

# Scottish Bereavement Summit



**Final Report**  
June 2023



# Executive Summary

## Introduction

The Bereavement Summit brought together 136 people who work within the bereavement sector in Scotland. The gathering gave attendees the opportunity to explore how to work together to improve experiences of bereavement in Scotland, focusing on three specific areas:

- **Formal bereavement services:** how can formal bereavement support services (which provide for example counselling and access to peer support groups) be strengthened and improved?
- **Informal bereavement support:** what can be done to support communities of all kinds (including workplaces, schools, families and neighbourhoods) to provide better informal support to people who have been bereaved.
- **Health and social care staff who experience multiple bereavements:** how can staff get the support they need at work.

Most of those participating in the Bereavement Summit work within the bereavement sector – as practitioners, researchers, managers, policy makers or another relevant role. However, people's views were also informed by personal experiences of their own and/or of family and friends.

## What happened at the Summit?

The Summit provided opportunities for delegates to:

- Share their experiences of current challenges facing the bereavement sector.
- Hear about recent reports exploring different aspects of bereavement support, and their accompanying recommendations.
- Discuss ideas and priorities for practical future action to improve bereavement experiences in Scotland.

Views were recorded and shared through a pre-conference survey, live digital questionnaire (Menti) and online flipchart (Padlet) during and following discussions.

## What does the Bereavement Summit add to the existing landscape?

Several reports have been published in recent years which provide helpful insights in terms of people's experiences of bereavement and some key areas for improvement<sup>1</sup>. The reports cover various geographies and populations and the recommendations are varied in terms of the detail they provide and the level at which they expect action to take place.

The Bereavement Summit provided an opportunity to take stock of these various reports/recommendations, look at areas of overlap and difference, and for their recommendations to be sense-checked with those working within the system.

Professionals working within the sector can bring helpful insights into what kinds of changes might help and, more importantly, what might be do-able within the current environment. Analysis at the summit indicates that there is a growing consensus over what the key areas of focus should be, and it is now important to focus on *how* these changes can be achieved.

Those working in the sector can also provide helpful insights about what initiatives, projects and networks already exist that could be learnt from, built on or scaled up, rather than starting from scratch or duplicating what already exists. They can also provide valuable views on what areas should be priorities, how the 'system' can be improved, and what barriers exist.

## Bereavement in Scotland: Where are we now?

In addition to the usual difficulties associated with bereavement, the covid-19 pandemic has left many bereaved people with unresolved issues that are having a negative impact on their wellbeing. Wider societal issues, such as the energy crisis and the cost of living crises are having a negative effect on people's experiences of bereavement.

### Bereavement Services

Delegates were clear that bereavement services are facing a number of challenges, highlighting the top four challenges as joining up systems; equitable access to services; demand for services is greater than service capacity; shortage of funding.

Delegates agreed that many barriers exist that make it harder for people to access formal bereavement support services, with the top three issues being that many people don't know about the services available, many need encouragement to access support, and cultural barriers exist for many who might benefit from services.

### Informal Bereavement Support

Everyone will be bereaved at some stage in their life, but not everyone will need to access formal bereavement services for support. Most people get the support they need from their usual social networks – friends, family and other communities they are part of.

People need to feel supported wherever they are, which means that everyone needs to be able to feel able and confident to offer informal support when someone is bereaved – whether that person is a friend, a cousin, a colleague, a student or a child.

Delegates agreed that many people don't get the informal support they need from others, particularly highlighting workplace and school environments as places where improvement is needed. It was felt that many people lack the skills, confidence or opportunities to offer support, and that education and culture change is needed to enable this.

### Bereavement experiences within the health and social care workforce

Many people working in health and social care experience multiple deaths at work as part of their job, and this affects their wellbeing. Even when staff's needs are understood and recognised, circumstances at work make it difficult for colleagues and managers to provide support, and staff and resource shortages make it difficult to give staff the time/space they need to take care of their wellbeing.

## Recommendations

Many and various perspectives and ideas were shared during discussions at the Summit. Section 7 of this report attempts to bring these together into a coherent set of recommendations for future action which reinforce and augment findings of previously published reports<sup>1</sup>:

1. Improve signposting to available support.
2. Increase public awareness, confidence, comfort and skills relating to bereavement issues.
3. Ensure strategic direction, accountability and responsibility for improving bereavement support.
4. Enable schools and educational institutions to be more supportive of people who are bereaved.
5. Address equity/equality issues and improve access to services for people with a range of needs.
6. Encourage and support workplaces to be better at supporting bereaved staff.
7. Support opportunities for professionals to network, learn and share good practice.
8. Improve bereavement support for Health and Social Care staff.
9. Improve how bereavement services, projects and initiatives are funded.
10. Ensure future action is informed by evidence, information and builds on existing work.

***Each recommendation is underpinned by an explanation of why each area is important, existing work that can be built on, and a selection of ideas/suggestions for future action in this area.***

## Next steps: What follows from the bereavement summit?

It is clear that delegates are keen to see concrete action to follow on from the Bereavement Summit.

Though there is incredible will and enthusiasm for change, the question remains, in a sector that is already over-stretched and hard-pressed, is further improvement possible without an influx of resource from somewhere?

It is clear that summit delegates are looking to Scottish Government to play more of a role: in developing a strategic approach, supporting leadership within the sector and improving funding. This report of the Summit will be shared with the Minister and Scottish Government colleagues, and efforts made to arrange a meeting to discuss how the sector and SG can work better together to make improvements.

Alongside this, there is an appetite to explore how the sector can continue to lead improvements from within, building on work such as that led by the Bereavement Charter Group, the Scottish Partnership for Palliative Care, and the Scottish Bereavement Network.

## Summary Report

A Summary Report providing an overview of the key findings from the summit is available here:

<https://www.palliativecarescotland.org.uk/content/publications/?cat=14>

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## 1 Introduction

This report provides:

- an overview of a pre-event survey, presentations and discussions at the Scottish Bereavement Summit on 13<sup>th</sup> October 2022.
- some recommendations for future work in this area.

The Scottish Bereavement Summit took place on Zoom on 13<sup>th</sup> October 2022. It was organised by a collaboration of organisations from the bereavement sector in Scotland (see Appendix 1). 136 people attended the Bereavement Summit, representing a huge range of stakeholders from across Scotland. (See Appendix 2) The programme for the summit can be viewed in Appendix 3.

The Bereavement Summit aimed to:

- explore key issues and potential ways forward for improving experiences of bereavement in Scotland, in the context of the publication of the Report of the UK Bereavement Commission.
- give a platform to a diversity of voices working in the bereavement sector in Scotland.
- discuss the development of a strategic approach to improving bereavement support in Scotland.

## 2 Insights from bereaved people

It is important that all work in this area is grounded in the experiences of people who are bereaved. The Bereavement Summit began with a compilation of some experiences shared by bereaved people, drawn from a wide range of sources. The presentation can be viewed here: [Insights from Bereaved People slideshow](#)

## 3 Insights from delegates – pre-summit survey

Delegates at the summit brought with them a huge amount of experience of working within the bereavement sector in Scotland, which can be helpful in bringing insights of how to improve bereavement support in future. In the week before the summit, delegates received a questionnaire asking them to share their thoughts/experiences within a short survey.

This survey focused on bereavement services in particular, with other areas of bereavement support being focused on in different sessions at the summit itself.

Donna Hastings (Child and Families Lead, St Columba's Hospice Care) presented a summary of the key findings from this survey to summit delegates. Findings are presented below:

### 3.1 Who answered the survey?

#### *Role*

70 people answered the survey questions. Of those 35% of respondents were bereavement practitioners, eg counsellors or support workers. 23% of respondents provided bereavement support as part of their wider role, eg nurse or social worker. 35% led a team

with responsibilities for bereavement support. 31% classified their role as 'other' and this included a mix of leaders, co-ordinators, volunteer, policy and research roles. (People could tick more than one box.)

This indicates that the survey responses were based on a range of experiences, including those working directly with bereaved people in various roles, those leading/managing/co-ordinating services, and those interested in bereavement from a research or policy perspective.

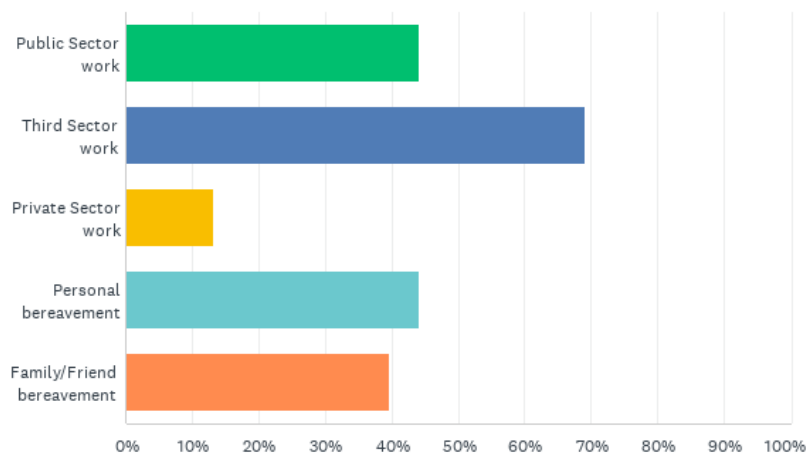
### *Sector*

44% of survey participants had worked in the public sector, 70% had worked in the third sector, and 13% had worked in the private sector. (Many people will have worked in different sectors over their career.)

### *Personal experiences*

Many respondents brought knowledge gained from both personal as well as professional experiences – 44% of respondent's views were informed by a personal bereavement, and 39% of views were informed by the experiences of family or friends.

Q7 Finally, have the insights you shared in this survey been influenced by:



### 3.2 What key challenges are bereavement services in Scotland experiencing?

The survey gave a selection of 'challenges' identified from previous research and discussions for people to choose from:

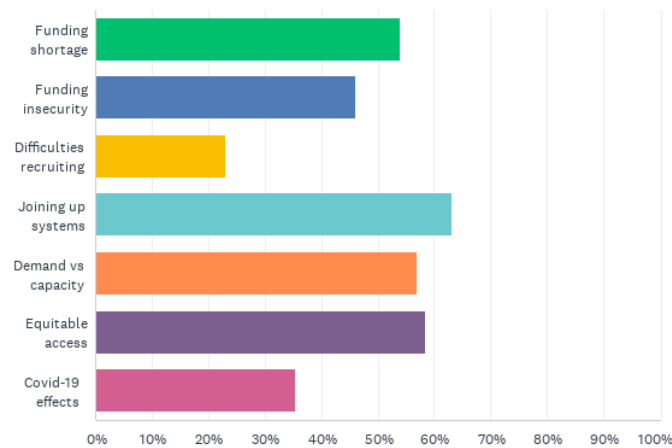
- Funding shortage
- Funding insecurity
- Inability to recruit and retain appropriately qualified staff
- Challenges joining up with other services within the system



- The demand for the service is bigger than the capacity to deliver the service.
- Ensuring an equitable access for all (eg age, gender, sexuality, race, culture, language, socio-economic status, geographical location etc)
- Responding to the needs people have due to the effects of the covid-19 pandemic.

65 people answered this question. Responses are shown in the graph below.

Q2 In your experience, what are the key challenges that bereavement services in Scotland are currently experiencing? (Please tick as many boxes as apply)



There was also a free text box where people could share additional challenges. Responses included:

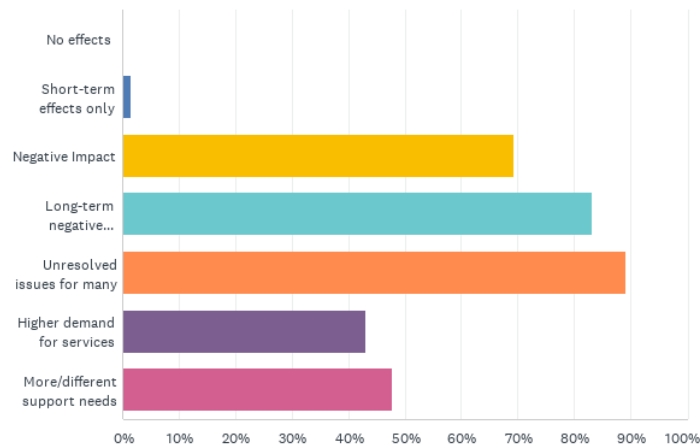
- cost of living crisis is isolating more people – travel costs to attend sessions etc
- the needs of different age groups, eg young people and staff
- general accessibility at time of bereavement – finding the right help for individual circumstances
- the services are undervalued by commissioners and other decision makers
- too much is expected in the role
- getting information about the services out and known at a community level
- confusion of the landscape and support available. No consensus on who is responsible for different aspects of support.
- too many services that do not talk to each other.
- staff do not have the skills to open up communication about death dying and bereavement.
- signposting.

### 3.3 Effects of the covid-19 pandemic on bereaved people

The third question briefly explored whether respondents felt that there were lasting effects of the covid-19 pandemic. Nearly 90% of respondents believed that being bereaved during the pandemic has left many people with unresolved issues that are having a negative impact

on their wellbeing. 83% of respondents agreed that we are still witnessing the negative effects of the pandemic on people who are bereaved. Over 40% of respondents believed that there is a higher demand for bereavement support since the pandemic and that people bereaved during the pandemic need more or different support from services.

Q3 How do you think the covid-19 pandemic is affecting the experiences of people who are bereaved? (Tick as many boxes as you like.)



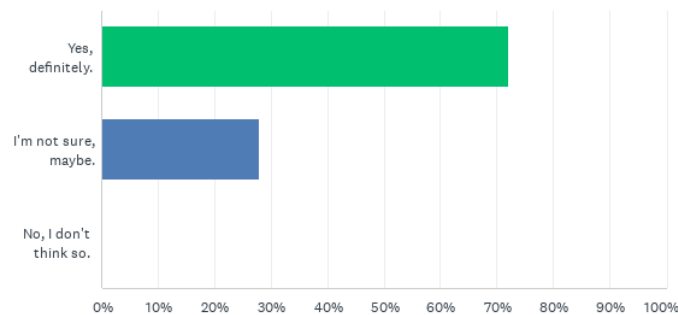
Individual comments by respondents included:

- The need for consideration of bereaved people during inquests into covid deaths.
- The suggestion that covid has helped us talk more about death as a nation.
- The complexity of those bereaved during the pandemic has increased. Many have grief which has built up over the time since their loss due to the nature of deaths experienced and their lack of contact with their loved one and others who could support their loss.
- Varying impact not all negative.
- I believe that bereaved people are experiencing complex and disfranchised grief and some have been unable to have a normal grieving process.
- The pandemic has highlighted how confusing the landscape is to navigate and the capacity pressures on services.

### 3.4 The impact of wider societal factors on people's experiences of being bereaved

Over 70% of respondents felt absolutely sure that wider societal issues, such as the energy crisis and the cost of living crises are having a negative effect on people's experiences of bereavement.

Q4 Do you think that wider societal factors, such as the energy crisis and the cost of living crisis, are having a negative effect on people's experiences of being bereaved?



Individual comments included the following:

- Any existential threats increase anxieties for people whose world is already changed due to a bereavement.
- I feel there could be more financial support when someone bereaved has to learn to live with a reduced income. At present if they qualify they are only given 18 months support. The ongoing issue of funeral poverty is also going to be more difficult.
- All these concurrent events have an effect on overall health and wellbeing.
- Significant concern that we are seeing an increasing trend of those who are not eligible for Funeral Support Payments from Social Security Scotland (ie working and not on a qualifying benefit), and are unable to afford the full cost of a funeral taking on debt to ensure their loved ones funerals can go ahead. Combine this with the likelihood of higher deaths this winter due to lack of funds to pay for heating and/or eating and the impact is stark.
- Having to struggle with heating and food whilst having the waves of grief overwhelm you is additional stress that will wear people down. Grieving is hard enough for some when life's basics are secure. To have to deal with loss and the practical tasks of living is enormously difficult, and the impact shouldn't be underestimated.
- I heard yesterday that my friend's school are crowdfunding to pay for the funeral of one of their pupils because the family cannot afford it.
- Bereavement can raise concerns about finance anyway so to have the additional stress of the energy crisis etc. adds to the already 'normal' concerns that may be in play and everything becomes so much bigger or frightening for people
- It is difficult for people to deal with their grief when there are other, often traumatic stressors in their lives such as cost of energy bills, paying for funerals, not having money to feed children etc.
- People may have financial concerns about paying for a funeral. They may also experience guilt at being unable to help vulnerable family and friends. Some might experience greater incidences of suicidal ideation.
- There is an effect on people's mental health and the financial impact of being able to live.

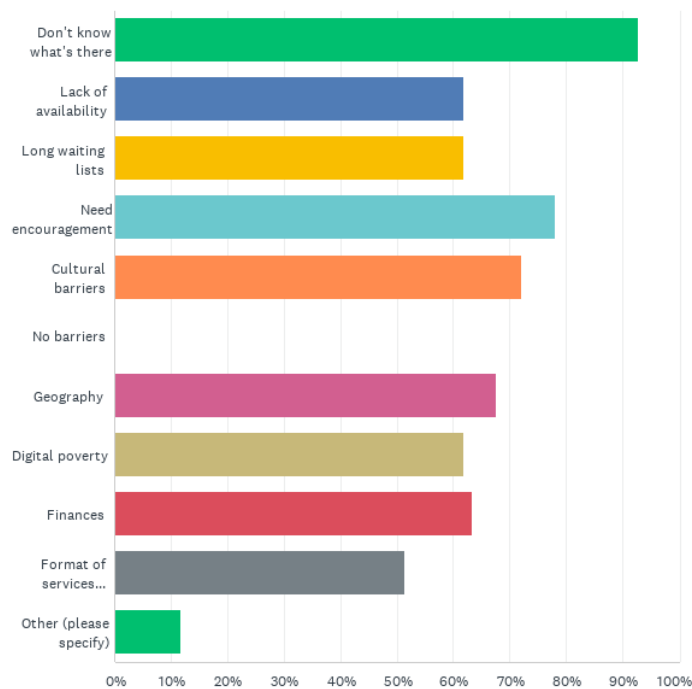
- They add another level or layer of worry and can affect mental health.
- Layered on top of grief there are now financial worries, also people may no longer have their support networks in place to discuss these challenges with. For children (and adults to some extent as well) the current geo-political situation can be fearful and reporting of death and destruction is daily across all media channels.

### 3.5 Barriers faced by bereaved people accessing formal bereavement services

All delegates felt that there were barriers for people accessing formal bereavement services. The most commonly cited problem (over 90%) was that many people don't know about the services available. The second most commonly perceived barrier (nearly 80%) was that many people need encouragement to access support.

The graph below shows these and other perceived barriers.

Q5 What barriers do you think that bereaved people face when trying to get the support they need from formal services?



Individual comments included the following:

- Length of time they can receive support for.
- Pre-support and immediate post-support are often not available and therefore people are left to wait whilst trauma sets in.
- Knowing who the best person is to speak to.
- The understanding that those grieving really struggle to deal with paperwork. They also struggle to concentrate and engage with services.
- Age and gender are specific issues. Also those disenfranchised by society.
- Lack of knowledge about funeral support payments, lack of desire to apply, complications of applying, delays in receiving go-ahead for FSP.

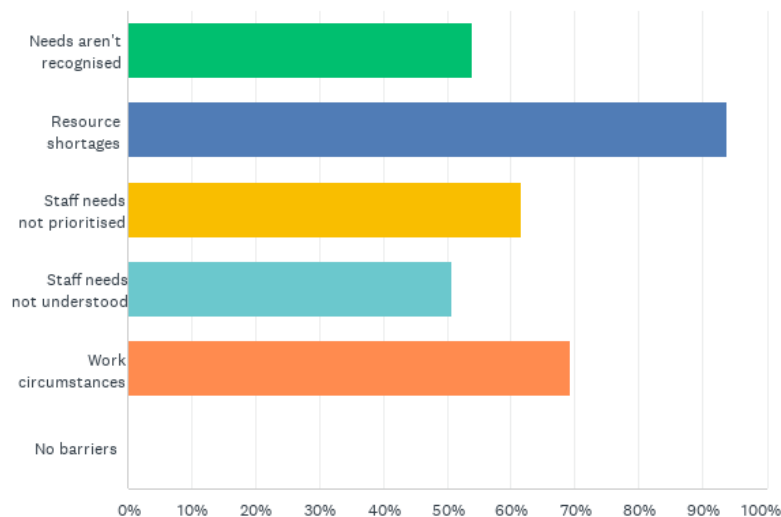
- Lack of societal acceptability of accepting support. There is still a significant level of stigma in relation to the need to ask for and accept support.

### 3.6 Bereavement experiences within the health and social care workforce

The sixth question explored the experiences of those who experience multiple bereavements as part of their job role, for example people working in health and social care. Delegates were asked what barriers exist to these people getting the support they need at work.

Around 50% of respondents felt that staff needs following a bereavement weren't understood or recognised, around 60% felt that staff needs weren't prioritised, and nearly 70% felt that colleagues and managers want to provide support, but circumstances at work make it difficult. 93% of respondents felt that staff and resource shortages mean that it is difficult to give staff the time/space they need to take care of their wellbeing.

**Q6 Thinking about people who experience multiple bereavements as part of their job role, for example people working in health and social care. What barriers do you think exist to these people getting the support they need at work?**



Individual comments included the following:

- The issue of confidentiality can be a positive and a negative as people do not share information which could lead to support being given or offered. Surely with consent from the individual some of this could be overcome.
- Culture - I often hear 'I just get on with it' 'it's my job' etc.
- This question has made me think quite a bit and probably needs more thought and reflection on my part.....But..... as a healthcare professional I do not feel that the experience of the death of a patient (even if as a GP who might have known a patient for a long time) is not akin to the death of my mum. I am therefore not sure that the term 'bereaved staff' is necessary helpful. Yes, staff who experience death within the workplace need support (and plenty of it) but I am not sure I agree with the label of 'bereaved staff' as

the relational context is different. Also, I think much of the 'suffering and distress' experienced by healthcare staff is caused by systems issues causing moral distress and injury rather than grief experienced because of the loss of the interpersonal relationship with an individual patient (and their family). But that is just my first impressions reading the question. Hope that makes sense:)

- I think organisations do wish to help, but given the uniqueness of each person's bereavement journey it can be difficult to ensure everyone is cared for. I think there is also a lot of fear from organisations that they will make things worse/not sure how to help.
- Our policy allows time off for funeral and managers are asked to encourage annual leave should more time be needed. This is the polar opposite of the supports expected to be offered to referrals to our service.
- The pressure of leaving a service understaffed means people come back to work before they are actually ready.
- Not enough education, not just employers but also of staff as death dying and grief are never top of the agenda.
- This is a huge area of concern.
- This needs to be led from the top via policy and action. If bereavement support is not prioritised by the Scottish Government (recognition, action and securely funded services) then this lack of leadership and accountability is then replicated throughout the public, private and third sectors resulting in staff who are burned out and may ultimately leave their roles.

## 4 Building on what we already know

A series of presentations were given to provide context to the day's discussions. These can be viewed here: <https://vimeo.com/760397204/c71b6019cc>

This included short presentations relating to each of five recently published reports which each have accompanying recommendations relating to how to improve people's experiences of bereavement:

- [Bereavement is Everyone's Business](#), Report of the UK Commission on Bereavement
- [Growing up Grieving](#), National Childhood Bereavement Project Final Report
- [Grief Encounters: Experiences of Bereavement Support in Later Life](#), Independent Age
- [A better route through grief: support for people facing grief across the UK](#), Sue Ryder
- [Every Story's Ending](#), Scottish Partnership for Palliative Care

The five reports all come from slightly different perspectives – they have various geographical focuses – Scotland/UK/England; and different population focuses, eg young people/old people; have drawn on the experiences of professionals and bereaved people to different extents; and the recommendations are varied in terms of the detail they provide and the level at which they expect action to take place.

However, there is much that these reports have in common. Several key themes recur between the five reports, including the need to:

- Increase awareness of bereavement issues among members of the public.
- Improve signposting to support that is available.
- Develop a strategic approach to improving experiences of bereavement in Scotland.
- Do some fact-finding/mapping/research to inform future action.

- Support schools and educational institutions to be more supportive of people who are bereaved.
- Encourage and support workplaces to be better at supporting bereaved staff.
- Allocate responsibility for improving bereavement support to individuals at a strategic level.
- Think about bereavement as a cross cutting issue.
- Support opportunities for professionals to network, learn and share good practice.
- Ensure more/better/different services.
- Tackle equity/equality issues.

(See **Appendix 4** for a more detailed analysis of key themes from the reports.)

Firstly, it is interesting to note that none of the reports focus solely on bereavement support services. All recognize that we can only improve experiences of bereavement if we look to improving the support people receive from the people around them – their workplaces, their schools, their communities, and if as we age we can continue to be connected to the people around us.

Secondly, some of the recommendations explicitly state the need for financial resources to support action in this area, and the need for resources is implicit in all of the recommendations.

## 5 Actions and priorities: what does the summit think?

This session used mentimeter.com to enable delegates to share their thoughts and reflections on questions in real time. (The full list of questions and responses is provided in Appendix 5.)

### *5.1 Did attendees Bereavement Summit agree with the key themes identified in previous publications?*

*Mainly yes...*

Small-group discussions at the Bereavement Summit tended to echo the 11 themes previously identified, providing helpful detail worth considering in future work.

For example, it was clear from discussions that ‘improve bereavement support services’ encompasses a huge range of issues, including increasing capacity, improving response rates, better needs assessment, better collaboration, and easier access to services.

Discussions indicated that ‘increasing awareness of bereavement issues among members of the public’ is about more than awareness – it is about people having understanding, knowledge, skills and confidence to offer informal support, including to children and young people, and that this requires access to information and education.

*But two further issues need to be considered...*

In addition to the 11 themes highlighted by previous reports, summit discussions highlighted two further issues not dealt with in depth in previous reports:

*The need to take action to support health and social care staff who experience multiple bereavements at work.*

Many staff deeply affected by the death of those they have supported, but are poorly paid and unsupported at work.

### *Funding*

The need for funding of some kind is implicit (and often explicit) in many of the recommendations given in previous reports. Though discussions about funding can be difficult, particularly in the present climate of austerity, it is important not to shy away from these issues – where funding is limited it is even more important to ensure that it is well spent.

As well as the eternal cry for ‘more funding’, discussions at the summit explored issues such as how to make more of the funding that already exists and how work might be prioritised to get maximum impact out of limited resources.

For example, it was suggested that:

- Barriers to partnership working are caused by the way funding is structured.
- Funding problems disproportionately affect the third sector.
- Services and projects that are recognised as being a positive benefit are very often funded only on a short-term basis, meaning that either services end or staff have to expend time and effort applying for more funding.
- Applying for funding is a burden for already stretched services, who often end up competing with each other for the same pots of funding.
- Where funding is short term, it is harder to make longer-term plans and recruit and retain good staff.
- The way most bereavement services are funded isn’t consistent with bereavement support being a core service and an issue that affects everyone.

### *5.2 What did summit attendees see as the most pressing priorities for action?*

Using the 11 themes identified within the previously published reports as a starting point, the menti survey gave delegates the opportunity to indicate how they would allocate relative priority/resource to each of these themes. The top four priorities as voted for by delegates were:

- 1) Improve signposting to available support.
- 2) Increase public awareness, confidence, comfort and skills relating to bereavement issues.
- 3) Develop a strategic approach to improving people’s experiences of bereavement.
- 4) Support schools and educational institutions to be more supportive.



## 6 Group discussions

The group discussion sessions asked delegates to focus on ideas for making positive change happen, with the prompt questions:

- What practical actions would result in improvements?
- Who is best-placed to take these actions?
- Are there any opportunities for collaboration?
- What good practice and innovations exist that can be built on?
- Could any of this be done without extra financial resources?
- What extra resources would be needed to achieve this?

Delegates split into small groups to talk about specific topics of most interest to them. Group topics were:

- Improving the experiences of bereaved children and young people.
- Improving bereavement support services.
- Improving the informal support provided in wider society to people who are bereaved.
- Improving support for social care and NHS staff who have experienced multiple workplace bereavements.
- Improving the support provided to bereaved people by the NHS.
- Improving the support provided to bereaved people by those working in social care.
- Next steps: What follows from the bereavement summit?
- Research.
- Policy: How can we shape policy at local, regional and national levels to improve people's experiences of bereavement?

Delegates recorded key points on an online padlet. At the end of the summit, delegates had opportunities to read/add thoughts to the padlet notes of other discussion topics. Padlets were also left open for additions for several weeks after the summit so that people could add thoughts later, and those who were unable to attend the summit could read through and add comments.

Sections 6.1-6.9 below attempt to record and categorise key points from these discussions.

## 6.1 Improving the experiences of bereaved children and young people

Below we have attempted to categorise the wide variety of suggestions and comments noted on the online padlet.

### **Improving how children and young people are able to deal with bereavement**

- Educate children on grief (how to support peers and self).
- Have sessions in schools regularly on bereavement throughout their school life so it does become normal and they know what to expect from their own emotions and others.

### **Improving how adults in the wider 'system' supports bereaved children and young people**

- There should be bereavement education for adults working with children, including teachers and social workers, and across education.
- Adults (family, teachers, social workers, GP's, Nurses) need to know that they might be enough support – specialist support isn't always needed. And how to identify when someone needs more support.
- It is important to ensure children and young people who have been bereaved are identified so they can get the support they need.
- Listen to the children - adults don't always know best, and what works for one child will not necessarily work for another.

### **Improving school support of bereaved children and young people**

- Teachers should receive education/further training/CPD relating to bereavement.
- Existing school resources and programmes relating to bereavement should be shared more widely.
- All schools should have a bereavement policy or guidance listing what help is available and identifying staff who are trained to work with bereaved children.
- The SPPC-publication A Road Less Lonely suggests a practical model for improving death education and bereavement support in schools that was developed in partnership with representatives from a range of organisations.

### **Improving how communities/society supports children and young people**

- Conversations about death and dying need to become more normalised, and all kinds of death need to be de-stigmatised.
- Communities need training and support to support people to know how to talk about death and bereavement with young people. The idea that someone can be 'too young' to learn and talk about death, grief and bereavement is unhelpful.

### **Improving ways of working**

- Online support can help, though this won't suit everyone.
- Bring together different areas of expertise together to support families, including working more with youth work services - young people engage with these and need an additional outlet and support away from school and home.

- Foster informal networks so that the young person can have a space just to be with others with similar experiences but not having to talk about bereavement.
- Respite support is needed.
- An option for a longer-term input to allow reflection on the experience rather than only the standard six week appointment.

### **Mapping available services**

- There is a need to map what support is currently available for bereaved children and young people.

### **Funding**

- Insufficient/short term funding leads to inconsistent support.
- Significant improvements could be made with a relatively small amount of increased funding.
- Barriers to partnership working are caused by the way funding is structured.
- Funding problems disproportionately affect the third sector.

## 6.2 Improving bereavement support services

Below we have attempted to categorise the wide variety of suggestions and comments noted on the online padlet.

### Types of useful services

A range of useful services were identified, including:

- Grief cafes for drop-in peer support
- Suicide prevention courses such as SafeTalk/ASSIST, and Ask, Help & save a Life programme.
- Early support to avoid grief metamorphosing into complicated Prolonged Grief Disorder
- Support for anticipatory grief – pre-bereavement services
- Intermediary services/advice/info?
- Mental health services
- Websites with information, support and resources for people, for example <https://www.ataloss.org/> and [www.goodlifedeathgrief.org.uk](http://www.goodlifedeathgrief.org.uk)
- Social prescribing
- Bereavement cuppas/ informed conversations
- Walking Groups/ Cooking groups

There was a suggestion of the need for a mental health hospital for mental health illness with A&E and urgent care.

### Problems to be solved

**Funding:** Services and projects that are recognised as being a positive benefit are very often funded only on a short term basis, meaning that either services end, or staff have to expend time and effort applying for more funding. Referrals to a service have to stop well before the funding runs out, for example if a service is due to stop in March, it will have to stop accepting new referrals around December. Applying for funding is a burden for already stretched services, who often end up competing with each other for the same pots of funding; funding is short term, meaning services aren't reliably sustainable and are harder to plan and organise and retain good quality staff; good initiatives stop when the funding runs out. The way most bereavement services are funded isn't consistent with bereavement support being a core service and an issue that affects everyone.

**Diversity of need and equity of access:** some people find it easier than others to get the support they need. People need personalised support depending on their needs. The support someone wants and whether they feel able/comfortable to access it can depend on various personal characteristics, including their faith, culture, religion, gender, sex, sexuality, race, age and socio-economic background. It can also be influenced by the type of bereavement they've experienced, eg suicide; different services are available in different areas, with rural areas highlighted as being less well serviced than other areas.

The UK Bereavement Commission Report argued that the right to appropriate bereavement support should be seen as a human right, central to other human rights. In particular there was a focus on the reality that those from minority groups often found it harder to access effective bereavement support; and those who were faced with socio-economic challenges were more likely to need support but least likely to access it because of barriers and costs. The UK Commission discovered that the specific needs of some religious and faith communities were not addressed in the bereavement support which was currently being offered.

**Funeral Poverty:** Not everyone can afford a funeral and this adds more stress at an already distressing time.

**Public awareness:** The public generally don't know what support is available and what to expect from services.

**Waiting lists:** Waiting lists are too long and this causes problems, for example having waited someone may no longer need the service, or their needs are more than the service can manage by that point.

**Needs assessment:** Improved bereavement support needs assessment is required so support for individuals can be targeted based on their level of need.

**Staff support:** Staff need to have a route to access a safe and confidential space for bereavement support.

**Over-reliance on volunteers?** There are downsides to models that rely on volunteers to provide bereavement counselling, and benefits to ensuring bereaved people can access support from paid practitioners in a stable role.

**Collaboration, co-ordination and leadership:** Problems result from a lack of collaboration, co-ordination and overall direction for bereavement services, for example duplication, confusion and silo-working. Bereavement extends into many areas ... employment, education, mental health & wellbeing, public health, social inequalities, etc ... how does this get pulled together in ScotGov?

What existing practice do we need to value and strengthen?

- Delegates repeatedly highlighted the importance of collaboration and co-ordination between sectors and services, and the importance of sharing good practice and learning from each other. Networking, learning and knowledge-sharing events (including the Bereavement Summit) are valuable – they can improve collaboration, inform research and service development and improve practice. Continuing to fund this kind of work is therefore important.
- Statutory and third sectors all have a role to play.
- By working together, services can improve people's experience by signposting/referring to a partner service if their support would benefit the individual involved.

Helping people to find the right support

Delegates highlighted the importance of enabling people to find a service which will help them with the right level of support.

This needs to be done by a combination of information provision (eg online information about services available), appropriate referral (eg professionals including GPs being able to identify those most at risk of complex grief and target services to them) and by services referring to other services when appropriate.

Ideas for action

- Improve equity of access: service design should be informed by an understanding of the range of needs people can have; services should be flexible to accommodate a diversity of needs and outlooks– there is no 'one size fits all'
- Improve leadership and direction: develop a national policy relating to bereavement, as well as local policies. Allocate a national bereavement lead of some kind, whether that be a

Minister, senior civil servant, or a new post at SG for someone with experience of working within the bereavement sector to provide co-ordination and leadership based on collaboration with the sector.

- Map what services are already available.
- Improve signposting to services: eg by introducing a national (Scotland) signposting, information and resource hub. This should include a helpline and website but also live information so that people are getting real time interactive support to find what they need. This team of people would have to be proactive in learning about availability, potentially link into the wealth of information from the established networks and not be precious or hierarchical about support.
- Improve support for anticipatory grief: develop links between services supporting people at the end of life and those providing bereavement support.
- Improve mental health services.
- All of the above requires services to be sufficiently resourced for staff to be able to take a little time to participate in networks and learn what other services are available.
- Cover the cost of a basic funeral for all.
- Develop a fit-for-purpose mechanism for longer-term funding of projects that have been proven to have value.
- Financial investment and transformation in bereavement services over the next 5 years - particularly targeting seldom heard groups and those experiencing financial insecurity.
- Look into how transport can help people access services, particularly in rural communities.

### 6.3 Improving the informal support provided in wider society to people who are bereaved

The purpose of these discussion groups was to explore how we can improve the informal support people receive in wider society; to look beyond formal services and think about how people can help themselves and each other.

#### **Everyone's business**

Discussions highlighted that bereaved people need to feel supported wherever they are – whether that be in their neighbourhood, at work, at school, in prison, or anywhere else. This means that there is a need for skills in informal bereavement support to be something everyone has, and for people who work in jobs such as emergency services or teaching, to receive training to enable them to support bereaved people they come across at work. Similarly, adults need to better understand the support that children and young people need when they've been bereaved.

#### **Information is essential**

People need to be able to find information not just about what formal services are available, but also about bereavement experiences, and how to offer informal support whether that be to a friend, family member, neighbour, colleague, or someone else. Such information could be provided both online and in leaflet format, in key locations such as libraries, pharmacies, schools, community centres, supermarkets, but also by people in key roles such as registrars, funeral directors, GPs and community link workers.

#### **Building understanding communities**

Delegates highlighted the importance of increasing understanding of bereavement, with several suggesting the need for some kind of publicity campaign. 'See Me' was cited as an example of a successful campaign that might provide a model for a campaign opening up conversations and understanding about bereavement, and there was a suggestion of working with the Script Writers guild, BBC to influence language used in the public sphere.

When someone is bereaved, they need informal support from the people around them – their family, friends and other communities they are part of. It was highlighted that rituals can be of comfort when someone is bereaved, but that this has been lost in many communities where the reduction in religious practices has not been replaced by equivalent humanist or similar rituals that are adopted and practised widely enough to form community cultures. Many people lack experience, knowledge or confidence in providing informal support, and our culture doesn't always support openness around bereavement. Suggestions for improving this included education in bereavement and how to talk about it, both at school and for adults working in all spheres including civil servants; increasing the role of faith communities; building more community connections and more supportive cultures in communities.

Within the discussion there was recognition that work within communities should be influenced by communities themselves, yet that the power dynamics of funding can create a barrier to this. It was also suggested that small community work can lack governance and accountability.

Work is underway in Scotland to address several of these areas, for example Good Life, Good Death, Good Grief works to support those trying to create more compassionate communities relating to death, dying and bereavement; runs public education to help people learn about these issues; has a public-facing signposting website; runs annual Demystifying Death and To Absent Friends weeks; and

has worked with the Bereavement Charter Group to support workplaces to take action to become more supportive of bereaved colleagues. Work is limited by resources available.



## 6.4 Improving support for social care and NHS staff who have experienced multiple workplace bereavements

This discussion focused on improving support for staff who have experienced multiple workplace bereavements, but also recognised that staff's personal bereavements can affect how they experience workplace bereavements, and also on their ability to perform their role.

Delegates agreed that mental wellbeing of staff has to be a priority, and is an element to be considered when commissioning services. Resourcing this is tricky, both in terms of enabling staff to have time to access support, and also finding resource for staff support services. It was pointed out that there can be many support services on offer to people but they are often not taken up for a variety of reasons, and that staff who are over-stretched, stressed and under pressure have many needs of which bereavement support is just one.

Proper support can help to prevent burnout, compassion fatigue and trauma fatigue. Supporting staff not only shows that they are valued, but will have long-term gains in reducing time off and helping to retain staff. Some of the effects of workplace bereavement can be hidden, for example recorded as 'stress', 'anxiety' or depression.

It was felt that social care staff have distinct needs that are not often supported. When a client dies, staff often miss not just the person, but also their family. Care home deaths are often investigated by police, which is traumatic for staff, and there's a feeling that care homes are continually under scrutiny. Those working in care homes can have difficulty accessing information resources. Social care workers are deeply affected by the death of those they have supported, poorly paid and unsupported.

Suggestions of ways to support staff included:

- Access to psychological support on a regular structured basis in a safe and confidential space.
- Management support such as creating time with staff, checking in with them, making time for conversations more often.
- Support from chaplaincy.
- Opportunities for debriefing.
- Access to complementary therapies.
- Potential of referring to external organisation for counselling.
- Peer support.
- Time at work to process death – people shouldn't have to give up extra time to process workplaces grief.
- Signposting proactively to relevant support.
- Models such as the reflective practice work in care homes.
- The potential for resources such as 'grave talk' to help staff have open conversations.
- Colleagues can show support by sharing feelings to model that it is ok for others to open up too if they wish.
- Review wording around compassionate leave policies, less reliance on general managers to interpret policies and a responsibility for HR to monitor procedures.
- Safe spaces to have conversations at lunch times
- Scheduled times for whole team to get together and share impact of work in break out rooms encouraging people to talk openly in workplace.
- Destigmatising normal grief reactions.

- People don't often hear about information until further down the line – there's a need to assess people's needs and offer access to information and support in a timely manner.
- Pre-bereavement support is vital. (ie Support for those who are supporting those who are dying as well as affected by the death thereafter.)
- Website where everyone can access information about support.
- More investment in the welfare of staff, both from statutory and independent providers.

## 6.5 Improving the support provided to bereaved people by the NHS.

This group was an opportunity to explore the support that the NHS provides to bereaved people.

The following issues were highlighted:

- We need to ensure expectations are realistic – people shouldn't be promised something that can't be delivered.
- Pre death support and information is very important.
- Diagnosing dying still poor in many places, meaning that family members may not be expecting to be bereaved, which in turn can affect the support they need.
- Over-stretched resources can make it difficult to see how improvements can be implemented.
- The support people receive depends on where they live – there needs to be more consistency.
- Covid has increased the number of people with complex grief.
- Most people cannot access bereavement support from NHS unless cancer-related or via a hospital related death or in-person support. Significant investment would be required for this to be mainstream. The third sector would most likely be able to provide this for much less if resource was put into it.

### **What can help?**

The third sector can support the NHS in supporting people who are bereaved, but often this needs to be recognised and better co-ordinated.

Signposting is key, whether to written information, websites, counselling, peer support, financial support or other types of support. Websites such as [www.ataloss.org](http://www.ataloss.org), <https://www.thegoodgrieftrust.org/> and [www.goodlifedeathgrief.org.uk](http://www.goodlifedeathgrief.org.uk) exist but aren't widely known about.

Review the booklet 'What to do after a death in Scotland' to ensure it has the best information for signposting for bereavement support.

Don't over-professionalise grief – let people know that grief is normal.

There is a need to ensure there is some "first aid" support, not just support after 6 months.

Signposting early on and checking in before families leave the NHS service.

A 'bereavement box' similar to a 'baby box' to help in the immediate aftermath of a death. (Victim Support is already creating a children's bereavement box.)

### **Identifying people who need support.**

Is there a tool that can help with this? Is there a common touching point for everyone who experiences in death in hospital - who can assess needs and signpost to support? Might resource be attached to the palliative care team to provide this role? So, someone can be triaged and reacted to -and give contact details so people can self-refer when the time is right.

All NHS staff come into contact with bereaved people, and therefore all need to know how to recognise ordinary grief and to provide basic support and signposting when someone is bereaved.

Enabling ward staff and family members to refer someone for support.

### **Examples of good work already happening**

The NES bereavement team offers resources and seminars to help staff learn more about supporting bereaved family members in various situations.

Mention was made of a model England where there is a bereavement support team post death for everyone.

The NES bereavement team offers resources and seminars to help staff learn more about supporting bereaved family members in various situations.

In some hospitals spiritual care have a big role in bereavement support.

In terms of children there is now a co-ordinator in every area that should be signposting parents bereaved of a child.

Many hospitals have a dedicated bereavement midwifery team.

NHS Greater Glasgow and Clyde have support for all staff affected by bereavement provided by Child Bereavement UK (funded by the childrens hospital charity).

6.6 Improving the support provided to bereaved people by those working in social care.

#### **Low attendance**

Only two people came to this group, and it is important to question why this might be. The summit was advertised via the networks of the SPPC, local bereavement networks and Scottish Care. Did social care staff not know about the summit? Weren't they interested? Were they unable to find time/be released to come to the summit? Do people not feel there's any point coming to such an event? Is bereavement support seen as peripheral to other concerns in social care? Did other attendees at the summit not feel they could comment on social care issues so attended other groups?

There was a good attendance at the group discussion of how to support health and social care staff, and it may be that this was the main issue that people wished to discuss in relation to social care.

#### **Needs of social care staff**

This group provided an opportunity to discuss how those working in social care can support people who are bereaved. However, notes indicate that other than highlighting the need for signposting to bereavement support, the discussion focused on the support that social care staff need themselves. These points have been added to Section 6.4 above.

## 6.7 *Next steps: What follows from the bereavement summit?* What can we do next to build on the momentum from the summit to make positive change happen?

These discussion groups provided an opportunity for delegates to explore what they'd like to see happen after the summit, including what they could do themselves as well as what action they'd like to see from others.

### **Overlapping discussion**

Notes indicate that much of discussions overlapped with areas focused on in other discussion groups, for example highlighting again the importance of:

- co-ordination and leadership relating to bereavement support.
- sustainable funding for work that has proven itself to be useful.
- mapping to identify what is available and where the gaps are.
- signposting so that people know what is available.
- training for people in all relevant roles, to enable better support and raise awareness of the importance of bereavement.

Points relating to these areas have been incorporated elsewhere in this report.

### **Maintaining the momentum from the summit**

Suggestions included:

- Think about some "quick wins" to build on collaborative relationships.
- Come together as a group of organisations to put pressure on the Government to implement changes- call for a Lead for Bereavement and Strategy on bereavement.
- Develop a register of groups and bereavement services to help communication, building on existing bereavement networks.
- Local Council Areas could develop plans.
- Bereavement Charter next steps: talk about it so that people know it exists!
- Create a network/group that regularly meets to progress work and share best practice a fit for purpose manner.
- Involve Journalists.
- There has to be a clear message from the SG that they are taking these recommendations seriously and they're open to re-examining their approach and working more collaboratively with the sector to make plans and decisions.
- We need influencers to get behind it otherwise it gather dust in the same way Shaping Bereavement Care did.

## 6.8 Research

These groups explored questions such as: What gaps in knowledge exist? How do we address these? What research should we be paying attention to? How do we join up research and practice in a more meaningful way?

### **What gaps in knowledge exist?**

- Lack of information available using large data sets.
- The way people die in Scotland is unique - and that shapes bereavement support... so longitudinal data would be really helpful.
- The widest gap between rich and poor needs to be better understood.
- We need better understanding of how people grieve in communities where deprivation is prevalent and how support would be better delivered.
- We don't have data on what services are where, and the impact on what that actually means for those communities.
- There is a role for the media in supporting how people know about services – we need more research into communication strategies.
- We need to know more about safe bereavement care and efficacy of this and how to join up services.
- What should the role of health and social care be in providing bereavement care?
- The impact of caregiving experience on bereavement.
- What is the impact of early intervention and pre-bereavement support? Also, at the other end of spectrum where people have not had access to support they wanted - what has been the impact? Join up where the benefits of early intervention have reduced risks of longer-term impacts.
- Bereavement experiences in marginalised groups have already been discussed - how do we develop and offer quality services that meet everyone's needs?

### **How do we join up research and practice in a more meaningful way?**

- Identify pockets of good practice.
- What can we learn from psychological models that we can share with bereavement services?
- Knowledge exchange.
- Make a directory of research evidence. (But how do we keep updates and ensure it gets to the right people?)
- Development of more targeted bereavement support interventions.
- Support interventions that work in busy clinical practice
- Create a mailing list / directory of those interested in bereavement support research? Could be a Uni that might do this / other interested groups.
- Need to share tools that assess bereavement support needs and outcomes. Some standardized assessment could be helpful to map the needs of different groups.
- Develop a bereavement research network for Scotland.
- We need to introduce the concepts of up-to-date models to those outside of bereavement world. That could happen in school learning, in workplace wellbeing, in community education.

Though all of these ideas were expressed during discussions, it would be helpful to establish the extent to which some of these things might already be happening.

## 6.9 *Policy*: How can we shape policy at local, regional and national levels to improve people's experiences of bereavement?

The following issues were raised on the online Padlet:

- Signposting was heavily referenced in the policy recommendations of each of the five reports presented at the Summit. This needs to be incorporated into upcoming Scottish policy eg Scottish Carer's Assistance, Funeral Support Payment.
- The need for improved bereavement support should be fed into the National Care Service consultation.
- There is a lot of information and evidence around, but a lack of a framework that would help pull everything together from a regional, local and national level, which would also facilitate joint working. Therefore we need cross-departmental, dedicated bereavement strategy, with funding attached. It was suggested this shouldn't be under mental health policy.
- We need a person/people with a lead/co-ordinating role in taking what we know and implementing it. Exactly what this would look like would need to be worked through. Suggestions included a Minister for Bereavement and a Scottish Bereavement Taskforce, similar to Scot Gov Victim's Taskforce.
- Clear responsibility at local and regional levels is very important.
- The Planning and Commissioning framework within HSCPs should be playing a role in ensuring support is being delivered at a local level.
- We need a standard and an expectation so that we are clear that everyone in Scotland has the same possibility of good bereavement support (even if they choose not to or are unable to access it)
- Perhaps a working group that has people with lived experience, research, policy and strategy so a full picture is able to be gathered to implement change across the board and not just a policy that sits on a shelf.
- We can shape local policies by using initiatives like the workplace toolkit and charter mark, and similar initiatives for other areas.

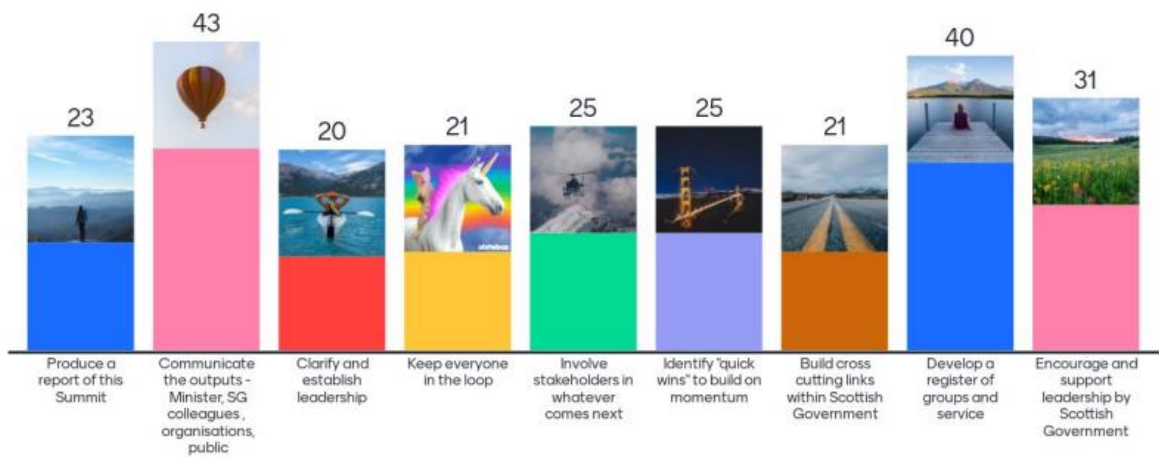


## 7 Next steps: What follows from the bereavement summit?

In a final Menti question, delegates were asked to vote on some ideas as to what should happen next. These ideas were drawn mainly from Discussion Topic G, and results are presented below.

# Next Steps on the Journey?

Mentimeter



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It is clear that delegates are keen to see concrete action to follow on from the Bereavement Summit:

### Scottish Government involvement

A key theme from the summit was the need for improved leadership, co-ordination and a strategic approach to enable improvements in all areas of bereavement support. Scottish Government are seen as being integral to this, with it seen as important to communicate the outputs of the meeting to the Minister and SG colleagues, and to encourage support and leadership by Scottish Government.

### Maintaining momentum

There was a clear desire to maintain the momentum and connections built by the summit, by producing a report of the summit, keeping everyone informed, involving stakeholders in whatever comes next, and perhaps by working together to achieve some 'quick wins' to build on collaborative relationships. Establishing a directory of services to assist signposting was seen as a priority.

## 8 Reflections and Recommendations

What insights have been brought by the Bereavement Summit?

Recently published reports/recommendations on bereavement issues<sup>1</sup> present helpful insights in terms of people's experiences of bereavement and some key areas for improvement. However, for these to be put into action, there is a need for recommendations to be sense-checked with those working within the system – this was an important aim of the Summit.

Professionals working within the sector can bring helpful insights into what kinds of changes might help and, more importantly, what might be do-able within the current environment. Analysis at the summit indicates that there is a growing consensus over what the key areas of focus should be, and it is now important to focus on *how* these changes can be achieved.

Those working in the sector can also provide helpful insights about what initiatives, projects and networks already exist that could be learnt from, built on or scaled up, rather than starting from scratch or duplicating what already exists. They can also provide valuable views on what areas should be priorities, how the 'system' can be improved, and what barriers exist.

Within this report, valuable insights from those working within the system have been used to inform recommendations which seek to reflect the Scottish context and experience and suggest practical, do-able ways forward which builds on existing work.

What Next?

Though there is incredible will and enthusiasm for change, the question remains, in a sector that is already over-stretched and hard-pressed, is further improvement possible without an influx of resource from somewhere?

It is clear that summit delegates are looking to Scottish Government to play more of a role: in developing a strategic approach; supporting leadership within the sector and improving funding. This report of the Summit should be shared with the Minister and Scottish Government colleagues, and efforts made to arrange a meeting to discuss how the sector and SG can work better together make improvements.

Alongside these efforts to engage with Scottish Government, is it possible for those working within the sector to make inroads to improvement within existing resource and without allocated responsibility/leadership?

The Bereavement Summit discussions indicated that there is an appetite to explore this further, as soon as possible. This will require interested organisations and individuals to take the initiative to move this forward.

A starting point might be to explore capacity for and interest in undertaking a collaborative project of some kind. This might be done through existing groups such as the Bereavement Charter Group, the Scottish Partnership for Palliative Care, and the Scottish Bereavement Network, depending on their capacity to take on this work.

## Recommendations

To assist future work in this area, this section brings together summit discussions into practical ideas for future action, with the following ten recommendations:

1. Improve signposting to available support.
2. Increase public awareness, confidence, comfort and skills relating to bereavement issues.
3. Ensure strategic direction, accountability and responsibility for improving bereavement support.
4. Enable schools and educational institutions to be more supportive of people who are bereaved.
5. Address equity/equality issues and improve access to services for people with a range of needs.
6. Encourage and support workplaces to be better at supporting bereaved staff.
7. Support opportunities for professionals to network, learn and share good practice.
8. Improve bereavement support for Health and Social Care staff.
9. Improve how bereavement services, projects and initiatives are funded.
10. Do some fact-finding, mapping and research to inform future action.

These recommendations reinforce and augment findings of previously published reports<sup>ii</sup>. This section summarises why each area is important, what work exists that can be built on, and some potential practical ways of achieving these recommendations.

## Recommendation 1: Improve signposting to available support.

### Why is this important?

People can't benefit from available support if they don't know it is there. It is therefore essential that people can find support that can help them, whether that's written information, websites, counselling, peer support, financial support or other types of support. Though signposting websites and leaflets are helpful, they quickly go out of date and generally don't provide crucial information about who is eligible for support from different places. Websites are no substitute for a person/people with knowledge of bereavement and the sector with up-to-date knowledge of what's available who can provide personalised, interactive support to help someone find what they need and navigate the complexities of the system. In addition to signposting, it is also important that efforts are made to proactively direct people to support that could help them.

### What work exists that can be used and built on?

Websites with signposting information about available bereavement support exist but aren't widely known about, for example [www.ataloss.org](http://www.ataloss.org) and [www.goodlifedeathgrief.org.uk](http://www.goodlifedeathgrief.org.uk). NHS Inform is the 'go to' place for health information but doesn't signpost to many bereavement services. The website [www.aliss.org](http://www.aliss.org) aims to be a place where people can list health services of all kinds so people can find out about them when they type in their postcode. The Childhood Bereavement Co-ordinator Project did some mapping of services at the project's outset. CBUK supports local bereavement networks where professionals can learn about what other services are available in their area that they might be able to signpost people to, and also provides informal personalised signposting when needed. The 'What to do after a death in Scotland' booklet is designed to provide information to bereaved people.

### What could be done?

- Establish a national (Scotland) signposting, information and resource hub which includes a regularly updated database of services website but also a helpline providing real time interactive support to help someone find what they need. Those staffing the helpline should be proactive in learning about service availability and potentially link into the wealth of information from the established networks, and also could help with some of the bullets below.
- Sustain and grow existing professional networks, to provide a mechanism for professionals to learn about other relevant services, and a potential hub of education/information about bereavement support in Scotland. (This work could be efficiently combined with the suggestions in the first bullet point.)
- Educate professionals to enable them to direct people to appropriate services – not necessarily straight to counselling / medication.
- Encourage/support appropriate organisations to help with signposting, eg Funeral services, NHS Inform, GPs, Citizens' Advice, Faith Groups, HealthyWorking Lives, Social Security Scotland, Registrars, Tell Us Once Service etc.
- Those working in the field should be aware of what other services are available in their area so they can direct people to a partner service if their support would benefit the individual involved.
- Review the booklet 'What to do after a death in Scotland' and the NHS Inform website to ensure it has the best information for signposting for bereavement support.
- Provide families with information early on, and before they leave NHS services.
- Incorporate appropriate signposting into upcoming Scottish policy eg Scottish Carer's Assistance, Funeral Support Payment.

## Recommendation 2: Increase public awareness, confidence, comfort and skills relating to bereavement issues

### **Why is this important?**

Everyone who is bereaved needs a supportive response from their existing social networks, whether that is their family, friends, workplace, school, faith community, neighbours or other community.

In order to be able to offer this informal support, people need to have awareness of bereavement and its effects on someone, an idea of how to offer informal support, and the confidence and opportunity to do so.

However, often people feel awkward, or don't know what to say, fear making things worse, or are operating within cultural norms where people feel unable to offer help.

### **What work exists that can be used and built on?**

The Bereavement Charter has been developed to raise awareness and knowledge about bereavement in Scotland, and the charter group is working to increase awareness of the charter, through seminars, social media, work with MSPs, development of guidance notes, films and charter mark. Good Life, Good Death, Good Grief is an alliance of organisations and individuals that is working to make Scotland a place where everyone can help when someone is caring, dying or grieving. It has initiated the annual To Absent Friends Festival, a participative festival which encourages communities to come together to share stories of those who have died, providing opportunities to share solace and social connection. GLGDGG has also created the End of Life Aid Skills for Everyone public education course (EASE), a free course for anyone who wants to know more about offering support to someone who is caring, dying or grieving. Child Bereavement UK and Cruse Scotland offer bereavement awareness courses.

### **What could be done next?**

Existing work relating to the Bereavement Charter, To Absent Friends and EASE could be built on and upscaled. For example:

- Organisations throughout the sector could use their networks to spread awareness of the bereavement charter work, and support the development of this work where time/resources allow.
- Interested organisations and individuals can volunteer to deliver the EASE course of charge in more communities.
- Interested organisations and individuals can organise To Absent Friends events in communities across Scotland.
- With further funding the work of the bereavement charter group, EASE and To Absent Friends could be strengthened/upscaled/ expanded and brought to more communities in Scotland.
- A public health campaign could be initiated to dispel some of the myths around bereavement.
- See also recommendations relating to schools (Recommendation 4) and workplaces (Recommendation 6).

## Recommendation 3: Ensure strategic direction, accountability and responsibility for improving bereavement support

### Why is this important?

Bereavement affects everyone, meaning that bereavement issues need to be recognised across many areas of policy and strategy - for example employment, education, mental health, health & social care, justice, public health, social inequalities, benefits. Effects of bereavement contribute wider pressures on mental health, social work, criminal justice and health and wellbeing services.

For a complex issue like this, having a strategic approach is particularly important. Without this there are risks that:

- bereavement issues ‘fall between two stools’ – everyone thinks someone else is dealing with it.
- duplicating/overlapping work takes place, which can be an inefficient use of resources.
- it is hard to explain why some projects/areas are funded over others
- decision-makers have to start from scratch in understanding the landscape and deciding what needs to happen next in the absence of an over-arching plan.
- bereavement services are likely to be undervalued by commissioners and other decision makers.

Alongside a strategy, there needs to be responsibility allocated for who will drive action towards meeting the strategic aims. Without allocated responsibility at a national level, bereavement is no-one’s priority.

As well as a lack of national leadership, participants at the summit highlighted that various problems are caused by lack of co-ordination of bereavement services at a local and regional level, meaning that:

- Organisations do their best to provide support, but there is often a lack of collaboration, co-ordination and overall direction.
- Without co-ordination there can be duplication, confusion and silo-working.
- Consensus is lacking on who is responsible for different aspects of support, and many services don’t talk to each other.
- There can be a lack of focus/collaboration on priority issues.

### What is there to build on?

Five recent reports are available that can help to inform a strategic approach:

- [Bereavement is Everyone’s Business](#), Report of the UK Commission on Bereavement
- [Growing up Grieving](#), National Childhood Bereavement Project Final Report
- [Grief Encounters: Experiences of Bereavement Support in Later Life](#), Independent Age
- [A better route through grief: support for people facing grief across the UK](#), Sue Ryder
- [Every Story’s Ending](#), Scottish Partnership for Palliative Care

These reports all come from slightly different perspectives – they have various geographical focuses – Scotland/UK/England; and different population focuses, eg young people/old people; have drawn variously on the experiences of professionals and bereaved people to different extents; and the recommendations are varied in terms of the detail they provide and the level at which they expect

action to take place. However, there is much that these reports have in common in terms of key areas of focus, and they contain various ideas for improvement that could be further explored.

Professionals working in the sector have experience and skills and energy and motivation to support building a more strategic approach; local bereavement networks built by CBUK provide a helpful mechanism to tap into local knowledge; SPPC is an intermediary organisation with skills and networks to support this type of work; the bereavement charter group provides a network of people engaged in initiating improvements; NES runs a network of NHS bereavement leads.

### **What can we do?**

- Develop a national strategy for improving bereavement support in Scotland which aims to take a co-ordinated approach to improving experiences of bereavement across different aspects including bereavement services; wider societal support; supporting staff who deal with multiple bereavements at work.
- Acknowledge bereavement support as a human right, and intrinsic to realising other human rights such as the right to health and the right to family life, which SG has committed to enshrining in Scots law through the forthcoming Scottish Human Rights Bill.
- Allocate overall responsibility for bereavement to a Minister and senior civil servant to lead Scottish Government support for example by sponsoring work, encouraging statutory sector partners' participation, facilitating the provision of sustained funding, promoting visibility of issues within policy, and modelling openness about bereavement issues at Scottish Government level.
- Create a national bereavement lead role to provide co-ordination and leadership based on collaboration with the sector.
- Create a Scottish Bereavement Taskforce, similar to Scottish Government's Victims Taskforce.
- Ensure that local NHS bereavement leads have the skills and resources needed to initiate improvements support collaboration across different sectors.
- Set up a working group (including people with lived experience and experience of practice, research, policy and strategy) so a full picture is able to be gathered to implement change across the board and not just a policy that sits on a shelf.

## Recommendation 4: Enable schools and educational institutions to be more supportive of people who are bereaved.

### **Why is this important?**

Children spend a huge amount of time at school, and school is not just where children learn about the world, but also where they build most of their social relationships. It is therefore important that schools are supportive places for young people who have been bereaved, and that schools are places where children can learn about death, dying and bereavement as being part of life. Schools are also workplaces for teachers, learning assistants, cleaners, janitors, management and administration staff, all of whom are likely to be bereaved at some point.

Compared to their non-bereaved peers, children and young people bereaved of a parent are more likely to experience a range of poor outcomes. However, when it comes to ill health, death and bereavement, in school communities, staff may feel uncertain about how to help or worry about making things worse. Due to this the bereavement needs of children can often go unmet and many children report having no-one to talk to. Support from peers is an important part of a child's social support networks.

### **What is there to build on?**

*Growing up Grieving*, the report of the National Childhood Bereavement Project, includes a section exploring the role of schools, and includes insights from young people who have been bereaved. It references several valuable pieces of work that could be learnt from or built on, including *Seasons for Growth*, *A Road Less Lonely*, *A Whole Schools Approach to Loss and Bereavement*, and relevant research in this area. The UK Bereavement Commission Report explores the experiences of children at school, some of the barriers to support provided, and some of the things that can help. The report *A Road Less Lonely* suggests a practical model for improving death education and bereavement support in schools that was developed in partnership with representatives from a range of organisations, with input from those working in education. Many resources exist, both within Scotland and beyond, designed to support teachers and schools to support bereaved young people and staff, and to provide death education.

Sally Paul (Lecturer in Social Work, Strathclyde University) is currently undertaking a study into Death, Grief and the Scottish Curricula. The Bereavement Charter Group, Good Life, Good Death, Good Grief, CBUK, St Columba's Hospice and Inverclyde Cares are exploring how schools might be supported, and this has included efforts to gather views from people working in schools. Part of this work is exploring the usefulness of working with schools to create a bereavement charter mark and toolkit for schools, using a similar model to the Workplaces Charter Mark that has been successfully piloted in Inverclyde. The Childhood Bereavement Network is gathering responses from teachers and school staff to a survey about grief education in schools. Most of the work in this area is being done on the basis of goodwill, with little-no funding allocated to support this area of work.

### **What further could be done?**

- Fund a project to bring together what has been learnt so far and move forward with proactive work to support good practice around grief education and bereavement support in school communities, including:
  - Creating an online and accessible resource bank where schools/teachers/management can find information about how to implement a whole school approach to bereavement,



including death education, bereavement support, bereavement training and bereavement policies.

- Encouraging and supporting schools to improve their approaches to death education and bereavement support. This should include promoting the resource bank outlined above; highlighting and promoting the importance of bereavement support and death education to primary schools across Scotland; actively building partnerships with and supporting schools to make changes.
- Provide funding to enable schools to access bereavement training from existing third sector training providers.
- Introduce bereavement as a part of teacher training.
- Explicitly call for/develop education about 'death' and 'grief' within the Curriculum for Excellence.

## Recommendation 5: Address equity/equality issues and improve access to services for people with a range of needs.

### **Why is this important?**

Some people find it harder than others to get the support they need. People need personalised support depending on their needs and what they feel comfortable with, and often people need encouragement or support before they'll access a service that could help them.

Whether someone is able/comfortable to access services can depend on various personal characteristics, including their faith, culture, religion, gender, sex, sexuality, race, age and socio-economic background. This can also be influenced by the type of bereavement they've experienced, and what their support needs are. Different services are available in different areas, with rural areas highlighted as being less well served than other areas.

Where someone has to wait a long time to access a service, this can cause problems, for example they may no longer need the service, or their needs increase and become more than the service can manage by that point.

### **What is there to build on?**

Evidence to the UK Bereavement Commission highlighted that some groups and communities faced particular barriers to accessing bereavement services, including older people, ethnic minorities, people who are socio-economically disadvantaged, bereaved parents, those in need of longer-term intensive support, and LGBTQ+ individuals. The Commission Report explores some of the challenges and barriers to support experienced by currently underserved communities, including ways of improving support for currently underserved communities, with a particular focus on racially and culturally minoritised communities, LGBTQ+ people, people with learning disabilities, people experiencing homelessness, and people in prisons.

### **What further could be done?**

Many of the previous recommendations within this report are aimed at improving services and access to services, for example through better signposting, improving leadership, taking a more strategic approach, improving collaboration, and education & networking opportunities for staff. Addressing equality/equity issues should be integral to all of this, and any work going forward should be informed by the needs and barriers faced by different groups of people accessing services.

In addition, the following ideas were raised at the summit:

- service design should be informed by an understanding of the range of needs people can have.
- services should be flexible to accommodate a diversity of needs and outlooks— there is no 'one size fits all'.
- there is a need to improve support for anticipatory grief, for example by developing links between services supporting people at the end of life and those providing bereavement support.
- improve access to mental health services.
- cover the cost of a basic funeral for all.
- target investment to support seldom heard groups and those experiencing financial insecurity.

- establish a bereavement grant for those in a precarious financial position as the result of a primary income earner dying.
- improve bereavement support needs assessment so support for individuals can be targeted based on their level of need.
- Look into how transport can help people access services, particularly in rural communities.

## Recommendation 6: Encourage and support workplaces to be better at supporting bereaved staff.

### **Why is this important?**

Many people spent significant amount of their lives at work, and workplaces provide the basis for many social interactions. Therefore, when someone is bereaved, how they are treated by their colleagues, manager and employer can make a huge difference to their experience of bereavement – making it a little bit better or a lot worse.

Workplaces can play an important role providing:

- flexibility to allow an individual to adjust to their new circumstances.
- information on financial, legal and other practical issues.
- understanding and social support.

Providing a supportive workplace can also have benefits for the organisation. However, many bereaved people find that their workplace is unsupportive.

### **What is there to build on?**

The UK Bereavement Commission Report explores bereaved people's workplace experiences and some helpful and unhelpful practices relating to workplace treatment of people who are bereaved. Good Life, Good Death, Good Grief launched the Bereavement-Friendly Workplaces Toolkit in 2022, which brings together resources to support colleagues, managers and employers to provide more bereavement-friendly workplaces. GLGDGG has worked with the Bereavement Charter Group to develop the Bereavement Charter Mark for Employers, designed to encourage and support workplaces to take action to become more supportive of employees. Inverclyde Cares, CBUK and GLGDGG have worked together to pilot the bereavement charter mark in Inverclyde, with positive results.

### **What further could be done?**

The bereavement charter mark for employers and accompanying toolkit provide helpful resources that could be used by workplaces to improve their support for bereaved staff. Efforts to encourage the Healthy Working Lives to promote these resources could be renewed.

A pilot in Inverclyde has illustrated how a dedicated person can increase the number of organisations applying for the Workplaces Bereavement charter mark, by encouraging and supporting employers to take action within their workplaces. Funding for a post to support employers to adopt the Workplaces Bereavement Charter Mark would help it to reach more people.

Recommendation 7: Support opportunities for professionals to network, learn and share good practice.

### **Why is this important?**

In order to provide the best support to bereaved people:

- bereavement support practitioners need to develop and improve their practice by learning about research findings, undertaking training, and learning from peers.
- staff who come into contact with bereaved people need to understand enough about bereavement to be supportive themselves, and also to direct people to other support.

Therefore, there need to be opportunities for professionals to keep abreast of recent developments, learn about good practice and make connections with other people working in their area.

### **What can we build on?**

Child Bereavement UK has worked in partnership with various organisations to establish local networks for people working in bereavement support for children, young people and adults in Lothian, Glasgow, Lanarkshire, Dumfries & Galloway, Inverclyde, Grampian, Fife, East Lothian and Forth Valley. Grief Matters has established a local bereavement network in Highland, and Cruse Bereavement Care Scotland and CBUK have led the establishment of a local bereavement network in Tayside. A Scotland-wide bereavement networking event took place in September 2022. This work has been done on the basis of short-term funding.

The UK-wide National Bereavement Alliance organises regular information-sharing and networking events which are much valued by those working in bereavement in Scotland, and produces a monthly newsletter. The Scottish Partnership for Palliative Care provides networking for professionals working in palliative care, and a free monthly e-bulletin with news relating to palliative care, including bereavement. NES bereavement team offers free resources and seminars to help staff learn more about supporting bereaved family members in various situations, and produces a monthly newsletter. NES co-ordinates a monthly meeting of NHS bereavement leads.

### **What further can be done?**

- Provide long-term funding to the networking activities initiated by Child Bereavement UK.
- Increase resource to networking activities to enable them to better facilitate cross-sector communication between third/private sector and NHS services.
- Further support the development of research and good practice, for example by:
  - o Identifying pockets of good practice.
  - o Knowledge exchange.
  - o A directory of research evidence.
  - o Create a mailing list / directory of those interested in bereavement support research.
  - o Sharing tools that assess bereavement support needs and outcomes.
  - o Developing bereavement research network activities.

## Recommendation 8: Improve Bereavement Support for Health and Social Care staff

### **Why is this important?**

Dealing with death at work on a frequent basis can affect someone's wellbeing, and their ability to do their job. In a care home or care at home environment, a member of staff will often have built up a relationship with an individual over months and years, and their death can have a profound impact. Depending on their role, health and social care professionals, and other roles such as emergency services, can experience multiple deaths at work, some of which may be traumatic in some way.

That death is a regular and expected part of many people's job role needs to be recognised and supported. Some of the effects of workplace bereavement can be hidden, for example recorded as 'stress', 'anxiety' or depression. Proper support and a supportive culture in the workplace can help to prevent burnout, compassion fatigue and trauma fatigue. Supporting staff is not just an important part of valuing and looking after staff, but will have long-term gains in reducing time off and helping to retain staff.

### **What work is there to build on?**

At the Summit, many examples were given of helpful ways to support staff, including:

- Access to psychological support on a regular structured basis in a safe and confidential space.
- Management support such as creating time with staff, checking in with them, making time for conversations more often.
- Support from chaplaincy.
- Opportunities for debriefing.
- Access to complementary therapies.
- Potential of referring to external organisation for counselling.
- Peer support.
- Time at work to process death – people shouldn't have to give up extra time to process workplaces grief.
- Signposting proactively to relevant support.
- Models such as the reflective practice work in care homes.
- The potential for resources such as 'grave talk' to help staff have open conversations.
- Colleagues can show support by sharing feelings to model that it is ok for others to open up too if they wish.
- Safe spaces to have conversations at lunch times.
- Scheduled times for whole team to get together and share impact of work in break out rooms encouraging people to talk openly in workplace.
- Destigmatising normal grief reactions.
- People don't often hear about information until further down the line – there's a need assess people's needs and offer access to information and support in a timely manner.
- Website where everyone can access information about support.

The bereavement-friendly workplaces toolkit and charter mark provide helpful resources, and a model that could be explored in the context of health and social care workplaces.

**What can be done next?**

The pre-summit questionnaire indicated that over 90% of respondents felt that even where needs of staff were recognised, lack of resources was a barrier to them being met. This makes it difficult to suggest a way forward that doesn't involve more resources.

There could be exploration of the creation of a bereavement-friendly workplaces toolkit and charter mark specifically for health and social care employers.

## Recommendation 9: Improve how bereavement services, projects and initiatives are funded

### Why is this important?

Though often not mentioned explicitly in published reports and recommendations, the need for funding of some kind is implicit in many (perhaps most) of the recent reports about improving experiences of bereavement.

Clearly, the amount of money available is important in determining what services are provided and what projects are undertaken.

However, the processes used to determine funding allocation can also cause problems. For example:

- Barriers to partnership working are caused by the way funding is structured.
- Funding problems disproportionately affect the third sector.
- Services and projects that are recognised as being a positive benefit are very often funded only on a short-term basis, meaning that either services end or staff have to devote time away from delivering services in order to apply for funding.
- Applying for funding is a burden for already stretched services
- Organisations often end up competing with each other for the same pots of funding, and this can impede partnership working.
- Funding is often provided on a short-term basis, especially to third-sector organisations. Where funding is short term, plans are by necessity short-term, and it is harder to retain staff. This impacts on the organisational memory of organisations and skills and experience of those working in the sector.
- Without a strategic approach to improving bereavement that cuts across different policy areas, funding decisions are made without awareness of the bigger picture, resulting in duplication, inefficiencies and good projects coming to a close.

Though discussions about funding can be difficult, particularly in the present climate of austerity, it is important not to shy away from these issues – where funding is limited it is even more important to ensure that it is well spent.

### What work is there to build on?

Many of the problems outlined above were perceived as disproportionately affecting the voluntary sector whereas funding mechanisms for statutory sector organisations provide more stability. The Scottish Council for Voluntary Organisations (SCVO) has done work exploring how the third sector can benefit from changes to existing funding practices, and outlines four priorities:

- **Multi-Year Funding** – Longer-term funding models in place of the common annual cycle.
- **Flexible Funding** – Unrestricted or core funding, as well as greater flexibility from funders.
- **Sustainable Funding** – Specific measures and approaches to ensure funding is sustainable, such as full cost recovery and inflationary uplifts.
- **Accessible Funding** – Accessible applications and funding processes.

More information about this work is available here: <https://scvo.scot/p/54973/2022/10/17/fair-funding-collaborate-challenge-change-the-gathering-2022>



**What can be done?**

- The Scottish Government could publish a Bereavement Strategy backed up with a budget to support improvements.
- SG could review its funding system and make changes to minimise problems caused by short-term ad-hoc funding schemes.

**Recommendation 10:** Ensure future action is informed by available evidence and information and builds on existing work.

**Why is this important?**

In order to ensure that long-term work is focused on the areas that will have maximum impact, we need to base future actions on what has already been learnt and avoid duplicating effort.

**What is there to build on?**

Cruse Scotland and Child Bereavement UK have already done some mapping of services that could usefully inform future work. The Childhood Bereavement Co-ordinator Project did some mapping of services as part of the project. There is lots of existing research about bereavement needs and bereavement support that can help inform future work in Scotland. The Bereavement Summit discussion group on Research outlined some ways of joining up research and practice in more meaningful ways.

**What further could be done?**

- Review evidence/ literature around bereavement needs and bereavement support, including literature relating to the impact of COVID-19.
- Undertake a survey of public experiences of bereavement along the lines of recent population-based studies of bereaved people in Australia and Ireland.
- Resource networking and signposting activities (as outlined in Recommendation 1) to facilitate ongoing information sharing, collaboration and building on existing work.

## Appendix 1: Bereavement Summit Collaboration

The Bereavement Summit was organised/supported by a collaboration of organisations working in the bereavement sector in Scotland:



The Summit was organised relatively quickly, in hopes of helpfully coinciding the event with the publication of the report of the UK Commission on Bereavement.

Views were sought on the content and format of the summit over July-September 2022, using email contact lists of the Scottish Bereavement Networks, Scottish Partnership for Palliative Care and Good Life, Good Death, Good Grief. Local Scottish Bereavement Network meetings held during this time discussed ideas for the Bereavement summit.

Ideas and suggestions were pulled together into a Summit Programme by SPPC and CBUK staff.

The Summit was open to all, and interested individuals and organisations were encouraged to publicise the event within their networks.

A pre-summit questionnaire was sent to all delegates, to gather thoughts/views prior to the event.

Discussions at the event were captured by delegates themselves on an online padlet.

Following the summit, all resources from the Summit were [made available online](#) and those unable to come along to the event were invited to contribute to the [padlet](#).

Based on padlet notes, conference presentations, pre-survey and menti results, a report was drafted by Rebecca Patterson (SPPC, Lead Author) with input from Jennifer Somerville (Child Bereavement UK). The draft report was circulated to all delegates for their comments and suggestions, with a four-week window for comments. All comments received were incorporated into this final report.

## Appendix 2: Delegate List

Jo McIntyre	NHS Lanarkshire
Mark Hazelwood	SPPC
Lara Van de Peer	
Jacki Smart	Accord Hospice
Rebecca Patterson	SPPC
Pauline Ellison	SPPC
Jen Somerville	Child Bereavement UK
Samara Leibner	SPPC
Katie McMillan	NHS Dumfries & Galloway
Ruth Bickerton	University of Dundee
Donna Hastings	St Columba's Hospice Care
Sheila Rae	
Una McFadyen	NHS Scotland
Doreen Miller	
Ian Pallett	
Louise Mainland	Highland Hospice
Emma Jo Trotter	Education Worker, Fife Young Carers
Alison Bunce	Inverclyde Cares
Maureen O'Neill	Faith in Older People
Kirsty Boyd	University of Edinburgh
Mark Evans	NHS Fife
Joy Elliott	Accord Hospice
Anne Finucane	University of Edinburgh
Fiona Watt	EASE facilitator
Lynsey Kemlo	Care Inspectorate
Elaine Stevens	IANPC
Fiona	SANDS Aberdeen
Michelle Southgate	Sunrise Partnership
Letizia Perna	Winston's Wish
Neil Goudie	SA HSCP
Donald Macaskill	Bereavement Charter for Scotland
Jenni Morris	
Yvonne Caie	NHS
Angela Millar	Cornhill Macmillan Centre
Christine Crompton	Scotmid Co-Op Funerals
Rich Stafford	Child Bereavement UK
Hana Wilde	Scottish Government
Amy McLuskie	Scottish Government
Alison Payne	Reform Scotland
allanmc	
Linda McCurrach	NODA (No-one Dies Alone Ayrshire)
Margaret Muir	Marie Curie
Sineaid Bradshaw	NHS Lothian
Lynn Anderson	NHS Ayrshire & Arran
Linda Sterry	Funeral Link Dundee

Lynne Thomson	Victim Support Scotland Families Bereaved by Crime
Janice Turner	NHS Scotland
Colette McDiarmid	MND Scotland
Elizabeth Dougall	SA Health & Social Care Partnership
Bridget Johnston	University of Glasgow
Claire Donaghy	Independent Age
Wendy Thomas	NHS Lothian
Sallyanne Duncan	University of Strathclyde
Janette McGarvey	Prince & Princess of Wales Hospice
Heather Denham	Baby Loss Retreat
Nicola Reed	Cruse Scotland
Jacqui Marwick	Cruse Scotland
Allison	Team Jak
Margaret Mary Cowan	Kilbryde Hospice
Alison Provan	St Vincents Hospice
Nicola Russell	DWP
Sarah Howe	Community Link Worker Thurso
Jackie Johnston	NHS Scotland
Karen McIntosh	ARC UK
Sam Harrison	
Lynsey McPhail	Cruse Scotland
Kerry McCann	Victim Support Scotland
Claire McKenna	
Nina Vaswani	University of Strathclyde
Alison Blair	CHAS (Zoom Bereavement Project)
Denise Atcheson	Marie Curie
Sally Paul	University of Strathclyde
Emma Carduff	
Patrick Mullery	James Support Group
Helen Quinn	St Francis Xavier Primary School
Dawn Carnegie	Sunrise Partnership
Libby Milton	Marie Curie
Jemma Byrne	
Mona Vaghefian	CHAS
John Birrell	
Naomi Richards	University of Glasgow
Rhona Bain	
Ellie Wagstaff	Marie Curie
Hosay Zazai	Quarriers

Suzie Sturrock	MND Scotland
Susan Bolt	Scottish Government
Martha Rae	Scottish Families
Joy Farquharson	St Andrew's Hospice
Marie Manzi	Macmillan
Ashleigh Ward	NHS Scotland
Laura Murphy	Beatson Cancer Charity
Drew Collier	Includem
Jenny Watt	NHS GGC
Marie Stewart	NHS GGC
Lynne Thomson	Victim Support Sco Families Bereaved by Crime
Alison Blair	CHAS
Meg Thomas	
Clare Davies	
Jacki Smart	Accord Hospice
Sophie Meagher	Sue Ryder
Amitaśūrī Yule	
Sharon Dick	NHS Scotland
Paul Graham	NHS Lanarkshire
Louise	The Haven Centre
Amy Dalrymple	Marie Curie
Veronica Currie	WAY Widowed and Young
Amanda	
Diarmuid Ó Coimín	
Dominic Carter	Hospice UK
Jenni Morris	
Catriona Macpherson	NHS Scotland
Suzie Jones	Scottish Government
Barry Pattison	
Joanne Foster	NHS Lothian
Nina Huszarik	Sue Ryder
Denisha Killoh	Includem
Alyson Vale	
Emily Beever	
Elaine Stevens	University of the West of Scotland

## Appendix 3: Bereavement Summit Programme

9.30am	<p><b>Welcome</b> An introduction to the session, including recognition of Baby Loss Awareness Week.</p>	<p><i>Chair: Mark Hazelwood Chief Executive of the Scottish Partnership for Palliative Care</i></p>
9.45	<p><b>Insights from bereaved people</b> A short presentation sharing the experiences of a range of people who are bereaved.</p>	<p><i>Slides showing quotes from bereaved people.</i></p>
9.50	<p><b>Insights from delegates</b> In the week before the summit delegates will receive a questionnaire asking them to share their thoughts/experiences. This short session will provide a summary of the key findings from this survey.</p>	<p><i>Donna Hastings, Child and Families Lead, St Columba's Hospice Care</i></p>
9.55	<p><b>Prevalence, impact and the need to take action</b> Drawing on recent research, Sally Paul and Nina Vaswani explore the prevalence and impacts of bereavement and potential approaches to improving bereavement experiences in Scotland.</p>	<p><i>Sally Paul, Senior Lecturer, Social Work and Social Policy Nina Vaswani, Research Fellow, Children and Young People's Centre for Justice. University of Strathclyde.</i></p>
10.10	<p><b>Recent reports and their recommendations: a series of 5 minute presentations</b></p> <p>Report of the UK Commission on Bereavement</p> <p>National Childhood Bereavement Project Report</p> <p>Grief Encounters: Experiences of Bereavement Support in Later Life, Independent Age</p> <p>A better route through grief: support for people facing grief across the UK, Sue Ryder</p> <p>Every Story's Ending, Scottish Partnership for Palliative Care</p>	<p><i>Donald Macaskill, Chief Executive of Scottish Care</i></p> <p><i>Denisha Killoh, Project Lead, National Childhood Bereavement Project.</i></p> <p><i>Claire Donaghy, Head of Scotland, Independent Age</i></p> <p><i>Nina Huszarik, Policy Manager, Sue Ryder</i></p> <p><i>Rebecca Patterson, Director of Good Life, Good Death, Good Grief.</i></p>
10.40	<p><b>Where are we now?</b> A brief overview of some of the context and work currently underway in Scotland aiming to improve people's experiences of bereavement.</p>	<p><i>Jennifer Somerville, Bereavement Co-ordinator: Scotland, Child Bereavement UK</i></p>

10.55	<b>Break</b>	
11.05	<p><b>What does the summit think?</b> A session using mentimeter.com to enable delegates to share their thoughts and reflections on questions such as:</p> <ul style="list-style-type: none"> <li>• What do you think of the range of suggested ways forward outlined in the reports above?</li> <li>• What are service deficiencies / barriers experienced by bereaved people?</li> <li>• Are there particular groups who you feel are less likely or able to access bereavement support services?</li> <li>• Do you think Scotland needs a more strategic approach to improving people's experiences of bereavement?</li> </ul>	<p><i>Chair: Mark Hazelwood Chief Executive of the Scottish Partnership for Palliative Care</i></p> <p><i>This is an interactive session, so delegates should be ready to share their thoughts via mentimeter.com</i></p> <p>Menti code: 21003610</p>
11.35	<p><b>Summit discussions: What practical action can be taken to support improvements?</b> The pre-event survey and menti session explored potential problems and areas for improvement. This session asks delegates to focus on ideas for making positive change happen. What would you put in a strategy for improving experiences of bereavement in Scotland?</p> <p>Delegates can take part in two discussion groups – one at 11.40 and one at 12.10. All the groups will run twice – choose the two topics that you have most to say about.</p> <p><i>A: Improving the experiences of bereaved children and young people</i> <i>B: Improving bereavement support services</i> <i>C: Improving the informal support provided in wider society to people who are bereaved</i> <i>D: Improving support for social care and NHS staff who have experienced multiple workplace bereavements</i> <i>E: Improving the support provided to bereaved people by the NHS.</i> <i>F: Improving the support provided to bereaved people by those working in social care.</i> <i>G: Next steps: What follows from the bereavement summit? What can we do next to build on the momentum from the summit to make positive change happen?</i> <i>H: Research: What gaps in knowledge exist? How do we address these? What research should we be paying attention to? How do we join up research and practice in a more meaningful way?</i> <i>I: Policy: How can we shape policy at local, regional and national levels to improve people's experiences of bereavement?</i></p> <p>(Key points to be recorded on padlet.com and turned into a conference report later, and potentially used as the basis of developing a future plan for action.)</p>	
11.40	<p><b>Group discussion 1</b> (Choose from topics listed above.)</p>	
12.10	<p><b>Group discussion 2</b> (Choose from topics listed above.)</p>	



12.40	<p><b>Additional comments</b> Delegates can look at the padlet discussions of other groups and add to discussions they weren't able to attend.</p>	
12.50	<p><b>Next steps</b> Exploring what can be done next to build on the momentum from the Summit to make positive change happen.</p>	<p><i>Chair: Mark Hazelwood Chief Executive of the Scottish Partnership for Palliative Care</i></p>

## Appendix 4: Analysis of recommendations from previous reports

Key themes from the recommendations of five recent reports on bereavement are summarised below. This analysis was presented at the Summit to help inform discussions, provided the basis for some of the menti questions at the Summit, and has been drawn on in the development of recommendations for the Summit.

Bereavement is Everyone's Business <b>Bereavement Commission</b>	<i>Growing up Grieving</i> <b>Includem</b>	<b>Grief Encounters</b> <b>Age UK</b>	<b>A better route through grief</b> <b>Sue Ryder</b>	<b>Every Story's Ending</b> <b>Scottish Partnership for Palliative Care</b>
Scottish Government must commit to developing a new, cross-departmental bereavement strategy that recognises support following bereavement as a human right	Embed commitments to improving support for bereaved children and young people into wider national priorities	Better leadership and coordination at multiple levels to improve access to bereavement support, including a government-led strategy, mapping of need and provision, named leads,	The Government should lead a public health campaign supported by the bereavement sector to promote an awareness of grief and the support available	Fact finding: a) Rapid review of the evidence/literature; b) Survey of public experiences of bereavement; c) Mapping of formal bereavement services that builds on work already underway.
Scottish Government must invest 79p per person in the population for transforming bereavement services over the next five years, with particular focus on better supporting Black, Asian and ethnic minority communities, those experiencing financial hardship and others who are poorly served minority communities, those experiencing financial hardship and others who are poorly served	Promote greater awareness of children and young people experiencing grief	Improved signposting to support options, especially for those in later life	Integrated Care Systems (ICs) should further establish the adequacy of local bereavement support service provision, including reach, capacity and gaps.	Continue to fund Good Life, Good Death, Good Grief to lead a programme of activity in partnership with stakeholders to promote a culture of openness about death, dying and bereavement in Scotland,
All Scottish education establishments must have a bereavement policy, and provide opportunities for children and young people to learn about coping with death and bereavement as part of life	Establish a national secretariat for childhood bereavement, to provide information, signposting, admin support and a feedback loop.	A greater focus on tackling loneliness as one way of supporting people bereaved in later life	In partnership with our communities, charities and service providers should continue to conduct and commission research to improve bereavement support, including growing awareness of different cultures and barriers.	Action Planning: Establish a Bereavement Reference Group, with appropriate project-management/ administrative support to enable the group to reflect on what we know and develop recommendations for a co-ordinated Action Plan for improving bereavement experiences in Scotland.
All Scottish employers must work towards the National Bereavement Charter	Every school in Scotland must have a four-point approach to bereavement (universal bereavement policy; in the school curriculum; resource bank and training)	Improved access to mental health services when they are needed	Society should acknowledge the role we can all play in supporting others through their unique grief journey by being aware of the support services available to direct people to and encouraging others to have conversations about grief.	Policy-Level Co-ordination: SG should allocate a specific Minister and/or senior Scottish Government Official overarching responsibility for all aspects of bereavement policy.
The National Care Service must commission tailored bereavement support and signposting.	Develop clear and accessible advice on what to do when someone dies in Scotland			Networking: consider how to further resource and encourage national and local networking and sharing of good practice.
	Work to create compassionate, grief-aware Scottish workplaces and places of learning			As individuals engaged in delivering and/or improving care we should all seek to become more aware of the multiple ways in which inequalities are created, expressed and experienced towards the end of life.
	Establish a bereavement grant for those in a precarious financial position as a result of a primary income earner dying			

## Key theme: Improve signposting to available support

<p><b>Bereavement is Everyone's Business</b> <b>Bereavement Commission</b></p> <p>Scottish Government must commit to developing a new, cross-departmental bereavement strategy that recognises support following bereavement as a human right</p>	<p><i>Growing up Grieving</i> <b>Includem</b></p> <p>Embed commitments to improving support for bereaved children and young people into wider national priorities</p>	<p><b>Grief Encounters</b> <b>Age UK</b></p> <p>Better leadership and coordination at multiple levels to improve access to bereavement support, including a government-led strategy, mapping of need and provision, named leads,</p>	<p><b>A better route through grief</b> <b>Sue Ryder</b></p> <p>The Government should lead a public health campaign supported by the bereavement sector to promote an awareness of grief and the support available</p>	<p><b>Every Story's Ending</b> <b>Scottish Partnership for Palliative Care</b></p> <p>Fact finding: a) Rapid review of the evidence/literature; b) Survey of public experiences of bereavement; c) Mapping of formal bereavement services that builds on work already underway.</p>
<p>Scottish Government must invest 79p per person in the population for transforming bereavement services over the next five years, with particular focus on better supporting Black, Asian and ethnic minority communities, those experiencing financial hardship and others who are poorly served minority communities, those experiencing financial hardship and others who are poorly served</p>	<p>Promote greater awareness of children and young people experiencing grief</p>	<p>Improved signposting to support options, especially for those in later life</p>	<p>Integrated Care Systems (ICs) should further establish the adequacy of local bereavement support service provision, including reach, capacity and gaps.</p>	<p>Continue to fund Good Life, Good Death, Good Grief to lead a programme of activity in partnership with stakeholders to promote a culture of openness about death, dying and bereavement in Scotland,</p>
<p>All Scottish education establishments must have a bereavement policy, and provide opportunities for children and young people to learn about coping with death and bereavement as part of life</p>	<p>Establish a national secretariat for childhood bereavement, to provide information, signposting, admin support and a feedback loop.</p>	<p>A greater focus on tackling loneliness as one way of supporting people bereaved in later life</p>	<p>In partnership with our communities, charities and service providers should continue to conduct and commission research to improve bereavement support, including growing awareness of different cultures and barriers.</p>	<p>Action Planning: Establish a Bereavement Reference Group, with appropriate project-management/ administrative support to enable the group to reflect on what we know and and develop recommendations for a co-ordinated Action Plan for improving bereavement experiences in Scotland.</p>
<p>All Scottish employers must work towards the National Bereavement Charter</p>	<p>Every school in Scotland must have a four-point approach to bereavement (universal bereavement policy; in the school curriculum; resource bank and training)</p>	<p>Improved access to mental health services when they are needed</p>	<p>Society should acknowledge the role we can all play in supporting others through their unique grief journey by being aware of the support services available to direct people to and encouraging others to have conversations about grief.</p>	<p>Policy-Level Co-ordination: SG should allocate a specific Minister and/or senior Scottish Government Official overarching responsibility for all aspects of bereavement policy.</p>
<p>The National Care Service must commission tailored bereavement support and signposting.</p>	<p>Develop clear and accessible advice on what to do when someone dies in Scotland</p>			<p>Networking: consider how to further resource and encourage national and local networking and sharing of good practice.</p>
	<p>Work to create compassionate, grief-aware Scottish workplaces and places of learning</p>			<p>As individuals engaged in delivering and/or improving care we should all seek to become more aware of the multiple ways in which inequalities are created, expressed and experienced towards the end of life.</p>
	<p>Establish a bereavement grant for those in a precarious financial position as a result of a primary income earner dying</p>			

## Key theme: Increase awareness of bereavement issues among members of the public

Bereavement is Everyone's Business Bereavement Commission	Growing up Grieving Includem	Grief Encounters Age UK	A better route through grief Sue Ryder	Every Story's Ending Scottish Partnership for Palliative Care
Scottish Government must commit to developing a new, cross-departmental bereavement strategy that recognises support following bereavement as a human right	Embed commitments to improving support for bereaved children and young people into wider national priorities	Better leadership and coordination at multiple levels to improve access to bereavement support, including a government-led strategy, mapping of need and provision, named leads,	The Government should lead a public health campaign supported by the bereavement sector to promote an awareness of grief and the support available.	Fact finding: a) Rapid review of the evidence/literature; b) Survey of public experiences of bereavement; c) Mapping of formal bereavement services that builds on work already underway.
Scottish Government must invest 79p per person in the population for transforming bereavement services over the next five years, with particular focus on better supporting Black, Asian and ethnic minority communities, those experiencing financial hardship and others who are poorly served minority communities, those experiencing financial hardship and others who are poorly served	Promote greater awareness of children and young people experiencing grief.	Improved signposting to support options, especially for those in later life	Integrated Care Systems (ICs) should further establish the adequacy of local bereavement support service provision, including reach, capacity and gaps.	Continue to fund Good Life, Good Death, Good Grief to lead a programme of activity in partnership with stakeholders to promote a culture of openness about death, dying and bereavement in Scotland,
All Scottish education establishments must have a bereavement policy, and provide opportunities for children and young people to learn about coping with death and bereavement as part of life	Establish a national secretariat for childhood bereavement, to provide information, signposting, admin support and a feedback loop.	A greater focus on tackling loneliness as one way of supporting people bereaved in later life	In partnership with our communities, charities and service providers should continue to conduct and commission research to improve bereavement support, including growing awareness of different cultures and barriers.	Action Planning: Establish a Bereavement Reference Group, with appropriate project-management/ administrative support to enable the group to reflect on what we know and develop recommendations for a co-ordinated Action Plan for improving bereavement experiences in Scotland.
All Scottish employers must work towards the National Bereavement Charter	Every school in Scotland must have a four-point approach to bereavement (universal bereavement policy; in the school curriculum; resource bank and training)	Improved access to mental health services when they are needed	Society should acknowledge the role we can all play in supporting others through their unique grief journey by being aware of the support services available to direct people to and encouraging others to have conversations about grief.	Policy-Level Co-ordination: SG should allocate a specific Minister and/or senior Scottish Government Official overarching responsibility for all aspects of bereavement policy.
The National Care Service must commission tailored bereavement support and signposting.	Develop clear and accessible advice on what to do when someone dies in Scotland			Networking: consider how to further resource and encourage national and local networking and sharing of good practice.
	Work to create compassionate, grief-aware Scottish workplaces and places of learning			As individuals engaged in delivering and/or improving care we should all seek to become more aware of the multiple ways in which inequalities are created, expressed and experienced towards the end of life.
	Establish a bereavement grant for those in a precarious financial position as a result of a primary income earner dying			

## Encourage workplaces to be better at supporting bereaved staff

Bereavement is Everyone's Business Bereavement Commission	<i>Growing up Grieving</i> Includem	Grief Encounters Age UK	A better route through grief Sue Ryder	Every Story's Ending Scottish Partnership for Palliative Care
Scottish Government must commit to developing a new, cross-departmental bereavement strategy that recognises support following bereavement as a human right	Embed commitments to improving support for bereaved children and young people into wider national priorities	Better leadership and coordination at multiple levels to improve access to bereavement support, including a government-led strategy, mapping of need and provision, named leads,	The Government should lead a public health campaign supported by the bereavement sector to promote an awareness of grief and the support available	Fact finding: a) Rapid review of the evidence/literature; b) Survey of public experiences of bereavement; c) Mapping of formal bereavement services that builds on work already underway.
Scottish Government must invest 79p per person in the population for transforming bereavement services over the next five years, with particular focus on better supporting Black, Asian and ethnic minority communities, those experiencing financial hardship and others who are poorly served minority communities, those experiencing financial hardship and others who are poorly served	Promote greater awareness of children and young people experiencing grief	Improved signposting to support options, especially for those in later life	Integrated Care Systems (ICs) should further establish the adequacy of local bereavement support service provision, including reach, capacity and gaps.	Continue to fund Good Life, Good Death, Good Grief to lead a programme of activity in partnership with stakeholders to promote a culture of openness about death, dying and bereavement in Scotland,
All Scottish education establishments must have a bereavement policy, and provide opportunities for children and young people to learn about coping with death and bereavement as part of life	Establish a national secretariat for childhood bereavement, to provide information, signposting, admin support and a feedback loop.	A greater focus on tackling loneliness as one way of supporting people bereaved in later life	In partnership with our communities, charities and service providers should continue to conduct and commission research to improve bereavement support, including growing awareness of different cultures and barriers.	Action Planning: Establish a Bereavement Reference Group, with appropriate project-management/ administrative support to enable the group to reflect on what we know and and develop recommendations for a co-ordinated Action Plan for improving bereavement experiences in Scotland.
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	Work to create compassionate, grief-aware Scottish workplaces and places of learning			As individuals engaged in delivering and/or improving care we should all seek to become more aware of the multiple ways in which inequalities are created, expressed and experienced towards the end of life.
	Establish a bereavement grant for those in a precarious financial position as a result of a primary income earner dying			

**Key theme: Think about bereavement as a cross cutting issue**

<p><b>Bereavement is Everyone's Business</b> <b>Bereavement Commission</b></p> <p>Scottish Government must commit to developing a new, cross-departmental bereavement strategy that recognises support following bereavement as a human right</p>	<p><i>Growing up Grieving</i> <b>Includem</b></p> <p>Embed commitments to improving support for bereaved children and young people into wider national priorities</p>	<p><b>Grief Encounters</b> <b>Age UK</b></p> <p>Better leadership and coordination at multiple levels to improve access to bereavement support, including a government-led strategy, mapping of need and provision, named leads,</p>	<p><b>A better route through grief</b> <b>Sue Ryder</b></p> <p>The Government should lead a public health campaign supported by the bereavement sector to promote an awareness of grief and the support available</p>	<p><b>Every Story's Ending</b> <b>Scottish Partnership for Palliative Care</b></p> <p>Fact finding: a) Rapid review of the evidence/literature; b) Survey of public experiences of bereavement; c) Mapping of formal bereavement services that builds on work already underway.</p>
<p>Scottish Government must invest 79p per person in the population for transforming bereavement services over the next five years, with particular focus on better supporting Black, Asian and ethnic minority communities, those experiencing financial hardship and others who are poorly served minority communities, those experiencing financial hardship and others who are poorly served</p>	<p>Promote greater awareness of children and young people experiencing grief</p>	<p>Improved signposting to support options, especially for those in later life</p>	<p>Integrated Care Systems (ICs) should further establish the adequacy of local bereavement support service provision, including reach, capacity and gaps.</p>	<p><b>Continue to fund Good Life, Good Death, Good Grief to lead a programme of activity in partnership with stakeholders to promote a culture of openness about death, dying and bereavement in Scotland,</b></p>
<p>All Scottish education establishments must have a bereavement policy, and provide opportunities for children and young people to learn about coping with death and bereavement as part of life</p>	<p>Establish a national secretariat for childhood bereavement, to provide information, signposting, admin support and a feedback loop.</p>	<p><b>A greater focus on tackling loneliness as one way of supporting people bereaved in later life</b></p>	<p>In partnership with our communities, charities and service providers should continue to conduct and commission research to improve bereavement support, including growing awareness of different cultures and barriers.</p>	<p>Action Planning: Establish a Bereavement Reference Group, with appropriate project-management/ administrative support to enable the group to reflect on what we know and and develop recommendations for a co-ordinated Action Plan for improving bereavement experiences in Scotland.</p>
<p>All Scottish employers must work towards the National Bereavement Charter</p>	<p>Every school in Scotland must have a four-point approach to bereavement (universal bereavement policy; in the school curriculum; resource bank and training)</p>	<p>Improved access to mental health services when they are needed</p>	<p>Society should acknowledge the role we can all play in supporting others through their unique grief journey by being aware of the support services available to direct people to and encouraging others to have conversations about grief.</p>	<p>Policy-Level Co-ordination: SG should allocate a specific Minister and/or senior Scottish Government Official overarching responsibility for all aspects of bereavement policy.</p>
<p>The National Care Service must commission tailored bereavement support and signposting.</p>	<p>Develop clear and accessible advice on what to do when someone dies in Scotland</p>			<p>Networking: consider how to further resource and encourage national and local networking and sharing of good practice.</p>
	<p>Work to create compassionate, grief-aware Scottish workplaces and places of learning</p>			<p>As individuals engaged in delivering and/or improving care we should all seek to become more aware of the multiple ways in which inequalities are created, expressed and experienced towards the end of life.</p>
	<p>Establish a bereavement grant for those in a precarious financial position as a result of a primary income earner dying</p>			

**Key theme: Develop a strategic approach to improving experiences of bereavement**

<p>Bereavement is Everyone's Business <b>Bereavement Commission</b></p> <p>Scottish Government must commit to developing a new, cross-departmental bereavement strategy that recognises support following bereavement as a human right</p>	<p><i>Growing up Grieving</i> <b>Includem</b></p> <p>Embed commitments to improving support for bereaved children and young people into wider national priorities</p>	<p>Grief Encounters <b>Age UK</b></p> <p>Better leadership and coordination at multiple levels to improve access to bereavement support, including a government-led strategy, mapping of need and provision, named leads.</p>	<p>A better route through grief <b>Sue Ryder</b></p> <p>The Government should lead a public health campaign supported by the bereavement sector to promote an awareness of grief and the support available</p>	<p>Every Story's Ending <b>Scottish Partnership for Palliative Care</b></p> <p>Fact finding: a) Rapid review of the evidence/literature; b) Survey of public experiences of bereavement; c) Mapping of formal bereavement services that builds on work already underway.</p>
<p>Scottish Government must invest 79p per person in the population for transforming bereavement services over the next five years, with particular focus on better supporting Black, Asian and ethnic minority communities, those experiencing financial hardship and others who are poorly served minority communities, those experiencing financial hardship and others who are poorly served</p>	<p>Promote greater awareness of children and young people experiencing grief</p>	<p>Improved signposting to support options, especially for those in later life</p>	<p>Integrated Care Systems (ICs) should further establish the adequacy of local bereavement support service provision, including reach, capacity and gaps.</p>	<p>Continue to fund Good Life, Good Death, Good Grief to lead a programme of activity in partnership with stakeholders to promote a culture of openness about death, dying and bereavement in Scotland,</p>
<p>All Scottish education establishments must have a bereavement policy, and provide opportunities for children and young people to learn about coping with death and bereavement as part of life</p>	<p>Establish a national secretariat for childhood bereavement, to provide information, signposting, admin support and a feedback loop.</p>	<p>A greater focus on tackling loneliness as one way of supporting people bereaved in later life</p>	<p>In partnership with our communities, charities and service providers should continue to conduct and commission research to improve bereavement support, including growing awareness of different cultures and barriers.</p>	<p><b>Action Planning: Establish a Bereavement Reference Group, with appropriate project-management/ administrative support to enable the group to reflect on what we know and and develop recommendations for a co-ordinated Action Plan for improving bereavement experiences in Scotland.</b></p>
<p>All Scottish employers must work towards the National Bereavement Charter</p>	<p>Every school in Scotland must have a four-point approach to bereavement (universal bereavement policy; in the school curriculum; resource bank and training)</p>	<p>Improved access to mental health services when they are needed</p>	<p>Society should acknowledge the role we can all play in supporting others through their unique grief journey by being aware of the support services available to direct people to and encouraging others to have conversations about grief.</p>	<p>Policy-Level Co-ordination: SG should allocate a specific Minister and/or senior Scottish Government Official overarching responsibility for all aspects of bereavement policy.</p>
<p>The National Care Service must commission tailored bereavement support and signposting.</p>	<p>Develop clear and accessible advice on what to do when someone dies in Scotland</p>			<p>Networking: consider how to further resource and encourage national and local networking and sharing of good practice.</p>
	<p>Work to create compassionate, grief-aware Scottish workplaces and places of learning</p>			<p>As individuals engaged in delivering and/or improving care we should all seek to become more aware of the multiple ways in which inequalities are created, expressed and experienced towards the end of life.</p>
	<p>Establish a bereavement grant for those in a precarious financial position as a result of a primary income earner dying</p>			

**Key theme: Do some mapping, fact finding and research to inform future action**

<p><b>Bereavement is Everyone's Business</b> <b>Bereavement Commission</b></p>	<p><b>Growing up Grieving</b> <b>Includem</b></p>	<p><b>Grief Encounters</b> <b>Age UK</b></p>	<p><b>A better route through grief</b> <b>Sue Ryder</b></p>	<p><b>Every Story's Ending</b> <b>Scottish Partnership for Palliative Care</b></p>
<p>Scottish Government must commit to developing a new, cross-departmental bereavement strategy that recognises support following bereavement as a human right</p>	<p>Embed commitments to improving support for bereaved children and young people into wider national priorities</p>	<p>Better leadership and coordination at multiple levels to improve access to bereavement support, including a government-led strategy, mapping of need and provision, named leads.</p>	<p>The Government should lead a public health campaign supported by the bereavement sector to promote an awareness of grief and the support available</p>	<p>Fact finding: a) Rapid review of the evidence/literature; b) Survey of public experiences of bereavement; c) Mapping of formal bereavement services that builds on work already underway.</p>
<p>Scottish Government must invest 79p per person in the population for transforming bereavement services over the next five years, with particular focus on better supporting Black, Asian and ethnic minority communities, those experiencing financial hardship and others who are poorly served minority communities, those experiencing financial hardship and others who are poorly served</p>	<p>Promote greater awareness of children and young people experiencing grief</p>	<p>Improved signposting to support options, especially for those in later life</p>	<p>Integrated Care Systems (ICs) should further establish the adequacy of local bereavement support service provision, including reach, capacity and gaps.</p>	<p>Continue to fund Good Life, Good Death, Good Grief to lead a programme of activity in partnership with stakeholders to promote a culture of openness about death, dying and bereavement in Scotland,</p>
<p>All Scottish education establishments must have a bereavement policy, and provide opportunities for children and young people to learn about coping with death and bereavement as part of life</p>	<p>Establish a national secretariat for childhood bereavement, to provide information, signposting, admin support and a feedback loop.</p>	<p>A greater focus on tackling loneliness as one way of supporting people bereaved in later life</p>	<p>In partnership with our communities, charities and service providers should continue to conduct and commission research to improve bereavement support, including growing awareness of different cultures and barriers.</p>	<p>Action Planning: Establish a Bereavement Reference Group, with appropriate project-management/ administrative support to enable the group to reflect on what we know and and develop recommendations for a co-ordinated Action Plan for improving bereavement experiences in Scotland.</p>
<p>All Scottish employers must work towards the National Bereavement Charter</p>	<p>Every school in Scotland must have a four-point approach to bereavement (universal bereavement policy; in the school curriculum; resource bank and training)</p>	<p>Improved access to mental health services when they are needed</p>	<p>Society should acknowledge the role we can all play in supporting others through their unique grief journey by being aware of the support services available to direct people to and encouraging others to have conversations about grief.</p>	<p>Policy-Level Co-ordination: SG should allocate a specific Minister and/or senior Scottish Government Official overarching responsibility for all aspects of bereavement policy.</p>
<p>The National Care Service must commission tailored bereavement support and signposting.</p>	<p>Develop clear and accessible advice on what to do when someone dies in Scotland</p>			<p>Networking: consider how to further resource and encourage national and local networking and sharing of good practice.</p>
	<p>Work to create compassionate, grief-aware Scottish workplaces and places of learning</p>			<p>As individuals engaged in delivering and/or improving care we should all seek to become more aware of the multiple ways in which inequalities are created, expressed and experienced towards the end of life.</p>
	<p>Establish a bereavement grant for those in a precarious financial position as a result of a primary income earner dying</p>			



**Key theme: Support schools and education institutions to be more supportive of people who are bereaved**

<p><b>Bereavement is Everyone's Business</b> <b>Bereavement Commission</b></p> <p>Scottish Government must commit to developing a new, cross-departmental bereavement strategy that recognises support following bereavement as a human right</p>	<p><i>Growing up Grieving</i> <b>Includem</b></p> <p>Embed commitments to improving support for bereaved children and young people into wider national priorities</p>	<p><b>Grief Encounters</b> <b>Age UK</b></p> <p>Better leadership and coordination at multiple levels to improve access to bereavement support, including a government-led strategy, mapping of need and provision, named leads,</p>	<p><b>A better route through grief</b> <b>Sue Ryder</b></p> <p>The Government should lead a public health campaign supported by the bereavement sector to promote an awareness of grief and the support available</p>	<p><b>Every Story's Ending</b> <b>Scottish Partnership for Palliative Care</b></p> <p>Fact finding: a) Rapid review of the evidence/literature; b) Survey of public experiences of bereavement; c) Mapping of formal bereavement services that builds on work already underway.</p>
<p>Scottish Government must invest 79p per person in the population for transforming bereavement services over the next five years, with particular focus on better supporting Black, Asian and ethnic minority communities, those experiencing financial hardship and others who are poorly served minority communities, those experiencing financial hardship and others who are poorly served</p>	<p>Promote greater awareness of children and young people experiencing grief</p>	<p>Improved signposting to support options, especially for those in later life</p>	<p>Integrated Care Systems (ICs) should further establish the adequacy of local bereavement support service provision, including reach, capacity and gaps.</p>	<p><b>Continue to fund Good Life, Good Death, Good Grief to lead a programme of activity in partnership with stakeholders to promote a culture of openness about death, dying and bereavement in Scotland,</b></p>
<p><b>All Scottish education establishments must have a bereavement policy, and provide opportunities for children and young people to learn about coping with death and bereavement as part of life</b></p>	<p>Establish a national secretariat for childhood bereavement, to provide information, signposting, admin support and a feedback loop.</p>	<p>A greater focus on tackling loneliness as one way of supporting people bereaved in later life</p>	<p>In partnership with our communities, charities and service providers should continue to conduct and commission research to improve bereavement support, including growing awareness of different cultures and barriers.</p>	<p>Action Planning: Establish a Bereavement Reference Group, with appropriate project-management/ administrative support to enable the group to reflect on what we know and develop recommendations for a co-ordinated Action Plan for improving bereavement experiences in Scotland.</p>
<p>All Scottish employers must work towards the National Bereavement Charter</p>	<p><b>Every school in Scotland must have a four-point approach to bereavement (universal bereavement policy; in the school curriculum; resource bank and training)</b></p>	<p>Improved access to mental health services when they are needed</p>	<p>Society should acknowledge the role we can all play in supporting others through their unique grief journey by being aware of the support services available to direct people to and encouraging others to have conversations about grief.</p>	<p>Policy-Level Co-ordination: SG should allocate a specific Minister and/or senior Scottish Government Official overarching responsibility for all aspects of bereavement policy.</p>
<p>The National Care Service must commission tailored bereavement support and signposting.</p>	<p>Develop clear and accessible advice on what to do when someone dies in Scotland</p>			<p>Networking: consider how to further resource and encourage national and local networking and sharing of good practice.</p>
	<p>Work to create compassionate, grief-aware Scottish workplaces and places of learning</p>			<p>As individuals engaged in delivering and/or improving care we should all seek to become more aware of the multiple ways in which inequalities are created, expressed and experienced towards the end of life.</p>
	<p>Establish a bereavement grant for those in a precarious financial position as a result of a primary income earner dying</p>			

## Other issues

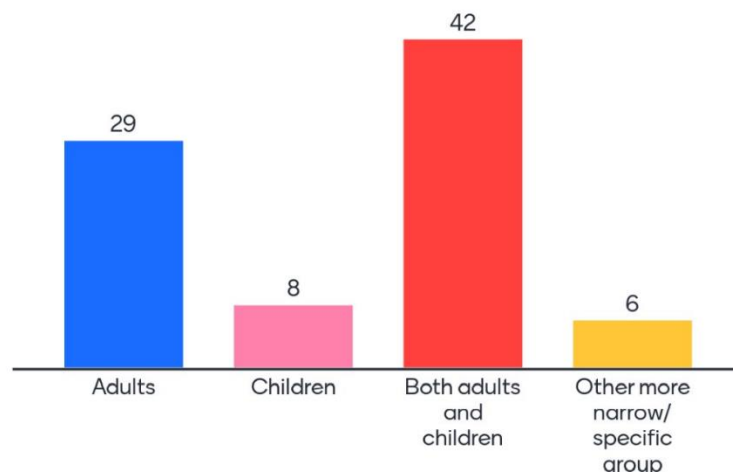
Allocate responsibility for improving bereavement support to individuals at a strategic level; Networking opportunities for professionals; More/better/different bereavement support services (orange); Tackling equity/equality issues (dark purple); Financial support; Improve information available after a death

Bereavement is Everyone's Business Bereavement Commission	<i>Growing up Grieving</i> Includem	Grief Encounters Age UK	A better route through grief Sue Ryder	Every Story's Ending Scottish Partnership for Palliative Care
Scottish Government must commit to developing a new, cross-departmental bereavement strategy that recognises support following bereavement as a human right	Embed commitments to improving support for bereaved children and young people into wider national priorities	Better leadership and coordination at multiple levels to improve access to bereavement support, including a government-led strategy, mapping of need and provision, named leads,	The Government should lead a public health campaign supported by the bereavement sector to promote an awareness of grief and the support available	Fact finding: a) Rapid review of the evidence/literature; b) Survey of public experiences of bereavement; c) Mapping of formal bereavement services that builds on work already underway.
Scottish Government must invest 79p per person in the population for transforming bereavement services over the next five years, with particular focus on better supporting Black, Asian and ethnic minority communities, those experiencing financial hardship and others who are poorly served minority communities, those experiencing financial hardship and others who are poorly served	Promote greater awareness of children and young people experiencing grief	Improved signposting to support options, especially for those in later life	Integrated Care Systems (ICSS) should further establish the adequacy of local bereavement support service provision, including reach, capacity and gaps.	Continue to fund Good Life, Good Death, Good Grief to lead a programme of activity in partnership with stakeholders to promote a culture of openness about death, dying and bereavement in Scotland,
All Scottish education establishments must have a bereavement policy, and provide opportunities for children and young people to learn about coping with death and bereavement as part of life	Establish a national secretariat for childhood bereavement, to provide information, signposting, admin support and a feedback loop.	A greater focus on tackling loneliness as one way of supporting people bereaved in later life	In partnership with our communities, charities and service providers should continue to conduct and commission research to improve bereavement support, including growing awareness of different cultures and barriers.	Action Planning: Establish a Bereavement Reference Group, with appropriate project-management/ administrative support to enable the group to reflect on what we know and develop recommendations for a co-ordinated Action Plan for improving bereavement experiences in Scotland.
All Scottish employers must work towards the National Bereavement Charter	Every school in Scotland must have a four-point approach to bereavement (universal bereavement policy; in the school curriculum; resource bank and training)	Improved access to mental health services when they are needed	Society should acknowledge the role we can all play in supporting others through their unique grief journey by being aware of the support services available to direct people to and encouraging others to have conversations about grief.	Policy-Level Co-ordination: SG should allocate a specific Minister and/or senior Scottish Government Official overarching responsibility for all aspects of bereavement policy.
The National Care Service must commission tailored bereavement support and signposting.	Develop clear and accessible advice on what to do when someone dies in Scotland			Networking: consider how to further resource and encourage national and local networking and sharing of good practice.
	Work to create compassionate, grief-aware Scottish workplaces and places of learning			As individuals engaged in delivering and/or improving care we should all seek to become more aware of the multiple ways in which inequalities are created, expressed and experienced towards the end of life.
	Establish a bereavement grant for those in a precarious financial position as a result of a primary income earner dying			

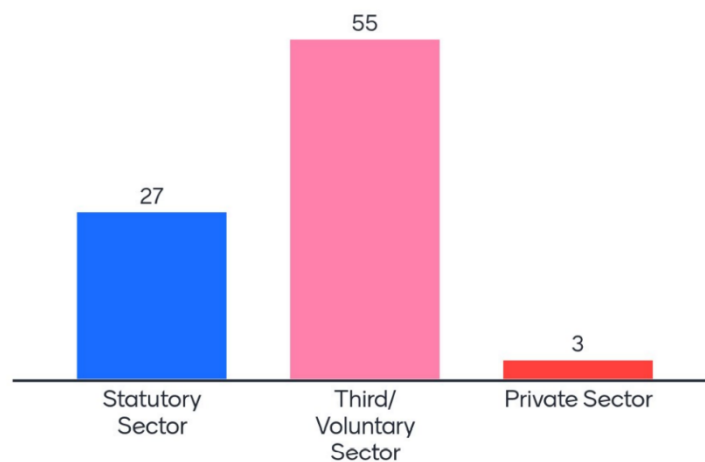
## Appendix 5: Menti survey

Below is the survey that was delivered live on menti during the summit.

**What best describes the people you aim to support during bereavement?**



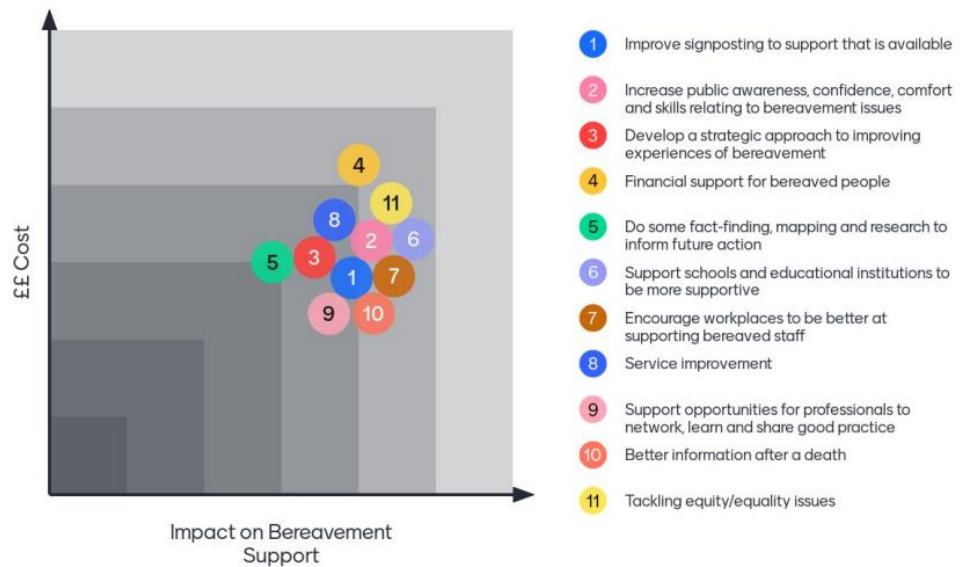
**What sort of organisation do you (mainly) work for?**



# What relative importance would you give to the recommendations/themes of the recent bereavement reports?



# Which of the themes/recommendations would have the biggest bang for the bucks?



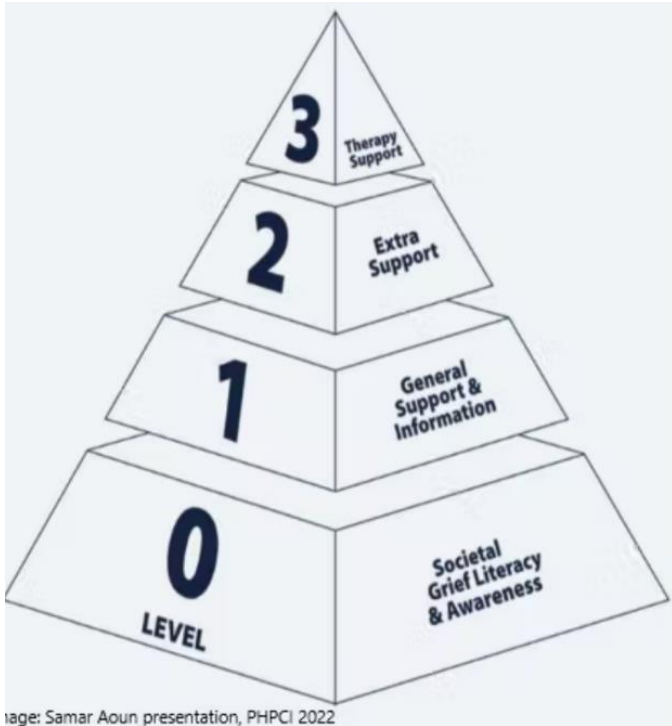
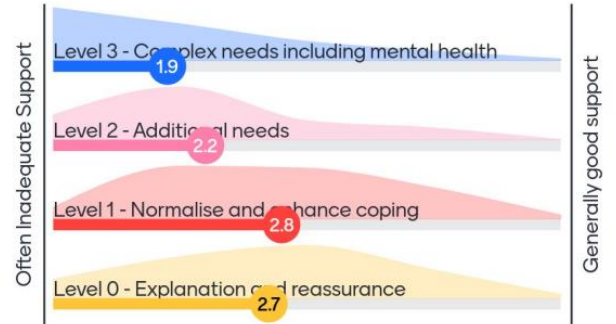


Image: Samar Aoun presentation, PHPCI 2022

## How well are different levels of risk/need met?

Mentimeter



80

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## Key References

<sup>i</sup> The Bereavement Summit considered the following recent reports that have a key focus on improving experience of bereavement:

[Bereavement is Everyone's Business](#) (2022) Report of the UK Commission on Bereavement

[Growing up Grieving](#) (2022) National Childhood Bereavement Project Final Report

[Grief Encounters: Experiences of Bereavement Support in Later Life](#) (2021) Independent Age

[A better route through grief: support for people facing grief across the UK](#) Sue Ryder

[Every Story's Ending](#) (2021) Scottish Partnership for Palliative Care

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The Scottish Bereavement Summit took place on 13 October 2022.

It was supported by a collaboration of organisations working to improve bereavement support in Scotland:



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