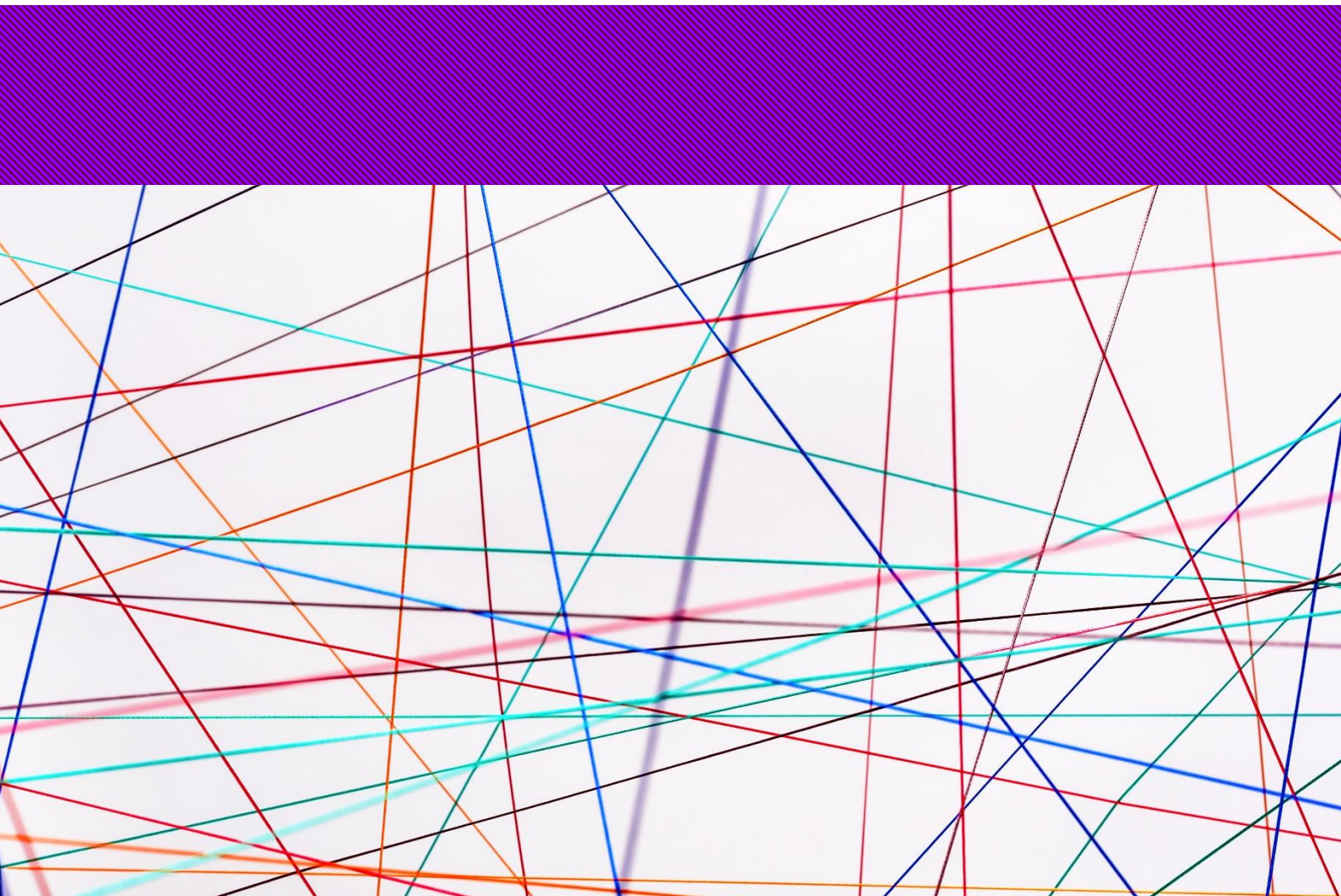


We've shared something in this room

**An Evaluation of Rethink Ireland's Impact Fund for
Munster Four Compassionate Culture Network Projects
Run Through Irish Hospice Foundation**

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Introduction

The experience of bereavement caused by someone's death is often a major psychological trauma and considered one of the most potentially negatively impactful life-changes that a person can experience (Brown and Harris 1978; Caplan 1961; Rahe 1979). Bereavement has all of the criteria for 'psychosocial transition' in that it requires the individual to undertake a major revision of their assumptions about the world, is lasting in its implications and takes place over a relatively short space of time so that there is little opportunity for preparation (Parkes 1971).

Theories of Grief

There exist various generalised theories and conceptual frameworks of grief and grieving which have developed over time. Early work by (Bowlby 1961; Freud 1961, Winnicot 1961 - 1986) suggested that grief could be both symptomatised and managed over a short period of time (Lindemann 1944). Kubler-Ross (1970) and Worden (2008) proposed the concept of grief as something experienced in 'stages' or 'phases' that could be moved through and that grief would resolve when an individual moved through the phases in order to detach from a deceased person.

More recent models of grief theory promote the idea of a dual process model of coping where adaptive coping is enabled by both alternatively confronting and avoiding the trauma of loss, allowing for adaptation (Stroebe and Schut, 1999). This evolved into a social constructivist approach to 'meaning-making' in grief counselling involving the creation of meaningful narrative and active participation in response to the loss in a social context, so that grieving is situated as an interpretative and communicative activity (Neimeyer, Klass and Dennis 2014).

The purpose of grief has also produced different theories. Some consider it the inevitable side-effect of the breaking of a loving bond (Parkes 1996) or it may be a way in which we can adapt to a new reality without the person who has died (Attig 2001), a way of 'relearning' the world without someone, albeit a very painful one. A part of this relearning can be described as finding a way to carry the person's memory and meaningfulness forward in the life of the bereaved individual – what is termed 'continuing bonds'. These bonds may often be symbolic in nature, and necessarily internalised (Klass, Silverman and Nickman, 1996)

Helpful concepts to consider in grief

A number of concepts relating to grief are useful to consider and are explained here:

Prolonged Grief Disorder or Complicated Grief

While grief is recognised in all models as a 'normal' process, it should be considered that, for a minority of people (7% to 10%), grief can be derailed and may present significant clinical challenges and an inability to function. There are now established criteria in ICD-11 and DSM-V to assess for the presence of Prolonged Grief Disorder (PGD). In parallel with the establishment of these criteria, there are proven

therapeutic interventions available to support people who develop such difficulties (Prigerson, Shear and Reynolds, 2022).

Notwithstanding the adoption of criteria for PGD, it should also be noted that the development of such medical models has raised concerns that medicine has become involved in the 'policing' of grief, framing grief as an illness to be cured (Walter 2000) rather than a psychosocial transition that requires support for bereaved individuals (Parkes 2007). Further work remains to be done to align 'normal' and complicated/ disrupted or prolonged grief (Eisma 2023)

Disenfranchised Grief

So called 'appropriate' ways of grieving may be learned and constructed through observing and interpreting the grief of others (Neimeyer et al, 2014) but when someone's grief is not recognised or validated by those around them, this may result in 'disenfranchised grief' (Doka, 2019). A paid carer may experience grief in the wake of a service user's death. As their relationship is interpreted as monetary, however, the grief of the paid carer may not be considered an appropriate reaction to the death.

Anticipatory Grief

The notion of opportunity to prepare for the death of someone is contained in the concept of 'anticipatory grief', most often when individuals are caring for someone in stages of advanced disease (Sweeting and Gilhooly 1990). Anticipatory grief, however, rarely ameliorates the grief that is experienced after the actual death (Shore et al 2016) and, instead, reflects the losses experienced in real time associated with illness, caring and dread of the future with the person who is ill.

A Good Death and the COVID-19 Pandemic

An idea that is now central to the discussion on death and dying is the concept of a 'good death', which is characterised by some level of control over events surrounding death (Block and Parry 1982). A recent Irish Hospice Foundation (IHF) report defines a good death as one that is 'comfortable, calm and free from pain or suffering...[honouring] the end-of-life wishes of the patient, allowing them to die with dignity in a place of their choosing with those they wanted present...in the home...where families and carers were empowered to provide suitable care to patients' (IHF 2023).

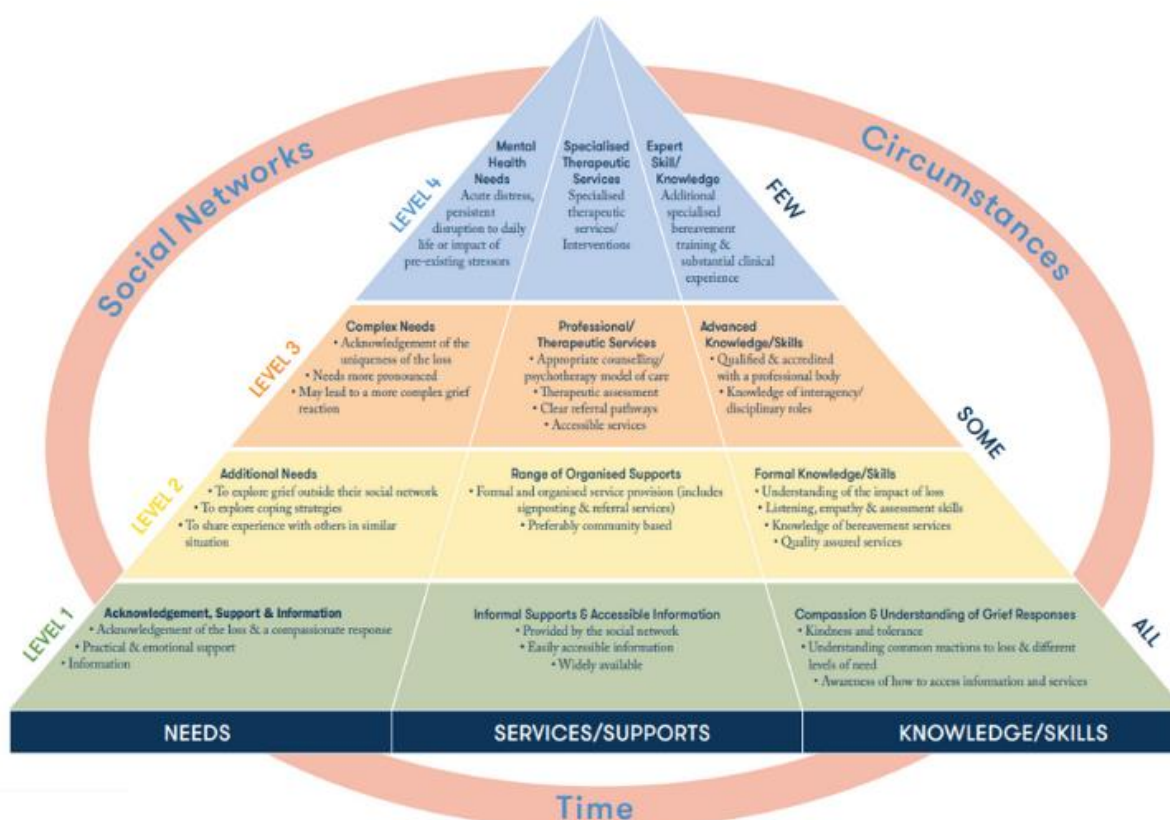
'Bad deaths' on the other hand are characterised by physical discomfort, social isolation and psychological distress. A bad death can be one of the factors that lead to a bereaved survivors' symptoms of depression, anxiety and anger (Wilson et al 2016). During the COVID-19 pandemic, this was exacerbated by the erosion of the normal coping resources of social support and face-to-face mourning rituals which provide a sense of community (Carr, Boerner and Moorman 2020)

After-death rituals such as funerals were restricted during the COVID-19 pandemic and while the effect of this is inconclusive in terms of the mental health of the bereaved at the time (Burell and Selman 2022) it could be considered that the wider social circumstances may have led to many 'bad deaths'.

Public Health Model of Bereavement Support

All bereaved people have needs. The public health model of bereavement care, as set out in the Adult Bereavement Care Pyramid, privileges social support, compassion and access to accurate information for the majority of bereaved people.

The model, however, acknowledges that people’s lives are different in terms of complexity, social and economic stressors, mental health challenges in bereavement, the nature of a death (whether sudden or expected, violent or natural) and the nature of the relationships lost also differ. Consequently, the model describes that, as needs become more complex, so a range of services to meet those need should become available. These services may include community peer-support (such as in the case of bereaved parents) or more formalised counselling up, to and including specialised treatment for Prolonged Grief Disorder (Aoun et al 2015; IHF 2023). In the model, a range of supports are described. These range from Level 1 Compassionate Community approaches up to Level 4 therapeutic approaches.



Irish Hospice Foundation Response to Bereavement during the COVID-19 Pandemic

Recognising the level of loss and, in some instances, extreme loss during a period where normal patterns of grieving were disrupted, IHF engaged in a number of grief-support initiatives. The Bereavement Support Line was set up as a national service by IHF in partnership with the HSE in June 2020, and an extended set of information resources on coping with grief in exceptional times was made available through the system. As the pandemic persisted, IHF established a Compassionate Culture Network (CCN) pilot programme in 2021 – 2022 as a rapid COVID-19 response with the support of Creative Ireland. Through the pilot programme, IHF explored the programme's potential, using Family Resource Centres and cultural centres as community hubs for the CCN.

The concept of the CCN was built on the belief that the arts can be a way to help process sensation into meaning. Linking experienced artist-facilitators with the wider public in properly resourced sessions initiated meaningful conversations on death, dying, and bereavement. It also signposted other health-related services available locally for those in greater need. IHF identified a local artist-facilitator, a local support worker and a venue. The artist-facilitator and support worker co-designed their approach with IHF. The artist-facilitator then led a 12-week, one day a week, programme on the theme of 'loss' for either broad (all comers) or specific (targeted populations) groups of participants.

The model was that IHF provided grief awareness training and support for the CCN artist-facilitators and support workers who, then, connected with each other as peers in a learning network. As peers, their connection would enable them to continually learn from each other. Where available, they would also connect with local health systems and other bereavement supports, such as charities and / or the HSE.

Financial resources were used to address the fees of artist-facilitators and support workers, materials, venue rental where needed, and IHF provided online support and production support.

In addition, IHF used its social networks, communication / marketing tools, newsletters, and direct referrals to promote attendance at the activities. It also engaged with Local Authority Art Officers and CEOs, HSE PsychoSocial Response Support Officers, and the Public Participation Networks (PPNs) with the aim of highlighting the CCN.

Evaluating the programme

With the concepts of how and why people grieve being contested in the literature, as indicated above, it is clear that there is no one way to construct a summative evaluation against a set of pre-existing standards or quantifiable goals. What is more helpful is to use a qualitative methodology to explore what the experience was like for those concerned, using themes which appear in the literature that appear to best reflect the way in which the CCN was conceived, in accordance with a Theory of Change methodology (see below). To do this, it is important to indicate some issues that have shaped the evaluation framework.

How do people grieve?

All people grieve differently and ways of dealing with bereavement are influenced by the norms of an individual's cultural identity which, in turn, inform help-seeking and coping (Smid et al 2018).

On an individual level, people may be *intuitive* grievers, where they are focused on emotions and feelings (how they *felt* during their grief), or they may be *instrumental* grievers (cognitively *working through* their grief via projects and tasks). Smid et al (2018) propose that grief counselling may suit intuitive grievers but not instrumental grievers and so the CCN may provide an otherwise unavailable outlet for processing aspects of grief (Doka and Martin 1999, 2011).

Bereaved people may need to dip into and move away from their grief as part of the challenge of coping with loss (Stroebe and Schut, 1999). The activities in the CCN provide an opportunity to engage in the work of grief.

A way of providing a counterbalance to disenfranchised grief, is to provide a social space where grief can be acknowledged by the grieving person and potentially shared with others in a group. The acknowledgement of grief can be symbolic, through art as much as through words. Again, the CCN provides a forum for addressing this type of grieving.

As a central aspect of grieving can be to find meaning while relearning the world and to create a continuing bond and connection with the person who died, then engagement in new activities and arts-based exploration, as provided through CCN, may provide a helpful forum.

Finally, Romanoff's model (1998) on grief rituals provides us with a frame of activities within which the CCN work might be explored, i.e. that people are:

- Continuing the connection with the person who is dead
- Marking a transition to a new role without the person
- Transforming their sense of self

This evaluation recognises the variety of responses within grief and so it is not about whether those involved reached some standard or agreed end point but how they experienced changes during the process. It also explores how people felt but also what they did. It is mindful of ways in which they connect to the deceased person, their experience of some type of transition and whether they felt changed by the process.

What is helpful to bereaved individuals?

The literature identifies helpful support as that which includes contact with a similar other person or group, and an opportunity to express feelings (Lehman, Ellard and Wortman 1986). The most often used sources of support are informal (family, friends) and bereaved people receive the greatest amount of positive support from their social networks This has been established in Australian research and replicated in Ireland (Aoun 2018, Aoun et al 2020). Emotional support that is the most important includes holding a space for someone to grieve, being available, listening, being open to emotion and not trying to fix someone

(Cacciatore et al 2021). This support can be characterised as fundamental to Level 1 and 2 of the Adult Bereavement Care Pyramid model.

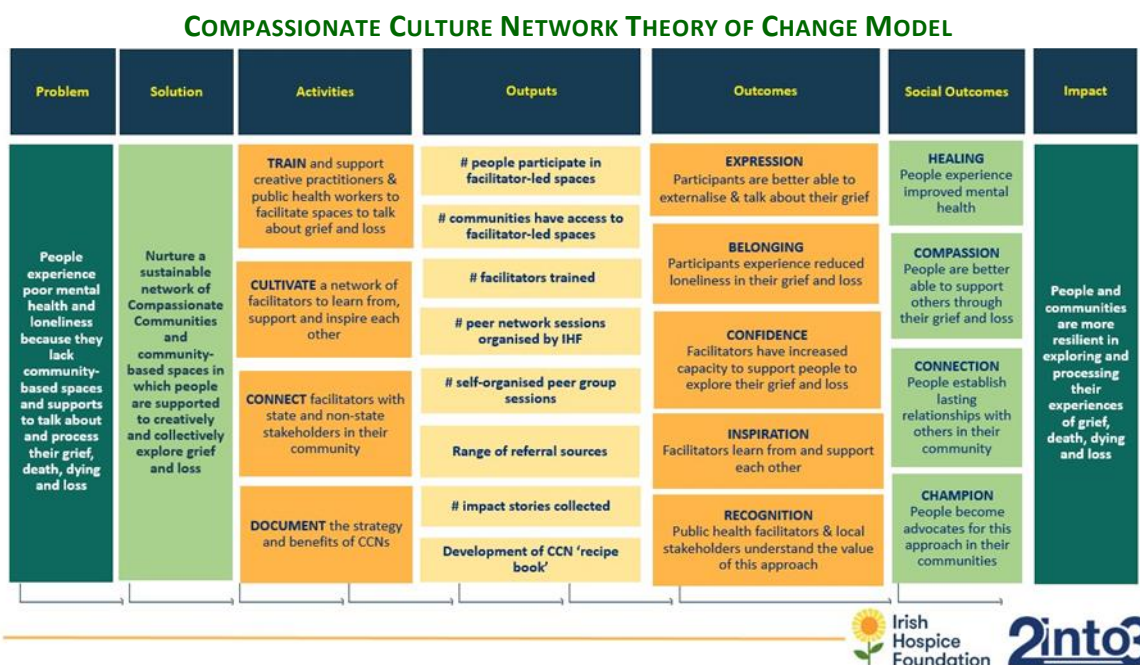
There is empirical evidence of the need to incorporate bereavement supports into community development approaches, such as can be seen in the ‘compassionate communities’ movement (Aoun 2018, Aoun et al 2020).

As noted earlier, the IHF introduced a CCN as a pilot over the period at the end of the COVID-19 pandemic. This was run in six locations, during the open/closed periods of 2021 to 2022. Its focus was on producing a service and intervention in this context. A previous evaluation of this pilot suggested the benefit of peer networks for project leadership as well as generic values for participants though, at the time, more granular observation was not possible.

This evaluation is focused on the kinds of emotional supports that are provided, offered and encouraged among the group but also conscious that other supports such as instrumental support, like people doing favours for one another, may also arise. It considers how ongoing community development and advocacy for this approach are being promoted through people’s experience of the CCN.

Evaluation using a Theory of Change Model

Evaluation provides an opportunity for learning and adaptation (Hall 2017). In any new initiative, it is useful to establish a framework against which evaluation is possible. While the nature of grief is an intensely individual one, it is possible to utilise a Theory of Change framework for evaluating the learning outcomes of the pilot CCN programme.



The Theory of Change Model suggests a communitarian approach to consider a collective element within which people can find their own grieving processes. It is about creating a

community that validates someone's grief so that it no longer feels inappropriate or disenfranchised (Doka, 2019).

It encourages compassion as a central dynamic to allow for more helpful grieving. In terms of a model for understanding compassion, while Strauss et al (2016) recognise that there is not one consensus model of compassion as a concept, they propose the following elements would be part of such a model:

- 1) Recognising suffering
- 2) Understanding the universality of suffering in human experience
- 3) Feeling empathy for the person suffering and connecting with the distress (emotional resonance)
- 4) Tolerating uncomfortable feelings aroused in response to the suffering person (e.g., distress, anger, fear) so remaining open to and accepting of the person suffering
- 5) Motivation to act/acting to alleviate suffering

This construct also situates loneliness as an issue in grief, which is borne out in the literature (Fried et al, 2015).

The Theory of Change model allows the evaluation to focus on the facets of bereavement support that the literature indicates is most helpful to the bereaved in terms of social outcomes.

There are four categories of social support defined in the literature that have been widely used over the past four decades. Structures and processes of social support, broadly speaking, include:

- 1) informational
- 2) instrumental
- 3) appraisal
- 4) emotional

All of these contribute to a sense of perceived and actual connection to a caring social system which are key components in compassion networks (House, Umberson and Landis 1988).

What does the evaluation explore?

In viewing bereavement as a psychosocial transition which requires compassion it is important that we gain an understanding of how the process of grief is ameliorated by participating in the CCN workshops. To that end this evaluation explores the following:

Social Outcomes:	
Social Outcome 1	Did participants feel a sense of healing or improved mental health?
Social Outcome 2	Did participants feel enabled to offer support to others by using compassion?
Social Outcome 3	Did participants feel they had built a lasting connection with others in their community?
Social Outcome 4	Can participants advocate for the CCN workshop approach?

Outcomes	
Outcome 5	Do stakeholders understand and articulate the value of the approach?

Methodology

This data gathered for the evaluation was during four recorded focus groups of 90 minutes each, conducted over Zoom, which were arranged by IHF. Information was provided to all 16 participants who all provided verbal consent to their participation and confirmed that they were aware of the purpose of the evaluation, that they could withdraw at any point or ask for their data to be removed from the study following the workshop, without consequence to them.

The schedule of focus groups was as follows:

- The first was with **six participants** on the morning of Thursday 7th September, four of whom were together in one physical space with the final two participants on Zoom within their home environments. The group of four had been part of one workshop group, while the other two were in two other workshops
- The second focus group was with **five facilitators** also on the morning of Thursday 7th September. Four of the facilitators had worked together, while one had worked in a different part of Munster independently of that group. One facilitator had connectivity issues and so only contributed for part of the workshop
- The third focus group was with **three stakeholders** on Monday 18th September who provided some level of organisational support for the workshop in their area. Two were based in local authorities and one was in an arts centre
- The final focus group was with **two facilitators** on Friday 22nd September who had worked together on workshops in a particular geographical area that had yet to be represented in other focus groups

On completion of each focus group, the recorded discussion was transcribed and anonymised. Repeat words which can occur when spoken by participants were also deleted. Once this transcription was completed, the audio files were deleted.

The transcripts were then systematically analysed and coded against each of the Social Outcomes and Outcome 5 listed in the Theory of Change model supplied by the Irish Hospice Foundation.

Due to the nature of the work, it was decided that the evaluation should, where possible, rely heavily on the directly reported responses of participants in the focus groups in order to illustrate the effect of the workshops on all concerned.

Social Outcome 1: Healing

Did participants feel a sense of healing or improved mental health?

This section considers the ways in which participants considered that they went through some type of healing or improvement in their grief and how that was expressed.

Recognition of the need for healing

All participants stated particular losses of people close to them with some identifying something that remained unresolved or prolonged within their grief:

[P5]: So I still had a lot going on in my own head, so I thought I would go.

[P6]: Yeah, I think with my grief anyway, I think, because I've no one in my friend group that went through it, it's sort-of... not hidden but... it's not talked about in our day-to-day when I meet up with people.

One participant also stated that they had been involved with a local group that had done grief awareness training so it is possible that they saw this as further training in the area of grief, regardless of the fact that this person was also dealing with the death of a relative. While this is just one remark from one participant, it may be interesting to consider whether participants need to 'justify' to themselves as to why they attend the workshop, such as whether their grief is 'bad enough' to warrant attendance.

This is further reflected in one facilitator's experience of trying to tap into pre-existing community organisations and groups where trust had already been built in order to access participants for the workshop:

[F7]: So one of those groups, some of the participants came because they were on a break... their worker was gone. They came anyway themselves. And I think their feedback is actually: 'This was not that [heavy]... it was more thoughtful, it was more contemplative. We'd like actually, for them to come and do it with us again'. So I think that's the change in the perception of what this might be.

One facilitator also spoke about tapping into pre-existing community organisations and groups where trust had already been built in order to access participants for the workshop. They expressed concern, however, about the significant time that this required.

Articulating the difference it has made

A number of participants did express a transition or resolution that had occurred for them during the workshops. These expressions were based in metaphor such as being a closed book that is now open or of putting their anger away in a locked box:

[P3]: I know that when I joined the group, I was very much a closed book within my grief whereas..., put it this way, by the time we were finished, the book was opened and some of the pages were turning. That's all I can say to you, I was beginning to see a little bit of light outside the darkness and definitely the group helped with that.

[P5]: I had a lot of anger from the time my [family member] passed away when [the person] was diagnosed with the [degenerative condition]. And I got past that anger.

Now, I think of [the person] more pleasantly and happily. I've just much better thoughts. And I've that side of it put away in a box now and locked up and accepted. So for me that's where, yeah, I think that was probably one of the ones that was in the back of my head.... but that was something I always had with... something I could never talk about anybody. Yeah, so definitely yeah. That was good for me.

Another participant identified the building of a skill through exposure. By having a space to speak about the person who had died, they built the confidence to be able to do that without it feeling inappropriate:

[P6]: But I think, yeah, my own confidence. I think I'm okay talking about grief anyway. But I think the more I talked about it with strangers, the more helpful it was for me. I think my confidence talking about grief. Yeah, my confidence talking about this person that, you know, no one knows. It's really just explaining who it is and what happened. And I think my confidence talking about grief, I think anyone can say like, 'Oh, I lost my relative', and then that's sort-of it. You don't ask any questions. But once you say like, 'Oh, he was like this' and you tell their personality.

Facilitators also reported on examples of the kinds of differences they had seen in the workshops. One facilitator relayed an incident where one person had been unable to speak about the tragic death of a relative:

[F7]: She'd never told us that before. But it was a really, really important step for her to be able to say it and realise that we, there was nothing that came back on her. We totally held her for that. And I know at the end of the meeting, she gave me a huge hug. I just felt a sense that she had been holding this for years, years and years. I'm sure people knew about it, but to actually speak openly about it. The trust was built. And she was able to say: 'Yes, this was what had happened'.

Emotional content of the work

Participants did recognise that there was potential for a high level of emotional content in the work, even if this did not actually materialise in the workshops:

[P4]: I mean, this is completely new. I've been to artists' sessions. This is completely on a different level, on an emotional and psychological...measure.

It was also acknowledged by some of the facilitators that the work was very emotive:

[F5]: I've delivered a lot of, you know, over the last 20 years, a lot of workshops, and I've never been in a workshop where people have cried so much... Did tears, you know, and I've had, I've worked with young people and children where they've got a bit stropy and maybe cried a bit, but not the emotional level or extent that this workshop took people to, which... yeah... was amazing.

[F6]: How close their grief was to the surface, because at many points, there were, you know, it was bordering on tears. Although I don't think we had anybody break down in tears but, you know, you could feel that grief close to the surface for some people.

Facilitators did recognise that these emotions were not necessarily difficult or oppressive:

[F5]: Yeah, maybe I didn't think about it too much. I didn't. Yeah, I didn't know what would come up. And I don't think too much came up. Actually. It was just quite an emotive experience. I don't think it was heavy or overwhelming. It was just it just emotions came up. And it was amazing to it was it was an honour to be amongst that really...

High emotion, however, is not a given for workshops with one group not eliciting the same level of raw emotional response:

[F2]: We've been having those conversations naturally, I think that when I went to, to do the session with them, there was an expectation that it was going to be a big, heavy, traumatic, y'know therapy lots of tears, nobody ever cried in any of my sessions. Just there was no, I had no tears at all. But actually, at the end of that one session, one of the women said, said, 'Thank you. So this was such a thoughtful session'

This was reflected in the comments of one participant who had worked with that facilitator. They recounted that, at one stage, a juggler came in and taught them how to juggle. This was then referred back to later in the focus group:

[P6]: Yeah. Like I've told my friends about it. And I think one of my friends had this really, she just thought like, we're all sitting in a circle crying. That was her grief that she thought was happening. [laughs] And I was like: 'Well, I've learned to juggle' like that's what everyone says just like: 'Oh my God, I never thought like you'd be doing that'. I was like: 'Yeah, like, it's not just sitting in a circle crying your eyes out. You can do more than that about grief'.

This approach may challenge the perception of what 'should' happen at these workshops and that while it may be appropriate and necessary to allow participants to express or experience strong emotions during the workshops, it is not necessarily a given. Strong emotion is also not a key indicator of the success of the workshop.

There is an exploration of the distinction between this work and therapeutic practice under Outcome 5 later in this report.

Social Outcome 2: Compassion

Did participants feel enabled to offer support to others by using compassion?

Considering the model of compassion proposed by Strauss et al (2019), what is explored in the data are instances where participants recognised suffering; understood grief as a universal experience; reported empathy; showed tolerance of difficult emotions; and were motivated to act.

Recognising suffering

It is suffused throughout the data that this is a space for convening people who are or have experienced difficulty. It is a given for all involved rather than something which might not be acknowledged:

[P4] You can go and talk with like-minded people in a safe environment, who understand that there is an emotional content to this.

[P3]: You know, maybe within the group, around teatime or that to have maybe ten minutes would be adequate, eh to say to somebody: 'Is anybody really hurting badly today? Does anybody want to say anything in particular? Could we have a little bit of a chat?'

Understanding grief as a universal experience

Participants and facilitators did acknowledge the universality of grief and that while individual reactions to grief may be different, the experience has a universal element:

[P4]: And, but I did know, it is, you know, a subject that everybody has to go through at one time or another. And it's an important thing.... And of course, when you get to my age, which is quite considerable, you do lose people on the way.

[P4]: And everybody tries to make sense of it. But I find poetry things like that very, very interesting. It resonated with me.

[P1]: So and maybe, during the workshop too that, maybe to recognise that, you know, we were all grieving in different ways. That that we do, you know, it's a personal thing is like our fingerprints, the way we grieve

[F7]: It's everybody experiences it; everybody goes through grief. But we don't often have the opportunity that this group has created. Yeah, I mean, even for myself, you know, I've kind-of been mulling over deaths, recent deaths that have, that I haven't had a chance to do anything with, you know, in terms of honouring or thinking about talking about. And I think that's the same for others in the group.

One element to this recognition of the universality of grief is the motivation for these statements. It may be that, by placing grief in a universal frame, it provides people with 'permission' to give time to this work, and that while everyone grieves differently, this is a 'normal' experience that is shared among humans.

Reporting empathy

Once again, considering that most workshops were attracting people who were bereaved, it is unsurprising that people expressed empathy for others in their groups:

- [P2]: And I suppose the contribution I would make is that there was very clearly within this group, a wonderful comradeship, a wonderful acknowledgement of similar loss. And we could talk about that as much or as little as we wanted to. And we were there to support each other and to benefit from the support of each other.
- [P3]: And I really honestly think sometimes people don't say, and they go through this 'You poor thing and you don't drive, and your [family member] is dead and you've no family' and you feel like saying, 'Keep going' [laughs]. And they think they're helping, but it can be hard enough to get somebody who can genuinely listen and your... have your back as it were, so that I found with the group.
- [P2]: And, you know, and it being okay to laugh and just putting all of those things... And when somebody else says and you hear back to you, 'I know', you know that they know, and they're not saying that in the way that 'You know yourself, like'.
- [F1]: Um, I hope, and I think because I have heard it said that often they felt that they were no longer alone in... in their sadness and, and that they sort-of had this kind of sense of belonging. And, yeah... it's something about camaraderie and this feeling of, like, being in it together. And, and he actually used the word 'love' as well, you know, that he felt that love in the group.

Showing tolerance of difficult emotions

As mentioned previously, the workshop settings were not all emotionally charged but for those who did identify that difficult emotions emerged, it appears that there was a high level of acceptance of those emotions:

- [P3]: So I very quickly learned that in certain situations, you did not shed a tear. But here was some place you could; you felt comfortable, you didn't feel different. Somebody else took time to say, 'Are you alright?'. And that's what is so important. Yeah, they were... I actually wrote an article about it and I'll send it into a paper sometime, to say: 'It's alright to cry'.
- [P6]: I think when things... hard things come up, I think all you have to do is just sort-of sit with them and just try and be as comfortable as you can [...] But yeah, I think you just sit with people, I think whatever, whatever. You mirror back what they feel, I think yeah.
- [P5]: There was some very emotional times and I think everybody at some point, did shed a tear and open their heart up fully. And we would sit with it. Somebody might put their hand across the table and hold yours, somebody else might get up and give you a hug, you know. It was supportive, and everybody understood, and everybody was ready for you just to keep talking, probably when you needed to, and continue talking and not keep interrupting. Yeah, it was good.
- [P2]: And therefore, there was no need for anybody to feel any apology, or any discomfort or embarrassment, or any of those things that... because if I'm not crying now, I will be in a minute, or I was a minute ago. It's that kind of a... And I totally get that they need to cry, I totally get the feeling of... it being strange to laugh.

[F7]: So we try to... with some of the participants as well found bits of poetry, and we sourced bits of poetry, to try and bring out actually, these difficult moments. But they were held in the group really well, you know, if somebody what you felt was, was really resonated with something and felt very emotional, you know, that there was a silence and an understanding and, you know, there was, nobody tried to stop it, or, you know, correct it, there was no correction needed.

Motivation to act

As can be seen from the data above, people did act within the moment, reaching out a hand, giving a hug or simply remaining silent rather than trying to fix or 'correct' an emotional response. There was also, in the data, two considerations of how ill-equipped people beyond the workshop have been in being able to act when someone is bereaved but that even this question is complex:

[P2]: I think one of the things with that, because we're all sharing the same experience, and because we talk about what people outside might be doing wrong, not knowing what to say or not... And then we were talking about well 'What *do* you say?' and we kind of shared with each other what we would like people to ask us. And, you know, it's okay to not know what to say and just to give you a hug or if not, it's okay to not know what to say. And you don't have to go... be embarrassed by that

[F6]: We had discussions about what could people do? Because one discussion came up that: 'People don't know what to say to me; people don't know. Like, they see me in the street...' And this was one of the participants that had just had some... lost somebody. And they said: 'They don't know what to say to me. They... some... they don't know whether they should ignore me, or they feel uncomfortable'. And we had a discussion about what is the right thing to say; is there a right thing to say, you know, is there a right thing that they could do? And that kind of opened up lots of discussion. And basically, everyone saying that: 'We understand'; no one knows what's the right approach. So everyone's just trying to be kind and trying to show you that they care, but there is nothing that can particularly take away your pain.

Social Outcome 3: Connection

Did participants feel they had built a lasting connection with others in their community?

This section considers the social connections that were built by participants through their involvement in the workshops. It also explores if these connections have a particular purpose or functions in line with House, Umberson and Landis' model (1988) of instrumental, informational, appraisal or emotional.

Building relationships

A number of respondents reported that they will be meeting up or keeping in touch with one another after the workshops have finished:

[P5]: And yeah, we're still meeting up. We're meeting up again now hopefully at the end of the month. So yeah, it was very beneficial.

[P3]: She's given everybody her phone number and we're meeting up in a few weeks.

[P3]: we think that, you know, the friendships we have made, will continue.

[P2]: I had and would have a strong hope that... not that the grouping would continue in a formal setting necessarily at all, but that the that the individuals who have met and shared would continue to meet and share.

And this was confirmed by the facilitators in two locations regarding their comments:

[F5]: During our feedback session, there was something that came up that would... we'll be able to wink at each other in the market and know what we meant. You know, you'd have a little wink, 'you know', 'you know'; it's something we've shared, we've shared something in this room'. And, and it felt really sp... and tender, definitely, that shared experience. And that was not... and there was no hierarchy at all, between us and the participants. We all have moments of, you know..., so that was... Yeah, I think that definitely, they would have felt it was very inclusive.

[F6]: But definitely, and I think some of the people in the group would have known each other to see each other or, you know, say hello to type-thing. But I think, even now, what like, going forward, they've all become much closer, because of the stories that they've shared that I'd say even there's friendships that will have come out of this, that they feel they have the support of that person, because they both sat in the same room and shared their story. And now it won't be a case of just walking past each other in the street. So that was really nice to see.

[F5]: And even some of them, we've got a WhatsApp group, they've decided to maybe try and run it without us in [location] and continue the process without... just as a group, because they felt empowered to... they knew what, you know... they enjoyed the process, and they felt like they could do it themselves.

Having a sense of closeness and bonding

The participants also recognised that there was a sense of bonding and closeness built up through the workshops.

[P5]: I wouldn't be a big talker in the group. Individually, in between and over the coffee, you know, you talk to the person beside you... to talk openly, when you knew everybody, and they knew who you were and who you were talking about. You might not express as much as what you wanted to say but, one-to-one in between, you did the talking.

[P1]: I felt it was a lovely... as [P2] says and the others, it was just a comfortable group. We bonded so easily, and I suppose when people are sharing their vulnerability and that's really what brings the closeness and it did that, yeah

[P3]: I had to miss one session, and I just hated missing it. I felt... So when I came back, one of the artists said to me, 'We really missed you last week'. So that really made me feel that I was so much part of the group. Very bonded. You know, it had been great to bond us, again, as I said, with the, with the vulnerability, sharing the vulnerabilities. So it was a part of that, that I was important in this group, you know?

[P2]: Yes, I would have been conscious... I don't know that there was anything that somebody said, but I would have been very conscious of there being a bond with the other people individually and collectively, when I had left the room. [...] they were people that were important to me, and, and I knew that... I knew that was replicated, I knew that was shared, it mattered how they were. And that, that, there's great learning in that.

It is also worth remembering that a number of these workshops were taking place in towns rather than cities and so there was a likelihood that people would know of the other people participating even if they did not have a prior relationship with them:

[P5]: I knew everybody except one. Some of them I knew quite well, because [L3] is a small town. So everybody knows everybody, you know, you either know their younger brother or their older sister. There was one that I... lady I never met before.

This, of course, does not imply that building bonds is easier in smaller settings - in fact, people may be reluctant to open up in such settings.

It may warrant further exploration about the different dynamics for those workshops that take place in city settings rather than town settings as participants are less likely to be meeting by chance.

Types of relationships

None of the data reflect the nature of the ongoing relationships that may occur for participants. Due to the relatively recent completion of the workshops, it may not be possible for people to predict the nature of those relationships. It appears, however, that people wish to continue with the emotional bond created, rather than for their groups to have other functions.

Social Outcome 4: Champion

Can participants advocate for the CCN workshop approach?

This section considers the ways in which participants in the workshops expressed their support for the workshops and how they have promoted them and expressed their benefits.

Endorsement during the evaluation

When asked if they had any final comments, participants spontaneously endorsed the workshops and were insistent that they acknowledged and appreciated the worth of the workshops:

- [P3]: I think it was such a good model, don't break it.
- [P1]: But it would have a ripple effect. And I just wanted to say on record, three artists that we had, were just super Oh, they're fabulous. Fabulous. Fabulous.
- [P5]: Well tell them it was money well spent. Yes, yes. Because I know, all of our members definitely got a lot out of it.
- [P1]: Sponsors certainly can be very satisfied with how the money was spent.
- [P5]: And our facilitators, [facilitator names] were wonderful. They made it very easy to relax in and communicate in class.
- [P6]: Yeah. Anything about grief and death, I'm there.
- [P2]: And it was the bit like, 'this is going to be a beautiful warm duvet'. And you're not a bit surprised when it's a beautiful warm duvet but its really handy that the sun is shining as well. I don't know if that makes any sense to anybody, but it makes sense to me... it exceeds your expectations, I suppose in a lot of ways.

Enthusiasm for the work

It was clear from the data that the participants were able to articulate the connection between the art practice and the purpose of the workshops.

Even at its most basic, the art practice became a focus through which people could justify being in the space without feeling that they needed to open up on a subject. This was expressed in the example of juggling earlier and in this comment:

- [P5]: We did a lot to do with nature in collecting raw materials like and making mobiles, nests, lamps, lanterns. So, while your hands were busy, the chat flowed. And I think we all benefited from it.
- [F3]: You know, the art brain and the art hands kind of get, you know, the conversations happened. And anyway, that's, yeah, yeah, that's great.
- [F2]: I think it's really interesting, that process of doing something with your hands as a community frees up your mind to talk about things. And so as we would sew or cut, or, you know, like do like we were working with our hands... And that that matching of doing something with your hands so that you free up your brain and your mouth

to talk and you sort of distract your hands so that then you can kind of... you can be a bit freer with each other

Participants, however, also connected the activities and artefacts to the subject matter in interesting ways:

[P1]: Once I got hooked on the Haikus I just loved.... And I found myself writing them and the artists gave us little notebooks that we could carry around just like this one here. And then we could, when we were inspired to write I found myself writing by the sea, on a walk.

[P3]: And it was lovely, I loved the art end of it [...] And you could speak, especially between the broken jars and that, and our lives are broken, and they won't fit back together completely. But certainly they fit again, and be mended. And there'll always be that broken-ness there. Yes, I got a lot from it. I really did. Poetry was fabulous, I loved it. And you could take it home and again, it's there, and you can reread it, and you'll get that enjoyment.

[P1]: We also what do you call the art... Japanese art? [...] Anyway, it was an area that we knew nothing about, just like grief, like when we're plunged into grief, with no..., we know nothing about that... it's different no matter how much theory you know, and many... what you've studied in the grief when you're hitting your own family, and it's... your... it plunges you into a strange land. So the... like, the Japanese art, we were plunged into some... a land, and we didn't really know anything about

[P2]: So for me, writing a Haiku is a very particular kind of exercise and I love it because it's challenging. It's hard. It's not... And I like that. Sometimes the feelings of loss can be huge and they can feel out of control and they can feel overwhelming and making yourself write anything down I find it helps me... not control but express and kind-of go again and... and writing has always been that escape valve when something is huge as the loss of so many people, it is such an ever-present awareness and you know, I said to [P3] one time you don't get over a bereavement; that's only American psychobabble nonsense. You learn to live with the hole in your soul and you just... that become then a part of you.

[P4]: And so the Japanese Haikus, learning about the different models and their meaning and how, how peaceful you know, they just made me feel very peaceful. And writing them was quite difficult at first, but then I got into the rhythm for it. And then all sorts of things came up. And all sorts of emotional experiences came. Which is very good, because you can let it go then and let things go.

[P3]: Well, I would have written poetry like I would be in the group with [P2] but put all your feelings in three or four sentences [in a Haiku] is quite an achievement. What it does is, you know, with an ordinary poem, you can ramble and thinking as it moves along. With this, you have to be specific. And it did help afterwards in being definite about how you felt. And you were sorting it out in your life, that you had to make decisions and decisions had to be done quickly and not ramble in that area, it helped

a lot [...] You listen to people sometimes go on and go on. And, you know, you tune out, whereas with a Haiku, you don't get that opportunity.

And, to further illustrate how the art practice became entwined with the participants' own engagement with the activities:

[P3]: While you were asking there and talking, I just wrote a tiny Haiku, and it says:

*You're asking questions,
Have to think, ease the problem:
Stay in place, peace will come.*

.... It's easier than trying to explain it.

Promoting the workshops in other contexts

It is clear that participants are willing to promote the course and discuss their participation and display the artefacts that were created. These endorsements bode well for the further promotion of the workshops and to normalise the existence of a non-therapeutic space within which people feel safe to explore loss and bereavement:

[P3]: The morning that we had, it coincided with Arts Alliance Week, and what was going on in the parish. [...] And we were in [artist's name] studio, and she very kindly opened the whole place up to us and we had tea and coffee, and we were able to invite the public in. And the public were fascinated and kind of saying 'Where was it? and, you know, 'We didn't know what was on' or 'Oh my goodness, I'd love to have gone to that'. So obviously in an hour and a half in that morning, we connected with so many more people, you know, and they were intrigued by what we were doing.

[P2]: And you can buy our book of Haiku in all the best bookshops now. [laughs] It is expensive, but it's well, well worth it.

[P5]: Oh, yes, absolutely. And it should be available in every town and city around the country. I have a friend in [L5]. And I was telling her about this [gives details of family relationship and current living circumstances] And she has a huge loss and has a hard time dealing with it. And we did try to find out what was the course going on in [L5], but unfortunately, it wasn't. But the facilitators of our course gave me a lot of literature and phone numbers, which I passed on to her [...] And I feel if she went to a network like this, you know, and had someone to talk to and express and see that she's not on her own, it would really brighten up everything for her.

[P6]: Yeah. Like I've told my friends about it. And I think one of my friends had this really, she just thought like, we're all sitting in a circle crying. That was her grief that she thought was happening. [laughs] And I was like, 'Well, I've learned to juggle' like that's what everyone says just like, 'Oh my God, I never thought like you'd be doing that'. I was like, yeah, like, it's not just sitting in a circle crying your eyes out. You can do more than that about grief. You could talk about things so yeah, I think um, I think I'd definitely recommend it to anyone. I think it's nice that I think you feel like there's no pressure to go every week. I think just knowing that it's there.

[P5]: Well, I was just saying that I was doing this course. And that... how we talked about our feelings. And I was saying about the Haikus. And I showed her my book. And I

said, you could talk as much as you want, or talk as little as you want. And I said I wouldn't be a big talker in the room. But what you get from everybody else, you know, I'm very much a get-up-and-do and a hug rather than words. And she found it interesting and, as I say, I got the bit of literature from this to hand over to her. [detail about nature of family relationship] So we were talking about that subject where I was saying I was doing the course and it came up that way. Yeah, you don't get any specifics, you just talk in general, or my own personal thing, because obviously, you treat it like the AA like, you know, yeah, it's totally private. And that's it.

Outcome 5: Recognition

Do stakeholders understand and articulate the value of the approach?

This section explores what the stakeholders, who, for the purposes of this evaluation, are the local authority/arts centre staff, interpreted as the value of the approach taken. It looks at what they perceive as the purpose of the workshops, their impressions of it, where the workshops exist in relation to art therapy, finding participants and sustainability of the network.

Other related issues are also included in this section such as facilitator needs, models of grief and grief rituals.

Purpose of the workshop space

Participants talked about what they saw as the function of the workshop space, as a convening space where there would be like-minded others that could provide safety:

- [P4]: Everybody goes to the funeral, but nobody talks about death, and dying. So first, somewhere where it's a place where you can go and talk with like-minded people in a safe environment, who understand that there is an emotional content to this.
- [P6]: Yeah, I think with my grief anyway, I think, because I've no one in my friend group that went through it, it's sort-of... not hidden but... it's not talked about in our day-to-day when I meet up with people.
- [P3]: So I very quickly learned that in certain situations, you did not shed a tear. But here was some place you could; you felt comfortable, you didn't feel different. Somebody else took time to say: 'Are you alright?'. And that's what is so important. Yeah, they were... I actually wrote an article about it, and I'll send it into a paper sometime, to say: 'It's alright to cry'.
- [P3]: The first morning I came in, I thought, 'What am I doing here?' I presumed we'd be talking about our loved ones and that. But as the weeks went along and we got involved with, you know, all the different projects, it was like a warm blanket of care. That's all I could explain to you. It was lovely.
- [P6]: And I think with my friend group, it hasn't really happened to them, so I don't really have anywhere to talk... I could talk with my [family member], obviously, but there was no really where to go. And em I just think in society as a whole, especially with COVID, we just don't talk about [death and grief]

This is echoed by the stakeholders in their understanding of the purpose of the workshops by relating it to their own experience or empathising with those who experience loss.

- [S2]: It opens up a nice space for people to be able to engage with brutally difficult topics, but in a very supportive and caring environment, [...] Because, you know, we all face these kinds of issues at one point or another throughout our lives, nature of life, tragically, and so it is... to know that there's these types of supports out there for people to be able to have space to think about it in a productive and creative way.

- [S3]:** And look, I haven't suffered a great deal of loss in my life, but I know that it affects people very differently. And people can, you know, have this grief forever. You know, I can't imagine losing a parent or a sibling or a child or anything like that. It just, I can't even get my head around it. So I think it is a really useful thing for somebody to do to just lose themselves for a few hours. And I got the sense that it was a very calming group to go to - I kind of got the sense that people were very supportive.
- [S1]:** It's extraordinarily complex. And so without getting too, kind-of, into an entire essay, I would say that our key objective was to, was to participate and access the arts, and the commonality of loss being in the room was [...] that the commonality in the room and the social engagement has, and does have proven positive effects. [...] the main objective is, in our involvement, is about opening up a conversation with an artist, and providing access to creative engagement at a time of loss.
- [F2]:** I think art is a way of expressing things that sometimes you can't express in other ways. So, you know, people use poetry and music and painting and places [...] When talking directly and generally, [people] might not be able to encapsulate what it is you're feeling internally, and we're experiencing. So you can use, you know, other means to help to kind of make external what's internal [...] they can use colours to explain, or poetry, as I said, is for some people, it does kind of, sometimes it can hit the nail on the head better than you trying to describe it to yourself.
- [S3]:** You'd feel like you were given a space, you were given an outlet for your grief in an alternative way, and not just people saying they're sorry for your loss, and you try to hold back the tears. [...] I'd like to think that they would say that, you know, they felt very comforted there.
- [S3]:** I'd like to think that people are talking about building relationships, even from it, you know, we're really connecting with people on a deeper level than just your normal kind of run of the mill, funeral stuff.

One stakeholder also referred to the same idea brought up by both a participant and a facilitator, of arts activity being something to do while speaking about grief, in line with Smid's (2018) concept of instrumental grief:

- [S3]:** I think it's about the process of creativity rather than the end result. So it's not about what you're... what you're actually making; it's about just spending the time doing it. [...] I think it's just it's like a distraction technique. [...] And you're not always coming out with a masterpiece. It's practice, and it's trial and error. [...] to actually not really make anything; to just test a few techniques.

That stakeholder also echoed the contribution of a younger participant who had felt they had no outlet among their peer group to discuss grief:

- [S3]:** I think there's probably a whole other minefield to deal with when it's a younger person... when it's unexpected.

The stakeholders and facilitators also saw the workshops as a way, unlike the participants, of tapping into suppressed or unrealised creativity:

[S3]: A lot of people hold this trauma like that they've been insulted at some point by a teacher growing up: 'Oh sure you're no good at drawing'. And so, in your head, then you're like, 'I am not good at art'. But that's not to say that you're not creative, and I think that's what people need to realise, you know, whether they're young or old is that I think as Irish people especially, we all have a huge amount of creativity inside us, whether it's music or our drawing or dancing or poetry or anything like that.

[F6]: The drawing was always... but I suppose I knew that myself [...] the drawing is intimidating; if you give somebody a pencil and say, 'Okay, we're just going to doodle and there's no pressure', they still feel the pressure. It's like, I feel like you're trying to trick them into... [laughs] It's like, 'yes, just scribble... just do whatever'. And they're like, 'No, no', they feel it has to be a perfect drawing.

One stakeholder identified how the dynamic of group creative work can have an interesting interplay with a sense of achievement during a difficult time.

[S3]: But I think when you're in the early days, when you're just trying something new, it's... it is about having somebody there next to you saying 'Well, that's actually really nice. You know, I love how you did that'. And, you know, it's just kind of reinforcing it in you instead of... Most true... most true artists are like, they make something and then they go: 'Well, that's terrible. That's awful. I hate it. And I never want to see it again'. When there's someone next to you that's actually saying: 'No, no, you did really well there' and, you know, gives people a confidence boost as well. I think I think people would leave that feeling better, feeling a little bit lighter. You know, obviously, you know, when it comes to grief, you can't walk out smiling or anything, but I think it gives people a break anyway.

First perceptions of the programme

Due to changing personnel within the stakeholder organisations, it may be helpful to understand how those stakeholders who are new to the programme think of it. Two of the stakeholders were relatively new to it but both had a very positive perception of it:

[S3]: Oh sure, I thought it was the loveliest thing. The first time I actually saw it, we were in the [location of the workshop] in this specific area that it had been on. And I think it had been on that very morning, if not, it was the day before, and they had left one of their pieces on the table for us to see because there was a few stakeholders in the room between the Council and the HSE and, you know, some of the, like, FRCs and things like that.

[S2]: And, to be honest, I didn't know much about it, until now. But I do work with a person in another capacity, who is partly... who was involved with it, and just from chatting with them [...] it's a very important and necessary network to have.

Therapeutic but not art therapy

As acknowledged earlier under Social Outcome 1, there can be a high level of emotional content within the workshops, although this is not a given for all workshops. The data shows how this work operates adjacent to therapeutic work or art therapy (with one facilitator now pursuing a qualification in art therapy) but must distinguish itself rather than creating unrealistic expectations:

- [P1]: And they were... the facilitators introduced themselves as artists, and they weren't therapists, they weren't art therapists. So that was a different angle and a lovely angle to come from.
- [F7]: I think when whenever we've had a new person, we always explained if we've got one of the mental health nurses there that sometimes you might want to step out of the room, it might become overwhelming for you that, you know, give us a thumbs up if you're okay.
- [F6]: People brought up so some raw emotions in their discussions, but I think, as we kind of kept the conversation moving, and then like, we introduced poetry and there was never, like, I suppose, a therapeutic feel that any like... I suppose there was... or even maybe from the counselling side that it was never... 'Okay, steps of what to do next'; that wasn't the line that we went down; it was 'Thank you for sharing and now we're going to read a poetry that might resonate with some of you' or, do you know, we kind-of moved on if... and then we also explained that the nurses were here, like, at all times, and if anybody felt they needed to explore it further, that that option was there. So I think, like [F7] said there, it was just keeping the conversation flowing, and so that it didn't go down the therapeutic route.

One facilitator did highlight an issue where a participant took it upon themselves to provide 'therapeutic' responses to other participant's contributions and that this needed to be managed. While the facilitator was careful not to discount this response, they made it clear that this was one way to look at it, but other ways were also helpful.

There appears to be an understanding among the stakeholders that while the workshops themselves may provide a sense of healing that this is neither art therapy nor counselling, although it may be something that provides a route into or out of those experiences:

- [S3]: You couldn't just walk into a room untrained, you know, with just your arts, [...] when you're talking about a grief workshop is that people would need to know, or need to try and understand or empathise what these people in the room have gone through up until now. And from what I understand, as well, the group, some of them were freshly bereaved and some of them had lost somebody years and years ago. And you know, they're working through it in their own specific ways.
- [S2]: It's very welcoming to hear that you know that there was the support from the Irish Hospice Foundation to support the facilitators into... to do that training. I think it's important that there is a support for those in that side of the work as well as you know, the supports that have been offered to the people who are kind of joining in

on the workshops... that the facilitator are supported and that's, you know, it's really good to know that. [...] but I think maybe, you know, to ensure, and perhaps the training that they do, the Irish Hospice Foundation covers this, but that, you know, that there is the correct boundaries, as to what is the outcome of this event, and what is expected out of this facilitator [...] I do think it's a very important part of this work that there is some form of support network... chain... system in place to help support facilitators as well

[S1]: Our job was to recruit a support worker, and we supported one with a clear background in kind-of, I suppose, care support. So, it's about signposting then, if there was something more personal, which would be outside of our remit, really. But so, therefore, then signposting but the framework of support would notice if something was difficult, or I think that was all really well done in this project, and really well considered, but I think in our job, it was about recruitment. Getting the right person

[S3]: So they're as prepared as they can be going in. But at the same time, if something goes beyond their own capabilities, that they have somebody to turn to who was able to... deal with whatever is happening.

In this context, it is also important to understand that facilitators may require supports in order to process the emotional content of the work:

[F1]: I did find myself sometimes waking up at two in the morning [...] and thinking, 'What did I say?' That I could have handled that better. And I'm really worried about that person, at two in the morning. So all that kind of stuff was coming up, as well.

[F1]: I don't have any training in counselling, or, and I was talking to [F4] a bit about this actually, yesterday is that we don't have training, therapeutic training in any way. And yet, I don't know if you are... the other people who agree, but it felt like sometimes we were kind of it would kind of go into that kind of a group. And that... that's just where it was kind of turning into a kind of therapeutic group, but we are not trained therapists and that's actually something that I think is quite important to consider is that we're trained artists, but not therapists. And yet it does become therapeutic.

Finding participants for workshops

As mentioned earlier, one facilitator, who was working through a number of pre-existing local groups, highlighted the difficulty of recruiting people into the workshop and the inaccurate preconception that the workshops would be 'heavy'. The stakeholders were sympathetic to the challenge of finding and encouraging participants:

[S3]: I think it's just the struggle of getting people to go the first time. And I think if they went once, they'd realise the benefits of it.

[S2]: one of the biggest challenges we have with general things in the arts is audience development at times is to ensure that they're there, and, and that it's accessible, or it's, you know, it's in the right place, or at the right time [...] I think that like the

confidence to go, it's very difficult, especially at a time when someone's feeling so vulnerable, you know to try and to make that push can be quite hard. [...] and I think it's trying to get the messaging across that what people are partaking in isn't... I'm trying to use the right words, but you know what I mean that it's a very hard, heavy kind of topic. It's not going to be a heavy hard event, you know what I mean

Sustainability

Stakeholders, however, were also conscious that the Network could fulfil future needs but would need to be sustained as it builds a level of community trust so that it could be there when someone needed to or was ready to engage with it:

[S1]: And I think the biggest issue is in maintaining service. So a wonderful pilot program that then serves an incredible need is able to continue and, therefore, become a service that people know is there. And you don't have to work so hard then to, you know, kind of promote or say, 'This service is here'. But it's there all the time, [...] people get to know it, and people get to trust it. And so sustaining, I think, is possibly one of the most challenging things for organisations and sustaining the expertise to deliver on those three things are all challenges for everything. And this one wouldn't be an exception to that I'd say. [...] we were very lucky in that, I suppose we have a team of artists who are... we've been working to train and develop over time.

But that there was a need to create a peer-supporting network that was diverse and sustainable:

[S1]: We were lucky because we were able to link into our existing infrastructure, and train... having trained artists, but we are constantly working at that. And we have other sources of support for that. And I think what was really important was the network for the artist, so that they weren't doing it... And the training and the support that the Irish Hospice gave as part of this program were... were critical... critical parts of making it work well and enable the artists to go into the work fully prepared and supported.

Other related issues

Facilitators' needs

There may be an expectation among the artist-facilitators that there must be an artefact for display at the end of the process, something to show or exhibit for others to see.

Emphasising the process-based nature of the activity is important in this regard:

[F2]: I think if I can jump in, I think for me, the sort of lack of an output it always makes me nervous. We're so used to there being a product, there has to be a product at the end, you know, like, like the previous project where I knew we were working towards having these wall hangings. So and [IHF] going: 'That's okay. It's okay that there's not a product; we're going to see where it goes. We're going to see where the group goes. We're going to see... whether that turns into something or not. And both of those are okay'. It was like: 'Oh, gosh, what if it... what if it doesn't go anywhere?' And it's like, actually, that's okay, too, if it doesn't go anywhere. If nothing is made, if nothing is made at the end, that's also fine.

More broadly, this work is seen as novel and, as such, may be uncharted territory for prospective artist-facilitators:

[F1]: I mean, I think with a lot of arts participation projects, and maybe especially this one is that it... there... we're not following a map or a template or anything, so I always feel like I am jumping into the deep end. And, you know, moment by moment, I'm just trying to be present.

The artist-facilitators were did have access to one another for support, despite any feelings of nervousness:

[F3]: You know, and [F1] ... [F1] was a great lead. And the first session I, you know, I definitely was about observing how [F1] spoke. And listening to how..., yeah, so it was quite, I was quite nervous. The first session, for sure.

[F6]: For me, it was the support-wise and like [IHF] put those fears to rest straightaway. Because he said: 'Well, we're going to have the support of the nurses with us'. If there was anything raised that we didn't feel we were skilled in to cope with or support the participants that the nurses would be there to step in at any point. I know [F7] had the training for the bereavement side that she could use those skills as well. But I suppose for me personally, I felt I'm... I don't have those skills yet. So that's where I felt there was a gap and but that was put to put like the reassurances were put there that we would have the nursing staff with us as well.

One or two facilitators, while working with someone who had the IHF training, had not received it themselves. This appears to be due to coming onto the project at relatively short notice during this delivery:

[F3]: In the in the initial email, it said that they would, the Hospice Foundation would provide some training. Before we would go in and meet participants, so that didn't happen, because it was very short notice.

To ensure that there is always a hinterland of trained artists is addressed in sustainability above but it is important to have a wider pool of artist-facilitators in the Munster area with the requisite training from which to draw.

Grief rituals

While previous parts of this report address the transformation and transitional living without the deceased person, there were also times when the workshops connected with the person who had died:

[P5]: Yeah, and I just want to say another thing that we did one day, and we only did it for a short time, and I think would have been lovely as a full session. One of the artists was also a musician. So we, we did a singsong. And it was like remembering songs that meant to the person that left us, or songs that we connected with them. And it was absolutely beautiful. It was very emotional. We cried a lot doing the singing and some of it. But some of us couldn't sing at all. But we all did it. It was a real, an enjoyable hour. Yeah. But it was nice to think like my father now would always sing

[old Irish song], whereas my mother would always sing [old Irish song] or, you know, and to share it with the others, the songs or music of... from old was lovely. Yeah.

[P3]: I suppose the crafts and making the currach... the boat em... we made a lovely boat, and you know, as Christy Moore song would say, you know, 'life is an ocean and love is a boat' and that had a particular effect on me. I thought it was beautiful. And it brought back some memories of my dad because they were [description of father's profession and how it connected to the craft work].

Understandings of grief

[P1]: Somebody that we meet, and they're always sad, and *bhfóire* and, you know, always in grief, and they won't give themselves permission to go and enjoy themselves, that it's okay to go to a film, or it's okay to go and have coffee with your friends and have a laugh. All of that. Yeah. So and maybe, during the workshop too that, maybe to recognise that, you know, we were all grieving in different ways. That we do, you know, it's a personal thing... it's like our fingerprints, the way we grieve

[P2]: Because for all of us, there's... you laugh and you smile, and you cry and you remember, and like, I remember now and in a minute's time, when I put on the kettle and I go on and do the things I'm doing today, and like I say, you... you live on and you never stop missing but you live on and you remember them all the time and having an awareness that there were other people who have a similar experience and that they know that they care about you. That's huge, like.

[P1]: So maybe just to go in a little bit to, to maybe to chip in to say that are different models of grieving and different ways to grieve, some people kind of match... you know, matches the grief of some particular model, you know, some people might be trying to find meaning, some people might like to continue in the bonds they had, somebody else might like to, you know, to look at Tonkin's Model, of Grief where they..., you know, where they know that grief is always there, it will always remain there but our lives around grief grows, and those kinds of things.

There is a reference to the dual nature of grief as described by Keese et al (2008) where participants had a safe space to laugh, as opposed to crying, and not feel judged that this behaviour was inappropriate:

[P1]: I felt there was a, there was a... looking at here is a grief, I feel there was a dual process, [...] going on in the workshop. And we're genuine with the grief, but we're also laughing and chatting, and we were enjoying, and then we're going back, maybe somebody has something that somebody would do, but I would have liked, maybe it's a... but that may need to be recognised that thing that was happening that it was okay... sometimes people kind of feel they have to be in the sadness mood all the time. And that it's okay to laugh and enjoy each other's company, so that dual process was going on all the time in the workshop.

One of the stakeholders referred to meaningful engagement, which echoes the work of Neimeyer et al (2014) in meaning making in grief:

[S2]: I would hope that they felt that they had, you know, a meaningful cultural engagement with something... a creative engagement, that did have kind-of meaning to it, that they felt it was worthwhile. And that they felt comfortable, supported, and eager to try again, and come along another time.

Conclusion

It is clear from the focus groups that those who participated wholeheartedly endorse this programme. Participants articulated thoughtful and meaningful experiences and were explicit in their support for such activities continuing. Artist-facilitators were also enthusiastic about the prospect of a continued programme and stakeholders highlighted the many ways in which a programme like this is coherent with their mission in promoting meaningful arts encounters.

At a more specific level, the data collected strongly suggests that the programme did achieve the social outcomes set out:

- While participants did not use the word 'healing' and may even contest that word, there were a number of examples expressed by both participants and facilitators of people making a transition, through the workshops, to a situation of improved mental wellbeing;
- It was also clear that the elements of compassion were clearly fostered in the workshop around recognising the suffering of grief, empathising, sitting with difficult emotions and acting where appropriate;
- There were also clear ongoing connections made as well as a sense of bonding during workshops although this appeared to be more likely in less urbanised settings;
- It was also clear that participants have become active champions for the workshops among their peer groups and in their communities, through both showing their artefacts and discussing the process with those who they feel would benefit from such activity.

And, based on the data, there are clear indications that the general outcome explored in this evaluation was also achieved:

- There was also a clear recognition among local stakeholders of the value of this work in both the promotion of wellbeing and in the encouragement of artistic engagement and encounters.

Areas for consideration that emerged during the evaluation are as follows:

- While explicitly not a therapeutic intervention, artist-facilitators may have questions following workshops about the emotional state of participants and whether their own actions were appropriate in the context. The inherent supports that exist within the network may need to form into a more formal structure;
- More generally, there is a need to ensure that artists, who may be entering the programme at different times during its lifecycle, receive the induction, training and support that is supplied by IHF, so that they feel prepared to focus on the participants. Also, it is important that they remain conscious of the 'process' rather than 'outcome' nature of the workshops and that this continues to be discussed with artist-facilitators entering the programme;

- While some participants were drawn to the workshops due to unprocessed grief, there appears a prospect that these workshops may provide other outcomes more generally around grief and loss. While this is not the intention as captured in the Theory of Change model, this may warrant exploration;
- The different approaches taken by different artist-facilitators in different contexts, such as rural and urban, would benefit from further investigation as the programme matures, particularly around creating ongoing connection in a more urban environment.

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Appendices

Appendix 1: Participants Interview Schedule

Introduction and Consent

Intro

It would be great if by way of introduction, you could tell me the type of workshop that you participated in and what you made or did during that workshop.

Initial impressions

Can I take you all back to the start? How did you hear about the workshops in the first place?

What did you expect before you started?

Had you done creative workshops like this before or was this new?

The Process

If you made or wrote or did something, can you describe how you did it – the process you went through and what you had at the end of it.

Was there a point where you felt a change had occurred (either in you or in the group)? Can you describe when that was and what it looked or felt like?

The Group

Did you know the people in the workshop before it started?

Were there things you felt the group had in common?

Were there any noticeable differences in the group?

Because these were about loss, is it fair to say that difficult things came up during the workshops for different people? How was that handled do you think?

Would you be okay to share how it made you feel when something difficult came up for someone else?

In retrospect

Now that you've done the workshops, what do you think the effect of them has been?

Do you feel that you have changed in any way or not?

Was there anything that anybody said or did that will stay with you do you think?

How do you describe the workshops to other people if they ask about them?

Would you recommend them?

What, if anything, would you feel people should watch out for?

Do you still see people from the workshops or is there any way that you keep in touch? How has that worked out?

Finally, I'd just like to ask you if there's anything you'd like to say about the workshops that I didn't ask you?

Appendix 2: Facilitator Interview Schedule

Intro It would be great if by way of introduction, you could tell me a bit about your practice and the kinds of workshops that you run.

Initial impressions

Can I take you all back to the start? What attracted you to the work in the first place?

What did you expect before you started?

What were you looking forward to?

What did you anticipate would be a challenge?

Did you have an idea in your head of what grief was and how it worked? Can you describe that?

The Process

Can you give me an idea of the process you took people through with maybe some context of the choices you made?

Was there a point where you felt a change had occurred (either in you or in the group)? Can you describe when that was and what it looked or felt like?

The Group

Had you worked with people in this group before? How would you characterise the group?

Because these were about loss, is it fair to say that difficult things came up during the workshops for different people? How was that handled do you think?

Would you be okay to share how it made you feel when something difficult came up for someone else?

Supports

Can you talk to me about interacting with other facilitators? What were the main things you got from that?

What do you feel you contributed to that process?

In retrospect

Now that you've done the workshops, what do you think the effect of them has been (on the participants; on you)?

Was there anything that anybody said or did that will stay with you do you think?

How do you describe the workshops to other people if they ask about them?

What is the most valuable thing about the workshops you delivered – that if you were doing them again you would be sure to keep?

If you had the chance to redo them with a new group, is there something you would do differently?

Finally, I'd just like to ask you if there's anything you'd like to say about the workshops that I didn't ask you?

Appendix 3: Participants Interview Schedule

Introduction and Consent

Intro

It would be great if by way of introduction, you could tell me how your organisation got involved with the Compassionate Culture Network.

Initial impressions

Can I take you all back to the start? How did you hear about the work in the first place?

What did you expect of it?

How did you think of it in relation to it being creative but also fulfilling a function for those people bereaved?

The Process

What are the challenges of a programme like this for your organisation?

How were the facilitators identified?

What kinds of supports are there for facilitators?

In retrospect

If you met a participant on the workshops, what do you think they would say about it? What would they have got out of it?

Finally, I'd just like to ask you if there's anything you'd like to say about the workshops that I didn't ask you?

Appendix 4: About the Compassionate Culture Network

With all citizens affected by loss, some by extreme loss, and during a period where normal patterns of grieving were disrupted, Irish Hospice Foundation established our Compassionate Culture Network (CCN) pilot programme in 2021 – 2022 as a rapid Covid –19 pandemic response with the support of Creative Ireland.

Now, with support from Munster Impact Fund, we are now setting out to replicate and expand this pilot programme at community level. It uses creative practice to establish places where people can talk about loss and grief. Building from the pilot with West Cork Arts Centre these will be in West and North Cork, Kerry and Limerick.

Where is the space for loss and grief in contemporary life?

How might we build a Republic of Care?

Through the pilot programme, we discovered this programmes potential. Family Resource Centres and cultural centres are community hubs. The arts help process sensation into meaning. Linking experienced artist-facilitators with a wider public in properly resourced sessions, initiated meaningful conversations on death, dying, and bereavement, while signposting other health related services available locally for those in greater need.

All CCNs build from local circumstance, assets and opportunity. To make them happen IHF need to identify a local artist-facilitator, and a local support worker, and a venue. The artist-facilitator and support worker designs with IHF, then leads, a 12-week, one day a week, programme on the theme of 'loss' for either broad (all comers) or specific (targeted groups).

IHF provides grief awareness training and support. All our CCN artist-facilitators and support workers connect with each other as peers in a learning network. As peers, they'll be continuously learning from each other. Where available, they connect with local health systems and bereavement supports, either charities and / or the HSE.

We are aiming to start the programme by identifying venue, artists and support workers immediately. Face to face work could beginning in April, and the programme completed by July.

We have resources to address artist-facilitator and support worker fees, materials, venue rental where needed, IHF provide online support and production support.

In addition, IHF will use its social networks, communication / marketing tools, newsletters, and direct referrals. We engage with Local Authority Art Officers and CEOs, HSE PsychoSocial Response Support Officers, and the Public Participation Networks (PPNs).

You can find all about our Compassionate Culture Network 2021 – 2023 here:

<https://hospicefoundation.ie/our-supports-services/ihf-in-the-community/arts-and-creativity/compassionate-culture-network/>

WHY? What is the value of this project?

In November 2021, IHF launched Time To Reflect, a national survey about people's experiences and views on death and bereavement during the Covid-19 pandemic. The

survey was open to all individuals aged 18 years and over living in Ireland. Ethical approval for the study was granted by the Research Ethics Committee of RCSI University of Medicine and Health Sciences.

Early findings indicate an unprecedented impact on all who have been bereaved (whatever the cause), and all those who cared for the dying (be they professionals or family and friends) with significant challenges ahead as grief evolves into poor mental health and wellbeing issues.

Over 2,200 people responded to our survey invitation, and what follows is a taster of what we have learned so far:

- 68% reported the pandemic changed their attitudes towards dying, death, and bereavement.
- 64% said their experiences of death were negatively impacted.
- 68% were bereaved during the pandemic. 43% had multiple bereavements.
- 69% had family / close friends excluded from funerals.

For convenience these findings are illustrated in the attached infographic. More initial information resulting from our survey can also be seen on the IHF website here: <https://hospicefoundation.ie/bereavement-news/time-to-reflect-national-survey-findings/>

We also know from feedback given by both facilitators and participants following the CCN pilot that the experience of two 'pandemic' years had, and continues to have, a significant effect on all ages, all counties, leaving many confused and distressed. Having been tested and evaluated during the pilot phase, the CCN prototype is equipped to respond to the needs of citizens. Whilst living with grief is a process not overcome in a single moment, establishing a nationwide CCN is one opportunity to ease the grief and loss through a sustained programme of engagement.

But perhaps the best way to explain how CCN will meet the needs of Irish communities is to invite you to watch one of the short films profiling the pilot CCN's. Our main Compassionate Culture Network page is here and the initial projects are:

- CCN Donegal ArtLink
- CCN Cork 'Haiku Shelter'
- CCN Kildare Embrace Music
- CCN Wicklow Forest Bathing
- CCN Galway Grief Café
- CCN Tallaght Dance and Movement

IHF now sees that in the longer term, CCN may align with the wider Social Prescription movement by establishing a training programme for the delivery of creativity and health programmes responding to grief and bereavement. It benefits local agencies by establishing this using local assets that connect to national expertise via a peer network.

