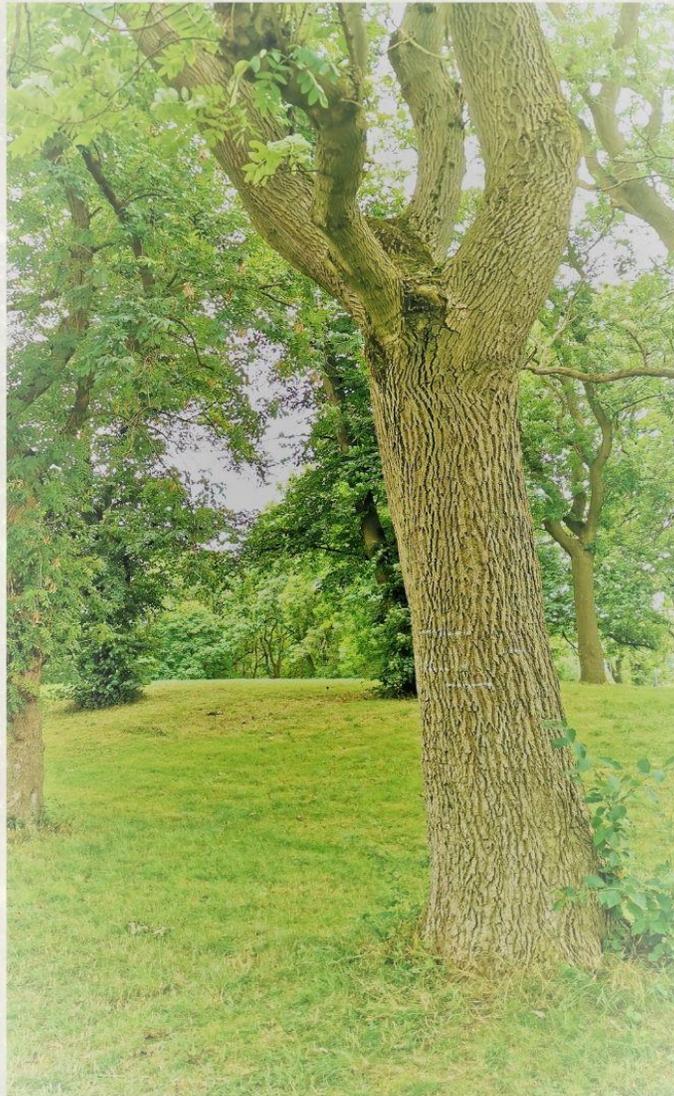


A Home for Grief Project Evaluation



Dr Sandra Varey

September 2021

International Observatory on End of Life Care

Lancaster University

'...the one that really struck me and I think I cried at this point actually was walking up to the tree with all the different height markings on it, and seeing all those dozens of different height markings spread out in lots of different ways and then marking my own height, because that's something that I know lots of families do but it's something that my family did [...] and there's still a door frame back in my parents' house that's got our heights marked on it...'

(Cohort 3 Participant 2)

Acknowledgements

Thank you to all participants who took part in the interviews and gave their time so generously to the evaluation. It was a pleasure to talk with you and to hear about your experiences of the *A Home for Grief* events.

2

The cover image has been reproduced with the kind permission of Cohort 3 Participant 2.

With sincere thanks.

Dr Sandra Varey
International Observatory on End of Life Care
Faculty of Health and Medicine
Health Innovation One
Lancaster University
Lancaster LA1 4AT

Contents

Overview of Key Learning	4
Introduction, Aims and Objectives	7
Methods	8
Findings	10
The participants	10
Motivations for taking part in the AHFG events	10
The Sound Walk	13
The one-to-one performance	20
The live art installation	25
Experiences of using the technology	28
Impact of the events on participants	30
Participants suggestions for future AHFG events	34
The importance of interaction and connectedness	37
Conclusion	39

Overview of Key Learning

Motivations for taking part in the AHFG events (see page 10)

- Many participants were interested in and passionate about contemporary theatre;
- They heard about the AHFG events in a range of ways, and some participants already knew of Fabiola's work;
- Personal and professional motivations informed participants' decisions to take part in the AHFG events;
- In their interviews, participants discussed personal experiences of different types of loss and grief, including but not confined to those related to death.

The Sound Walk (see page 13)

- The Sound Walk was positively received and experienced;
- It was an emotional experience for many participants;
- The interaction afforded by the different activities was important and, though these activities, participants described feeling connected to others;
- The walk enabled participants to express their different experiences of grief in different ways;
- The timing of the narrative throughout the walk provided participants with both reassurance and space. This sense of 'nearness and proximity' was important to participants;
- Although most participants did the walk alone, they described how they had not felt alone during the walk, with many connecting with the voices and stories within the audio narrative;
- Many participants made reference to the discovery of new places and locations when taking part in the walk;
- Some participants experienced interruptions in busy areas of the Sound Walk, while in quieter parts of the walk some felt unsure or unsafe when walking alone and wearing headsets.

The one-to-one performance (see page 20)

- The one-to-one performance was described as a unique and powerful experience by participants;
- The Sound Walk had prepared participants for taking part in the one-to-one performance, and they felt it was important that they took part in the former before engaging in the latter;
- Particular aspects of the performance prompted participants to consider their own mortality, a powerful though not necessarily comfortable experience;
- The interaction afforded by the performance activities was important to participants;
- A degree of uncertainty and anxiety was experienced by one of the two participants in this cohort;
- There was praise for this event, and participants described feeling connected with others during the performance.

The live art installation (see page 25)

- The live art installation was described by participants as feeling very different to the preceding Sound Walk;
- For one participant the transition from the Sound Walk to the installation felt disjointed;
- There was praise for this event and, as with the other AHFG events, there is evidence of participants forming connections with others through the event's activities.

Experiences of using the technology (see page 28)

- Participation in the AHFG events required the use of some technologies. This was straightforward for some participants, but not for all;
- Some participants experienced difficulties using the app during the walk, including when switching between different functions;
- For a small number of participants, this result in them missing parts of the Sound Walk;
- One participant commented that the technology had felt like 'a huge barrier' during the live art installation event.

Impact of the events on participants (see page 30)

- The AHFG events had an impact on participants in a number of ways, in relation to both their personal and professional lives;
- On a personal level, the AHFG events provided some participants with time and opportunity to reflect on their grief, and to think about this in different ways;
- Others talked about how they had learned to approach issues around death and dying differently as a result;
- The sharing of experiences of grief in the AHFG events was important to participants and made many realise they were not alone in how they were feeling;
- On a professional level, there were examples of how the AHFG events have informed participants' research interests and academic practice;
- Participants are more aware of different forms of loss and grief as a result of the AHFG events, including cultural differences relating to loss and grief;
- Participants referred to ways in which they were carrying this new learning into various aspects of their lives.

Participant suggestions for future AHFG events (see page 34)

- The information received in advance of the AHFG event was described by some participants as unclear or difficult to understand;
- Some participants would have liked more explanation and support to accompany the AHFG booklet with which they were provided;
- Many participants commented that they had not known what to expect of the AHFG event. This seemed more important in relation to the one-to-one performance than the other two events;
- Some frustration and annoyance was expressed about the absence of the male experience of grief within the events. There was support from participants for the project to also include male voices and experiences regarding loss and grief.

Introduction, Aims and Objectives

A Home for Grief (hereafter AHFG) is a project by emerging BAME artist Fabiola Santana, which focuses on loss and grief. Fabiola is a dance artist whose work explores performance as a way for people to connect and relate to each other in relation to experiences of loss and grief.

The AHFG project comprised three key events, each of which took place at different times and locations in 2021, as follows:

- **Sound Walk:** a 40 minute guided walk experience during which participants listened through headphones to interviews (conducted by Fabiola) with women of diverse backgrounds and ages on the topics of loss and grief. This event took part in Lancaster in June 2021;
- **One-to-one performance:** a 60 minute ritual of care in which participants were led by Fabiola in quiet interactions to reflect on personal experiences of loss and grief. This event took part in Liverpool in July 2021;
- **Live art installation:** providing a place for participants to contemplate grief with a wider community. This event took place in Manchester in July 2021.

The aim of this small-scale evaluation was to gain an in-depth understanding of people's experiences of the above events. Through qualitative interviews, the study explored individuals' experiences of taking part in the events, the impact of the experience on participants, and how this relates to wider experiences of loss and grief.

Methods

Participants were recruited to the evaluation through the use of Information Sheets and Expression of Interest forms which were made available to people attending the three events. The aim was to recruit eight people to take part in the evaluation from across the three AHFG events. Seven participants were recruited to the study. Table 1 provides an overview of the participants recruited to each cohort, with further participant information provided in the Findings section of this report.

Table 1: Overview of participants recruited by cohort

Cohort number	Cohort event	Number of participants recruited
1	Sound walk – Lancaster	3
2	One-to-one performance - Liverpool	2
3	Live art installation – Manchester	2

Data were collected through qualitative telephone interviews, with each evaluation participant taking part in one interview. The recruitment process ensured a few weeks between a person's participation in an event and taking part in an interview. This period of time was important as it ensured participants had a period of time to reflect on the experience before discussing it in an interview.

An interview guide was developed for each of the participant cohorts, to allow an exploration of participants' experiences of taking part in an AHFG event, their reflections on the events, and any impact it may have had on them. This included exploring motivations for taking part, and gathering participants' reflections on their experiences of loss and grief, both pre- and post-intervention. In the interviews, there was both opportunity and time for participants to discuss their personal experiences of loss and grief where they so wished.

Consent forms were completed verbally; with each participant's knowledge and consent, these conversations were captured on an audio device. This approach avoided the reliance on paper consent forms being posted between the researcher and participants at a time when people's activities may have been limited as a result of the COVID-19 pandemic. With participant consent, each interview was audio recorded and fully transcribed. Interview duration ranged from 37 to 65 minutes, with a total of 336 minutes' recording across all interviews. To protect participant identities, all interview data were fully anonymised at the point of transcription. In addition, participants are referred to throughout this report using their cohort and participant number within this cohort (e.g. C1 P1 is used to represent Cohort 1 Participant 1). The interview transcripts were analysed thematically with the aid of Nvivo qualitative software. Identification of emerging themes and coding was undertaken by the Principal Investigator and Researcher, Sandra Varey.

This is a sensitive research topic and great care was taken in the planning and undertaking of each interview. Participants were provided with a Participant Information Sheet which listed some helpful resources should they experience any distress as a result of the interview. A distress protocol was also developed for this study, to ensure the consideration of any participant distress that may arise.

The evaluation received ethics approval from the Faculty of Health and Medicine, Lancaster University (reference FHMREC20073).

Findings

The participants

The four men and three women who took part in the interviews ranged in age from early 30s to mid-60s. While ethnicity was not noted for all participants, one participant self-identified as African, with several others describing themselves as White British. Six participants were currently living in the northwest of England, with another having grown up in the northwest of England and now living overseas.

Motivations for taking part in the AHFG events

Key learning:

- Many participants were interested in and passionate about contemporary theatre;
- They heard about the AHFG events in a range of ways, and some participants already knew of Fabiola's work;
- Personal and professional motivations informed participants' decisions to take part in the AHFG events;
- In their interviews, participants discussed personal experiences of different types of loss and grief, including but not confined to those related to death.

Many participants were interested in and passionate about contemporary theatre. Some had heard of the event through a friend or colleague, while others discovered it through social media and theatre advertisements. Some participants already knew of Fabiola's work and had attended for this reason:

'I really rate Fabiola, so when I found out she was back I was glad.' (C1 P1)

Participants discussed a range of professional and personal motivations for attending one of the three AHFG events. Their professional interests included academia and research relating to dance, drama, grief, performance and theatre. A number of participants also worked in professions which involve supporting people with complex needs, and they expressed connections between their professional lives and loss, bereavement and grief.

The focus on grief in the AHFG events was also important to many participants on a personal level. In the interviews, participants talk about their personal experiences of grief in relation to the death of family members, current illnesses of loved ones, their own ill health, and the ending of significant relationships. Experiences of loss and grief were not confined to death, with the interviews highlighting the impact of other forms of loss:

'...nothing's forever, and family have also been unwell and still are unwell, so again it just reminds me there is an end time and [...] grief can affect you even before the person has passed away...' (C2 P1)

'[I was] coming to terms with what was a long term relationship coming to an end and trying to kind of get a degree of closure [...] even though it's not explicitly alluded to in the [AHFG] work, actually mourning isn't just about loss of life, it is a loss of something [...] it's trying to bring back somebody who's no longer with us really...' (C2 P2)

'I have suffered with locational disassociation I'll call it, so I have all my life since my dad died very suddenly, I have had disassociation. And that's not with people with but places...' (C1 P1)

Some experiences of loss were very recent, with one participant's grandparent having died only the week before attending the AHFG event. In other interviews, participants talked about loss that had happened some time ago. For some, their loss had been very sudden, while for others it had been expected, for example following a long period of illness. The COVID-19 pandemic appeared to have had an impact on some participants' experiences of loss and grief. One participant told of how her mum's funeral was streamed online, and described how the pandemic had affected her grieving process:

'In some ways [the pandemic] helped because there's been a lot of time for reflection [...] it's meant that I've really started to sit with my grief, I mean more than I would have done [...] [but] I've not been out dancing with my friends or having a drink with my friends or all of those things like talking about her death, I didn't really talk to anyone about it. Only on the phone which is not the same [...] I didn't hug her relatives, I didn't hug my brothers [...] I remember my brother passing me the ashes and I remember wiping the box [...] And I've not seen my brothers [much] so I've not grieved with them.' (C1 P1)

Another participant told how recent experiences of grief had informed his interest in attending the AHFG event:

'I've seen a lot of people around me struggle with grief over the last two years, and also I've struggled with grief and with loss [...] so I'm interested in grief and that is something I was interested about when I went to see and experience the show.' (C3 P2)

The Sound Walk

Key learning:

- The Sound Walk was positively received and experienced;
- It was an emotional experience for many participants;
- The interaction afforded by the different activities was important and, though these activities, participants described feeling connected to others;
- The walk enabled participants to express their different experiences of grief in different ways;
- The timing of the narrative throughout the walk provided participants with both reassurance and space. This sense of 'nearness and proximity' was important to participants;
- Although most participants did the walk alone, they described how they had not felt alone during the walk, with many connecting with the voices and stories within the audio narrative;
- Many participants made reference to the discovery of new places and locations when taking part in the walk;
- Some participants experienced interruptions in busy areas of the Sound Walk, while in quieter parts of the walk some felt unsure or unsafe when walking alone and wearing headsets.

All three AHFG events had a Sound Walk element, and all participants took part in a walk. The majority took part in the walk alone and, while a small number had previous experience of a Sound Walk, the majority did not. The Sound Walk was very positively received and experienced:

'I don't think I was expecting it to be as powerful or as personal or poignant as it was [...] I have been on audio sound walk type things before prior to that, and I was never I was never super impressed by them [...] it was the first audio tour type thing that I actually really enjoyed and thought yes this is absolutely the correct medium to deliver this within.' (C3 P1)

Participants described how much they enjoyed various aspects of the walk – including the flowers, ribbons and chalk – which were handed to them in something similar to ‘a little sweetie bag’ (C2 P2). They appreciated the interaction that these activities entailed, something they hadn’t necessarily been expecting, and through these activities they felt connected to others:

‘...the box was already full of flowers when I put mine down and that was poignant, I could feel myself choking up [...] And I think the way that you do those activities had a sense of like sort of joint ritual to it, which is really nice, like secular grieving ritual and that was really touching and really beautiful’ (C3 P2)

‘I was becoming aware of my senses being heightened, that I was interacting with the building, so I tied a ribbon onto the window, there was a flower to place, there was the chalk where you recorded your height, and I loved that because it wasn’t just a walk around something. I was being asked to interact with things that are living, with places that people visit, so I was making a mark where other people might walk and also place a similar mark, it’s like you were in one bit of time together, doing the same activity. And I really enjoyed that.’ (C2 P1)

‘I particularly liked the lamp post that we marked with chalk, and in many ways it was the ordinariness and the lack of overt symbolism that I liked, it’s just an ordinary rather dilapidated lamp post. But something about, it had a sense of history there, which made you feel that other people had been there before and you were the latest people to be there.’ (C1 P2)

The Sound Walk was an emotional experience for many participants. As one person described, the walk ‘was so much about the person doing the walk’ (C3 P2). Participants emphasised the

importance of the activities in allowing them to express their different experiences of grief in different ways:

'...the activities that you did were really great because they gave you space to experience it about anything that you wanted to experience it about. They gave you space to do it in any way you wanted to do it and any timeframe you wanted to do it in. And you could rush it if you wanted to, you could just get it over and done with, but each one was just a small ritualised sort of remembrance and I really liked that.'
(C3 P2)

The timing of the narrative throughout the walk was noted by a number of participants, and was described as providing both reassurance and space to those taking part. The sense of 'nearness and proximity' was important to participants:

'...the artist had this really really clear understanding as to when to kind of come back into the frame and suddenly they're there and it's almost like they're sat next to you and it's just that little sense of reassurance. And then they know where and when you want to be on your own and when you need them there to be a little bit with you. That I think was very very effective ...' (C2 P2)

'I think probably the strongest moment for me was when we were half way up the path quite close to the wall, on the other side of which is the priory, and we're looking out over the wall, and that sense of Fabiola being close, as if she was actually hiding on the other side of the wall and the refrain that was there in the piece of 'I'm going ahead now' or 'I'm near you' or that sense of nearness and proximity was important[...] people that you know and cherish, and have known and cherished for a long time, nothing changes in your memory of them, of the day before they've died

and the day after they've died, so there's a strange sense of your memory of them is very present even though bodily they've become, you know biologically they've become absent. And I think that that sort of paradox, that paradox is evoked through the present absence of Fabiola through the device through which we were listening.'
(C1 P2)

Although most participants did the walk alone, they described how they had not felt alone during the walk, with many connecting with the voices and stories within the audio narrative:

'I just found that my reflection mixed with [Fabiola's] dad's reflection and then my thoughts mixed with her voice and it was like we were one big family, it was like we were all experiencing this thing called grief together' (C1 P1).

'I was quite engrossed in all the stories and then I remember sitting by this big willow tree and that's absolutely beautiful, hearing all these stories and feeling really connected to them as well.' (C3 P1)

'... what I really really appreciated was just the plurality of different voices on grief, and those moments where you needed that adequate space to walk out and reflect on what's just been said, and those moments to sit and ponder ...' (C2 P2)

For many participants, the route of the Sound Walk was largely familiar to them. The choice of location for the walk was often described by participants as somewhere they knew well and had previously walked, often a number of times. Many participants made reference to the discovery of new places and locations when taking part in the walk:

'I have walked up to the river and close to the route and I've also been to the castle from the other side, so the walk kind of helped me to connect the two. So it was a kind of a new discovery [...] I hadn't connected the two points, so the walk was helpful to kind of let me identify a new location.' (C1 P3)

'I could see the main entrance to the cathedral and I was astounded by how beautiful the building really is, I'd never been to the cathedral before so that was just something to take home with me and I'll go back and have another look at some point.' (C2 P1)

'And then it took me around a park that I've been in on a hundred times but it took me in a way that I've never been in before and what was really nice as well was I felt like I discovered new parts in that park including a statue that I'd never seen before, which was really cool. So I kind of felt like I was rediscovering a part of my home which was lovely [...] it was familiar but new.' (C3 P1)

Some participants experienced interruptions during the Sound Walk. This included someone trying to talk to a participant in a busy street while they were listening to the audio (C1 P1), and another trying to concentrate on the walk in a busy area with 'people walking past you all the time' (C2 P1):

'It was a bit of a distraction to be honest, 'cos I could hear other people's conversations when I was in the park and there was another couple having a row and there was a dog barking and they took away for a moment what was happening through my headset [...] I could hear one or two people you know having chats and things and telling the kids off and that sort of thing ...' (C2 P1).

'...when I got to the priory, the place where you put the name, there was a man on the phone talking about absolute nonsense really loudly, right in that corner and I kind of got a bit like oh why are you here? You know you've ruined the end of it and then I just thought that's alright, he doesn't know where he's standing, so I didn't do that, I didn't finish it, and I'm going to finish it one day when I'm ready.' (C1 P1)

Some feedback was also received about the quieter parts of the walk, with a small number of participants feeling unsure or unsafe when walking alone while wearing headsets:

'...I went up to the priory, there's that walk up and because I've got headphones on, that's not something I would normally do as a woman on my own, 'cos it's quite quiet around there isn't it, and [where I'm originally from] you don't walk around with headphones in quiet areas as a woman [...] I suddenly felt fear just came straight in 'cos fear is a big part of grief and it's one that people don't talk about [...] so I actually took the earphones out that bit because I couldn't do both, I couldn't walk up that steep on my own, 'cos there were loads of men that passed me as well, and I felt quite vulnerable, so I was really glad to get up to the priory [...] I'm sure Fabiola would have she will have done that on purpose right? [...] Grief isn't comfortable is it, if it had just been a nice cutesy walk through you know picture chocolate box England, you know that's not truthful so I think it was intentional, I've got no doubt it's intentional.' (C1 P1)

'I didn't personally feel unsafe, although when I was going into the park there was one stretch where there was nobody walking with me and it did cross my mind of oh this would be a place not a place you'd like to walk in the evening, it was there was no light, it was there was trees over the pathway, but it was only for a few moments

while you walk down into the main part of the park but it did cross my mind that you'd need to be careful.' (C2 P1)

The one-to-one performance

Key learning:

- The one-to-one performance was described as a unique and powerful experience by participants;
- The Sound Walk had prepared participants for taking part in the one-to-one performance, and they felt it was important that they took part in the former before engaging in the latter;
- Particular aspects of the performance prompted participants to consider their own mortality, a powerful though not necessarily comfortable experience;
- The interaction afforded by the performance activities was important to participants;
- A degree of uncertainty and anxiety was experienced by one of the two participants in this cohort;
- There was praise for this event, and participants described feeling connected with others during the performance.

Two interview participants took part in the AHFG one-to-one performance, and both described it as a powerful experience. As one participant explained: 'At times there were high levels of emotions [and it] brought home to me how fragile life is and how close we all are to death' (C2 P1). The other participant in this cohort described how the different aspects of the performance culminated in a sense of him experiencing a unique and 'tailored process of mourning':

'I'm thinking ok so I'm in the space now, the rest of the piece will be me walking around and just us kind of experiencing fragments of some of the testaments I'd heard, it might be I don't know mementos or of the people they were talking about, they were mourning. What I wasn't expecting was that this was actually my own to some degree tailored process of mourning, having this opportunity to do what not many human beings get to experience [...] to kind of mourn one's absence, because when we think about mourning we're thinking about mourning of other people, we never think about mourning ourselves ...' (C2 P2)

Participants described feeling like the walk had prepared them for the one-to-one performance, and that it was important they had taken part in the former before engaging in the latter:

'... and what I was conscious of as we went into the second performance, is how I think I was being guided into experiencing the senses, so using the chalk and the ribbon and touching the stone, and observing things and the different smells and then the auditory, all tied into one, it became clear as we were going through what was expected of me.' (C2 P1)

'...the audio performance prior to that, that really kind of primed me and got me into that appropriate headspace I think for that performance. I was trying to think about it in my head as I'd just gone into the performance without that, I don't know if it would have had as much power I don't think.' (C2 P2)

There were particular aspects of the one-to-one performance that the participants described as prompting them to consider their own mortality. This was not necessarily a comfortable experience, but was described by both as very powerful:

'Now the next bit, I still recall how I felt, was really uncomfortable and she appeared with what looked like a body tied up, and then opened this like a shroud of what looked like other people's handiwork and she sat down and I thought am I looking at my own deathbed? And that was, it was brilliant how it was done, if that was what the intention was I thought this is absolutely amazing. But I'm looking at myself, my drawing of me with the character looking at this shroud as if it was my final days and I thought wow this is amazing. So I could see where it could put some people off

perhaps and could be very disturbing, but it worked for me, it was quite moving.’ (C2 P1)

‘...there’s something inherently powerful about standing over what in a sense is you know a representation of your body, and watching somebody perform essentially last rites on you, and then you’re helping put that body away you know and seeing that treatment, that’s a glimpse that nobody gets to see [...] being able to be present for that I think was just it was a bit of a gift really [...] there was just a real great power in that really but just really was a profound effect and moving.’ (C2 P2)

The two participants discussed the different aspects of the one-to-one performance at length, with one commenting: ‘I could recognise stages of grief along the way’ (C2 P1). As with the Sound Walk, the interaction within these activities was important:

‘She invited me to help her to tie up the sheet and then to place the last words which she cut from the sheet and to tie them onto a rocking chair which I thought was quite nice. And I love that kind of interaction, it’s almost like a buffering effect between loss and grief, but she was addressing how you might feel and how you could feel which I thought was interesting.’ (C2 P1)

‘I got to wash my hands, there was this kind of ritual with this bowl and a drop of oil in there, scented and again you can’t help but think about the religiosity of that washing of the hands, the oil, and it’s another sense, you know. I’ve had taste, I’ve had a lot of sound in the audio walk, touch, the material, a very clear acuity there regards to the materials, the muslin, the biscuit, the timer, taste and smell, smell becomes a part of that as well.’ (C2 P2)

One of the participants described experiencing some uncertainty and anxiety at the start of the performance, commenting on the unexpected language difference:

'... she started to talk to me in I thought it was Spanish and then I thought I think it's Portuguese and that put me off because I thought do I need to know the language to understand what's going to come next? And I almost said to her, I don't speak any Portuguese, can you speak English, and then something in my head said no shut up, just go with the flow. But that put me off a little bit, I wasn't expecting a different language and I couldn't understand why I was being spoken to in another language, I tried to process that since and come up with some answers. But she made me understand what was going to happen which was key ...' (C2 P1)

The participant described how she had also felt uncomfortable when invited to lie down, which again had been unexpected. The reason for doing this was not initially clear, and the participant felt comfortable once the reason became apparent:

'Now at this point I thought you've got to be kidding me, you want me to lie down, I wasn't expecting this and if I do lie down what are you going to do? Because I think to lie on your back you become very vulnerable. And I wasn't sure what she was going to do, so I'd have preferred not to if I was being really honest but I went along with this to experience it [...] and then I quickly realised that she was going to draw around me and that was fine, and she was very kind and helpful and she was making sure that I was comfortable every step of the way, so I did feel that if I wanted to decline something I could.' (C2 P1)

There was praise for the event, with comments including 'It exceeded my expectations' (C2 P1), and 'The piece could almost have its cake and eat it' (C2 P2). As with the Sound Walk, participants described feeling connected with others during the performance:

'... one can't help but feel that you're not on your own here, you're not kind of stood out here because you've got all these echoes, this kind of palimpsest, this layer of everyone who's come before you, you're literally placed on top of everyone else, all the way, you're literally tying a ribbon and tying a scrap of this kind of muslin the rocking chair, conscious of all the other people who have gone before you.' (C2 P2)

'...we washed our hands together and I really enjoyed that sharing of an activity, that we were both in this together, washing our hands ...' (C2 P1)

'...so I sit down, have the cup of tea, and then if memory serves me correct, I had to show positions of my body where I feel certain bits of grief, and the artist reflects that themselves by I couldn't work out what this was, it was like almost like a jelly of some sort, they kind of smearing on themselves in particular places, and there was something really interesting about this process of transference, of again this shared sense of grief [...] there was something about them kind of sharing the weight of it I suppose, through the body, this idea that grief and mourning is embodied, that was something that came across.' (C2 P2)

The live art installation

Key learning:

- The live art installation was described by participants as feeling very different to the preceding Sound Walk;
- For one participant the transition from the Sound Walk to the installation felt disjointed;
- There was praise for this event and, as with the other AHFG events, there is evidence of participants forming connections with others through the event's activities.

Two interview participants took part in the AHFG live art installation. Both participants commented how the live art installation felt very different to the preceding Sound Walk:

'...so we got back to the theatre and then we were in the installation part of it then. Which did feel pretty different I guess [...] the walk is kind of the journey and the kind of not the warm up but like it's kind of you know it is like reflecting the journey that you take within that and then the installation bit is [...] kind of reflective of the end of life once someone going towards the end of life and in their palliative stage and then they've finally passed and there is no more to do, you know, there is everything just suddenly like drops you know the kind of urgency and the panic and the anxiety kind of stops because they've finally passed in a way and it's just that like still space. So it also kind of felt like that to me.' (C3 P1)

For one participant, however, the transition from the Sound Walk to the installation felt 'slightly disjointed' (C3 P2). As described below, this was in part the result of a long wait between the two instalments, and the reason for the delay not being clear:

'It was slightly disjointed [...] I was very aware that I was being sort of like made to wait [in the theatre], I wasn't sure what was going on, also I had no idea of what the installation was going to be whatsoever [...] I think in my mind I thought I was going to see a single artwork piece [...] And then it became apparent that actually it was an installation of several different items going round the room and you were, you were in a queue to put it bluntly, so I had to wait for people to sort of do number one and then do number two and then do number three and then I was allowed to go in on number one, so there was sort of a slightly odd we're queuing round this room sort of feel to that room when I went in.' (C3 P2)

The participant described how the disjointed feeling was compounded by a notable shift which he described as 'a negative jarring process':

'...it was slightly odd, the person who brought me in asked me to read a sign on the wall and I was like I'm not really in a place to be reading signs and like understanding things right now, maybe that's my fault, maybe I should have taken a break between the two parts of the experience but I didn't feel that was necessary to me and then I was very much out of the experience and being told to worry about health and safety forms and being instructed how to use an app again and being told where to stand and where to go and I was like I'm not about this right now, that's not what I want.' (C3 P2)

There was praise for this event. One participant described it as 'was the most personal a show has ever felt and I've been to a lot of shows' (C3 P1), while the other said 'it was just one of the best pieces of art I've ever seen' (C3 P2) and told of how:

'...the tapestries, the different women were beautiful, and really inspiring and really really clear [...] I really enjoyed the process of hearing the story around them and hearing how they came to be and hearing what had impacted them...' (C3 P2)

As with the other AHFG events, there is also evidence of participants forming connections with others through the event's activities:

'...she had those fabric pictures of where the grief was [...] that was amazing, it was like a map wasn't it of where you feel the grief in your body and I was like wow, I loved that bit [...] She probably feels things very physically and I also feel things very physically [...] and I never even considered how grief is in the physical body, so I found that wonderful and really again it's kind of like when someone makes that connection with you and you're like ah God I'm not the only one you know.' (C3 P1)

Experiences of using the technology

Key learning:

- Participation in the AHFG events required the use of some technologies. This was straightforward for some participants, but not for all;
- Some participants experienced difficulties using the app during the walk, including when switching between different functions;
- For a small number of participants, this result in them missing parts of the Sound Walk;
- One participant commented that the technology had felt like ‘a huge barrier’ during the live art installation event.

Participation in the AHFG events required the use of some technologies. For the Sound Walk, for example, participants were required to download an app to their phone and use this during the walk while wearing a headset or earphones. For some, this was straightforward, with one participant commenting that it was ‘a nice app’ and had been ‘remarkably easy’ to use (C1 P1). However, this had not been a straightforward experience for all:

*‘Yes, so initially I had a problem connecting with the app. I was able to download and it was a bit difficult launching itself so I’m not sure whether it was a problem for my end or it was the app itself. But later on I was able to kind of get it done with the assistance of Fabiola, and I was able to get the app on before I embark on the walk.’
(C1 P3)*

‘...it was expected that we should supply our own smart phones, and I’m one of those few people who actually don’t have a smart phone, I just have a hand me down from one of my sons. And so I had to go with my partner [...] I went with my partner, starting off at the library and she has a smart phone, but we couldn’t listen to it

though ear pieces, we had to hold you know we took turns to hold her iPhone close to our ears, so that there was a sense of proximity between the two of us as well as the proximity to the different stations along the way. And there was also, we became very aware of just how noisy Lancaster can be, particularly on a Friday which is when I think when we did the walk.’ (C1 P2)

Some participants experienced difficulties using the app during the walk, including when switching between different functions. For a small number of participants, this result in them missing parts of the Sound Walk:

‘The first section was a bit troublesome, I had some trouble getting the app to do exactly what I wanted it to. There were a couple of points where the app gave the instructions and [...] I’d do it and that would interrupt the voice recording and then I couldn’t go back to the middle of the voice recording [...] So I had the choice of either moving onto the next part of the walk or and reading the transcript, or standing there and listening to what I’d listened to already, again.’ (C3 P2)

One participant also commented that the technology had felt like ‘a huge barrier’ in the live art installation:

‘I felt the technology formed a huge barrier in the installation, it just hadn’t on the walk at all, there were issues with the technology on the walk, little blips and bits and pieces but overall everything gelled very smoothly on the walk, but coming into the installation there was a big jarring moment of getting back into the headspace of what I’m doing and then scanning the QR codes and listening to the audio again felt very artificial.’ (C3 P2)

Impact of the events on participants

Key learning:

- The AHFG events had an impact on participants in a number of ways, in relation to both their personal and professional lives;
- On a personal level, the AHFG events provided some participants with time and opportunity to reflect on their grief, and to think about this in different ways;
- Others talked about how they had learned to approach issues around death and dying differently as a result;
- The sharing of experiences of grief in the AHFG events was important to participants and made many realise they were not alone in how they were feeling;
- On a professional level, there were examples of how the AHFG events have informed participants' research interests and academic practice;
- Participants are more aware of different forms of loss and grief as a result of the AHFG events, including cultural differences relating to loss and grief;
- Participants referred to ways in which they were carrying this new learning into various aspects of their lives.

The AHFG events had an impact on participants in a number of ways, in relation to both their personal and professional lives. One participant, who had experienced locational disassociation since the sudden death of her father some years ago, described the experience as 'quite miraculous' and told how she was 'very grateful for the grief walk' (C1 P1):

'I feel like the universe has sent me this walk because [...] when we went to the river and the ribbon, my disassociation went just completely disappeared and I saw Lancaster almost for the first time, even though I've been living here for [a number of] years [...] it's like a visor or something lifted from my eyes [...] I've literally had the most vivid few weeks since. 'Cos this disassociation's gone, everything, I know it's been nice weather but everything is more vivid, everything's more accurate, I'm really

in the space of feeling more present with my children. Honestly, it's been incredible [...] it's been a really fantastic few weeks.' (C1 P1)

There were a number of other examples in the data of how the AHFG events had helped participants on a personal level. Some discussed how the event had provided them with the time and opportunity to reflect on their grief and to think about this in different ways (for example C1 P1 and C2 P2). Participants talked about how they had learned to approach issues around death and dying differently as a result (for example C1 P3 and C3 P2). Here, one participant explains how the event enabled him to process his relationship with loss and grief:

'I think the artist with great sensitivity really managed to strike that aspect of balance between their own story, but also opening it out for as resonance you know found with the other types of mourning, there isn't just one way to mourn, but also providing that point of entry for me to kind of process what my relationship with mourning is.' (C2 P2)

31

The events made many participants realise they were not alone in how they were feeling, and many described feeling stronger and better as a result. The sharing of experiences of grief in the AHFG events was important to participants:

'I do feel as though I have gotten a lot of [...] strength from knowing what others have been through and what others have experienced and also realising [...] how this feels, it's a universal experience you know like it's bizarre how little we talk about grief [...] it was my first encounter of other stories, that relate to what I was experiencing at the time [...] it felt like the first time I'd encountered somewhere where it really went in depth, it wasn't just like oh I'm so sorry for your loss [...] it actually went really deep

into like how it felt before, how it felt after, how it feels in your body, how it's affected all your other relationships, how it's affected your outlook on life...' (C3 P1)

'...the stack of all the different grief maps was really hard to look at in some ways but it was also really touching to be like well there are there's 40 different ways of feeling grief on that table in one place, so that has made it easier for me to empathise or be caring to people that are grieving in different ways, I hope that has.' (C3 P2)

The impact of the AHFG events on participants' professional lives was equally wide ranging. One participant described how her Master's degree research plans had been informed by the AHFG experience, while another told how the AHFG event will inform his academic practice in the coming year:

'...this will be a case study in one of the lectures I'll be giving this year [...] I will encourage my students to do the actual audio walk and I will probably you know source some of the props [...] I'll give them chalk, I'll give them some flowers and I'll give them a ribbon and I'll get them to go and do the audio walk...' (C2 P2)

Participants talked about how the AHFG events had raised their awareness of different forms of loss and grief, along with an increased awareness of cultural differences relating to loss and grief. Participants referred to ways in which they were carrying this new learning into various aspects of their lives:

'...because [my work] is very global in nature, [I work with] people from Asia, North and South America, you know, Europe, Africa and what have you, so you'll be able to kind of see through what other people are you know talking about and to kind of move away from maybe that temptation to see things through you know a particular

perspective wholly, but to kind of understand how people grieve and how people respond to grief in different situation and in different context.’ (C1 P3)

‘...it’s really interesting for me to be like oh I know how to communicate this better in the future [in my professional life].’ (C3 P2)

Participant suggestions for future AHFG events

Key learning:

- The information received in advance of the AHFG event was described by some participants as unclear or difficult to understand;
- Some participants would have liked more explanation and support to accompany the AHFG booklet with which they were provided;
- Many participants commented that they had not known what to expect of the AHFG event. This seemed more important in relation to the one-to-one performance than the other two events;
- Some frustration and annoyance was expressed about the absence of the male experience of grief within the events. There was support from participants for the project to also include male voices and experiences regarding loss and grief.

The information received in advance of the AHFG event was described by some participants as unclear or difficult to understand. As a result, one participant messaged a friend for help (C3 P2) while another sought support at the event itself (C1 P3). In addition, some participants would have liked more explanation and support to accompany the AHFG booklet with which they were provided:

'Yeah so, they gave us some book a smaller book, you know a grief map and I think it was very fascinating, talking about you know which or where in your body do you keep your grief, I think that needed much more maybe exploration, we did talk about it but I know it's very tempting to believe that you know issues about grief of course it's near your memory and your memory's in your head so what about the stomach, the hands and that kind of thing so that was an area that I quietly didn't kind of grasp well. I was looking forward to maybe a future session to kind of go into that one more in detail ...' (C1 P3)

'I think that it would be quite good for maybe some sort of interaction after the walk [...] it might take some people by surprise how affected they are. And I'm just wondering if there was some way that they could have a paragraph afterward with I don't know if there is this but it wasn't accessible, I didn't know about it, just to give them some numbers to call or some sort of a place to go if they needed to talk to someone after it.' (C1 P1)

Many participants commented that they had not known what to expect of the AHFG events. This seemed more important to participants in relation to the one-to-one performance than the other AHFG events. One participant had found some information about the event online, stating that 'the trail will lead you to a home', but this had not been the case:

'I thought I was going to end up in a house, that the walk would end in a building somewhere that was an actual house and I had a feeling that I was going to go into this house and there'd be some actors in there and they would interact in some way about a body that was lying in the house, that's what I'd built up in my mind. So I was really surprised when it ended at the theatre.' (C2 P1)

Another recurring discussion in participant interviews was the absence of male voices and narratives in the AHFG events. Male participants in particular commented on this and noted that it had not been clear from the event information that it would focus solely on women's experiences of grief. Indeed, the absence of the male experience prompted frustration and annoyance from some participants, with one participant referring to it as the 'silencing of male voices' (C1 P2):

'I think [the gendering of grief] is a real problem. Inevitably grief becomes gendered. I mean it's interesting the subject of the conversation in the people who died were often male figures [...] It was a strange, it just fits into too many clichés to my mind. You know along the lines of emotionally articulate women and you know emotionally constipated males who can't you know who have to be strong for everybody and don't give voice to their grief.' (C1 P2)

'I didn't expect it to be all female and [...] I remember myself feeling ready to be less touched by it, to have less of an impact on it on me because of that, and that just wasn't the case at all.' (C3 P2)

It was suggested that future events make clear the subject of the event is women, perhaps with a strap line accompanying the title. However, there was support for the project to also encompass the male experience of grief:

'[The event] could have a strap line [...] something that would make it clear, or even this is part of a long term project that will have a male side to it later on.' (C1 P2)

'Men are terrible at grief [...] So I wasn't surprised that it was talking about female experiences of grief, because I think you'll get more mileage out of that. But I think it would be interesting to see a piece of art that was about the male experience of grief.' (C3 P2)

The importance of interaction and connectedness

Connectedness is an overarching theme throughout the interview data, with participants feeling connected through the AHFG events to the voices and stories they heard, to locations and places they visited, to the artist, and to themselves. These connections were made possible through the activities and interactions within the AHFG events. As a result of these interactions and connections, participants were able to engage with and reflect on their own and others' experiences of grief. These positive experiences tended to be in contrast with participants' previous experiences of loss and grief, which were often characterised by aloneness and isolation. The AHFG events were a welcome opportunity for many to explore and process their thoughts and feelings about loss and grief:

'...to kind of engage with the subject and with loss and grief and mourning, to actually have that opportunity to meditate on it was wonderful because it's something that we don't usually set ourselves time to do unless unfortunately we have to.' (C2 P2)

'I carried a lot of guilt around and I carried a lot of problems around it [and the walk] made me realise the different kinds of grief in that regard and the difference between guilt and grief and how the two get tied up a lot of the time [...] the walk, the audio and the talking of the artist was very good at that in that she definitely guided you into thinking positively about grief and about positive people you are grieving for rather than negative people or negative experiences.' (C3 P2)

'It left me feeling [...] astonished that there isn't more opportunity to explore these feelings, realising the reason why is probably because there's a lot of shame and awkwardness about discussing such feelings [...] I'm [in my thirties], why is this the

first point in my life where I have been able to process death outside of a funeral? And outside of my own bedroom.’ (C3 P1)

Conclusion

This is a small-scale evaluation involving seven participants. However, the findings from the interviews demonstrate there is both an appetite and need for events such as *A Home for Grief*. Among the evaluation participants, there is a desire for a shift in attitudes and approaches to grief and loss, and the suggestion that theatre is one way to achieve this. There are some learning points to take on board and consider regarding the information and support provided to participants both in advance of and following the AHFG events, along with participant feedback about the technology. The absence of the male experience of grief from the AHFG events also requires some consideration. It is clear, however, that the AHFG events were positively received and experienced by the evaluation participants, and had a positive impact on their lives. Participants learned about and developed their understandings of loss and grief – and often themselves – as a result of the AHFG events, and were carrying this new learning and understanding into various aspects of their lives.

