from his [...] job (which his wife wants him to do) in case an abyss of emptiness opens up in front of him and he immediately gets ill again - he knows many people who've retired and then immediately died with heart attacks or strokes, or (worse, he said) lived long slow deaths with dementia. [...] It was "impactful" because it was an in-depth and serious conversation between two strangers who were meeting each other around a profoundly significant concern (for both of us, though I didn't say much about me). I got the impression that he hadn't really had the opportunity to talk about the way he felt after having his life saved..." (Guide, End of Project Survey)*

Many of these interactions between visitors and Guides reveal strong emotions ranging from anger and distress to anxiety, grief, reflection and relief. The Guides' role included dealing with intense, sometimes challenging, situations including hearing from people with terminal diagnoses, recent bereavements and complex grief.

*Lady told me her husband was 'slaughtered' by the hospital. Very angry and upset. (Guide, End of Day Reflections)*

*She just wanted to pour out her grief. (Guide, End of Day Reflections)*

In a small but memorable minority of instances, Guides had to deal with people who were angry or distressed about TDL or its content or were even suicidal (in which case TDL was seen as a safe haven to send them to).

*A very distressed lady who only came to the doors of the Departure Lounge, she would not enter. She was speaking incoherently in sobs. I held her arm gently and spoke to her gently to try to reassure her and to hear what she was saying – words I managed to understand were "this place is really distressing me...last Sunday...the big C" She ran off into the shopping centre and disappeared. It is so impactful as she was so distressed and she left with that distress. (Guide, End of Project Survey)*

*A lady said we should not be talking about death & dying – her strength of feeling was clear. (Guide, End of Day Reflections)*

### **5.3.4 Emotional response are shaped by personal experience**

There was a notable contrast in the responses to TDL in those with or without personal experience of bereavement.

Although both groups would discuss and reflect on death, the former often found themselves revisiting and sharing their loss and grief or looking for support in TDL. If the loss was longer ago this took the form of gentler reminiscence, but the Guides reported a number of visitors who were recently bereaved. These reminiscences could be upsetting and made uncomfortable listening, but many of these people appreciated being able to share their story.

Those with little experience of death or for whom it's far from top of mind – often younger visitors who were perhaps children when grandparents died – found themselves considering death in more abstract terms (they thought less about EOLC). In having it brought to top of mind, some of these people connected it to their own experiences, recalling autobiographical memories and reflecting on their views of death or on their current family situation.

Visitors with limited or more distant experience:

*Well I'm definitely thinking about death more now. It's quite an eye opener - especially where you've got the suitcases with the experiences and people's opinions. I'm only 21 so I'm not really going to think about death right about now. But then reading stories where parents have lost their infant or people have lost their sister or brother it makes you think more about I might not be expecting to die soon but anything can happen. (Interviewee 18)*

*[when her great grandmother died some family members saw a white butterfly flying out of a cupboard] ... I was quite young when she died, and I don't really have any memories of her, the only memory I really have of her is her being a butterfly, so it's kind of weird that I still now see a white butterfly and I'm like, hey, I don't really know you but hey. (Interviewee 11)*

Visitors with significant experience of death:

*I think with death, with bereavement, you have to experience it. You experience it with your body. You don't experience it intellectually or anything and you can't really convey the horror to another one. (Interviewee 19)*

*She had looked at the "locker" which mentioned dignity and hospice care. She became very angry and quite upset but wanted to share her experience. Her father had been very ill in hospital and was, in her view, subjected to needless, undignified and painful investigations even though it seemed obvious that he was approaching end of life. She and her brother did not feel listened to, and her father was too unwell to express his wishes. She felt that he only recovered his dignity and was treated with compassion when he was belatedly transferred to a hospice[...] As a nurse[...] I felt that I*



*needed to apologise to this lady for her family's experience, which she seemed to accept with some surprise and gratitude. (Guide, End of Report Survey)*

Responses from interviewees and observations from the Guides indicate that a visit to TDL could act as a safe space to acknowledge and even progress through grief.

Interviewee 1 talked about having a difficult time when her mum died 6 years ago. She would really like to talk to her grandmother and aunt about her mum, but they seem unwilling. She thought TDL had “made me a bit more clear in the head”. She took leaflets and postcards and took photographs of parts of the installation. She wanted to use these as starting points for talking with her grandmother and aunt as well as sharing with friends and exploring her own views. *Yeah, that would be interesting to hear people's answers, as well as, you know, what your own thoughts are on it.*

*A couple told the story of their 6 year old son's death[...] I approached him asking what he thought and immediately his face lit up, he then keenly told me their story of the loss of their son[...] He proudly showed me a large tattoo of a child's face on his upper chest[...] He told me how pleased he was to be able to talk freely about his son and some of the negative experiences he had had with not finding people to listen[...] After a while his wife joined him and she also talked about her experiences of the loss of their son[...] After they had left I went over to the gallery wall curious to see what she has said to share with others and it was at this point that I experienced sadness. She had given detail about the death of their son, he'd been born with a life limiting illness and had spent the majority of his short life in hospital enduring harsh treatments. She said how when they were told there was nothing more that could be done how it was their goal for him to die at home with them and that is what happened... It was impactful because it was great loss, but with the ending they had wanted and believed to be right for them and their boy had been achieved. Also because the lounge had allowed them space to express themselves and as they said in their own words "made them feel normal". (Guide, End of Project Survey)*

But for others TDL did not provide the answers they were looking for.

*A woman had recently lost both of her parents within 6 months and was looking for advice on death cafes. She was having therapy sessions but was looking for more support. It stands out because I really felt for her. She was bereft and looking for answers. Dealing with death can be very isolating and lonely. (Guide, End of Project Survey)*

Interviewee 19 described her experience of multiple, traumatic bereavements in her immediate family. *“It was such a painful exercise, you know. Those screams ring in your ears today. She should not even have been in the hospital if nothing can be done and she was constantly aware of the fact that she has been abandoned in the hospital[...]”*. This visitor had come to TDL looking for relief and answers - perhaps for somebody to talk to who will listen and understand - but she didn't find the practical or emotional answers she sought, despite engaging with all aspects of the installation. *“But the installation has limitations – it couldn't go into a lot of detail – its more about making people aware that they can talk about death without becoming completely morbid and depressed.”* She also didn't feel TDL reflected her own experiences *“I felt in the end that the point was being missed about ‘a good death’ which was talked about a lot. Not being prodded and poked with the very latest ... regular medical staff knowing that this is the limit and making it clear to the family and the person. ...We are all living longer and that we're in the hospital for the end and we're not having a normal death, you know. But that was not so much in the face I felt – you had to infer it.”*

### 5.3.5 Overcoming emotional barriers

Many visitors were initially hesitant, even wary, of engaging with TDL and the topic of death, citing cultural norms, needing more time to reflect or acknowledging that they'd automatically avoided engaging with the thought of death at an emotional level. The Guides and Hosts, as well as TDL's appealing, non-morbid design, played a key role in easing some visitors past that initial hesitancy.

*They wanted to read all the stories but didn't feel emotionally able to as it made them remember recent losses/ deaths (Guide, End of Day Report)*

Interviewee 20 experienced TDL through empathy for the personal stories shared by other people but articulated feeling uncomfortable relating the topic more directly to himself or his own friends and family. *It's raised questions about preparing for the end of life, even like funerals and cremation. Even as I say this to myself there's a part of me that says 'god, don't think about that', you know. It's instinct[...] Literally as I'm saying, 'let's do a will', something in me is saying 'let's not think about that'. When probed on whether that internal battle was happening in the space he responded: No, because I was intaking other people's lives. Now that you're asking me about it and I'm saying it and I'm clearly in two minds about that. In there was pretty much about others and their stories.*

TDL was recognised by visitors as providing knowledge as a counterpoint to fear and ignorance: "we fear what we don't know or understand". A number of interviewees referred to generational differences in who was comfortable engaging with TDL's themes of death and dying. Interestingly, this included instances both of a younger generation saying it was their elders who were reluctant to discuss death, and vice versa.

When asked in interview what prevented him raising his concerns regarding a relative's EOLC, Interviewee 10 cited his parents' reluctance to have the conversation. *On one point it's a knowledge thing. So I wasn't aware of certain options which were available which would allow me to bring those topics up. But it's also that death is such a taboo subject in the UK and my parents would be a lot more reluctant to speak about it than I would.*

By contrast Interviewee 20 noted the social norms amongst his peers (younger adults) of 'stiff upper lip' and glib references to death on social media like '#RIP' which he sees as creating barriers to really thinking about and dealing with death and grief. *I've got the equivalent of that stiff upper lip in my family. But that's another reason we need to talk about it because sometimes being strong IS broaching the subject. Maybe our definition of strength needs to change. Invincibility... stiff upper lip a lot of men feel, speaking about it, speaking about death, writing about death, thinking it is a weakness.*

Feedback from both Guides and visitors indicated that visitors often needed time for their "guard to come down" before they were ready to talk about themselves. Visitors could feel "not yet ready" to capture their stories (on the acetate sheets) or what they thought about TDL in the Embedded Digital Survey. One Guide noted that people seemed more comfortable writing their story down after they'd shared it out loud, for example through a conversation with a Guide.

*Many discussions where people felt nervous to do survey/write their thoughts and said they'd think and come back. (Guide, End of Day Report)*

*[A Guide] asked if I'd like to write anything down on the wall which I was unsure about at the time because I hadn't got my thoughts together. (Interviewee 10)*

### 5.3.6 Providing emotional support

Hosts and Guides recognised the emotional impact of the installation's topic and were observed providing reassurance, emotional support and signposting to additional support and resources.

*Her husband was unwell – I spent some time listening and talking with her then offered to stay with her. We sat together for a few mins - silence was important. (Guide, End of Day Reflection)*

The private booth was also an important and valued resource when supporting the minority of visitors for whom TDL triggered marked emotional responses.

*One interaction that stands out is a lady (31yo) who has become the carer to both elderly parents and the emotional toll this is paying on her own health and wellbeing and her feeling of not being able to cope and make decisions for them. It was impactful because she was initially sceptical of the Departure Lounge upon entry with walls that were high but then spent 2.5 hrs unravelling her own thoughts with me and expressing her feelings openly in the private booth. (Guide, End of Project Survey)*

*There was one elderly man who came in and saw my name and my role as a doctor and he asked to speak specifically to me. We spent about 45 minutes talking in the private booth. He told me he had just lost his wife 10 days ago. They had been married for 40 years and he was struggling a lot with the last few weeks of her life wondering if he should or could have done more to help her. I think that interaction will stay with me for a long time. It has been almost 2 weeks since I met him and I still think about how he is doing. (Guide, End of Project Survey)*

Offering this emotional support was valued by the Guides and Hosts, who gave much thought to how best to engage and support visitors, supported by the training day and resources provided by AMS. Although observations and the Guides' daily reflections reveal that their most frequent interactions with visitors involved answering basic 'what is this?' questions, the Guides own reflections on their role are primarily about how to connect and make people comfortable: listening, finding out and then meeting visitors' needs. This is what requires thought and is rewarding and memorable for them.

*Overcoming that initial visitor reaction phase of 'turn and run' can be challenging but once the first hurdle of 'ok it's about death and why do you want to talk about something so morbid' response, the follow up conversation can be more fluid, straightforward and natural. Quite often, I found that walls were built up quite high on some visitors where the conversation was an uneasy one due to recent experiences they had been dealing with. Taking the conversation at their pace and having patience for them to find the words for themselves was really key to maintaining engagement on the topic. (Guide, End of Project Survey)*

Some Hosts and Guides reflected on how they could look after themselves and one another, in recognition of the emotional impact of the role. The Academy of Medical Sciences also acknowledged this by providing relevant training and signposting resources in the Hosts and Guides Training Day as well as offering 'Decompression Sessions' with a therapist for all project staff who would like it.

*Take time out if you need. (Guide, End of Day Report)*

*Watch for others who are stuck with an individual, to help remove from or support with the situation. (Guide, End of Day Report)*

## 5.4 Impact on visitors – empowerment and choice

The value of TDL is acknowledged by Guides and visitors because it is “good” and “important” to talk about death and EOLC. Some articulate that this is so one’s wishes can be understood and honoured. Many know they ought to do something but it’s a dormant and slightly vague thought – TDL brings this importance back to top of mind. Death and EOLC are also repeatedly described as a “difficult” subject with barriers in knowledge, emotions and cultural norms making it hard to discuss, or even to think about.

Following a visit to TDL and with the importance of the subject top of mind, many people show awareness that they have agency and choice with some visitors resolving to take action. It seems visiting TDL may have provided the impetus and motivation they needed. Some visitors say they will use the installation itself, or elements of it, as tools to scaffold difficult conversations – they plan to return with members of their family or discuss the postcards or content of the installation at home. Visiting TDL does not tend to be treated as a fact-finding exercise but the Guides are used by some visitors as a sounding board and a source of information and advice.

But what actions are they empowered to take? Generally, visitors resolve to talk to someone about death and EOLC wishes or to do something to prepare for this moment themselves. Many talked vaguely about “making provision” but often, rather than talking about EOLC, they meant making arrangements for after death, such as making wills or planning funeral arrangements. Those that do talk about EOLC tend to talk about medical treatments or whether they would put a loved one in a care home. Intentions were often expressed cautiously, suggesting a lack of clarity in exactly what the next steps would be or a hesitancy in addressing this with family.

Notably, as with the emotional impact of visiting TDL, visitors’ empowerment and future actions are shaped by personal experience – specifically, whether they have experience of death and EOLC. Those with experience seemed more familiar and comfortable with the terminology and concepts, more likely to raise such issues, to know what to ask or to describe actions they intend to take. By contrast, those without prior experience of EOLC seemed more likely to simply say “this has given me lots to think about”, to defer taking action, to be less specific about what action they might take or to talk about ‘after death’ actions.

Acetates, personal stories, the Guides and the Booth were all observed to enable and support another form of agency in TDL: moments where bereaved visitors took the opportunity to unburden themselves of their experience of loss. This could be seen as small steps in processing and taking some control of their grief.

Through the Visitor Interviews, Embedded Digital Survey questions and Guides reflections, choice and empowerment were explored: do visitors understand they have choice in end of life care and decisions about death; do they know the tools available to give them choice (such as advanced directives); do they recognise the importance of thinking about and discussing these choices; and do they understand the impact of not choosing for them or their family?

The different manifestations of empowerment and choice range from discussing the importance and also the difficulty of talking about death and EOLC, to requesting information and advice, beginning that difficult conversation in the space or resolving to take action after they leave.

### 5.4.1 Thinking and talking about death is important but difficult

Of 36 discussions about death and EOLC recounted in the Guides' end of day reflections in answer to the question 'What types of interactions did you have with visitors?', 16 related to the importance or the challenge of talking about the subjects (see Figure 3 above).

[We mostly talked about] *Their thoughts about death, whether they felt able to talk about it, whether they had had a difficult experience or they didn't know how to start a conversation with family members. Most had not thought through the implications of not preparing. I also spoke with people about grief* (Guide, End of Project Survey)

The importance of discussing the topic is regularly cited by visitors as the reason they appreciate TDL. A visit to TDL re-establishes the importance of the topic for those for whom it's not top of mind.

*Several people were passing and come in out of curiosity, not knowing what it was but said what a good/important idea it was.*" (Guide End of Day Reflections)

*I think speaking about it helps one's perspective on life: speaking about death. When people, particularly in my age bracket, don't value their life, I think understanding that it will end, helps.*" (Interviewee 20)

Interviewees thought that it was important to make decisions as this would ensure their wishes were carried out.

*I'd rather my children be aware of what I want, rather than them thinking 'my dad liked this' and 'my dad liked that' and it might be completely opposite to what I like.* (Interviewee 3)

*That's another reason why we have to talk about it [death] cause when that time comes, I'd like to take control of that situation – not control everything but you want to say 'I'd like this; I'd prefer this'. Some people don't even feel they can say what they want in that stage of their life. They feel so powerless that they're facing the issue anyway, so I think talking about it helps that. There was a statistic on one of the suitcases that said 45% of people don't make their wishes known pass without their wishes being known. Even if people don't want to broach the emotional element of it, just getting a say in the practical.* (Interviewee 20)

For interviewees who were already prepared for EOL, usually older visitors, they saw TDL as playing a vital role in reminding people to communicate their wishes with loved ones. Through experiences they had had of friends and relatives dying, they knew how important it was to get this in place, to support family in a time of grief (by writing down what they would like to happen at their funeral), to ensure their final wishes are known which gives them a sense of peace, and to make sure legal requirements are in place.

Interviewee 8 visited as part of the Pensioners Forum. She strongly advocated for communication and planning as a result of experiencing some "bad deaths" among friends and associates. For example, she talked about a man whose estate was taken by the Council because he had not left a will nor paperwork showing he had legally adopted his stepchildren. And of a friend who died while in Guyana and who had been buried with family there when her wishes had been to be buried with her husband in the UK. She talked about the importance of letting your children know your wishes and had herself written her eulogy, chosen hymns, had given copies of her will to family and a solicitor, and had a case packed with the dress she wanted to be buried in. She thought TDL was important in raising awareness for many people.

A visit to TDL triggers reflections on the difficulty of thinking about and talking about death. This difficulty is frequently raised by TDL visitors and noted by Guides.

*People are prepared, in that they've set aside money for funerals etc, but they aren't actively discussing it with family as it's uncomfortable (Guide, End of Day Reflections)*

Cultural norms were cited as a reason for this difficulty, specifically the topic of death being a widely-observed 'taboo' in certain cultures.

*I wouldn't talk to my dad about it [death] just because... maybe it would be more comfortable to speak to my kids about it. Because growing up in the Caribbean for my parents talking to your children about death was sort of a taboo subject. My view's different[...]* (Interviewee 3)

Other reasons given include lack of knowledge, perceived resistance or discomfort on the part of the person they'd like to raise it with or wanting to protect/ not offend people.

*You know, like, things like that, it's like it's such a taboo thing to talk about. You can't actually talk to your Mum. Like, even if your Mum had had a heart attack, you wouldn't want to go, like, Mum, you might die and what'll happen [...] it's a bit forward.* (Interviewee 16)

*I'm Asian, so in our culture, it's kind of, like, we don't want the person who's dying to know that they're dying. So even though she'd [her grandmother], got like a terminal cancer diagnosis we did not tell her at all. It's quite common for Asians to do that. And she received treatment and things like that, but I think some of the treatments were not out of her will, I would say, because it's more a thing what the doctor wants to do and then the family members will say, maybe we shall listen to the doctor and things like that. But I think if I'm in her shoes, I might not choose to take the treatments if I know that I'm dying* (Interviewee 9)

When asked at interview whether there was any action he might take after visiting TDL, this younger visitor focussed on explaining the reluctance he and his peers feel in considering the subject of death.

*[What will I do?] Maybe writing a will. But that's why young people won't even broach the subject because even broaching the subject of will making makes you think about dying and it's a downer.* (Interviewee 20)

## **5.4.2 TDL provides impetus and resolve to take action**

### ***Providing impetus and motivation***

The Embedded Digital Survey data suggests visitors' experiences in TDL might prompt them to take action or feel empowered to do so: most said they were likely to talk to someone about death and end of life wishes or do something to prepare for this moment themselves. Only 7/146 said they were unlikely to do anything as a result of their visit. (This data may over-represent overall likelihood of taking action or feeling empowered as observations suggest that visitors who completed the Embedded Digital Survey tended to have stayed in TDL for a longer time and were more likely to have had a significant interaction with a Guide.) Additionally, observations by Guides and Evaluators, as well as testimony from visitor interviews, support the Embedded Digital Survey findings that a visit to TDL provides impetus and motivation to take action. Many interviewees already had some awareness of provisions they felt they ought to make relating to death and EOLC; the TDL experience reminded them to do this. Additionally, some interviewees felt TDL now gave them the confidence to make the next steps. (It should be noted that interview data may also over-

represent general visitors' likelihood of being prompted to take action as interviewees all engaged with TDL for significantly longer than average.)

*One Guide recalled a woman saying to her: "Thank you this has really helped. I will go and speak to my son". Another visitor was heard saying "I haven't finished the letters to my children – today has prompted me". (Guide, End of Day Reflections)*

*One lady walked past, looked in, then walked backwards and into space. She sat down, didn't look round but said she was profoundly affected. Really pleased she came in and will try to talk with the carer of her mum in 80s who's really poorly. (Guide, End of Day Reflections)*

In some instances, TDL is the trigger that brings the subject of death and EOLC back to top of mind.

*Me and my wife talked about it [EOLC] in the early part when we first got together. We're quite clear about what we want. We know we don't want to be in a hospital - that we want to look after each other. That's just how it is. It's never really come up again. We probably will chat about it after this - I guarantee we will. (Interviewee 3)*

*I have made a will but hadn't considered being ill and decisions being made by doctors, so I need to think about this (Embedded Survey Respondent 80)*

### **Providing a scaffold**

Visitors often treated or describe TDL in terms that suggest it is providing them with support to take action. Either the installation itself, or aspects of it, are used as tools to scaffold difficult conversations.

Some visitors said they intended to bring family members to visit TDL, likely in light of the safe space and listening ear it is seen to provide.

*In one End of Day Reflection, a Guide recalled that one 16yo girl who was recently bereaved, wanted to talk to her grandma about her wishes. The girl was thinking of bringing her Grandmother to TDL.*

Others refer to using the postcards to organise their own thoughts or to initiate or structure a conversation.

*I think I will [use the postcards with my family] – my grandma is at that stage of life now where she's close to the end and my parents are trying to deal with that as much as possible. They're sheltering me and themselves from it by pretending things are better than they are. (Interviewee 10)*

One interviewee described how the multifaceted nature of TDL provided him with ideas for multiple ways to approach this difficult subject with family.

*You've got stats, you've got academic, you've got more personal - literally personal handwriting, you've got visual, you've got random arty things with the suitcase labels, you've got the postcards so it's just multidimensional. You take that and you think of a new way to broach it with my family - maybe I'm not broaching that subject in the way that's suitable for them. Maybe there's another way to do it. The exhibit helps with that. (Interviewee 20)*

For some TDL visitors, interaction with the Guides seemed to ease them past their initial hesitancy to engage with the topic and in some cases to enable conversations within TDL that families had previously struggled to have.

*The teen was afraid but the mum wanted them to discuss. We used the postcards as a way of breaking that barrier and to start future conversations. (Guide, End of Day Reflection)*

*A woman in her late 30s came in with her mother. She walked in commenting that she thinks this concept is really cool, and afterwards said she really enjoyed it. Her mother seemed much less interested, and after a quick walk around she just sat down. The daughter then filled out one of the cards to add to the wall about what she wants when she dies, and she asked her mother to go over and she read out what she wrote. I think it's really nice for people to be able to use this particular exhibition/pop-up to start the conversation with their family. (Guide, End of Project Survey)*

But there remain those who can't be persuaded to engage:

*Some people made it very clear they did NOT want to talk e.g. those who thought it was a suitcase shop or a travel agent, and when they found out what it was, immediately wanted to leave [...] I think this reaction from some people is not surprising, but worth noting. (Guide, End of Project Survey)*

### **5.4.3 Knowledge – new knowledge and playing back existing knowledge**

Whilst visitors to TDL did not tend to treat their visit as a fact-finding exercise, one aspect of the Guides' role that has already emerged from their end of day reflections and end of project survey responses is their role as a source of information and advice on death and EOLC. As well as giving advice they provided a sounding board for visitors' existing or emerging views on these infrequently aired topics. (See Guides Interactions in section 5.2.4.)

Information that seemed particularly new to visitors was awareness of the 'death rattle', that death is relatively painless, finding out about living wills and the right to refuse medication.

*one thing that I wasn't actually aware of was the actual process of dying and the actual medical facts side of it. That it's not actually that painful even though you might hear particular sounds. (Interviewee 19)*

Armed with knowledge, visitors may be more inclined or more able to take action.

One young male interviewee expressed satisfaction at the factual elements of TDL (contrasting these to the personal stories) and sounded emboldened to have a conversation with his family, armed with more information: *It's probably something I'll discuss with my parents because they've actually named me as one of their executors. I don't think they're aware of all of the options available to them because I for instance would definitely prefer to die at home rather than in a hospital. He described that such conversations had been avoided in the past: I think they try to shelter me quite often. I'm their youngest child so they generally don't have those conversations with me and I'm probably the most blunt child as well, and the most honest so... (Interviewee 10)*

Visitors with experience of death and EOLC come with pre-existing views on EOLC which they share with Guides or play back when interviewed. They describe the EOLC approach they favour, re-affirming their own empowerment and choice.

*I do have a DNR but that's slightly different [to the right to refuse treatment]. I have said to my doctor that I don't want another major operation again. If anything's wrong, that's it. It's not that I've had enough but I don't want my body messed about. (Interviewee 7)*



*My dad's 89 and there's no way I'd ever let him go to a hospice or anything like that - no. My family's too big and we're too close anyway. We wouldn't allow it. There's so many places for him to go [within the family] to be looked after. If it meant me thinning down my hours at work to look after him then I would do that. There's no greater love than a parent's love and you give that back as well. (Interviewee 3)*

#### 5.4.4 What action to take?

When asked what their experience in TDL made them think about, interviewees mentioned the following examples of agency and choice: the need to talk to parents, spouses or children about death or end of life care to prepare for the future or to deal with a current situation; thinking about what their end of life wishes might be; the need to be prepared. This was in addition to responses sharing broader experiences and concerns: their experiences of friends or family dying, how their family doesn't talk about the subject, their fear of dying, that death is a reality.

The Embedded Digital Survey provides a snapshot of what action visitors might take. When survey respondents were asked if there was anything they will do now as a result of their visit to TDL, most said they were likely to talk to someone about death and end of life wishes or do something to prepare for this moment themselves.

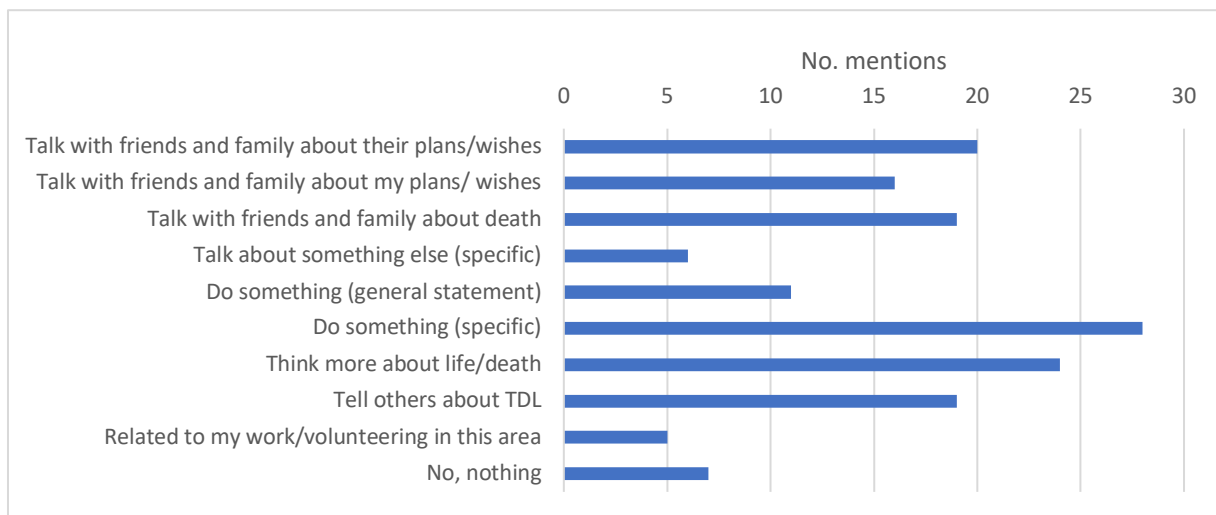


Fig. 5 Is there anything you will do now as a result of your visit to TDL? (Embedded digital survey, n=146)

Sixty-one survey respondents said they were likely to talk to others. Of these 20 said they would talk to others to find out about their plans or wishes...

*Use the exhibition to talk to my parents, to at the very least introduce the idea of talking about death without it necessarily being a 'big thing', without it necessarily being 'depressing'. (Embedded Survey Respondent 2)*

Sixteen said they would talk to friends and family to tell them about their plans or wishes...

*Make sure people really know what I want for end of life care (Embedded Survey Respondent 8)*

Nineteen wanted to talk about death with friends and family...

*I would encourage people to be more comfortable in thinking about death (Embedded Survey Respondent 45)*

And 6 wanted to talk specifically about something else: power of attorney (2), "my friend's prognosis", "tell my grandparents I love them", with grieving friends, teach future children about death

Twenty eight individuals said there was something specific they would now do as a result of visiting. These were: make a living will/advance directive (16 individuals), write a will (13), talk or listen to grieving friends or family (5), designate a lasting power of attorney (2), communicate their care preferences (2), make funeral plans (1), contact old friends (1), look at the website (1).

*Look up living will (Embedded Survey Respondent 33)*

*Eventually, make a will, I know at some point I will definitely do an advance care plan. I've thought that since I came here. (Embedded Survey Respondent 13)*

A further 11 individuals said they would make plans but did not give specifics.

*Yes. I will prepare for my departure. Having taken notice of the travel cases I became mindful of something I did not think about. (Embedded Survey Respondent 88)*

For 24 individuals the experience has made them think more about life and death.

*To live life to the fullest as we humans have stopped living (Embedded Survey Respondent 96)*

Nineteen people said they would tell others about TDL.

*I am going to invite my family to meet me at this lounge to start a conversation that has been long overdue (Embedded Survey Respondent 89)*

Five people talked about doing something that was related to the work they already do in this area.

*I am an end of life researcher and I spend a lot of time wondering how to empower people to talk and think about death, and to continue being the autonomous authors of our lives up to the end. This is such a good idea, and reaches so many people. I really hope I can spread the format. (Embedded Survey Respondent 115)*

### **End of life vs after death**

The Embedded Digital Survey and Visitor Interviews both explored empowerment, choice and what action people might take, by asking TDL visitors "Is there anything you might talk to future medical carers or the people you love, that you hadn't considered before today?". Interviewees were also asked if there was any other action they might take as a result of their visit.

All interviewees talked about decisions that would play out after death, with fewer also discussing end of life care or the tools available to them to make choices. The majority of responses at interview were that TDL had prompted visitors into "making provision", often expressing their wishes with regard to funeral arrangements or making a will.

*I suppose I should write a will [...] but what assets do I have? (Interviewee 13)*

Those that did discuss end of life care mostly talked about whether they would put loved ones in a care home.

*It's not something that I think of. But being out there in Departure Lounge I guess it makes me ask my grandmother 'ok so what is the plan for him [terminally ill grandfather] and how does it work and where do you plan on going. What kind of advice are you trying to get? Are you going to have someone help us, or...?' (Interviewee 18)*

Guides also noted the tendency for people to talk about making provision for after death rather than end of life:

*There was a lot of talk about preparing funerals and ensuring children were "looked after" when they had died. (Guide, End of Project Survey)*

*People have often planned for their funeral but not discussed what they would want if they couldn't express their wishes (Guide, End of Day Reflections)*

### **Specific vs general intent**

Sometimes interviewees' intentions were expressed cautiously suggesting a lack of clarity in exactly what the next steps would be (some mentioned going back to collect leaflets or get more information from the Guides) or a hesitancy in addressing this with family.

*I'm going to go back to speak to them [the Guides] because I'll probably, I want to get more on the legal aspects and [...] how to make a living will. (Interviewee 2)*

*I was thinking, like, wow, I should probably do that too, but then I don't know, like, I don't know, do you have to go to a lawyer to write a will or can you just, like, write one and stick one in an envelope and like hide it somewhere and just...? (Interviewee 13)*

However, sometimes visitors did discuss something specific they would do next. One interviewee for example – who was a Jehovah's Witness – said she'd found out about making a living will. She hadn't thought before about if she was unable to make decisions for herself (her religion meant she could not accept blood products). A couple of others mentioned finding out about DNR orders.

*So I haven't even said whether I want to be resuscitated or not. I'm a Jehovah Witness, I don't believe in taking blood, I would have to have plasma. I've never said that to my kids, to my family or anything and it's only when I was reading, I thought, I haven't told my kids. I've told them about my death but [...] I'd always thought about, you're either here or you're not, I hadn't thought about being here and not being able to make decisions for myself. That needs a lot more consideration and a lot more discussion . [...] a living will, I'd never thought about that (Interviewee 2)*

Notably, almost none of the interviewees mentioned talking to future medical professionals – their experiences in TDL were tied to their personal experiences with death or end of life of family and their role within this.

Data from the Embedded Digital Survey backs up this impression from visitor interviews that, whilst visitors recognise the importance of thinking through issues connected to death and EOLC, they often weren't particularly clear or confident in what action they could or would take.

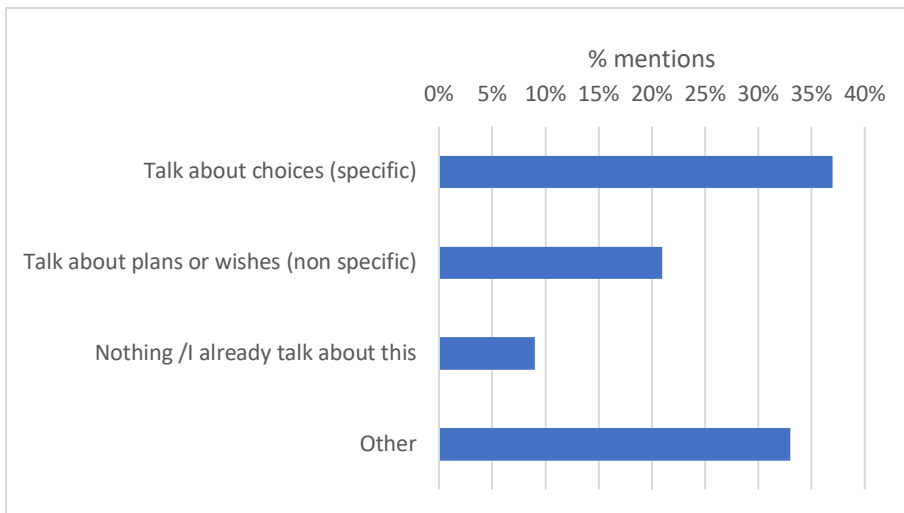


Fig 6. Is there anything you might talk about to future medical carers or the people you love, that you hadn't considered before today? (Embedded digital survey, n=136)

When asked if there was anything they might now talk about to future medical carers or loved ones, 37% of Embedded Digital Survey respondents referred to specific death/ EOLC choices that are open to them. (We might have expected this % to be higher since observations suggest these visitors tended to have spent longer than average engaging with TDL content or were more likely to have had a significant interaction with a Guide and awareness of choice was a key objective for TDL.) They used words like “discuss”, “be clear” and “what I want” suggesting they were aware there were options and they had a choice. They were concerned with medical treatments (25, plus an additional 4 who mentioned a living will or advanced directive), where they wanted to die (8), care preferences (4), organ donation (3), making a will (1).

*To discuss treatment available towards the end of life* (Embedded survey respondent 126)

21% only talked in general terms about making plans and were not specific about what they'd do.

*Talk with my husband about what we should do when we die* (Embedded survey respondent 77)

The remainder either don't know what to discuss with future medical carers or the people they love, have had these conversations already or are not planning to have a conversation.

### ***Future actions shaped by personal experience***

Visitors with personal experience of death and EOLC came with pre-existing knowledge of the issues and choices that they and their families will face again in the future. In Visitor Interviews and general observations they seemed more familiar with terminology and concepts, and more likely to raise such issues and describe decisions they've taken or actions they intend to take. They seemed more likely to know what to ask and to engage in detail with the specifics and technicalities of EOLC.

Interviewee 7 who was in her eighties said she'd picked up “One or two of the practical details I didn't know” but “because I've made lots of arrangements I'm feeling quite comfortable about all that.” She spoke spontaneously and confidently about DNR orders, the right to refuse treatment and assisted suicide.

By contrast, those without prior experience of EOLC seemed more likely to simply say “this has given me lots to think about”, to defer taking action, to be less specific about what action they might take or to talk about ‘after death’ actions like funeral plans rather than ‘end of life’ actions.

It was most often the interviewees with little experience who, when resolving to make plans, naturally diverted to wills, funerals, care costs and other practicalities or referred to EOLC only in very broad terms. For these people, TDL had highlighted something about end of life care that was new to them, however, often they remained cautious and had questions about how to take this forward.

*what you want from your funeral. I think, 'cause that takes the stress off your family. 'Cause that's quite stressful, they're thinking, what do they want, you know, what songs do they want to play and stuff like that. So I think that's made me think about that more, that I would communicate that with my family. Or I would want to communicate with my family if any of them were dying, then I would want to know all of that and I would probably ask them now, when I wouldn't have done that I think if I hadn't been there [at TDL] (Interviewee 12)*

*I think encouraging the conversation will help, I think so, because I think with my grandmother, like, the last three months for her, she was basically in a hospital, she was just sitting on a bed all day. It was boring. So definitely I think if it's my parents, I would want them to choose whether they want to stay at home or something like that or having someone to, like, go to theirs, like a carer or something like that. (Interviewee 9)*

But some younger interviewees didn't think it was something they needed to plan for yet.

*if you've turned 60, I'd be like, maybe I should start planning my death and you have to actually just accept that, like, once you get to 60, you've got to start thinking (Interviewee 15)*

#### **5.4.5 Taking control of grief**

In addition to visitors taking action there were instances of another form of agency in TDL: moments where bereaved visitors took the opportunity to unburden themselves of some of their grief by weeping, by telling their story to a Guide or by writing down a memory of a loved one. This could be seen as small steps in processing and taking some control of their grief.

*“[A visitor] Wrote in detail about a recent bereavement and seemed lighter for it” (Guide, End of Day Reflections)*

*A woman whose mother had died earlier this year... asked about death cafes. I spoke to her fairly briefly and she then spent quite a while writing two lengthy experiences on the acetates. I think it felt like it was tangibly doing her good to spend time thinking about this in a space which encouraged rather than refused to acknowledge it. (Guide, End of Project Survey)*

The acetates, the personal stories, the Guides and the booth were all well placed to enable and support this process. The welcoming environment and tone of TDL allowed some visitors to feel they could ask for help, such as the example of the recently bereaved man seeking reassurance that he'd made the right decisions in his wife's final days (see Emotional Impact section 5.3).

The Guides data supports this. They described signposting additional sources of help to some visitors in need.

## 5.5 Awareness of research around death and dying

Visitors' awareness of health research and innovation around death and dying, where it did occur, mostly focussed on statistics mentioned in the installation such as increase in age at death and causes of death in men and women. This is unsurprising given that there is relatively limited coverage of health research in the exhibits. Some Guides talked with visitors about their research, usually when asked by the visitor, suggesting messaging about increasing visitors' awareness of health research was not part of the Guides brief.

The objectives of TDL included “providing opportunities for researchers to talk meaningfully with publics about their work and contribute to better people-centred health research” and “increasing public awareness of health research and innovation around death, dying and the ageing population”. Visitor interviews, therefore, explored whether visitors had come across any research around death and dying while in TDL. Analysis of Guide feedback explored whether they had talked directly about their research.

Interviewees mentioned research they had come across on the pillars, luggage and Departure Board – they responded with statistics they had read such as the increase in age at death, the biggest causes of death for men and women and the percentage of people who do not make their wishes known. However, often this information was not forthcoming and for most interviewees was not the most impactful aspect of their visit – except for one interviewee who felt he had gained statistical knowledge to better make his case with his family over the care of his grandmother.

*it also said at the beginning that now it's expected that one in three people that are born today will live until they're 100. I didn't realise it was that high. Imagine living 'til you're 100, that is such a long time to be alive! (Interviewee 13)*

*There was one thing that's, something like the highest cause of death in males is heart problems and for women it's, like, Alzheimer's, Dementia, stuff like that (Interviewee 2)*

None of the responses, however, were about health research. (Note: all interviewees had quite short interactions with Guides – perhaps discussion about research would only come about during longer interactions.) There was, however, relatively little opportunity for visitors to learn about health research in TDL – there, volume of content on the topic is limited and – with the exception of the statistics on the pillar, is interwoven with other content rather than highlighted or otherwise given prominence.

In fact, analysis of the Guides daily reflections suggests few mentioned talking about their own research and those that did, did so in response to visitors' questions. Notably there is little in the Guides reflections about messaging – what they wanted visitors to know/ takeaway beyond encouraging talk about death and end of life care.

*[I spoke about] The aims of the project - why it was set up, who it was set up by, what the Academy are hoping the project will achieve (encouraging people to have more conversations about death and dying to help them prepare for end of life decisions and care). I also spoke to people about their experiences of death, dying and bereavement, religious beliefs, opinions about assisted dying, the importance of talking to family members about their wishes at the end of their life, reasons why it is difficult to talk about death. (Guide, End of Project Survey)*

*[I talked about] What The Departure Lounge was about and who had funded it. I also talked a little about my research to those who asked. (Guide, End of Project Survey)*

It seems, therefore, that there was almost no discussion of end of life care research or policy. It seems that EOLC services available are seen as a static offer that visitors tend to know little about, rather than as something that might evolve and regarding which the public could have agency or influence. It seems the project's objectives related to this were not part of the brief for the Guides interactions. Instead Guides promoted talking about death and looked to the audience to see what they wanted or needed.

## 5.6 Impact on the Guides

Most Guides were involved in the project because they were motivated to engage the public with the topic – often citing motivations that supported their professional or voluntary practice. While already experienced in working in death and dying with the public, the majority found their experience in TDL to be a learning one with many saying they had learned more about the process of helping people talk about death or dying: learning from the experience of talking with a diverse audience and also learning from other Guides and Hosts. 25 out of 31 Guides said their work in TDL would impact on their professional practice in some way – by getting involved in other public engagement events, using the resources and ideas with other communities, informing their interactions with patients and when teaching. Others mentioned having a better understanding of palliative care, informing research directions, the importance of having conversations with patients early, and feeling “reinvigorated” for their work.

### 5.6.1 Motivations

21/31 Guides said they had taken part in TDL because there was something they particularly wanted to communicate about death or end of life care. Most of those who replied ‘no’ to this question said they had wanted to listen to visitors’ views and perspectives.

Those who took part because they wanted to communicate something about death or EOLC mentioned...

- providing information or encouraging people to do advanced planning (6 mentions)
- supporting people in overcoming fear of talking about death (4)
- helping people have difficult conversations with friends and family (4)
- understanding that death is a natural part of life (3)
- build understanding of hospices or awareness of place of care options (3)
- demystifying the process of dying (2)
- developing own public engagement skills (2)
- understanding the support needed by loved ones (1)
- giving voice to people with learning difficulties (1)
- acknowledging death can happen at any age (1)

*That it is so invaluable to know what you or your loved ones want or would not want. I've spent long enough on the dementia wards seeing families toiling with decision making that puts patients through interventions that are invasive and unpleasant. It is still very rare to have a family member say they know what their loved one would or wouldn't want at the end of life. (Guide, End of Project Survey)*

*I didn't sign up because there was something I wanted to communicate, but because I wanted to listen and learn. I'm starting out on some research into inequalities in end of life care, and want to look at what some of the barriers are in thinking about end of life care for people from low-income communities. (Guide, End of Project Survey)*

## 5.6.2 Personal impacts

Guides were asked what they had learned as a result of their experiences in TDL. While many Guides clearly had much experience already of talking with people about death and dying, many said they had learned more about the process of helping people talk about death or dying. They mentioned holding back and letting people lead the conversation, listening for cues, using open questions, giving people time and allowing for silences. They mentioned the importance of listening and of giving people time for reflection.

*It's interesting letting people lead you on topics they want to discuss. I'm used to leading the conversation at work. (Guide, End of Project Survey)*

*Some people will always shy away from the word "death". However, a carefully phrased question, or using silence to encourage thoughts, may open up a conversation in an amazing and positive way. (Guide, End of Project Survey))*

Some reflected on how they needed to be in order to encourage people to talk. They learned that they didn't need to be so serious, that it was OK to smile, that it was important to relax.

*It taught me that if you are relaxed about a subject then the other person will be. (Guide, End of Project Survey)*

Some Guides talked about learning how differently people approach the topic: about different preconceptions, how scared some were, that people held very different views. Some learned that it's not possible to tell how people will respond to a topic, or who wants or needs to talk about the subject.

*I'm fortunate that I have been involved in this area of work for more than three decades, but I am still reminded what a difficult area it is for the vast majority of people. (Guide, End of Project Survey)*

*It taught me that there are people who want to and need to talk about these things and that you can't tell by looking at them which ones it will be. (Guide, End of Project Survey)*

Two Guides specifically mentioned feeling more confident in talking about death and dying with the public and two others said they would use skills learned in their work. One said it was nice to get feedback that she must be good at her job.

*I now feel more confident in engaging people with death and dying issues (Guide, End of Project Survey)*

*It was lovely to hear from some people how they could see that I do well at my job and its ideal for me!! (Guide, End of Project Survey)*

Four Guides specifically talked about the words 'death' and 'dying' and how to use these so they were less frightening to people.

*Saying death and dying in one sentence is more frightening! Then just saying dying. Or death. On its own. (Guide, End of Project Survey)*

Two Guides were encouraged by the responses of the people of Lewisham to the subject and that this gave them hope of normalising the subject.



*I learned that the people of Lewisham are lovely, engaging and curious. This gives me hope that this taboo topic can be brought out into the open so that people tell others of their wishes and have a positive experience at the end of their lives (Guide, End of Project Survey)*

Two Guides talked about learning how good design and quality materials can support public engagement with a difficult subject.

*Loved the idea of going out into a shopping centre, having a 'pop up' space, and using creative and imaginative design and high quality materials to engage people - and it seemed to have worked extremely well! So I would say I have learnt that if you get out there, make the effort (and commit the resources!) to engage well, thoughtfully, with careful attention, then many people WILL engage ... even some who find the subject matter scary, uncomfortable, painful... Also that is IS worth being experimental, taking risks, trying new ways to engage. (Guide, End of Project Survey)*

Guides were also asked whether they had learned anything from other staff working in TDL. They said they had been interested to find out people's professional backgrounds and motivations for taking part in TDL. Some said they had learnt more about EOLC as a result of this. They also learned from each other about how to talk to the public about death and dying. Additionally, Guides highlighted learning from the experience of the Hosts – younger people who didn't have professional backgrounds in death and EOLC but who were able to get visitors to engage with the subject. Guides talked about the support, friendliness and openness of other staff working in the installation. Some said they had made new contacts or would keep in touch with new friends they had made.

*I thought both hosts were fantastic, very calm and competent with great personalities. They were both very supportive and I enjoyed hearing about their experiences on previous days in the Departure Lounge. The two guides were both palliative care doctors and were very knowledgeable, sensitive and kind, I enjoyed their company and support very much. (Guide, End of Project Survey)*

*Knowledge of their areas of work and their experience. Able to refer members of the public to other people occasionally who had better knowledge of a specific area. Also just good to reflect with them informally on interactions with the public throughout the day, and informally debrief after difficult conversations. (Guide, End of Project Survey)*

### **5.6.3 Impacts on their work**

While 6 Guides felt their professional or voluntary practice would not be changed by their experience in TDL ("It was a useful experience but I don't think that it will change my practice"), 25 said it would change their practice in some way.

Six Guides thought they would like to get involved in or deliver other events including Death Cafes, flat pack Departure Lounges or as a death doula. They mentioned using the resources and ideas from TDL with other communities. One mentioned being more proactive on social media.

*I will look into my local death café and see if I can contribute and also work with my palliative care team at my hospital about running events with our staff and patients to encourage the discussion around death, dying, and being prepared. (Guide, End of Project Survey)*

*Having the installation as a way of engaging people in the topic worked brilliantly - there were lots of different ways for people to choose to engage, e.g. absorbing information, talking about their own experiences with guides or people they've come with, writing down their thoughts, filling in a*

*questionnaire... Will use this in my own engagement activities - and hoping to have a flatpack version to use at public events. (Guide, End of Project Survey)*

Six talked about using what they had learned about how to talk to people, and what people were interested in knowing about.

*Yes, definitely. I think I will be able to approach this topic with patients more confidently when appropriate in my clinical role (Guide, End of Project Survey)*

*...how one might talk to someone about making a will, power of attorney etc. (Guide, End of Project Survey)*

A couple of Guides mentioned using what they had learned in their teaching.

*will also think about how I could incorporate my experience into teaching trainee Clinical Psychologists about working with older people (Guide, End of Project Survey)*

Others mentioned: having a better understanding of palliative care, considering working with new audiences, the experience has informed research directions, the importance of having conversations with patients early, feeling “reinvigorated” for their work, understanding death from the public’s perspective, the need to look after professional’s wellbeing.

*I am very glad to have had the chance to take part. Think it has shown the importance of having these conversations earlier in our care. I've shared information about the project with my colleagues and the trust communications team will be sharing it in the next trust magazine. (Guide, End of Project Survey)*

*Perhaps not so much 'change' as 'enhance'. I have always enjoyed public engagement work, and this has strengthened my motivation to try to do more of it in new settings, and with people who do not already have a connection with end of life services (e.g. are not already patients or carers, and do not have an immediate relationship with any given end of life care services...). Am also very interested in doing more public engagement work with people who are traditionally under-served by existing EOLC services (e.g. from disadvantaged social groups/cultures/communities) (Guide, End of Project Survey)*

*I think it will. I work as a researcher in end of life care topics. [...] I think this experience gave me a better understanding about the type of care people can access in the community at the end of life, as well as how people feel regarding that care. That will be useful to approach my research. (Guide, End of Project Survey)*

*...having conversations like this regularly can have an impact, although I've never felt it but maybe I need to look a bit deeper at how we care for ourselves more in this role. (Guide, End of Project Survey)*

#### **5.6.4 Guides’ suggestions for improvement**

At the end of each day, Guides were asked to reflect on what they would do next time to take forward this learning into their next session in TDL or to share with other Guides and Hosts. Their reflections are primarily about how to connect and make people comfortable. Responses were:

- No feedback; or no changes needed (30%)
- Reflections on how to connect with visitors (31%) – advice about being on the threshold/ being welcome but not too pushy; about opening lines such as ‘we’re not selling anything’/ ‘we’re not a shop’; and offering leaflets/ postcards as an opener
- Reflections on how to be with people and what to expect from these interactions (18%) - such as giving people time/ being ready to listen/ going with the flow of the conversation.
- Reflections on how to look after yourself/ support other Guides (11%) - take time out, watch out for others, discuss experiences
- Suggested improvements (6%) - more on this below

*Quite often, I found that walls were built up quite high on some visitors where the conversation was an uneasy one due to recent experiences they had been dealing with. Taking the conversation at their pace and having patience for them to find the words for themselves was really key to maintaining engagement on the topic (Guide, End of Project Survey)*

*Watch for others who are stuck with an individual, to help remove from or support with the situation (Guide, End of Day Reflections)*

In the End of Project Survey, Guides were asked if they had enough support or information to carry out their role in TDL. 28/31 said they did and praised the thorough initial training, online folder of information, supportive Hosts who provided continuity and built on learning experiences each day, and tips from other Guides.

However, ten Guides offered areas for improvement in their End of Project Survey, six also suggested areas for improvement in their End of Day Reflections. Combined, their suggestions for improvement include: training, their role in the installation, and the experience in TDL particularly the two visitor feedback methods:

- More on the aims and details of their role at the initial Training Day
- AMS staff to be present at their sessions for extra support
- The two visitor feedback methods (Ipsos MORI interview and Embedded Digital Survey) proved difficult to manage. Two surveys were too much for some visitors, and there were mixed messages to Guides on which should be prioritised.
- Concern over the visitor feedback methods – the embedded iPad was slow and lagged, some Guides thought the wording of the Ipsos MORI questions/ instructions were unclear, some Guides were uncomfortable about asking the Ipsos MORI questions
- Additional literature needed in the installation on specific topics – either this wasn’t available or was removed because it wasn’t on brand (sited behind the scenes, visitors left when the Guide went to collect it)
- A couple of Guides reported Hosts not always being on task
- One Guide found the design of TDL difficult to work in – distracting soundtrack, distracting music from the shopping centre, low light levels/ harsh lighting.

*I think the support and information provided was more than enough. It was really useful to have support from the hosts that were there every day. The tips provided by other guides were also useful. I think the training section could have focused less on problematic interactions and more in what the Academy was expecting or wanted to learn from this experience. (Guide, End of Project Survey)*

*I am not entirely convinced that the Ipsos MORI mini-interview was right for that space. It was the most challenging aspect and I also don't think it got the best results. I had a lot of people decline, which I had no problem with. There appeared to be pressure to meet targets for numbers of*

*interviews too. From a personal perspective I do not think that these interviews were thought through well, I think there could have been far more creative ways of tapping into answers to these questions in that space. [...] I am not convinced that the Guides should have been doing the interviews, the issues include the fact that you have to switch gear/role from casual chat and listening to what I suspects comes across as a clipboard wielding researcher (however carefully you try and do it), it potentially erodes trust that has been built up. (Guide, End of Project Survey)*

*There were visitors who came that had experienced loss of their pregnancy and experienced friends/loved ones death through knife crimes. On the Saturday I put out the relevant literature that was in stock from back of shop resources however this was removed from visibility due to the lack of Departure Lounge branding, which I completely understand. However, one of the ladies on the Sunday didn't stay too long after asking about miscarriage. By the time I returned with the pamphlet from back shop, she had left. I would try and create a space for non-branded support literature so that visitors who do not want to talk can visit and leave with some helpful information that they can pick up. (Guide, End of Project Survey)*

## The Departure Lounge Website

Google Analytics recorded 2,505 users visiting TDL's website between May 10th and June 24th 2019, peaking within days of launch then showing a general decline which drops to a low background level of traffic (no more than 10-20 views/day) within a week of TDL closing in Lewisham.

The average session duration is 2 minutes 8 seconds and users view an average of 2.17 pages/ session, indicating only 1 click through beyond the departure-lounge.org homepage to pages which contain the deeper content that was also part of TDL installation in Lewisham. 18% of users are Returning Visitors.

54 of the website users (2%) completed the pop-up online survey. In answer to the question 'Having visited this website, how confident do you feel about talking to future medical carers or the people you love about death and dying?', the majority (31 people) responded that they were already confident talking about this. 16 people responded that they now felt more confident and 7 responded that they felt the same as before. This seems a higher level of confidence than was observed at TDL and suggests the majority of website survey respondents were perhaps already engaged or working in this area.

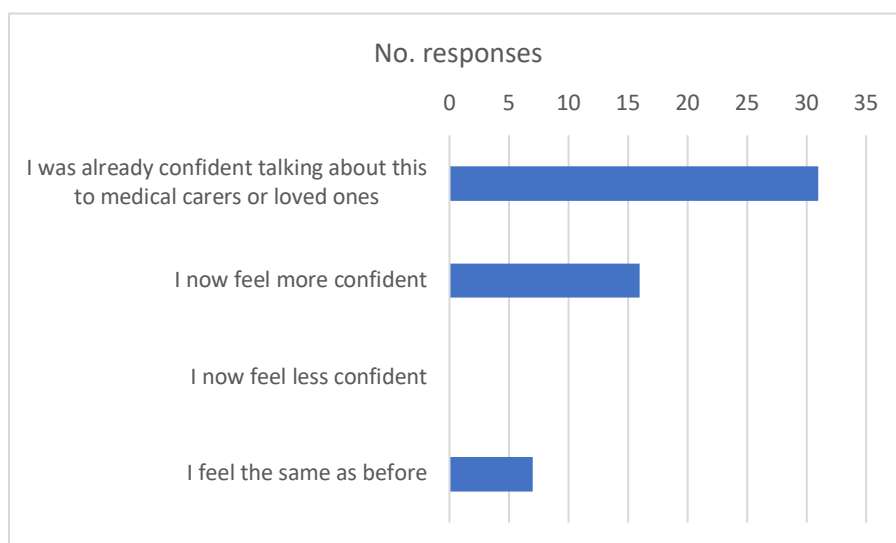


Fig 7. Having visited this website, how confident do you feel about talking to future medical carers or the people you love about death and dying? (Online Survey; n=54)

37 of the survey respondents were female, 16 were male and 1 would describe their gender in another way. Only three responses were received from people under the age of 35; responders' average age was 58, with the mode aged (55-64).

It's not possible to tell whether people who visited TDL in Lewisham also visited [departure-lounge.org](http://departure-lounge.org) before or after their visit, but the close correlation between higher web traffic and the period when TDL was open in Lewisham suggests that people who heard about or visited TDL were amongst those visiting online.

One Guide suggested that more could have been made of this opportunity by directing those reluctant or too busy to stop to the website instead, where they would have been able to access much of the same content and contributed evaluation data.

*Also, I wonder if for future projects it would have been good to have an app or website to direct people who didn't have time to stop so they could weigh in with their opinions - in a more private environment. People were happy to engage but many didn't have time to stop. I would send them away with leaflets but not sure if any would have directed them to an online survey....* (Guide, End of Project Survey)

## Dead Beats Event

As well as hosting community groups at TDL, AMS organised an off-site event, 'Dead Beats', at the Old Tigers Head pub, Blackheath, just over a mile from Lewisham Shopping Centre. Initially a number of events were planned aiming to reach an audience of 250 but in the end, other than the launch event, only this one went ahead. (Decisions and experience that led to this are discussed in a separate report on the learnings for the Project Team.) The Dead Beats event was a free event, hosted by comedian and science communicator Steve Cross of Science Show Off and Bright Club and featured seven comedians. Its subject matter was billed as 'What music do you want at your funeral? Will it make your guests shed a tear or get them dancing in their seats?'. The event was advertised on AMS website, through word of mouth, social media channels (Facebook, Twitter) and various mailing lists (Kings College London, Lewisham Shopping Centre, All in London and Psci-Comm).

The event was attended by 25 people. Of the 14 audience members that completed the Event Feedback Form, 10 described themselves as female and 2 as male, with the other two not providing this information. This aligns with observations on the night that estimated the audience was >80% female. They were mainly in the 18-44 age range with the mode being 35-44. They were mainly White and mainly of no faith/ atheist. Approximately half were local (living, working or studying in Lewisham). They were a fairly 'science-y' audience with five respondents working in science, three who actively seek out science news, information and events and three more who describe themselves as 'interested in science but don't make a special effort to seek it out'.

The audience had heard about the event through a range of channels; at least 6 of them flagged that they had a direct connection to AMS. When asked about their reason for booking they mentioned the topic (6 people, some saying it was "important"), and the comedy (4, some describing the approach to the topic was "fun") as well as personal recommendations and "being there to support colleagues", it being free, the compere and the venue/ location.

The event was well received by its audience with 10/14 Feedback Form responses rating it as 'Excellent', three as 'Good', and just one as 'Fair/OK' and as 'Poor'.

Like TDL, the event included people acknowledging their fears and sharing their personal experiences of death and dying. But it took quite a different tone to TDL in talking about death – generally lighter and more irreverent. Whilst the topic would inevitably have been brought to top of mind for audience members, very few (two) Feedback Form respondents reported feeling more confident talking about death and dying as a result of their experience at the event. Most (six) said they were already confident.

When asked ‘What might you talk about to the people you love or future medical carers, that you hadn’t considered before today’, some did not respond or said “songs at my funeral”, referring directly to the event theme. But others mentioned “speaking to my family about death”, “formalising my wishes”, EOLC preferences (non-specific) and wishes relating to *after* death, such as funerals, assets and wills.

## 6. Discussion

*For me, what was most impactful was that people (both men and women) of all ages, cultures, ethnicities, all religions and none were willing and interested to engage. Also: family groups (including children of all ages, from v. young to teenagers to people with adult children), single people, groups of friends. The variety and diversity of people who came and had conversations about death, dying & bereavement was what was most striking for me. (Guide, End of Project Survey)*

The breadth of the audience to the Departure Lounge was striking. As well as attracting older people who may be closer to considering death and dying, and purposeful visitors aware of TDL through the wide-reaching media coverage, other people visited too – younger adults, some teens and family groups, people of different ethnicities and socioeconomic backgrounds; in short, a broader demographic than might be expected to an exhibition in a conventional London museum or gallery space. The strategy of siting the installation in a shopping centre meant people encountered it in their everyday lives and consequently TDL’s audience reflected the diverse, local population. Although intergenerational groups did visit in small numbers (engaging intergenerational groups had been one of the project’s objectives), encouraging people of different ages to talk together about death and EOLC needed to be designed into the experience and marketing of TDL or become a focus of the events programme.

The size and breadth of the audience is also striking given the subject matter. There is a high barrier to engaging with an installation about death and dying – many people consider talking about it very difficult and some consider it taboo. On discovering what the pop-up shop was about, many people turned away in anxiety or disgust; but many also stayed, curious to explore further or share their stories. The broad audience interested in engaging with the subject could, perhaps, have been built on. AMS specifically invited community groups to TDL. Mostly these were groups for the elderly, but this could have been extended to younger audiences – for example, a local Philosophy & Ethics secondary school teacher was keen to bring her students, and young adults interviewed felt they would have valued discussing death and EOLC in school.

TDL is a space where unusually open conversations about life, death, loss and family occurred. It is a significant achievement for an exhibition to provoke such reflection and such an emotional connection in visitors. Since death and dying are universal human experiences, the topic is relatable to all; it resonated both negatively (in those that walked away) and positively – “everyone has a story to tell”. However, the topic also creates a distinctive challenge: it can be difficult to talk about and is emotionally charged, making it highly uncomfortable for some people. TDL succeeded in being considered a safe space to have a conversation about death for those that find death difficult to think about or for whom it’s far from top of

mind. People came in and opened up, often surprising themselves having thought (and sometimes saying) they did not want to talk about death.

Visitors' experience in TDL seemed to follow a journey: they were curious about the installation and quickly immersed in it – they felt safe. The content acted as a trigger, opening up existing thoughts and memories – sometimes getting people to “go there” when they would avoid doing so in their day-to-day life. These thoughts were emotionally impactful, and the content led to a realisation (or reaffirmed) that thinking about death and EOLC is important and that there are choices that need making. The experience often provided impetus to take action (or at least the resolve to do so). Most often this was to talk to friends and family about their wishes, or to “make provision” for themselves. Crucially, visitors didn't just connect emotionally – they also actively connected the concept to themselves and their own circumstances.

There were a number of features that supported visitors on this journey, ensuring the emotional connection was not overwhelming whilst communicating to visitors that they have agency.

- The design created a welcoming atmosphere, a place of calm in contrast to the rest of the shopping centre.
- The experience was accessible and compatible to the ‘shopping mode’ of potential visitors: from the glass front (there were no doors) visitors could see the extent of the installation; it was clearly self-guided; the content was grazable being distributed in bitesize, ‘moreish’ pieces (there were no off-putting long text panels); when populated, others seemed more likely to enter.
- The metaphor that ‘it's a journey’ was appreciated and made the content more approachable
- Visitors thought the content was objective (it contained both personal experiences and content from professionals), and they noted positive portrayals of death and EOLC
- The personal experiences in TDL meant visitors could see themselves and their own stories within the content – that it was about, and for, ‘people like me’.
- The experience encouraged purposeful sharing of visitors' own stories relating to death – an unburdening. This happened through visitors contributing thoughts on last journeys or sharing personal experiences of loss on the acetates, or through talking to the Hosts and Guides. They felt supported to do this and sometimes felt “lighter for it”.
- Hosts with retail experience greeted and acknowledged visitors, they were welcoming and set an appropriate tone for the experience.
- Guides, and Hosts, provided emotional support by listening, discussing, providing impetus, advising and signposting to other resources. They eased visitors past the initial hesitancy many displayed and were an essential part of appropriately supporting people for whom TDL unlocked difficult memories and grief. The Guides' professional expertise was an important part of managing the risk that encounters with TDL might trigger distress which might otherwise be left unsupported.

A key objective for TDL was to empower visitors to understand that they have choice in decisions about death and dying. ‘Empowerment’ suggests an increase in self-determination and confidence and gaining control over an important aspect of their lives. All interviewees thought talking about death and making provisions for death was important for them/their families and for society and most resolved to do something as a result of their experience. Visitors reflected on their own values and beliefs and expressed their own views and experiences in an environment of mutual respect – this was empowering.

However, although the experience helped visitors to think about death and EOLC and feel empowered to do something as a result, they did not necessarily leave with new knowledge on what actions they could take. This may have been because 1) some visitors maintained strongly held views about death and EOLC which affected what they noticed; 2) content on EOLC and after-death options were easy to miss amongst the rich array of non-hierarchical content, or only discoverable if the visitor raised this specifically with a Guide or Host or picked up the relevant leaflet. The experience provided impetus and resolve to take action but not all visitors were clear on what action to take, saying vaguely that they “will make provision”. A more explicit

roadmap of the options available and what people could do next was needed to scaffold their next steps. This could have been a through physical aspect of the installation, messaging provided by Guides or signposted resources on the website.

The audience thought the topic was important to think about in relation to them/their families and also important for the community. They thought the tone and location of TDL normalised a conversation that was rarely held and were grateful that TDL had come to Lewisham to provide this service. They thought normalising death meant people would be less fearful of it and would understand it to be a natural part of life. They also thought TDL provided a service by bearing witness and even provided solace to those living with EOLC dilemmas and grief. However, as discussed above, without clear messaging around next steps, the service TDL could provide was only the beginning.

*Thank you for coming to Lewisham [...] I love that it's in the place it's in. I read stories about in and around Lewisham of people, of crimes and things, and people passing [...] that area's been blighted with all kinds of stories that fit with the sort of thing we're dealing with today. (Interviewee 20)*

*This woman was very tearful so we sat in the booth and she said that the exhibition evoked a whole range of feelings within her about her mother's recent death, both good and bad. She felt it was so important to hold an exhibition like this one. (Guide, End of Project Survey)*

One of the AMS's objectives was to increase public awareness of health research and innovation around death, dying and the ageing population. Interviewees were able to recall statistics from TDL, but whilst these were impactful for some, they were appreciated less than the personal stories. Crucially, the project objective was about awareness of health research and the difference this is making to death and EOLC, and evidence of this being relayed to visitors was not captured in the evaluation data. It seems that unless they discussed the subject with a Guide, visitors found little of this content in TDL. However, visitors responded very positively to personal stories, so it is quite possible that adjusting the content to include more factual content might inadvertently undermine the high levels of engagement achieved by TDL. Although visitors did not leave with an understanding of this research, they did leave with a realisation that they have an active role in decisions about care and dying. It seems they might be prepared to have conversations about care and dying with their doctor or future medical/care professionals, or at least be aware that they can.

The Guides (and Hosts) were concerned about how to sensitively engage and support visitors with the topic and did so compassionately, professionally and with genuine interest and warmth. They listened attentively to establish visitors needs and then set about trying to meet them. However, they did not systematically talk about their work or broader research around EOLC. It appears there was no clear brief on what the outcomes of their interactions with visitors should be. In the absence of such a brief, the Guides (and Hosts) let the visitors take the lead, rather than consistently attempting to deliver specific messaging. In developing future public engagement experiences between researchers and the public, it would be worth outlining researcher messaging and outcomes and ensuring their tasks are aligned to project objectives.

Good communication between the Guides, Hosts and AMS was vital in ensuring support during and after shifts in TDL, and to guarantee learning from one day to the next. Hosts and Guides did experience angry, suicidal and deeply distressed individuals. The resources and strategies that AMS put in place – such as the code of conduct, training on having difficult conversations, the Distress Protocol and Decompression Sessions offered to project staff – demonstrated the importance of careful preparation. However, as predicted by staff at the training day (and the Advisory Group), a memorable minority of visitors had experience of violent or sudden deaths – suicide, knife crime and miscarriage were mentioned – and wanted to discuss these. TDL was not necessarily set up to support this in the same way as the deaths from illness which were its focus.



The Guides discussed how starting a conversation with visitors about death and EOLC was delicate. They approached this thoughtfully and with appropriate sensitivity – the tone and content of TDL supported this. However, Guides reported feeling less comfortable with the switch to the more formal intervention they found was required of them to deliver the scripted Ipsos MORI discussion guide. They felt this survey would have benefitted from piloting in TDL to find a form of words and a data collection method more appropriate to the style of interaction Guides were using with visitors in the installation.

Overall, TDL provided a unique and meaningful experience for its visitors, both those local audiences who came across it while in the shopping centre and those that purposefully visited. The latter included the science communication/museum community – exhibition and public engagement professionals drawn to experience The Liminal Space’s immersive design in this non-traditional location, and how audiences would respond to the challenging subject matter. Others were medical and health care professionals, some of whom have since taken the flat pack versions to new audiences across the UK (and beyond). In addition to its impact in these professional spheres, TDL has been impactful on the Guides too. They learned about the process of helping people talk about death and dying, about peoples’ different views of death and EOLC, and they developed their own confidence in engaging the public with this topic. 25 out of 31 Guides said their work in TDL would impact on their professional practice in some way – by getting involved in other public engagement events, using the resources and ideas with other communities, informing their interactions with patients and when teaching. Others mentioned having a better understanding of palliative care, informing research directions, the importance of having conversations with patients early, and feeling “reinvigorated” for their work. Despite a short run of just 24 days, the Departure Lounge may have a far-reaching legacy for its staff and AMS’s professional peers, as well as for its audiences.

# 7. Appendices

## Appendix 1 - Embedded Digital Survey

1. Is there anything you will do now as a result of your visit to The Departure Lounge?
2. What might you talk about to future medical carers or the people you love, that you hadn't considered before today?
3. What aspect of your visit has had the most impact on you? Why is that?

We'd love to know a bit more about you. The information you provide will help us understand who visits and how the experience works for you. We will not ask for any information that identifies you personally.

4. Please tell us how old you are.
5. Are you:  
Female / Male/ I describe my gender in another way/ Prefer not to say
6. How do you describe your ethnicity?
7. What faith, if any, do you practice?
8. Do you have a long-standing illness or disability that affects your day-to-day life?  
Yes/ No/ Prefer not to say/ Don't know
9. Do you live, work or study within the borough of Lewisham?  
Yes / No

## Appendix 2 – Demographics of Embedded Survey respondents referenced in the report

Respondent no.	Age	Gender	Ethnicity	Religion	Disability	Local
2	27	Male	White British	None - Agnostic	No	No
8	50	Female	Black African	Christian	No	Yes
13	30	Female	White British	Christian	No	No
28	25	Female	White British	No faith	No	no
33	61	Female	White Irish	Catholic	No	yes
40	27	Female	White Irish	Spiritual	No	yes
43	52	Female	African - English	Church of England	Yes	yes
45	71	Male	Chinese	Christian	No	no
48	50	Female	White European	Yoga	No	yes
53	84	Male	White British	C of E	Yes	yes
55	14	PNTS	White European	Nothing	PNTS	yes
56	61	Female	British and Pakistan	No religion	No	yes
63	67	Male	White British	None	Yes	no
77	65	Female	African	Church of England	Yes	yes
80	51	Male	British	Atheist	No	no
88	68	Female	African Caribbean British	Holy Ghost Christianity (King James Version)	Yes	yes
89	61	Female	African	Christianity	Yes	yes
91	25	Male	Chinese	No	No	no
96	45	Female	Black British	Christian	No	no
115	37	Male	White British	None	No	no
123	71	Female	Black Caribbean		No	
126	74	Female	White British	Open minded	Yes	yes
132	25	Male	African American	Not religious	No	yes
138	27	Female	South Asian	None	No	yes

## Appendix 3 - Interview Schedule

### Pre visit

- Are you comfortable using the D word: Death?
  - o If not: how would you prefer we referred to it?
- Do you talk about death and dying with friends or family or medical professionals?
  - o What do you talk about? (probe: what are they comfortable discussing, does topic differ with different people?)
  - o What do you not talk about?
  - o What prompts the discussion? (why do they have these conversations?)
- Is there anything you want to know more about?
- What do you think The Departure Lounge is about?
  - o What are your expectations of the installation?

### Post visit

#### *First – response to the installation*

- Tell me about the things you did in the space
- Is there anything that you did or saw or spoke about that stands out to you?
  - o What does it make you think about?
- How do you feel after visiting?
  - o Was there anything you found uncomfortable?
  - o Or reassuring?
- What do you know now, that you didn't know before?
  - o What facts did you find out? (Prompt: Did you come across any research by doctors about dying and aging? Anything else?)
- Did you talk to the guides?
  - o What about?
- Did The Departure Lounge meet your expectations? (can remind them what they were if they had any)
  - o What were you surprised about?

#### *Second – focus on their attitudes to discussing EOL care with others*

- Is there anything you might talk about to future medical carers or the people you love, that you hadn't considered before today? (prompt: Are there questions you now know you can ask/ choices you now know you have, that you didn't know before?)
  - o Why do you think that is important to discuss?
  - o Why wouldn't you have raised it before?
- Is there anything else you will do now, as a result of your visit?

- Do you have any questions about death and end of life care as a result of visiting/ things you'd like to find out more about?
- Anything else about your experience of the TDL you would like to tell us about?

## Appendix 4 - Guide End of Day Reflections

1. Estimate number of interactions you had with visitors today.
2. Record the types of interactions you had and who (what groups of people) you had these with.
3. Tell us about an interaction that has stood out to you.
4. What would you do differently next time (in your next shift, advice to other Guides)?

## Appendix 5 - Host Daily Record

How many pre school children visited today?

How many primary school aged children?

How many secondary school aged children?

How many younger adults (18-45)?

How many older adults (45+)?

Estimate % people visiting on their own

% visiting with other adults of a similar age

% visiting with other adults of a different generation

% of under 18s visiting either in a group or on their own

% in 'family' groups ie mix of adults and children

How did people find out about TDL? What attracted them/why did they cross the threshold? Are people visiting more than once? Do they say why?

What aspects of TDL did people spend more time with today? What aspects did they spend least time with?

How long did people tend to stay? Did you notice any patterns about who's staying the least or longest times?

Did certain aspects of the installation trigger conversations between people today? Which, if any, aspects generate intergenerational conversations between people of different ages?

Who tended to be willing to talk to the Guides today? Do you notice any patterns?

What unsolicited feedback did you get today - what did people like?

What criticisms did you hear today?

## Appendix 6 - Guide End of Project Survey

1. Your name
2. What did you talk about mostly with visitors?
3. What have you found out about how people/communities deal with death and dying, what they want to know or what their concerns are?
4. Did you sign up to this experience because there was there something you particularly wanted to communicate about end of life care? Did you? How did visitors respond?
5. What did you gain from your interactions with other Departure Lounge staff?
6. Will your experience in the Departure Lounge change your professional or voluntary practice in this field?
7. If you haven't already, please tell us what you have learned about how to engage people with this topic?

8. Is there anything else you want to tell us about your experience of working at the Departure Lounge?

## Appendix 7 - Host End of Project Survey

### *Your experience of engaging visitors with the subject*

1. What did you say or do that seemed successful in getting people to cross the threshold? Did this vary according to types of visitors?
2. What did people say or do who wouldn't go into TDL?
3. This is how I used the installation as a whole...
4. This is how I used the:
  - i. Desk at the front left
  - ii. The departure window/acetates
  - iii. The departure board
  - iv. The departure gate (including postcards and leaflets, iPad survey)
  - v. The luggage installation
  - vi. The information around the front pillar
  - vii. Private booth
5. What kinds of things did visitors say they would do or talk (with whom?) about as a result of visiting TDL?
6. Were there things visitors wanted to know about death and end of life care that you felt were not addressed or there were no resources for in TDL?

### *Your experience of working with staff in the TDL*

7. Please tell us about how visitors responded to the guides (generally without naming individuals) – what worked well and what could be improved. For example...How did interactions between guides and visitors happen? Did the backgrounds/experience/personalities of individual guides working on any given day alter the nature or topics of visitor interactions on that day? Were some more useful to visitors than the others? What should AMS do differently if employing guides to facilitate a similar space in the future?
8. Please tell us about managing the different staff over the duration of TDL. What worked well and what should AMS do differently when planning the staffing and operations for a future installation?

### *Support*

9. Do you feel you had enough support / information to carry out your role in TDL? Y/N  
If no what would you suggest could have been done differently/better? Please include specific feedback for AMS and Liminal Space.
10. Please tell us about any situations that you found uncomfortable or difficult to manage (either with visitors or other staff). What support did you receive from others (hosts, guides, AMS, Liminal Space) or what support would you have liked?

### *The impact on you*

11. Please tell us about a couple of interactions that particularly stand out to you? Why was this so impactful?
12. What have you found out about how people/communities deal with death and dying, what they want to know or what their concerns are?
13. Did you sign up to this experience because there was there something you particularly wanted to communicate about end of life care? Y/N
14. If yes - what did you want to communicate? Were you able to do so? How did visitors respond?

15. What did you gain from your interactions with other Departure Lounge staff?
16. If you haven't already, please tell us what you have learned for your TDL experience about how to engage people with this topic?
17. Is there anything else you want to tell us about your experience of working at the Departure Lounge?

## Appendix 8 - Website Pop-up Survey

We'd love to hear your thoughts. Tell us what you think about The Departure Lounge by taking our quick Survey.

Yes, I will give feedback/ No thanks

Thanks for visiting the Departure Lounge. We're interested in whether it got you thinking.

1. Having visited this website, how confident do you feel about talking to future medical carers or the people you love about death and dying?
  - I was already confident talking to about this to medical carers or loved ones
  - I now feel more confident
  - I now feel less confident
  - I feel the same as before
  
2. Please tell us how old you are
  - 12 or under
  - 12-17
  - 18-24
  - 25-34
  - 35-44
  - 45-54
  - 55-64
  - 65-74
  - 75+
  
3. Are you:
  - Female
  - Male
  - I describe my gender identity in another way
  - Prefer not to say

## Appendix 9 - Event Visitor Feedback Form

1. How did you find out about this event?

- Twitter     Facebook     Kings College mailing list     Lewisham Shopping Centre mailing list  
 PSCI-COMM mailing list     All in London.co.uk     Word of mouth     Other (please tell us where)

2. What were your reasons for booking it?

3. How would you rate the event?

- Excellent     Good     Fair/OK     Poor     Very poor

4. Has your experience at the event meant you feel more confident talking about death and dying?

- Yes, I feel more confident     No, I don't feel more confident  
 No, I was already confident     No, I feel the same as before

5. What might you talk about to the people you love or future medical carers, that you hadn't considered before today?

6. Is there anything else you will do, or change, as a result of your experience here tonight?

7. How likely is it that you will visit our pop up shop, The Departure Lounge, in Lewisham Shopping Centre?

- Extremely likely     Likely     Not sure     Unlikely     Not at all likely     Already visited

8. How likely is it that you will visit our website [www.departure-lounge.org](http://www.departure-lounge.org)?

- Extremely likely     Likely     Not sure     Unlikely     Not at all likely     Already visited

9. What did you find out about research into death and dying that you didn't know before today?

### About you...

10. Are you...     Female     Male     I describe my gender in another way  
 Prefer not to say

11. Please state your age...

- 17 or under     18-24     25-34     35-44     45-54     55-64     65-74     75+

12. How do you describe your ethnicity? \_\_\_\_\_

13. Do you have a long-standing illness or disability that affects your day-to-day life?

- Yes     No     Prefer not to say     Don't know



14. What faith, if any, do you practice? \_\_\_\_\_

15. Do you live, work or study within the borough of Lewisham?  Yes  No

16. Do you study science or work in a science job?  Yes  No

If not, which of these statements best describes your relationship with science?

- I actively seek out science news, information, events, etc.
- I am interested in science but don't make a special effort to seek it out
- Science is not for me

17. Is there anything else you would like to tell us about your experience at the event?

### Appendix 10 - Ages of visitors

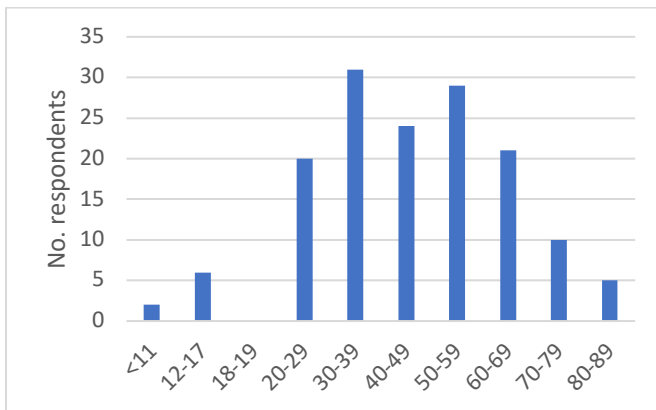


Fig 8. Ages of respondents (Embedded Digital Survey n=148)

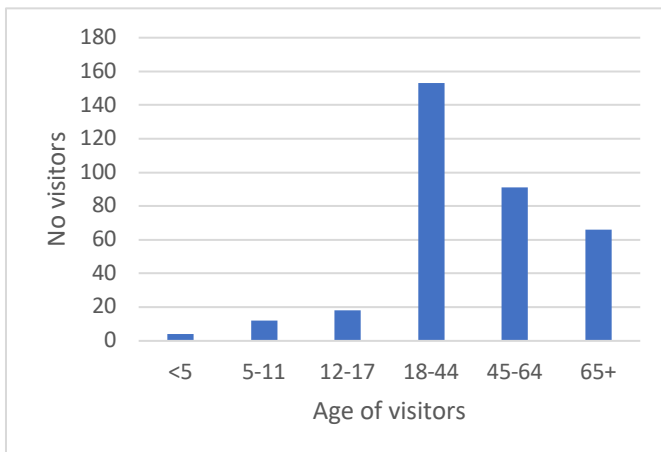


Fig 9. Estimated ages of visitors (Observations n=344)