Developing a Core Outcome Set for Bereavement Research and Evaluation in Palliative Care

Summary Reports of Two Consensus Days and Final Feedback Survey

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Contents

Background

The Marie Curie Research Centre, Cardiff University is conducting a Marie Curie funded project looking at the evidence base surrounding bereavement support services and interventions in palliative care. The first part of the project has involved a mixed methods systematic literature review looking at the evidence on bereavement support services for people bereaved through terminal illness. The second stage of this project is developing a Core Outcome Set which can be used in research and clinical evaluations of bereavement support services/ interventions in palliative care settings. This is in response to a well-documented lack of consistency in the outcomes currently used to evaluate bereavement support services and interventions, which makes it difficult to determine the relative effectiveness and value of different service models and approaches. Core Outcome Sets represent the minimum outcomes that should be measured and reported in all clinical trials or other types of evaluation relating to a specific condition or type of service or intervention (see www.comet-intitiative.org.uk). It is hoped that by developing consensus on which outcomes should be considered 'core', it will become easier in the future to compare the performance of different services and models, leading to an improved evidence base which can inform practice and service delivery and commissioning.

The Consensus Day

The systematic review was used to generate a list of outcomes and outcome dimensions which have been used by researchers to measure the effectiveness of different bereavement support services or interventions. This list was also supplemented by a review of the qualitative evidence on the impacts of Bereavement Support Services (BSS) and the grief and coping experiences of bereaved caregivers. On Friday 3rd March 2017 a consensus day was held with 22 delegates, from a variety of professional and non-professional backgrounds across the UK. This group of people included people with caregiving and bereavement experiences, social workers, bereavement counsellors, academic-researchers, project and support workers, palliative care and bereavement charity representatives, and a representative from the Welsh Government. The aims of the day were to; gather delegate views on which outcomes and outcome dimensions are most important to assess; to incorporate these into our outcome lists and adapt these lists as necessary; and to invite more general comments and observations relating to the project and subject area.

The day was split into morning and afternoon breakout sessions, with the groups organised into two professional groups and one group of people with caregiving and bereavement experiences. In the first group session participants were asked to identify and group together potential impacts, outcomes and outcome dimensions that they felt were important to capture when assessing how well a bereavement support service is working. In the afternoon session each table was given a copy of the outcome lists which were generated from the systematic review and asked to consider how the outcomes that they had identified in the morning sessions mapped onto the list generated from the literature reviews and to give their views on the outcomes and outcome dimensions in the list in general.

Findings from breakout discussions

Full summaries of the discussions which took place in each of the three groups are given in appendix one. Key points from the morning and afternoon sessions are detailed below.

Morning Sessions

At the start of the morning session participants were asked to write down up to three key ways in which a bereavement support service (BSS) should be helping those using it or having any other kind of impact and which could or should be used to assess how well the service is working. These ideas were read out and discussed within the groups and efforts were made to organise and cluster the different suggestions into similar types of outcomes using flip charts. All three groups identified a mix of service user outcomes and service orientated outcomes, as summarised in the tables below.

Service User Outcomes: Living and coping with grief

Group One- Bereaved group	Group Two- Professional group	Group Three- Professional Group
Dealing with grief: • Minimise negative consequences of grief • Information and understanding of bereavement and coping process (that experiences are normal, will have good days and bad days) • Having time to think about the person and enjoy memories • Channelling/being able to deal with anger (that comes from negative care experiences, etc.) *Coping:* • Coping is multidimensional (not just supported by counselling, e.g. accessing social support) • Being able to face the future • Meditation – helps to give distance (this should be more widely offered)	*Resilience and coping:* • Impact on personal coping/living with the grief: • Visits to GP/ primary care related to bereavement (physical/emotional wellbeing) • Ability to address finances • Ability to remember/talk about deceased person without being overwhelmed • Emotional and self-resilience and ability to function • Incremental moves from hopelessness to optimism • Ability to return to work • Being bereaved with additional caring responsibilities *Identity/sense of self:* • Impact on/re-emergence of sense of self-identity (short and longer term) • Self-directed recognition of wanting to end sessions (not pathologising/medicalising grief) • Identifying and validating the positive consequences of loss	*Psychological – understanding normality of grieving process:* • Help with psychological wellbeing and capacity to bear • Coping with feelings of loss and grief • Discovering and strengthening resilience • Ability to self-manage and rely less on health services *Psychological – processing feelings:* • Reduce anxiety • Reduce panic • Improve sleep quality • Understanding difference between depression and grief *Cognitive:* • Making sense of experience • Understanding normality of grief and the consequences for others

• Being able to 'enjoy' sorrow (guilt-free, pure grief)		• Understanding others' behaviours and actions • Identifying maladaptive thoughts and behaviours *Spiritual and belief systems* • Making sense of loss • Impact on personal identity (cultural and religious)

Service User Outcomes: Social support, interaction and adjustment

Group one:	Group two	Group three
Peer support: • Being listened to about all the little things (experiencing warmth, empathy, understanding) • Value of online, round-the-clock support (people to listen and talk to) • Need support of those with shared experiences and understanding (Expectations of friends and family can be difficult to manage- just 'getting over it' is not always that simple)	**Interactions:** • Impact on social isolation (how it is managed) • Return to normal functioning in the external world for the bereaved person • Relationships with others and with their community • Did it help? Continuum of useful to useless • Managing how others treat them • Improved wellbeing (however or whatever that may be)	**Social – individual:** • Adapting to change, e.g. 'post carer' role • Normality (expected, common) • Healthy coping and lifestyle strategies **Social – family/ wider society** • Help with connectedness and feeling less isolated • Ability to function in life roles and responsibilities • Relationships and communication • Managing conflict and misunderstanding (of different ways

| | | of dealing with grief) |
| | | • Ability to deal with social and financial insecurities and circumstantial factors |

Service Orientated Outcomes

Group One	Group Two	Group Three
Approaches to offering and giving help: • Allocated support for carer as well as patient (during end of life period) • Having formal offers of support at later stages (e.g. 6 months down the line – but not a case of a fixed time, need for the option of access at different times) • Recognising both emotional and practical difficulties/need for help • Publicity of services to raise awareness of what help is available • Provide insight/support for other family members so that they better understand what the bereaved person is going through. • Help with practicalities such as	**Service provision:** • Equity of service provision across all groups • Response to individual differences • What do participants want to get out of a BSS?	**Organisational culture:** • Transport links/accessibility • Information, signposting, navigation to/about service • Range of support with integration (with 'self' or 'others') – accessible when needed and in accessible formats • Staff, development, training and support • Recognition of and sensitivity to difference • Culture of integrity (including evidence-based knowledge) and commitment to Bereavement Care (BC) Standards. • Clarity of scope **Accessibility:** • Location

how to manage their possessions		• Timing • Formats (information – about service, about grief, about other services) **Integration:** • Signposting • Collaboration and partnership

Afternoon Sessions

The afternoon session aimed to elicit delegates' views on the list of outcomes and outcome dimensions (provided to each group member). They were asked to consider these lists in the light of their own discussions that morning, and to suggest areas where changes or additions could be made. A number of themes emerged across the groups in terms of more general observations relating to the lists and approaches to evaluation. A number of specific changes and additions to the lists were also recommended.

General observations

All three groups identified problems with using measures of grief to evaluate Bereavement Support Services. Groups one and two commented on the idiosyncratic and personal nature of grief, which makes it difficult to 'measure' using standardised tools. Group three felt that the list was essentially just describing the dimensions of grief which means that it is difficult to see how it can be used as an outcome for evaluating services, and it was suggested that a focus on coping would be more appropriate. Relatedly, group one also challenged the idea that BSS should be 'treating grief' which is a natural experience, and felt that there was too much of a negative focus in the grief and depression lists, as it "is ok to feel bad". However, the need to be able to specify when a person's behaviours have crossed a line from part of the 'normal' process of grief to something more serious was also acknowledged.

Group two described how they prefer to use person centred approaches which assess individual needs upon joining the service and use this to determine the outcomes of the service for that individual, rather than attempting to determine the collective impact of the service. The question was thus posed about how quality can be captured, particularly via a medicalised series of processes, with the group noting their preference for case studies. Group three also noted the need to consider background and context if looking at prolonged grief and the samples used to generate the different tools.

Groups one and three both felt that eating and substance abuse disorders were not specific to PTSD and could be common grief experiences, as could dimension 5 of post-traumatic stress (bodily symptoms caused by mental illness, e.g. pain) and dimension 7 (mood episodes and disorders). Symptoms like fatigue and tension were also felt by group one to not be specific to grief but could relate to various other conditions instead.

Groups one and three discussed social support as an important and achievable set of outcomes. Group one also emphasised the need for practical support to be treated with as much weight as emotional support, as it was felt that this might be overlooked. In group three it was suggested that a health-related QoL score would be useful, to position QoL in relation to bereavement.

Specific changes and additions to the list

Group One

Grief, Dimension number 9 (preoccupation with and yearning for the deceased) should be separated, as 'yearning' was something positive and different from preoccupation. Similarly, the group believed that a dimension accounting for dreams was missing from the list. Dreams were distinguished from nightmares (which were invasive and unpleasant).

Quality of Life, Dimension 2 (home management and housework) was also in need of further explanation. It was questioned whether this covers hoarding behaviour, which could indicate an inability to let go

Psychological; the importance of hyperactive states, whereby one threw oneself into work, exercise or other hobbies (e.g. displacement activities), which could theoretically be just as detrimental.

Group two

Group two raised the matter of capturing potentially negative consequences of bereavement support for some people. It was noted that the outcomes are all about positive results, but negative results will always exist (not everyone will have the desired response(s) to a BSS). The group were also interested in how to capture information and benefits of services for groups of people now accessing services, but who typically would not have accessed these services in the past.

Group three

Group three suggested two potential new domains which should be included. It was felt that there should be a domain that explores the provision of the service. In other words, the type of service provided, the quality, and the mapping of this against Bereavement Care Standards. One could then consider the question 'what constitutes a successful service?'

Reflecting the outcomes identified in the morning discussions, the need for a domain which covers service orientated outcomes was also discussed. An example of this (outcome for a service), would be influencing public and professional (e.g. GP's) understanding of grief.

Group three considered that cognitive dimensions should have a separate heading, and that there was little to account for culture, spirituality or meaning-making. At the same time, it was recognised that there would be overlap between the cognitive sub-themes and those that related to psychological and physical outcomes. It was also felt that the psychological outcomes list was missing a dimension on libido.

Concluding points and next steps for the project

The consensus day discussions brought to our attention a number of important points to consider for progressing the project, whilst also suggesting some amendments to the outcome lists generated from the literature reviews. Following review of the points raised in the

morning and afternoon sessions, the outcome lists used on the day have been adapted, with a number of new additions made to the list. These are provided in appendix two with new and amended items highlighted in colour. These lists are being used to directly inform the items that will be included in the DELPHI survey, following processes of further mapping and consolidation. The aim of this two round survey will be to try to reach consensus amongst different stakeholder groups on which outcomes/outcome dimensions should be included in the Core Outcome Set, using a structured scoring system.

As a result of the consensus day discussions we are also now more aware of the need to give greater consideration to the wording and organisation of the DELPHI statements, particularly given the apparent level of overlap between the 'dimensions' of the different outcomes. For example, with regards to service user outcomes, instead of listing the dimensions for each outcome as per original lists we will now be presenting as a combined list. This will avoid unnecessary duplication and should improve the manageability of the survey.

The day also raised important questions over how to differentiate between what is appropriate and realistic for clinical evaluation compared with research based evaluation. To address this we propose making clear that the DELPHI survey is going to be focused on addressing questions of 'what' to measure or assess when conducting evaluations, with an additional section for the service orientated outcomes which were identified on the day. Our final consensus day will be used to reach agreement on possible differences between 'core' sets of outcomes suitable for clinical compared with research evaluations, the most appropriate measures and methods of measurement for these core sets, and how these might also differ between clinical and research evaluations.

Next steps;

- To pilot, finalise and launch the on-line DELPHI survey (we hope that all consensus day delegates will complete the survey and distribute amongst colleagues and networks as appropriate).
- Analysis of DELPHI results to identify core sets of outcomes/outcome dimensions.
- To critically review and summarise measurement tools that correspond to the selected outcomes and identify those that have good 'fit' in terms of content, as well as good reliability, validity, applicability etc.
- To host final consensus and feedback day with stakeholders to agree set of recommendations for core outcome sets for research and clinical evaluation, including current 'best fit' recommendations and areas for future work and development.

Appendix one: summaries from break out group sessions

Morning session summary report – group 1 (bereaved group)

The session began with 3 post-it notes being handed to each delegate. They were asked to note down what difference a bereavement service should make to the people using it.

It was clarified that this did not refer to a specific time period (e.g. straight after bereavement). Rather, people were encouraged to think about whether there was a need for different options to be given in regards to this.

The overriding theme that emerged from a discussion of the post-it notes centred on support. The importance of receiving formal bereavement support was identified, as well as a recognition that it was not always offered. Those services that were available needed far more publicity; from the perspective of carers, it was the 'safety net' of knowing they were there even if people chose not to use them. There is plenty of support when the patient is unwell or dying, but afterwards, this network disappears, leaving the bereaved person isolated and alone. In many cases, there is no family around to mitigate the loss, which only intensifies the sense of loneliness. These people, in particular, have a pressing need for such services.

The timing of the delivery of support services was widely accepted to be crucial. At the moment, there is no accounting for the fact that people have different needs at different times. For example, support immediately following bereavement may not be appropriate. Yet 6 months down the line, that same person may be in critical need of support. They should not have to purposefully seek it out – active interventions at different time points should always be on offer. People do not overcome their grief, they learn to live with it. Hence, longer-term support, so that the bereaved person is able to move forward and face the future, was cited as necessary. Grief is entirely unpredictable and does not abide by a structured agenda; a 'low' period can hit at any time.

A distinction was then drawn between formal and informal support networks. The social side of informal support, for example, mixing with other people, having gatherings of bereaved carers etc. was identified as offering a way out of the loneliness and isolation that accompanies a bereavement and giving the person the belief that they would be able to cope with day-to-day life. There was a recognition that this entailed being listened to by people in a similar situation (and an acknowledgement by one carer that she found it difficult to be around 'normal', 'happy' people) and reciprocal displays of warmth and empathy. Ideally, such informal gatherings would take place in a coffee shop, in keeping with the relaxed and low-pressure environment.

In terms of formal support, it was agreed that people wanted knowledge and an understanding of the stages of bereavement. Key to this was reassurance. The carers expressed a need for someone to tell them that what they were feeling was normal, that they would experience fluctuations and that there would be 'good days' and 'bad days'.

They needed to be told that they were not 'failing' and that those days where they were overwhelmed by feelings of inadequacy or the inability to cope were all part of the grieving process.

Practical support is often overlooked, but in many ways, is just as important as the emotional support. There might be times, for example, when legal action needs to be taken, or complaints made. Help with the practicalities and processes involved in such disputes would be appreciated. Another example of the need for practical support was expressed by one of the group, whose ex-husband had died and whose daughter was the person most directly affected. This carer said that she would have benefited from a short course or some kind of training on how to support the person directly bereaved. Particularly in areas where formal resources are stretched. The importance of information packs, containing details of the available support services for the bereaved families was stressed. The example of a particular charity was cited, which had provided information packs for different groups, e.g. the parents of the deceased, grandparents, place of work etc. These were found to be extremely beneficial. Specifically with regards to the work environment, it was agreed that there needs to be an onus on the employer to allow the bereaved person as much time off as is needed. This will most likely vary from person to person, but such flexibility is important.

There were conflicting opinions on how to go about dealing with the deceased's possessions. On the one hand, it was suggested that a peer support group could be helpful in this regard – in developing a collaborative plan that worked for the carer, so that they could, for example, get rid of a certain number of items per week, rather than everything at once. Others observed that photographs, clothing and other memorabilia did not need to be disposed of, and that such items held therapeutic value in allowing the person to hold on to good memories. They need help with the management of such affairs (including moving house), but recognition of the personal and sensitive nature of this process is required.

Importantly, the carers in this group did not want to let go of their grief. They did not want an intervention that was aimed at minimising or alleviating the emotions that accompanied the death of a loved one. Sorrow, for example, was compared favourably by one carer to emotions such as jealously and greed. It was described as 'a fantastic emotion'; akin to a source of comfort, where this particular carer could go and seek solace if they so wished. Jealously, anger and greed were 'ugly' emotions, sorrow was not. It was 'pure', even when accompanied by less welcome emotions, such as guilt. It was an expression of love.

The sense of grief and loss was amplified for one carer, because his wife's illness was rare and under-researched. Therefore, treatment options were limited, which was difficult to come to terms with. However, he was nonetheless given, what he now perceived to be false hope. This mismatch between reality and what he was told made the 'crash' of his wife's death worse, as he had been equipped with unrealistic expectations. Likewise, much of the language used in the discourse on cancer and other diseases was damaging. Terms such as 'fight' or 'battle' were incredibly harmful, because they implied that a person could overcome their disease simply by virtue of being mentally strong. This led to feelings of guilt when defeat was eventually accepted.

In terms of what, specifically, had aided the carers in coping with the aftermath of the death, there was discussion amongst the younger participants (also members of Widowed and Young) around the helpfulness of online support groups and forums. These can mitigate any physical disability or social anxiety that the person may have and it was considered a positive that they were peer-based, rather than professional. Other beneficial coping mechanisms included mindfulness and meditation, which were considered self-help approaches and served to separate the person from their thoughts. It was also noted that visiting the deceased's grave every day was therapeutic. One carer had become friendly with a group of other bereaved relatives who did likewise; if one of the group was unable to visit for any reason, someone else would tend to the flowers on that person's grave. There was an acceptance that, for some people, work may provide a welcome distraction. Indeed, for one of the group who was retired, not having a job to go back to was something they found hard. It meant there was more time in the day to fill and increased their sense of isolation.

The attitudes of others could have a detrimental impact on the person's wellbeing. Comments that came across as insensitive, whether intentional or not, were harmful, and in some cases resulted in serious setbacks. Throwaway expressions, such as 'it was God's will', or 'everything happens for a reason' had been commonly experienced and were met with upset and anger. Closely related to this, are the expectations that family members have, and the difficulties they face in accepting that the person will never be able to go back to their 'previous world'. There was a pressure that emanated from family and friends; exclamations of pride at how well the person appeared to be coping only intensified feelings of guilt and fear of those periods that would inevitably follow where a sense of being unable to cope was present. Life for this group had changed and it now involved coping and adapting to these changes.

During this discussion, the following outcomes were identified and noted on flip charts:

Peer support:
- Being listened to about all the little things (experiencing warmth, empathy, understanding)
- Importance of online, round-the-clock support (people to listen and talk to)
- Need support of those with shared experiences and understandings (Expectations of friends and family can be difficult to manage- just 'getting over it' is not always that simple)

Dealing with grief:
- Minimise negative consequences of grief
- Information and understanding of bereavement and coping process (that experiences are normal, will have good days and bad days)
- Having time to think about the person and enjoy memories
- Channelling/being able to deal with anger (that comes from negative care experiences, etc.)

Coping:

- Coping is multidimensional (not just supported by counselling, e.g. accessing social support)
- Being able to face the future
- Meditation – helps to give distance (this should be more widely offered)
- Being able to 'enjoy' sorrow (guilt-free, pure grief)

Approaches to offering and giving help:

- Allocated support for carer as well as patient (during end of life period)
- Having formal offers of support at later stages (e.g. 6 months down the line – but not a case of a fixed time, need for the option of access at different times)
- Recognising both emotional and practical difficulties/need for help (eg managing possessions)
- Publicity of services and awareness of what help is available is needed
- Provide insight/support for other family members so that they better understand what bereaved person is going through.

Afternoon session summary report – group 1 (bereaved group)

The session aimed to elicit delegates' views on the list of outcome dimensions (provided to each group member). They were asked to consider these lists in light of the findings from their own discussions that morning, and to suggest areas where changes or additions could be made.

Grief:

Firstly, in regards to the dimension of grief, a common observation centred on the lack of positive aspects. This is in keeping with one of themes that emerged from the morning session, which refuted the idea that grief and sorrow were unwelcome emotions that needed to be 'treated'. There was agreement that much of the grief outcome needed to be reframed (e.g. rather than focus on how many times a person has failed to get out of bed in a week, to focus on how many days they did). It was also noted that the list was missing items that addressed personal feelings and subjective experiences.

Dimension number 9 (preoccupation with and yearning for the deceased) was disputed, in that actually, 'yearning' was something positive. The group agreed that a distinction needed to be made between this, and 'preoccupation', which, by common consensus, had far more negative connotations and was suggestive of something maladaptive and unhealthy. In keeping with this point, an overlap with dimension 9 and dimension 17 (reminiscence (and maintaining emotional closeness)) was recognised, although again, reminiscence was absolutely described as a good thing. Indeed it was psychologically beneficial to the bereaved, meaning that the desire by family and friends to avoid any discussion of it was unhelpful. Similarly, the group believed that a dimension accounting for dreams was missing

from the list. Dreams were distinguished from nightmares (which were invasive and unpleasant).

Dimension 20 (personal growth, new roles and responsibilities, optimism/hopefulness) also provoked much discussion. It was suggested that this may be applicable to a particular group of bereaved individuals, namely those who were older, had not been happily married, and had consequently 'found themselves' afterwards. However, examples were then given, citing people who went back to university, or discovered new hobbies in the aftermath of a death, which was not necessarily reflective of the fact that they had a renewed sense of freedom, rather that they had found a way to move forwards. Dimension 14 (non-acceptance of the death/disbelief) led one of the carers to believe that this was not possible (i.e. if someone has died, then we accept it because it has happened). Others disagreed with this view, acknowledging that some people still laid a place at the table, or expected the deceased to walk through the door – which signified an inability (or unwillingness) to accept that they were dead.

Finally, dimension 23 (auditory and visual hallucinations) was widely accepted as indicating serious problems in adapting and continue to function. It was suggested this could be specifically applicable to a traumatic death.

Coping, adaptation and quality of life:
Dimension 2 (home management and housework) could use further explanation. For example, hoarding behaviour could indicate an inability to let go. Those dimensions that mentioned doing 'new' things were considered by some to be rather irrelevant. In other words, if you had never done certain things, there is no reason you would now do them. This is not a coping problem relating to bereavement, and merely indicates that people would tend to stick with the comfort of familiarity; though it was accepted others may embrace 'new' challenges as a direct result of bereavement.

Psychological outcomes:
The main issue identified with this list was that there was a large emphasis on those dimensions that indicated a depressive state, e.g. a lack of motivation, desire to do anything etc. However, the group was keen to stress the importance of hyperactive states, whereby one threw oneself into work, exercise or other hobbies (e.g. displacement activities), which could theoretically be just as detrimental.

People needed to know that it was acceptable to feel bad. It does not always need to be 'fixed' through the administering of antidepressants or other kinds of medication. If the antidepressants prevented one from crying, this was not a positive, but a negative – as it was supressing the grief. However, the group also acknowledged that this was only fine up to a point. If such profoundly negative states persist for long enough, it is reasonable to assume that this has become a pathological issue that needs to be addressed. Hence, perhaps outcome dimensions such as these, need to somehow specify when a person's behaviours have crossed the line from part of the 'normal' process of grief to something more serious. Likewise, from a health professional's perspective, continuing to reassure someone that what they are experiencing is 'normal' may well be dismissive of problems that need help.

With regards to mood, specifically, some of the dimensions specified here, e.g. fatigue, tension, may not necessarily be symptoms of grief. They could be symptoms of an illness or side-effects of medication.

Under the discussion of post-traumatic stress dimensions, substance abuse was picked up as being potentially problematic. In keeping with what was discussed above, there is a point at which it moves from being a 'crutch' to abuse. An addictive personality is potentially more vulnerable to this, and indeed, it was recognised that food and shopping are also detrimental if taken to an extreme. The issue with alcohol is that there is a cultural tendency to normalise one another's drinking habits.

Social support:

The importance of practical support was emphasised as being very important but underrepresented on the scale in comparison with the number of dimensions that addressed emotional support. For example, a specific point was made in relation to the amount of paperwork completion required in the event of someone dying. This makes demands of the bereaved at a time when they are least capable of meeting them.

Morning session summary report – group 2 (professional group)

The session began with 3 post-it notes being handed to each delegate. They were asked to note down 3 key ways a bereavement support service (BSS) should be helping those using it, or having any other kind of impact and which they think could or should be used (as an outcome) to assess how well the service is working.

This group initially found it harder to engage with the first task, as they suggested that it was very much dependent on the individual. Every person is different, therefore approaches to help will also need to be different. It was mentioned that attitude to grief is an important factor; to measure how the person feels at the start of the journey and how that changes over time.

Each delegate then spent around 5 minutes noting down their 3 outcomes on the post-it notes, after which the group reconvened and a discussion was had on these:

- Coping with grief
- Health care use (e.g. GP appointment)
- Ability to address financial issues
    - Emotional stress might be difficult to address if the person has financial pressure. How to measure - debts/food shopping?
- Ability to talk about the deceased person without feeling overwhelmed
- Impact on emotional resilience
- People don't know what to expect from the services, or have a misleading impression.
    - Some people come with an idea that "you are curing me"
- Normalisation
- Ability to return to work
- Optimistic outlook on the future

- Only 1 in 7 might actually use the service, as most people get a lot of support from family
- Impact on social isolation:
  - Some people feel isolated even when they have friends/family. Might feel they have exhausted them (whilst caring for the deceased person).
- Return to normal functioning
  - e.g. getting outside the front door; getting dressed; going back to work
- Impact on relationship with others and community (the external world)
  - 'misery likes company'
- The 'new normal' – adapting to this new situation
- Work place adjustments for people who have been bereaved
- General feeling of wellbeing (measured by whatever is normal for that person)
- Impact of identity within the community setting. This might be affected by the amount of time spent caring for the deceased.
- The time that each person takes to move forward varies. Some might move forward relatively quickly, whereas others need more time to start the process.
- Sense of feeling when the beloved dies (e.g. having too much time)
  - Issue of validating emotions
- It is all about when the person is ready to engage. Bereavement is disengagement and the service aims to encourage engagement.
- Often the case that needs (in particular emotional needs), seem to be treated by health professionals. It is almost medicalising bereavement.
  - The pharmaceutical company might push pills to treat bereavement
  - Create a condition
- Identifying the positive aspects of loss (e.g. both in cases where there was severe cognitive declinea, and also small things like having more time on their hands)
- How appropriate/responsive service is to individual needs
- Impact on physical health
- Positive impact
  - recognising their strengths/resilience

Second morning session summary report – group 2

In this session, the group consolidated the outcomes that arose from their discussion earlier that morning into overarching themes, which were further supported by the following observations:

A BSS must account for people who have additional caring responsibilities, e.g. if someone is the 'matriarch of the family'. It is also important to define what bereavement is, when it starts and ends etc.

The group were unanimously agreed on the notion of 'resilience' and the need to have the right kind of support to develop this resilience.

Finally, it was suggested that factors such as why people join a bereavement service to start with, need to be taken into account. This includes consideration of what each person wants to get out of the service, how long it should be offered for, and a baselines assessment of the individual's needs. In accordance with this, services should initially be designed

according to population demographics (e.g. urban/rural, high or low levels of deprivation etc.). Barriers to accessing these services must, insofar as is possible be identified and removed.

Much of the grouping work had naturally occurred during the first discussion session, so there was relatively little work required to agree the final list of outcomes identified:

Resilience and coping:
- Impact on personal coping/living with the grief:
- Visits to GP/ primary care related to bereavement (physical/emotional wellbeing)
- Ability to address finances
- Ability to remember/talk about deceased person without being overwhelmed
- Emotional and self-resilience and ability to function
- Incremental moves from hopelessness to optimism
- Ability to return to work
- Being bereaved with additional caring responsibilities

Interactions:
- Impact on social isolation (how it is managed)
- Return to normal functioning in the external world for the bereaved person
- Relationships with others and with their community
- Did it help? Continuum of useful to useless
- Managing how others treat them
- Improved wellbeing (however or whatever that may be)

Identity/sense of self:
- Impact on/re-emergence of sense of self-identity (short and longer term)
- Self-directed recognition of wanting to end sessions (not pathologising/medicalising grief)
- Identifying and validating the positive consequences of loss

Service provision:
- Equity of service provision across all groups
- Response to individual differences

Expectations of participants:
- What do they want to get out of a BSS?

Physical health

Afternoon session summary report – group 2
The session aimed to elicit delegates' views on the list of outcome dimensions (provided to each group member). They were asked to consider these lists in light of the findings from their own discussions that morning, and to suggest areas where changes or additions could be made.

Group perception: The person defines their need and meeting that need defines the outcome.

The group struggled to deal with the third session when asked to place the outcomes they'd identified within the list generated through the systematic review. They felt doing this was asking them to think very differently and to take what they perceived to be a reductive and medicalised approach. This was in conflict with their person-centred approach (as epitomised by case studies).

The question was posed about how quality can be captured, particularly via a medicalised series of processes.

The limits of possibility: The outcomes are all about positive results, but negative results will always exist (not everyone will have the desired response(s) to a BSS).

Will participants who don't currently benefit, do so as a result?

Morning session summary report – group 3

The session began with 3 post-it notes being handed to each delegate. They were asked to note down 3 key ways a bereavement support service (BSS) should be helping those using it, or having any other kind of impact and which they think could or should be used (as an outcome) to assess how well the service is working.

The group identified the following outcomes:

Service orientated outcomes:
Organisational culture:
- Transport links/accessibility
- Information, signposting, navigation to/about service
- Range of support with integration (with 'self' or 'others') – accessible when needed and in accessible formats
- Staff, development, training and support
- Recognition of and sensitivity to difference
- Culture of integrity (including evidence-based knowledge) and commitment to Bereavement Care (BC) Standards.
- Clarity of scope

Accessibility:
- Location
- Timing
- Formats (information – about service, about grief, about other services)

Integration:
- Signposting
- Collaboration and partnership

User orientated outcomes:

Psychological – understanding normality of grieving process:
- Help with psychological wellbeing and capacity to bear
- Coping with feelings of loss and grief
- Discovering and strengthening resilience
- Ability to self-manage and rely less on health services

Psychological – processing feelings:
- Reduce anxiety
- Reduce panic
- Improve sleep quality
- Understanding difference between depression and grief

Social – individual:
- Adapting to change, e.g. 'post carer' role
- Normality (expected, common)
- Healthy coping and lifestyle strategies

Social – family:
- Help with connectedness and feeling less isolated
- Ability to function in life roles and responsibilities
- Relationships and communication
- Managing conflict and misunderstanding (of different ways of dealing with grief)

Social – wider society:
- Help with connectedness and feeling less isolated
- Ability to function in life roles and responsibilities
- Relationships and communication
- Ability to deal with social and financial insecurities and circumstantial factors

Cognitive*:
- Making sense of experience
- Understanding normality of grief and the consequences for others
- Understanding others' behaviours and actions
- Identifying maladaptive thoughts and behaviours

*These interact and are linked with psychological and social dimensions

Spiritual and belief systems:
- Making sense of loss
- Impact on personal identity (cultural and religious)

Afternoon session summary report – group 3

The session aimed to elicit delegates' views on the list of outcome dimensions (provided to each group member). They were asked to consider these lists in light of the findings from their own discussions that morning, and to suggest areas where changes or additions could be made.

It was first important to note that outcomes can be used in different ways. This particular group looked at outcomes as measured when a bereavement service intervention had been completed, reflecting the need to have a domain that explored the provision of that service. In other words, the type of service provided, the quality, and the mapping of this against Bereavement Care Standards. One could then consider the question 'what constitutes a successful service?'

The group had also made specific observations about aspects of the various outcomes. For example, the list containing the dimensions of grief appeared to identify research measures with regards to exploring grief, rather than outcome measures. As it stands, it appears to describe characteristics of grief, which is why this group decided to come at the task from a different angle and explore how services would look at outcomes. An example of this (outcome for a service), would be influencing public and professional (e.g. GP's) understanding of grief. It was also agreed that cognitive dimensions should have a separate heading, and that there was little to account for culture, spirituality or meaning-making. At the same time, it was recognised that there would be overlap between the cognitive sub-themes and those that related to psychological and physical outcomes. Finally, if prolonged grief is being measured, we need to consider the background and context. We also need to consider the research samples used to generate tools. A health-related QoL score would be useful, to position QoL in relation to bereavement.

For the psychological outcomes, under post-traumatic stress, the first 3 dimensions can be categorised as common grief experiences rather than as symptoms of something pathological. Like the bereaved carers, this group found the inclusion of the dimension accounting for eating and substance abuse disorders problematic, as this was not necessarily related to post-traumatic stress, and could actually be common, especially if previously experienced. One could apply this to dimension 5 of post-traumatic stress (bodily symptoms caused by mental illness, e.g. pain) and dimension 7 (mood episodes and disorders). It was also felt that the psychological outcomes list was missing a dimension on libido.

The list that related to social support was regarded as having far more achievable outcomes.

Appendix two: adapted lists following consensus day discussions

Integrated lists of outcomes and outcome dimensions

Carer group ; Professional group 2; Professional group 3

Underlined = confirmed by qualitative studies

Dimension*=added from list of qualitative outcome statements

Grief

Grief Dimensions
1. Physical health problems e.g. running nose, chest pains, dizziness, palpitations
2. Anxiety, worry and panic behaviour
3. Self-destructive behaviour
4. Cognitive reactions such as difficulty concentrating, remembering.
5. Sadness and crying
6. Hopelessness, pessimism, loss of meaning and purpose
7. Loneliness and emptiness
8. Painful, intrusive thoughts (e.g. memories of suffering and death*)
9. Preoccupation with thoughts of deceased.
10. Feelings of blame, guilt, anger, bitterness, regret (e.g. over care/ death experiences of loved one, family conflict*)
11. Shame and stigmatisation
12. Detachment and disconnection from self and others
13. Seeking an understanding for why death occurred
14. Non acceptance of death/disbelief
15. Avoidance and denial of distress and grief
16. Avoidance and denial of thoughts, feelings, reminders of deceased
17. Reminiscence (and maintaining emotional closeness*) (having time to think about the person and enjoy memories, yearning)
18. Coping ability and resilience (both discovering resilience and strengthening it)
19. Support/ lack of support from family/friends
20. Personal growth, new roles and responsibilities, optimism/hopefulness
21. Loss of role and identity*
22. Intensity of grief around the time of the death
23. Auditory and visual hallucinations
24. Pain in same parts of body as experienced by deceased
25. Dreaming of the deceased (positive experience)

Psychological outcomes

Anxiety and depression
1. General state of anxiety, characterised by feelings of tension, nervousness, panic and distress. /Reduced anxiety/ reduced panic
2. Lack of motivation and loss of interest or enjoyment in one's job, leisure activities and social life.
3. General state of depressed mood, characterised by a sense of hopelessness, pessimism and periods of crying.
4. Wide range of physical or physiological symptoms as a result of depression or anxiety.
5. Cognitive symptoms e.g. problems with memory and concentration, decision making
6. Feelings of irritation and annoyance
7. Feelings of self-blame and guilt
8. Suicidal thinking
9. Sleep-related problems, including insomnia. / improved sleep quality
10. Hyperactivity, inability to slow down (e.g. engagement in displacement activities)
11. Excess tiredness
12. Slowing down of movement, speech and thoughts.
13. Impact on libido
14. Anxiety or distress as a result of perceived presence of physical symptoms (eg pain) or worry about having a serious illness
15. Symptoms relating to paranoia, obsessive thoughts, feelings of discrimination
16. Symptoms relating to phobias
17. General state of calmness
18. Capability for insight

Mood
1. Feelings of anxiety, depression and distress
2. Fatigue
3. Anger and hostility
4. Tension
5. Loss of vigour
6. Feeling positive e.g. enthusiastic, alert, active
7. Sensation seeking

Post-traumatic stress
1. Avoiding activities and feeling distant (also common grief symptoms)
2. Arousal e.g. difficulty falling asleep, concentrating, easily startled (also common grief symptoms)
3. Intrusive thoughts and nightmares (also common grief symptoms)
4. Eating and substance abuse disorders
5. Bodily symptoms caused by mental illness e.g. pain
6. Psychotic symptoms and disorders
7. Mood episodes and disorders

Self-esteem
1. Feelings about yourself

Cognitive outcomes

Cognitive dimensions
1. Meaning making
2. Understanding normality of grief and consequences for others
3. Understanding others' behaviours and actions
4. Identifying maladaptive thoughts and behaviours

Physical health

Physical health
1. Health status and problems e.g. infections, blood pressure, other illnesses
2. Health behaviours
3. Health care use (e.g. visits to GP or primary care as a result of bereavement)
4. Mortality rates

Coping, adaptation and quality of life

Social functioning and adjustment
1. Ability to work (or return to work following bereavement)
2. Ability to perform home management and housework tasks (including hoarding behaviour)
3. Participation in social activities
4. Participation in private leisure activities or hobbies
5. Relationships with family
6. Relationship with spouse
7. Relationships with others (outside of family) and with community/ Relationships and communication
8. Ability to function in life roles and responsibilities
9. Forming new roles and relationships* (adapting to change post-carer role)
10. Forming new routines and structure to the day* (sense of normality)
11. Functioning as a parent and/or in family unit (being bereaved with additional caring responsibilities)
12. Managing conflict or misunderstanding (of different ways of dealing with grief)/ Managing how others treat them
13. Personality and behavioural traits e.g. assertive, controlling, submissive

Coping and resilience
1. Efforts to detach and distance oneself from a stressful situation
2. Efforts or ability to control one's feelings and behaviours (e.g. to channel anger)
3. Efforts or ability to find balance and channel grief i.e. focus on grief at certain times and focus on other areas of life at other times.* (Being able to 'enjoy' sorrow, 'pure' grief)
4. Ability to live with the grief and function in the external world (emotional and self resilience)/ minimizing negative consequences of grief/help with psychological wellbeing & capacity to bear/ coping with feelings of loss and grief, discovering and strengthening resilience
5. Efforts or ability to self-manage and rely less on health services
6. Efforts or ability to access support and maintain relationships
7. Efforts to escape or avoid problems
8. Efforts or ability to accept responsibility, take control and alter the situation/address the problem (e.g. look ahead and move forwards with life*)/ Being

9. Efforts or ability to think positively, find meaning and hope in new life situation and/ or the future (incremental moves from hopelessness to optimism)
10. Efforts or ability to accept, understand and find meaning in loss
11. Efforts or ability to accept and view grief experiences as normal* / understanding that experiences are normal/ understanding normality of grieving process/understanding difference between grief and depression/not pathologising or medicalising grief
12. Efforts or ability to find comfort, meaning or strength in religious or spiritual beliefs*
13. Efforts or ability to think positively about the care given to loved one and relationship with loved one at end of life.*
14. Ability to talk about the deceased person without being overwhelmed

Quality of life and general wellbeing
1. Physical health and wellbeing
2. Physical functioning i.e. being able to perform daily tasks
3. View of one's self
4. Emotional wellbeing and meaning in life
5. Mental health and wellbeing
6. Financial security and material wellbeing /ability to address finances/ Ability to deal with social and financial insecurities and circumstantial factors
7. Participation in work or recreational activities
8. Learning, creativity and vitality
9. Relationships with family and friends
10. Relationship with health professional
11. Satisfaction with home, neighbourhood and community environment

Locus of Control
1. Extent to which one perceives events and outcomes in life as within their control
2. Extent to which one wants to have control over specific events and outcomes in life
3. Extent to which one expects to have control over specific events and outcomes in life

Identity and Belief Systems
1. Impact on/re-emergence of sense of self
2. Identifying/validating the positive consequences of loss
3. Making sense of loss
4. Impact on cultural identity
5. Impact on spiritual identity

Social support

Interpersonal and Social Support
1. Access to physical or practical support (e.g. managing deceased's possessions)
2. Access to material support
3. Access to emotional support (e.g. experiencing warmth, empathy etc.)
4. Access to guidance and positive feedback
5. Participation in social activities
6. Able to express feelings openly and honestly
7. Take comfort, hope and strength from relationships with others (friends, family, professionals)*

8.	Feel understood and connected with others in similar situations* (e.g. access to support from those with shared experiences)/ help with connectedness and feeling less isolated
9.	Developing empathy with and helping others going through similar experiences*
10.	Difficult relationships and interactions with friends and family members* (Difficult to manage expectations of friends and family)

Capturing Negative or Unintended Consequences

The outcomes are all about positive results, but negative results will always exist (not everyone will have the desired response(s) to a BSS).

Process / Service mapping Outcomes

The type of service provided, the quality, and the mapping of this against Bereavement Care Standards. One could then consider the question 'what constitutes a successful service?'

Service Orientated Outcomes

1. Enabling help seeking and access to services
Allocated support for carer as well as patient (during end of life period); Having formal offers of support at later stages (e.g. 6 months down the line – but not a case of a fixed time, need for the option of access at different times); Publicity of services to raise awareness of what help is available
Transport links/accessibility; Information, signposting, navigation to/about service; Location; Timing; Formats (information – about service, about grief, about other services)
2. Ability to respond to individual needs for different types of support
Response to individual differences; Recognition of and sensitivity to difference; What do participants want to get out of a BSS?
3. Package of integrated support/ activities offered (eg practical, emotional, educational)
Recognising both emotional and practical difficulties/need for help; Provide insight/support for other family members so that they better understand what bereaved person is going through;
Range of support with integration (with 'self' or 'others') – accessible when needed and in accessible formats; Signposting; Collaboration and partnership; influencing public and professional (e.g. GP's) understanding of grief
4. Equity of service provision
Equity of service provision across all groups
5. Staff development, training and support
Staff development, training and support
6. Practice and provision informed by evidence based knowledge and commitment to BC standards
Culture of integrity (including evidence-based knowledge) and commitment to Bereavement Care (BC) Standards; Clarity of scope

Developing a Core Outcome Set for evaluating Bereavement Support Services in Palliative Care

Feedback Report and Exercise for Second Consensus Day, 13th April 2018

June 2018

Marie Curie Palliative Care Research Centre
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Background

The Marie Curie Research Centre, Cardiff University has been developing a Core Outcome Set which can be used in research and clinical evaluations of bereavement support services/ interventions in palliative care settings. By achieving consensus on which outcomes and dimensions should be considered 'core' we are aiming to identify one or two key measures of change which can be used to help determine the impacts that bereavement services have on their service users.

A systematic review of quantitative and qualitative literature identified a list of outcomes relevant to bereavement support. At the consensus day in March 2017 delegates discussed and amended the lists generated from the review. This informed a two round DELPHI survey designed to reach consensus on which outcomes and dimensions should be included in the Core Outcome Set.

During the final consensus day, held on 13th April 2018, delegates were presented with a series of lists of outcomes and outcome dimensions. Using electronic voting technology delegates voted on what they felt were the most important items. In the afternoon, the outcomes and outcome dimensions that were shortlisted were presented and delegates were invited to discuss these results and check that they a) felt happy with the items that were shortlisted and b) raise any concerns over items not shortlisted. Unfortunately, due to time constraints it was not possible to satisfactorily complete this exercise so it was agreed that these sets of results would be circulated to provide delegates with the opportunity to check and provide feedback.

Copy of Feedback Exercise with Results

We would be extremely grateful if you could complete the short feedback exercise below. For ease of reference all results from the day (including a summary of key discussion points) and tables of results from both Delphi Surveys are presented as appendices.

1. The 'selected' outcomes and dimensions

Based on the results from the Delphi Survey, the consensus days and a mapping exercise which analysed how the selected outcome dimensions related to the most popular outcomes, we are proposing that the two core 'overarching' outcomes should be 'Ability to cope with grief' and either 'Mental health and wellbeing' or 'Quality of life'. (See table below)

Top Six outcomes from Delphi Survey and consensus day ranking

Outcomes	% of respondents that rated important or very important	Ranking from consensus day voting
Ability to Cope	**96% (92% service users)**	**2**
Mental Health and Wellbeing	**92% (91% service users)**	**6**
Quality of life (QoL)	**91% (83% service users)**	**1**
Grief Intensity	87% (81% service users)	5
Social functioning and adjustment	85% (87% service users)	7
Resilience	85% (87% service users)	3
Social support	81% (75% service users)	4

The voting also covered outcome dimensions. The table below details the outcome dimensions which scored at least 80% in the Delphi Survey (our threshold for automatic inclusion in the Core Outcome Set), and also identifies which of the top three outcomes these dimensions relate to (based on our mapping exercise). The items in italics are those which were also shortlisted in the consensus day voting.

Core outcomes and outcome dimensions

Outcome(s)	Outcome dimension
Ability to cope with grief	*Feelings of loneliness and emptiness*
	Feelings of blame, guilt, anger, bitterness, regret
	Overwhelming thoughts and/or nightmares about loss
	Preoccupation with thoughts of the deceased
	Understanding and finding meaning in loss
	Positive reminiscience and remembering of the deceased
	Acceptance of loss
	Ability to take control/ look ahead and start to move forward with life
	Acceptance of grief experiences as normal
	Ability to find balance and channel grief
	Feeling understood by and connected with other bereaved people
	Accessing practical support if needed
	Accessing emotional support if needed
	Ability to express feelings openly and honestly
Mental health and wellbeing /Quality of Life	*Depression (a sense of hopelessness, pessimism, periods of crying)*
	Anxiety (feelings of tension, nervousness, panic and distress)
	Ability to function as part of a family
	Relationships with friends and family
	Ability to participate in social or other activities
	Sense of meaning and purpose in life
	Optimism and hopefulness
	Ability to perform daily tasks
	Ability to participate in work
Mental health and Wellbeing	Suicidal thoughts

1.1 Do you have a preference for either *Quality of Life* or *Mental Health and Wellbeing* as the second core outcome? (please select and if possible give your reasons)

Results: 11 responses, 1 confirmed that happy with results and didn't complete the survey.

Quality of life (4 Bereaved People (BPs); 1 Service Provider (SP); 1 Researcher (R))

QoL and WB (1 SP)

MHWB (2 BP; 1 SP)

Free text responses favouring Quality of Life

Importance of social networks-"nobody to discuss problems with" "become an empty shell" (BP, handwritten copy)

As mental health and well being is considered as a component of measuring one's quality of life, I would prefer not to put them together as alternatives. I would suggest to use quality of life as the outcome where both mental outcome dimensions (Depression,Anxiety, Relationships with friends and family, sense of meaning and purpose in life, Optimism and hopefulness) and physical outcome dimensions (Ability to function as part of a family, Ability to perform daily tasks, Ability to participate in work) were considered.
It would be easier to understand if the term 'ability' is more explicitly used. For example, 'Ability to participate in social or other activities' can be more explicitly expressed as 'Mental ability to participate in social or other activities' and 'Physical ability to participate in social or other activities'. I would also consider to include suicidal thoughts under the mental outcome dimensions of this 'quality of life' outcome. (BP)

Quality of life - is a broader concept, which captures measures of metal health and well-being, in addition to social and physical functioning. Quality of life is an important consideration when undertaking economic evluations of services. (R)

Quality of life. If this is good then good mental health and wellbeing should follow (BP)

Quality of life-it is a wider measure and mental health might be off putting (BP)

Mental Health and Wellbeing
Mental health and wellbeing: I think quality of life is more associated with physical functioning. Wellbeing is and easier concept to understand perhaps. (SP)
I think there is more that can be done to support people with their mental health, as there are certain clinical diagnoses which can be identified and treated, whereas 'quality of life' can mean different things to different people. This does not mean that is does not need to be considered, but I suspect that a service geared towards mental health will help with wellbing, whereas a service geared towards wellbeing may not have the skills-mix to deal with mental health. (BP)
I prefer 'mental health and wellbeing'. I think this is more specific to bereavement. 'Quality of life' is important but at the same time is quite generic and applies to almost any situation.(BP)

Quality of Life and Wellbeing
I am uncomfortable with all these concepts as they are so subjective. On balance, if forced to, I would choose Quality of Life and Wellbeing. I think both core outcomes are subjective and open to bias. Many aspects of mental health are influenced by factors other than bereavement, and to assess outcomes of bereavement care as 'failing' because the bereaved person continues to have mental health issues, can be misleading. Bereavement can exacerbate existing mental health conditions and/or bring on mental health challenges such as anxiety. It seems to me any core 'outcome' measures need to be non-static and assess change over time to show if the bereavement care intervention affected the bereaved person's mental health positively following their bereavement.
Also, Wellbeing (and for that matter, quality of life) needs to be self-evaluated, otherwise any measure risks reinforcing assumptions about what contributes to wellbeing. How do the Team

propose to create a self-directed measure? How will any measure allow someone to weight spiritual wellbeing compared to physical or financial wellbeing, for instance? (SP)

2. Areas of uncertainty/ inconsistency between Delphi Survey and Consensus Day results

The outcome dimensions in the table below were shortlisted in the voting exercises on the consensus day, but did not pass the 80% threshold in the Delphi Rounds. We would therefore like you to consider these items and answer the following question;

2.1 Do you think that the following dimensions should be included in the core outcome set?;

Outcome dimension	Yes (Include)	No (Leave out)	Don't know
Sense of identity and role	6 (3 BP; 2 SP; 1 R)	3 (1 SP; 2 BP)	1 (1 BP)
Avoidance and denial of distress, grief or other problems	2 (2 BP)	6 (1 R; 2 SP; 2 BP)	1 (1 BP; 1 SP)
Regulation and control of feelings and behaviours	1 (1 BP)	7 (1 R; 3 SP; 2 BP)	2 (2 BP)
Use of healthcare services	3 (1 R, 1 BP)	5 (2 SP; 3 BP)	2 (1 BP; 1 SP)
Intensity of grief experienced around the time of death	2 (1 SP, 1 BP)	5 (1 R; 3 BP; 1 SP)	2 (1 SP, 1BP)
Problems with memory, concentration, making decisions, speech	6 (2 SP, 4 BP)	3 (1 R, 1 SP, 1BP)	1 (1 BP)

The outcome dimensions in the table below scored poorly in the consensus day voting exercises but reached the 80% threshold in the second round of the Delphi Survey. We would therefore like you to also consider these items and answer the following question;

2.2 Do you think that the following dimensions should be included in the core outcome set?;

Outcome dimension	Yes (Include)	No (Leave out)	Don't know
Accessing financial/material support if needed	5 (2 SP, 3 BP)	4 (R, SP, 2BP)	1 (BP)
Tiredness and fatigue	5 (5 BP)	5 (1 R; 3 SP; 1 BP)	
General health problems (eg infections, blood pressure…)	5 (1 R; 2 BP)	5 (3 SP; 2 BP)	

The dimensions listed below scored between 70 and 79% in the Delphi and were not shortlisted in the consensus day voting exercises. Please check that you are in agreement that these **should be left out of** the core outcome set.

Accessing guidance if needed
Sleep related problems (2BP)
Feelings of detachment and distancing
Paranoia or obsessive thoughts
Hyperactivity and inability to slow down
Self esteem (BP)
Financial security and material wellbeing (SP,2 BP)
Behaviours such as eating disorders or substance abuse (2 BP)
Irritation and bad mood
Related physical symptoms (eg pain or sickness) (2 BP)

Please note here any dimensions from the above list that you **feel strongly should be include**d in the Core Outcome Set (responses indicated in above table).

3. Do you have any other comments relating to this selection of core outcomes and dimensions?

The majority of these seem to be alternative phrasing of the included dimensions above therefore can be left out in my opinion (BP).

As above, I think there is some overlap in the dimensions, and we need to be careful that the phrasing used doesn't become too specific or duplicate previous questions, as for example assessing 'tiredness and fatigue' will almost certainly result in answers including sleep related problems (therefore the latter can be omitted). Additionally we should be confident that the questions are broad and open enough to allow people who are experiencing the more extreme end of the grief spectrum to both express this in their answers, and be identified by the researchers so that they can be signposted to appropriate support services.(BP)

I think that those from the table above that are more important are covered elsewhere (BP)

I think, this is an excellent piece of work, the ideas around outcome dimension may be categorised according to mental/ physical component or sub-categorised under mental components. (BP)

Some repetition between dimensions (BP)

QUESTION 1: which of these **OUTCOMES** should be included in the Core Outcomes Set? (YOU HAVE THREE VOTES)

Fig 1: Summary of the results from the Consensus day voting to Q1

Q1: Which of these OUTCOMES should be included in the Core Outcome Set? (3 votes)

32%	1.	Quality of life
17%	2.	Mental health
22%	3.	Grief intensity/experiences
6%	4.	Signs of post traumatic stress
10%	5.	State of depression
13%	6.	Signs of complicated grief
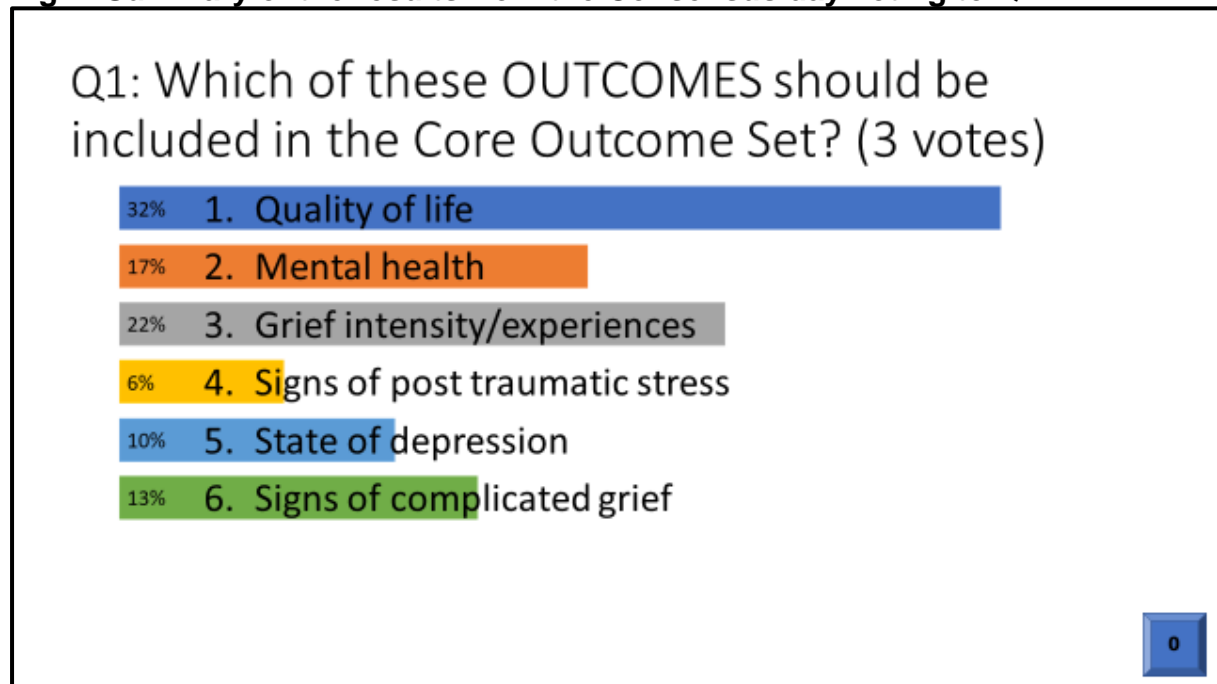
QUESTION 2: which of these **OUTCOMES** should be included in the Core Outcomes Set? (YOU HAVE THREE VOTES)

Fig 2: Summary of the results from the Consensus day voting to Q2

Q2: Which of these OUTCOMES should be included in the Core Outcome Set? (3 votes)

10%	1.	Physical health
24%	2.	Social support
31%	3.	Ability to cope
5%	4.	State of anxiety
3%	5.	Mood
27%	6.	Resilience (the ability to adjust to upsets and change)

Discussion points;

In Q2, there was some debate about 'resilience' and 'ability to cope' – whether these two items in fact had distinct meanings. It was agreed that 'resilience' meant one's ability to bounce back, whilst 'ability to cope' was more generic and meant to apply to everyday coping.
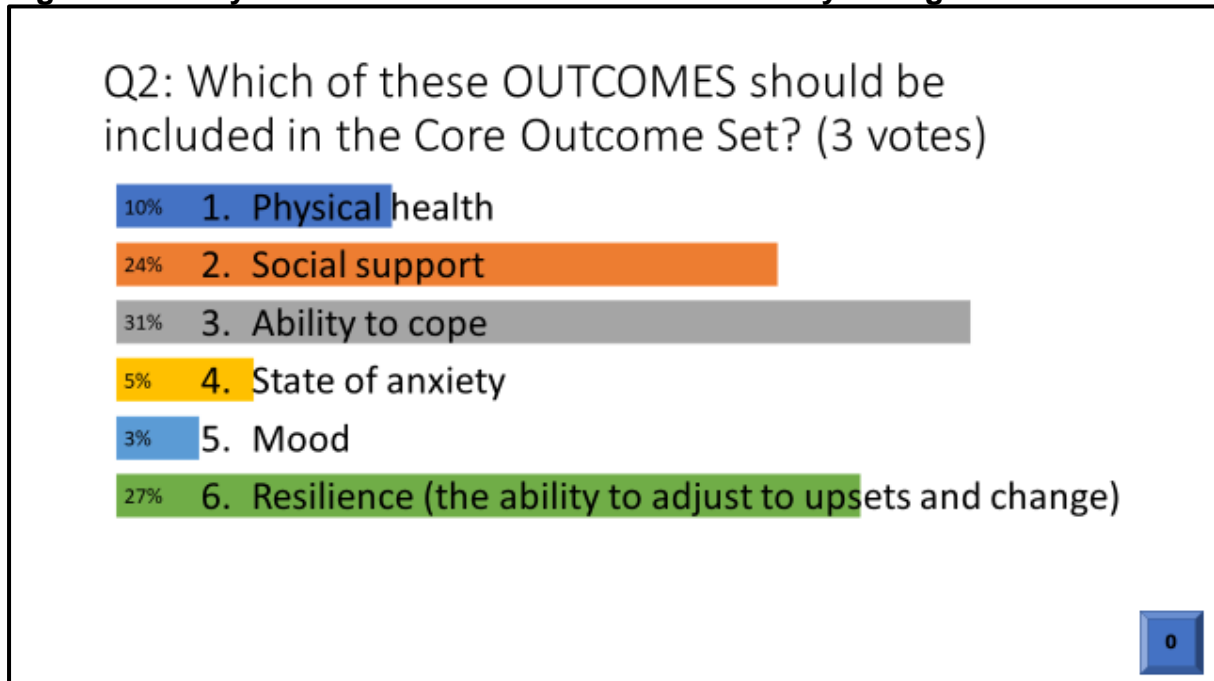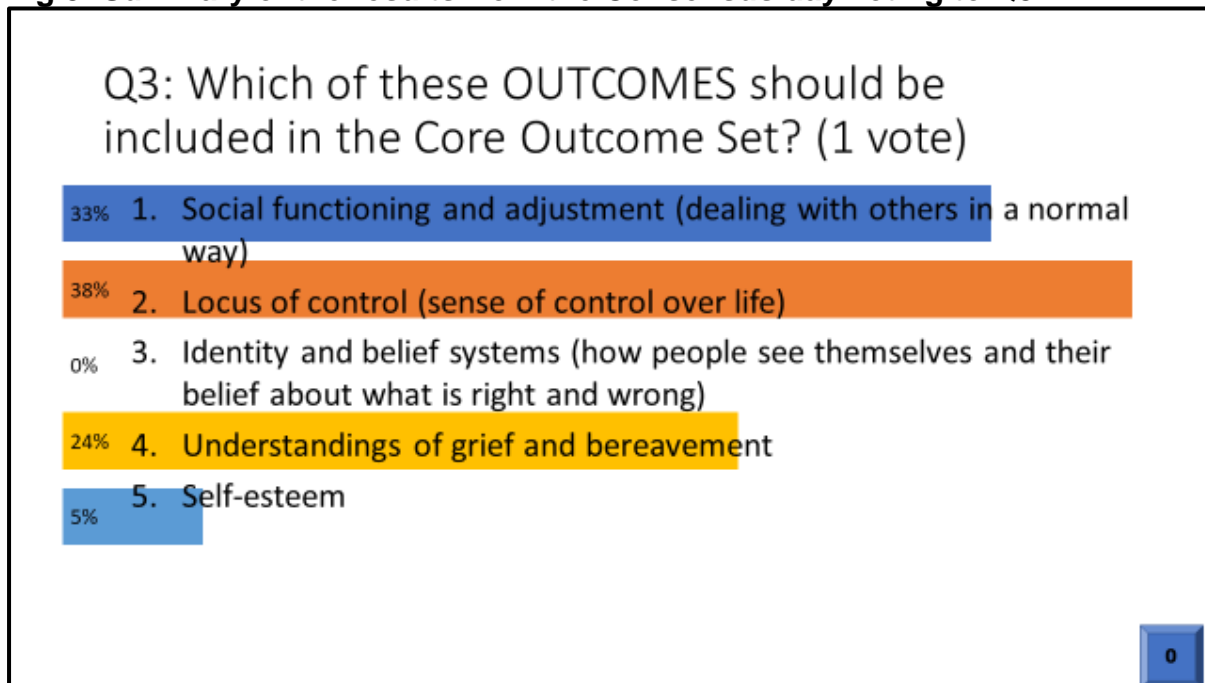
QUESTION 3: which of these **OUTCOMES** should be included in the Core Outcomes Set? (YOU HAVE 1 VOTE)

Fig 3: Summary of the results from the Consensus day voting to Q3

Q3: Which of these OUTCOMES should be included in the Core Outcome Set? (1 vote)

33% 1. Social functioning and adjustment (dealing with others in a normal way)

38% 2. Locus of control (sense of control over life)

0% 3. Identity and belief systems (how people see themselves and their belief about what is right and wrong)

24% 4. Understandings of grief and bereavement
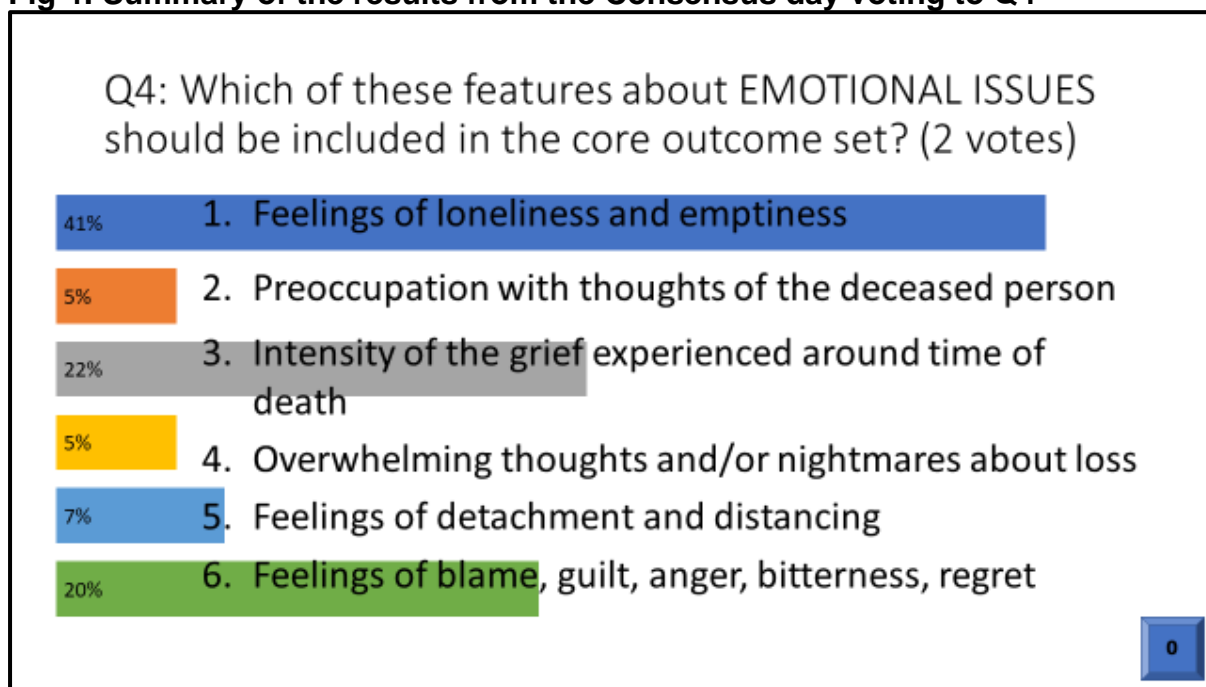
5. Self-esteem
5%

0

Discussion points;

It was mentioned in the Q3 discussion about the importance to respondents of the chronological ordering of items. 'Understandings of grief and bereavement', for example is more of an earlier outcome that service providers would try to achieve, in order to have an influence on other domains, such as mental health, further down the line.

QUESTION 4: which of these features about **emotional issues** should be included in the Core Outcomes Set? (YOU HAVE 2 VOTES)

Fig 4: Summary of the results from the Consensus day voting to Q4

Q4: Which of these features about EMOTIONAL ISSUES should be included in the core outcome set? (2 votes)

41% 1. Feelings of loneliness and emptiness
5% 2. Preoccupation with thoughts of the deceased person
22% 3. Intensity of the grief experienced around time of death
5% 4. Overwhelming thoughts and/or nightmares about loss
7% 5. Feelings of detachment and distancing
20% 6. Feelings of blame, guilt, anger, bitterness, regret

Discussion points;

In Q4, the bereavement journey, and where respondents are in relation to this, was brought up. The importance that someone assigns to 'feelings of blame, guilt, anger, bitterness, regret', for example, depends on where in that journey they occur.

QUESTION 5: which of these features about **emotional issues** should be included in the Core Outcomes Set? (YOU HAVE 1 VOTE)

Fig 5: Summary of the results from the Consensus day voting to Q5
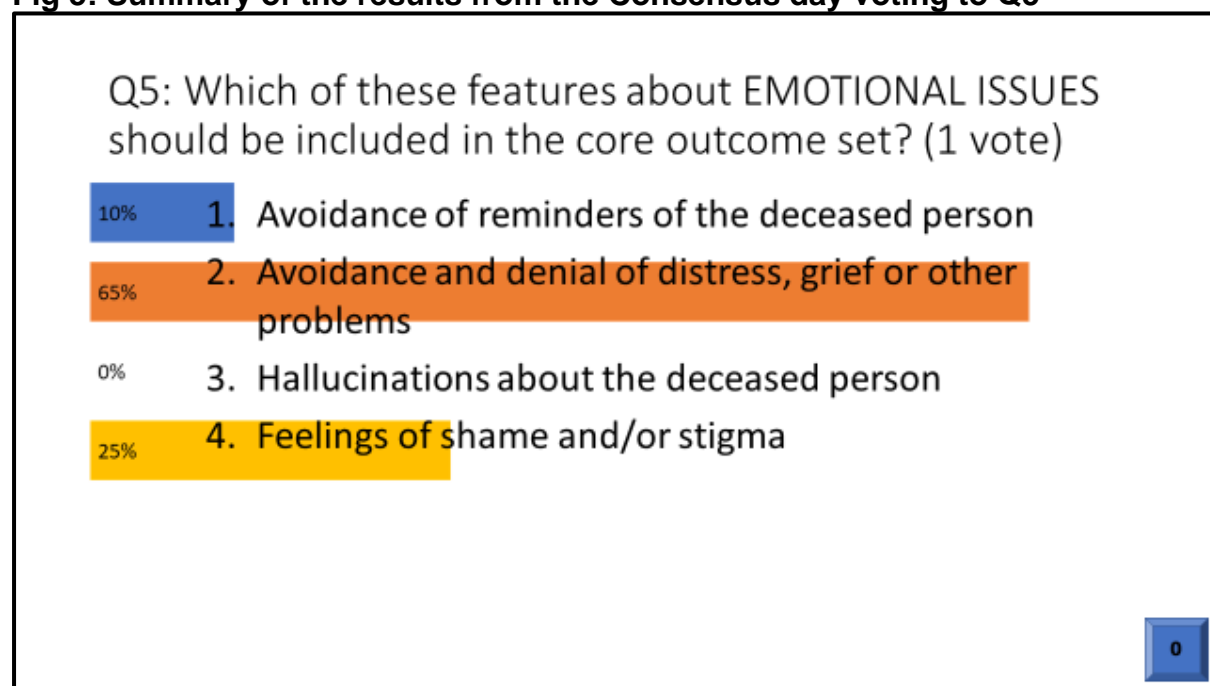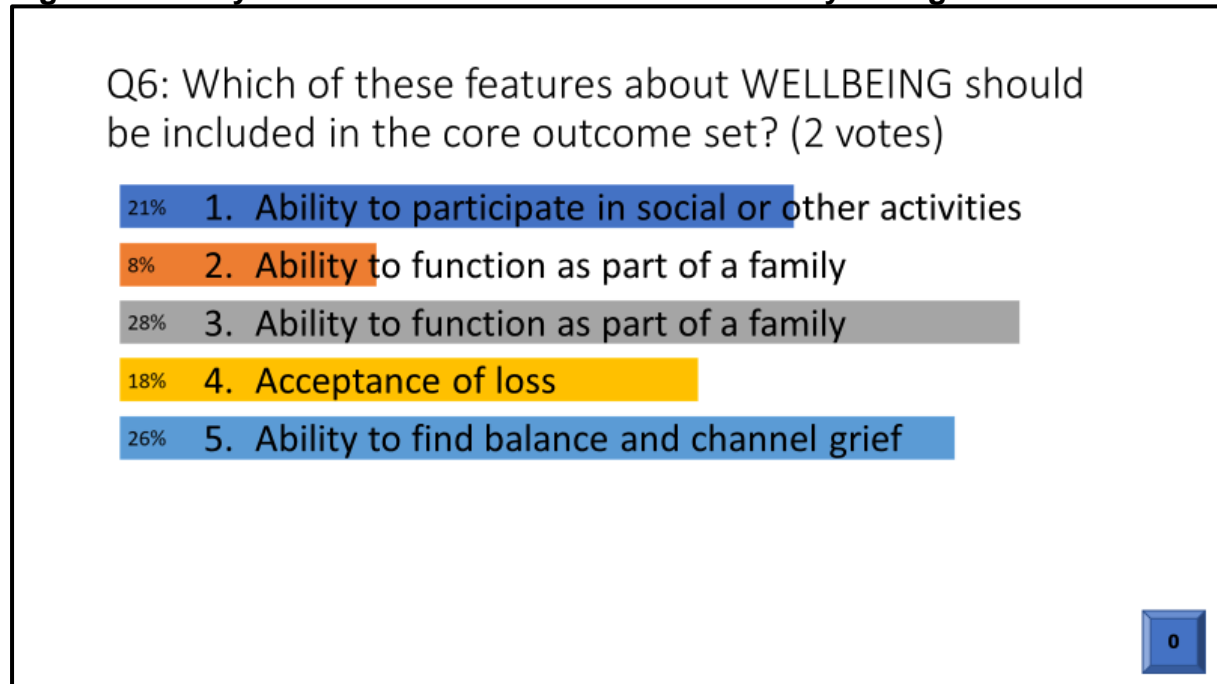

Discussion points;

- In Q5, it was mentioned that what is important, is whether the bereavement service has had an impact on how people handle, for example, denial – in other words, helping them to accept that denial is normal.
- It is interesting to observe the ways in which the different groups have answered (in terms of Delphi responses). A service user, for example, may not recognise 'avoidance/denial of grief' as a problem. From a service provider's perspective, how do you engage with that if the service user doesn't recognise that there is an issue?
- The outcomes it is important to measure in relation to an individual may differ from those it is important to measure when evaluating a service. To what degree will the outcome set be used for the individual therapeutic relationship?
- It was clarified that this process was being undertaken, specifically to look at what it is important to measure at a service level, rather than an individual level.
- It was also acknowledged that a service user would approach the process from a personal perspective, whereas a service provider would have an overview.

QUESTION 6: which of these features about **Wellbeing** should be included in the Core Outcomes Set? (YOU HAVE 2 VOTEs)

Fig 6: Summary of the results from the Consensus day voting to Q6*

THERE IS AN ERROR ON THE QUESTION SHWON ON THE SCREEN, ONE ITEM WAS COPIED TWICE. Item three should have read sense of meaning and purpose (this was correct on paper version and explained before voting took place)

Discussion points;

- There was some discussion, with regards to Q6, around what was meant by 'ability to function as part of a family'. It was agreed that the meaning was ambiguous, but that it could refer to family dynamics, or a person's ability to parent following the death of a spouse or partner.
- There is also a cultural aspect to grief, which relates back to the individualised approach. For example, in some cultures, it is more important that the group as a whole (the family) is able to function.

: which of these features about **Wellbeing** should be included in the Core Outcomes Set? (YOU HAVE 2 VOTEs)

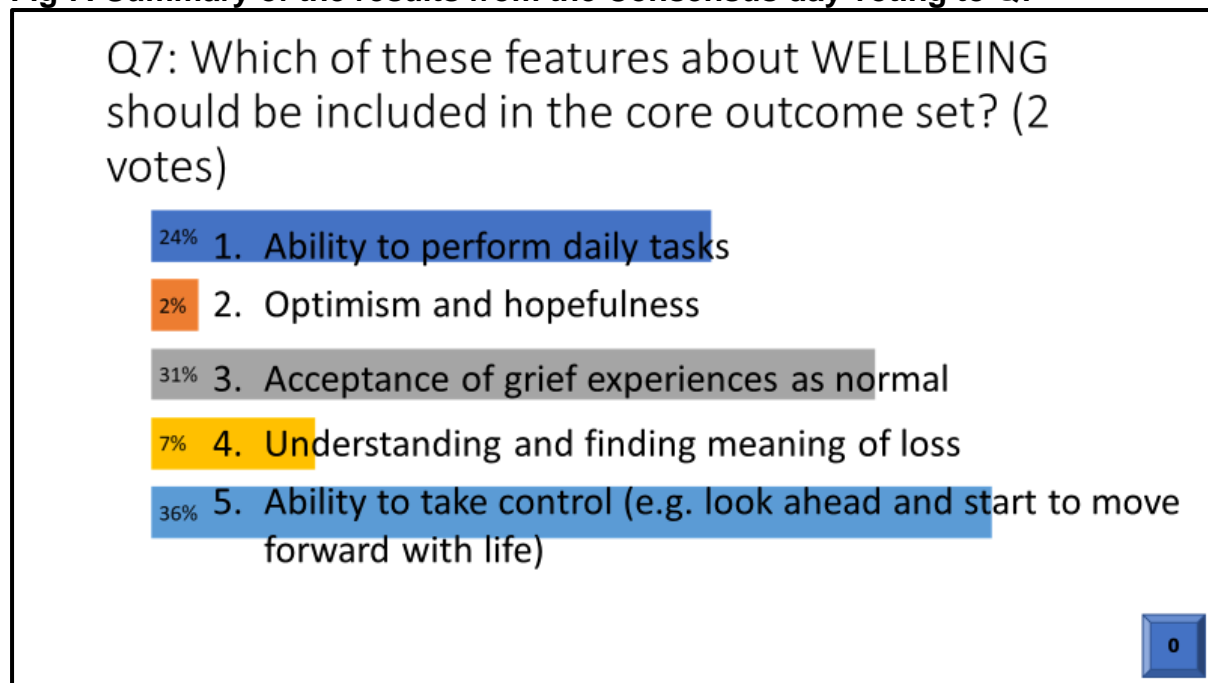**Fig 7: Summary of the results from the Consensus day voting to Q7**

Q7: Which of these features about WELLBEING should be included in the core outcome set? (2 votes)

24% 1. Ability to perform daily tasks

2% 2. Optimism and hopefulness

31% 3. Acceptance of grief experiences as normal

7% 4. Understanding and finding meaning of loss

36% 5. Ability to take control (e.g. look ahead and start to move forward with life)

Discussion points;

- In Q7, the meaning of the word 'control' was discussed. It was mentioned that this can mean different things in the bereavement context. How it is understood in relation to, for example, the Response to Loss model, is different from how it is seen as an important part of looking ahead/moving forward.
- It was agreed that the item should be re-worded to: 'ability to look ahead and start to move forward'.

QUESTION 8: which of these features about **Wellbeing** should be included in the Core Outcomes Set? (YOU HAVE 2 VOTES)

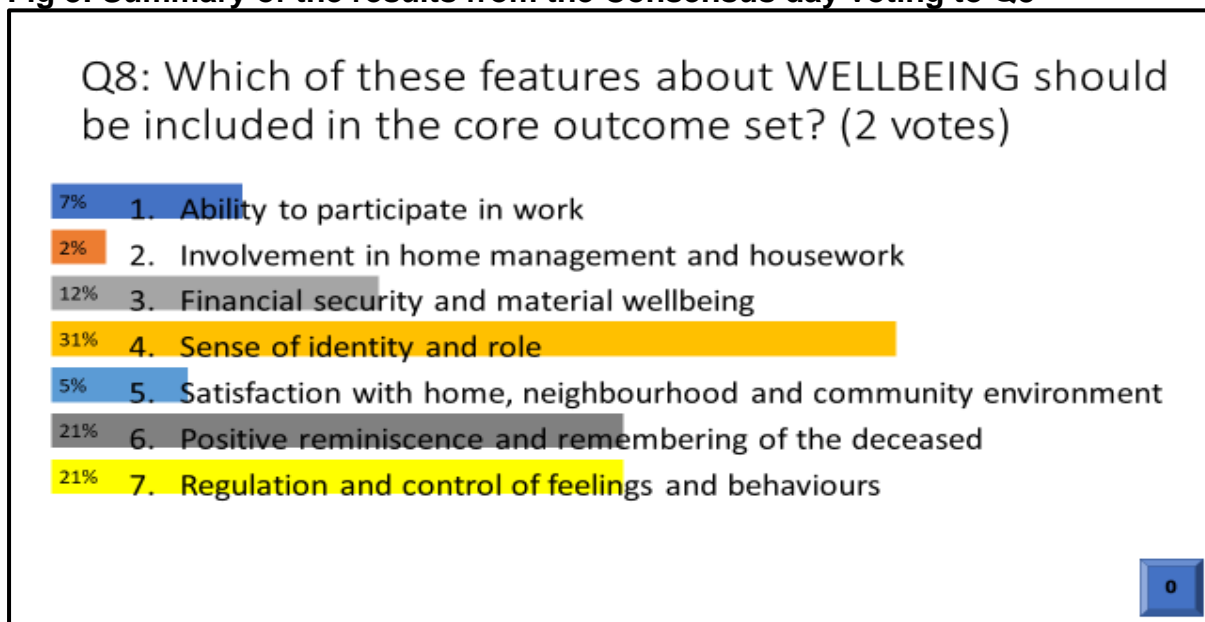**Fig 8: Summary of the results from the Consensus day voting to Q8**

Q8: Which of these features about WELLBEING should be included in the core outcome set? (2 votes)

7%   1. Ability to participate in work
2%   2. Involvement in home management and housework
12% 3. Financial security and material wellbeing
31% 4. Sense of identity and role
5%   5. Satisfaction with home, neighbourhood and community environment
21% 6. Positive reminiscence and remembering of the deceased
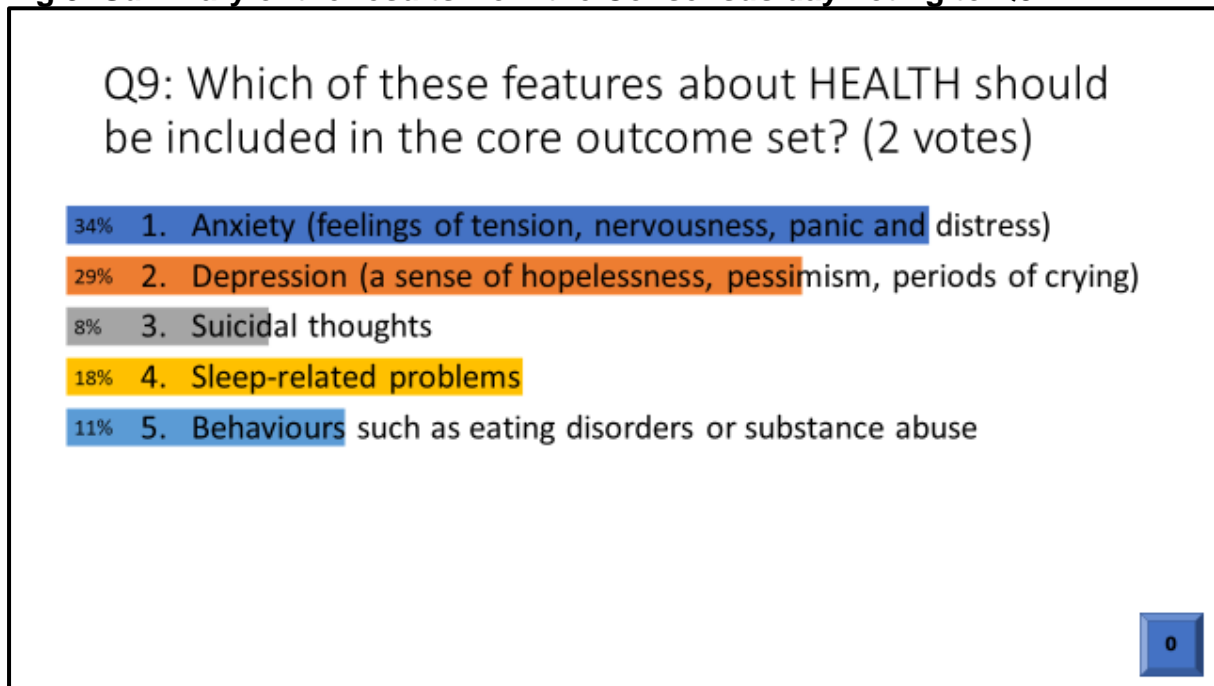21% 7. Regulation and control of feelings and behaviours

Discussion points;

- In Q8, the importance of financial security was raised, and how aspects of bereavement such as this are often neglected in favour of issues that relate solely to psychological wellbeing.
- It was also acknowledged that this was related to socio-economic status, and the potentially different needs of people from lower socio-economic groups.

Fig 9: Summary of the results from the Consensus day voting to Q9

Q9: Which of these features about HEALTH should be included in the core outcome set? (2 votes)

- 34% 1. Anxiety (feelings of tension, nervousness, panic and distress)
- 29% 2. Depression (a sense of hopelessness, pessimism, periods of crying)
- 8%   3. Suicidal thoughts
- 18% 4. Sleep-related problems
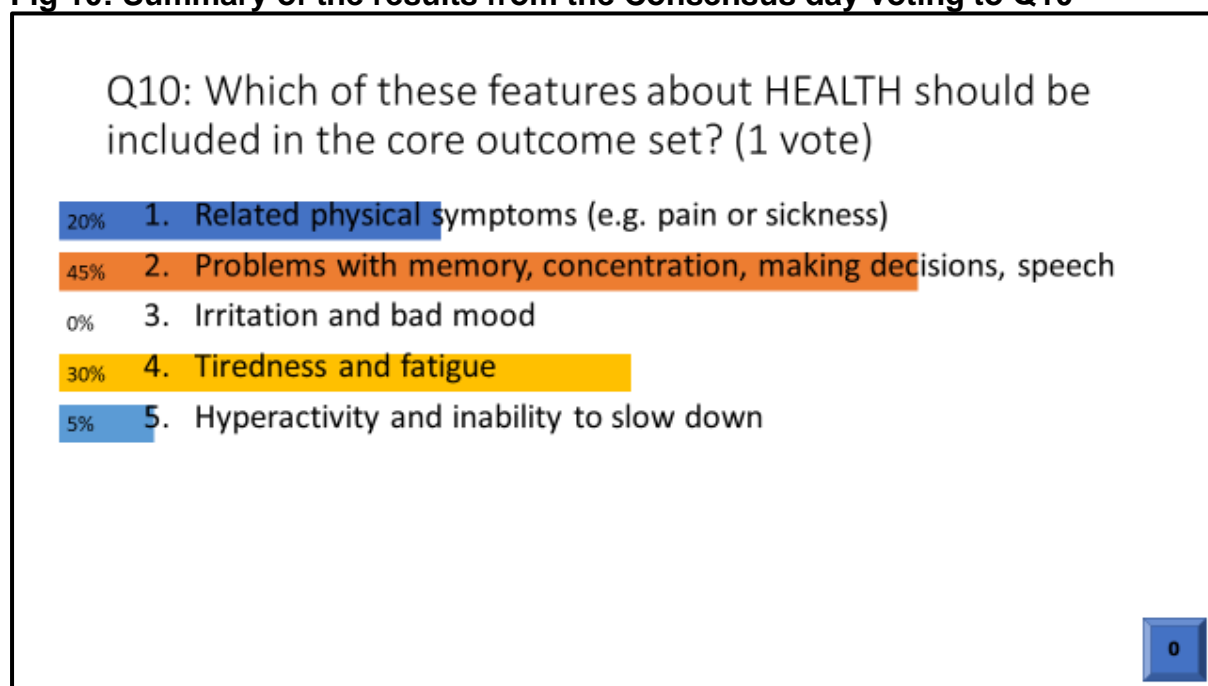- 11% 5. Behaviours such as eating disorders or substance abuse

Discussion points

It was clarified, during the discussion on Q9, that 'suicidal thoughts' was included as a separate item, and not combined with the item on depression, based on the evidence from the systematic review.

Fig 10: Summary of the results from the Consensus day voting to Q10

Q10: Which of these features about HEALTH should be included in the core outcome set? (1 vote)

20% 1. Related physical symptoms (e.g. pain or sickness)
45% 2. Problems with memory, concentration, making decisions, speech
0% 3. Irritation and bad mood
30% 4. Tiredness and fatigue
5% 5. Hyperactivity and inability to slow down

Discussion points

The items in Q10 produced less overall agreement based on the results of the Delphi. This may be because it is a complex area and it is difficult to clearly separate items from one another. For example, psychological wellbeing is often linked to physical symptoms.

Fig 11: Summary of the results from the Consensus day voting to Q11
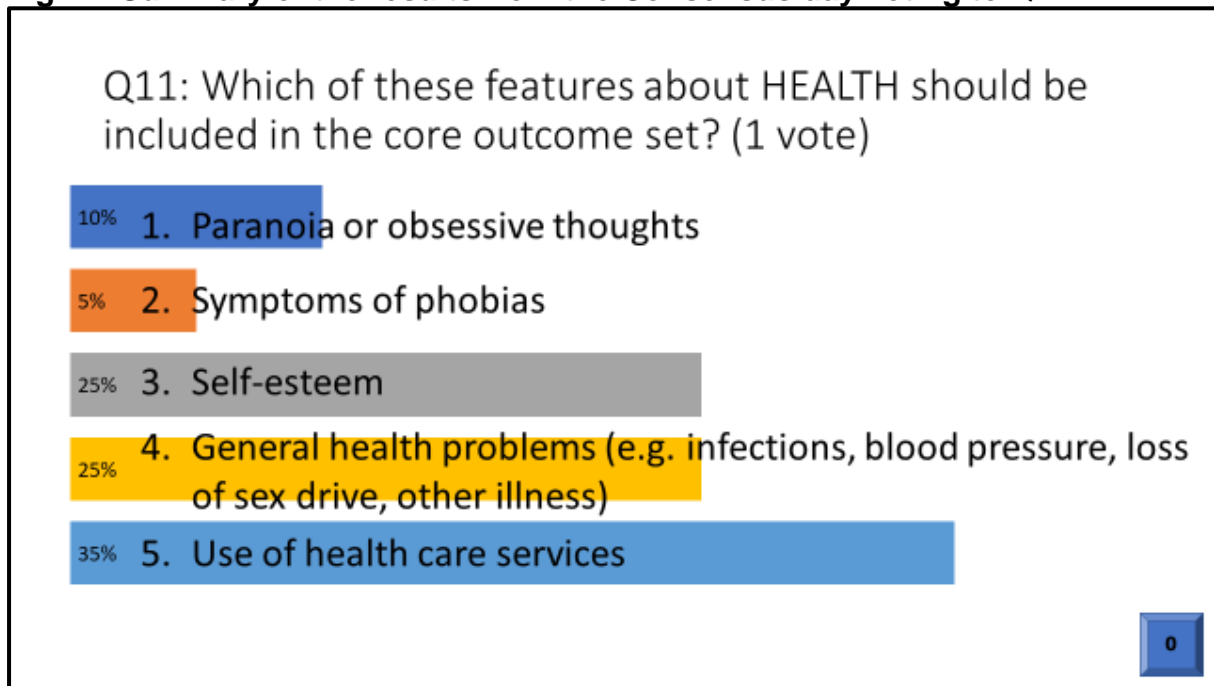
Discussion points;

The point was raised in Q11, that service providers will consider how this information is being used. They need to convince the commissioner that the burden on health care services will be reduced. Hence, they may well class 'use of health care services' as being an important item to measure, despite the fact that they may not consider it so when considering the core outcomes important in relation to a bereavement support service.

Fig 12: Summary of the results from the Consensus day voting to Q12

Discussion points

It was mentioned in Q12, that the item: 'accessing guidance if needed' had the potential to encompass all items in this cluster.

Fig 13: Summary of the results from the Consensus day voting to Q13

Q13: Which of these features about SUPPORT should be included in the core outcome set? (1 vote)

20% 1. Relationships with health and social care professional(s)

0% 2. Finding comfort, meaning or strength in religious or spiritual beliefs

80% 3. Feeling understood and connected with other bereaved people

0
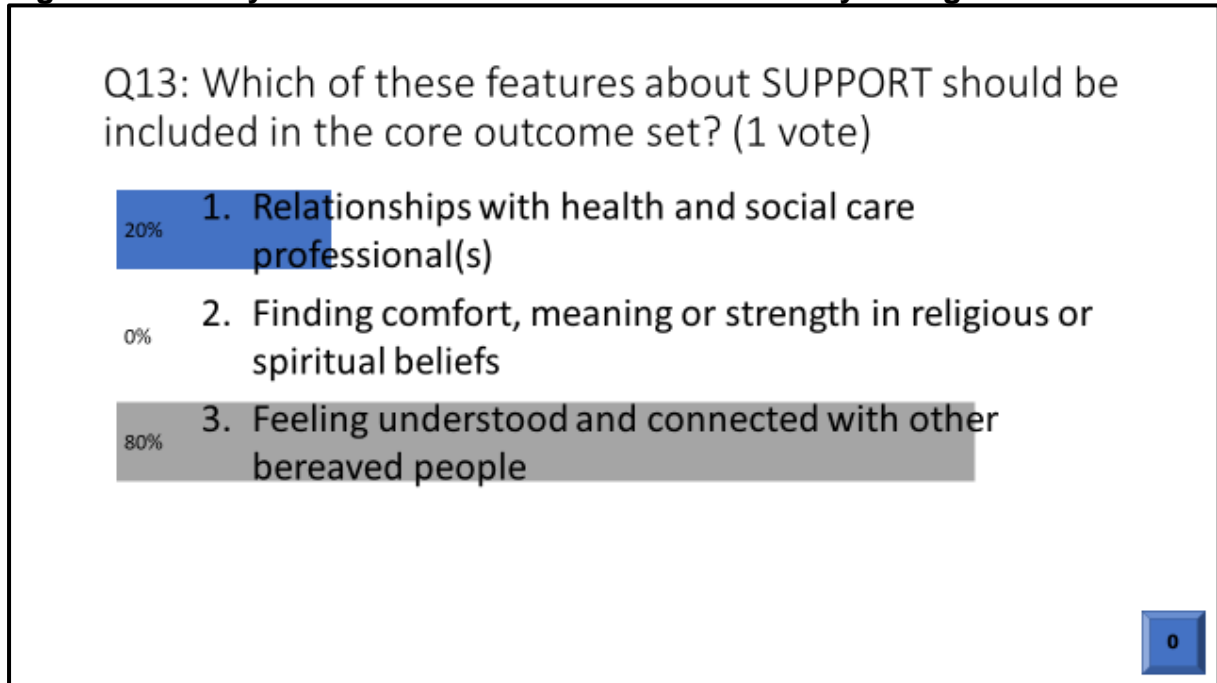
Discussion points;

The importance of the item: 'feeling understood by and connected with other bereaved people' relates back to social support and the impact of this on quality of life.

Appendix Two: Summary of discussion points from Second Consensus Day (13/04/2018)

Discussion points from consensus day afternoon session:

- It was clarified that the purpose of this session was to check that everything that people considered it important to include, was.
- It was mentioned that there was now nothing in the list of 'OUTCOMES' about physical health, and someone questioned whether this now fell under 'quality of life'.
- There was some discussion about this. It was suggested that, for most people, bereavement was an emotional experience, rather than a physical one. They may suffer physical effects, but these would not normally be long-lasting. There was also agreement about the notion that by addressing the psychological, this would help the physical effects to take care of themselves.
- There was uncertainty surrounding the 'locus of control' item, which related to the phrasing and meaning of this.
- The point was made that, when the audience was made up of members of the public, the wording needed to be as untechnical as possible. If you were to use the phrase 'ability to bounce back', for example, people would know what was meant by that. Whereas 'locus of control', 'resilience' etc. were terms not necessarily easily understood.
- Related to this, it was mentioned about the importance of the items also being clearly understood by researchers. 'Resilience', for example was one such phrase that would be easily understood by this group.
- In terms of the 'locus of control' item, however, the point was raised, that from a research perspective, it was potentially a problematic concept, due to reliability issues of measurement tools etc. It only came up once in the systematic review, and here again today. Yet it was questioned whether it was really necessary to include it when it meant different things to different people.
- A healthcare professional explained that she liked the definition 'sense of control over life'.
- Another delegate, in the nursing profession, clarified that to her, it meant that one was in control of one's own health and did not need to constantly visit the GP.
- From a research perspective, what it means had changed over the years. Some tools concentrated on self-efficacy. Things like that take into account external factors to do with control – not just your personal characteristics.
- It was agreed that a decision had to be made on whether to keep 'locus of control' (given that there were items that were ranked higher) and if it was kept, the wording around it needed to be changed.

- It was suggested that 'sense of control' could be used, but the counter point was made that this did not mean the same thing as 'locus of control', according to the literature.
- One delegate queried whether 'self-efficacy' was more appropriate and in line with 'sense of control'.
- There was then a discussion about the items 'ability to cope', 'social functioning' and 'social support'. One of the delegates observed that 'ability to cope' was more related to 'social functioning' than 'social support'. 'Social functioning' is concerned with how you interact with your environment, whereas 'social support' is concerned with who can help you.
- There was agreement for merging 'ability to cope' and 'social functioning' into one item.
- Mirella asked the group whether she could send them the revised lists and get their feedback on these, to which the group agreed. This would then allow us to explore which items could be merged.
- Discussion then turned to the different outcome dimensions. In terms of 'EMOTIONAL issues', several people voiced confusion over 'intensity of grief at time of death'. These issues centred on the fact that time of death might be a long time ago, and whether a bereavement service could realistically change this.
- However, the counter point was made that it still received a large number of votes.
- One of the delegates then speculated that it may be related to services offering pre-bereavement support.
- The 'WELLBEING issues' were then discussed. There was still confusion over 'locus of control' (which came up earlier as one of the outcomes) and 'ability to take control' (which was one of the wellbeing items).
- Someone suggested 'locus of control' may be to do with having a realistic perspective on what you can and can't control, and accepting the latter.
- Another delegate made the point that it wasn't helpful to have an item which had so many possible interpretations.

Appendix Three: Tables of overall results for Delphi Surveys

Results from the first Delphi Survey (Delphi One)

The tables below detail the percentage of respondent that rated the outcome or outcome dimension important or very important (as listed in the Delphi Survey). We have listed the results for the sample overall and for the service user subgroup.

Outcomes

	The all sample
Q3: Ability to cope	96
Q3: Mental health	92
Q3: Quality of life	91
Q3: Grief intensity/experiences	87
Q3: Social functioning and adjustment	85
q3: Resilience	85
Q3: State of depression	84
Q3: State of anxiety	83
Q3: Signs of complicated grief	82
Q3: Social support	81
Q3: Signs of post-traumatic stress	80
Q3: Mood	80
Q3: Locus of control	78
Q3: Physical health	75
Q3: Understandings of grief and bereavement	74
Q3: Identity and belief systems	65
Q3: Self-esteem	62

	Service users
Q3: Ability to cope	92
Q3: Mental health	91
Q3: Social functioning and adjustment	87
q3: Resilience	87
Q3: Quality of life	83
Q3: Grief intensity/experiences	81
Q3: Mood	81
Q3: State of depression	81
Q3: State of anxiety	79
Q3: Signs of post-traumatic stress	79
Q3: Signs of complicated grief	78
Q3: Social support	75
Q3: Locus of control	73

Q3: Understandings of grief and bereavement	71
Q3: Physical health	70
Q3: Self-esteem	68
Q3: Identity and belief systems	67

Outcome Dimensions

	The all sample (%)
Q7: Relationships with friends and	95
Q6: Depression (a sense of hopelessness, pessimism, periods of crying)	92
Q4: Feelings of loneliness and emptiness	90
Q5: Ability to perform daily tasks	89
Q4: Ability to function as part of a family	88
Q6: Anxiety (feelings of tension, nervousness, panic and distress)	88
Q5: Ability to participate in social or other activities	87
Q5: Ability to take control (e.g. look ahead and start to move forward with life)	87
Q6: Suicidal thoughts	87
Q7: Accessing emotional support if needed	87
Q4: Feelings of blame, guilt, anger, bitterness, regret	85
Q5: Sense of meaning and purpose in life	85
Q7: Ability to express feelings openly and honestly	85
Q4: Overwhelming thoughts and/or nightmares about loss	84
Q5: Understanding and finding meaning of loss	83
Q5: Acceptance of grief experiences as normal	82
Q5: Acceptance of loss	82
Q5: Optimism and hopefulness	81
Q5: Ability to find balance and channel grief	81
Q7: Accessing practical support if needed	81
Q4: Preoccupation with thoughts of the deceased person	80
Q5: Ability to participate in work	78
Q6: Sleep-related problems	78
Q7: Accessing guidance if needed	78
Q4: Feelings of detachment and distancing	77
Q5: Positive reminiscence and remembering of the deceased	76
Q4: Avoidance and denial of distress, grief or other problems	74
Q5: Sense of identity and role	74

Q6: Behaviours such as eating disorders or substance abuse	74
Q5: Regulation and control of feelings and behaviours	73
Q6: Self-esteem	72
Q4: Intensity of grief experienced around time of death	71
Q5: Financial security and material wellbeing	71
Q7: Accessing financial/material support if needed	71
Q6: Related physical symptoms (e.g. pain or sickness)	70
Q6: Problems with memory, concentration, making decisions, speech	70
Q6: Irritation and bad mood	70
Q6: Tiredness and fatigue	70
Q6: Use of health care services	65
Q4: Feelings of shame and/or stigma	64
Q6: Paranoia or obsessive thoughts	64
Q4: Avoidance of reminders of the deceased person	63
Q5: Involvement in home management and housework	62
Q6: General health problems (e.g. infections, blood pressure, loss of sex drive, other illness)	62
Q6: Hyperactivity and inability to slow down	61
Q4: Hallucinations about the deceased person	59
Q7: Relationships with health and social care professional(s)	59
Q7: Feeling understood by and connected with other bereaved people	59
Q7: Finding comfort, meaning or strength in religious or spiritual beliefs	58
Q6: Symptoms of phobias	50
Q5: Satisfaction with home, neighbourhood and community environment	45

	Service users
Q4: Feelings of loneliness and emptiness	91
Q5: Ability to perform daily tasks	91
Q7: Relationships with friends and	91
Q5: Positive reminiscence and remembering of the deceased	87
Q6: Depression (a sense of hopelessness, pessimism, periods of crying)	87
Q4: Feelings of blame, guilt, anger, bitterness, regret	86

Q5: Ability to participate in social or other activities	84
Q6: Anxiety (feelings of tension, nervousness, panic and distress)	84
Q4: Ability to function as part of a family	83
Q5: Ability to find balance and channel grief	83
Q7: Ability to express feelings openly and honestly	83
Q5: Ability to participate in work	81
Q5: Sense of meaning and purpose in life	81
Q5: Acceptance of grief experiences as normal	81
Q7: Accessing emotional support if needed	81
Q4: Overwhelming thoughts and/or nightmares about loss	79
Q5: Acceptance of loss	79
Q5: Ability to take control (e.g. look ahead and start to move forward with life)	79
Q6: Suicidal thoughts	79
Q4: Feelings of detachment and distancing	78
Q6: Sleep-related problems	78
Q7: Accessing guidance if needed	78
Q4: Preoccupation with thoughts of the deceased person	76
Q4: Avoidance and denial of distress, grief or other problems	76
Q5: Optimism and hopefulness	76
Q5: Understanding and finding meaning of loss	76
Q6: Behaviours such as eating disorders or substance abuse	76
Q6: Self-esteem	76
Q5: Sense of identity and role	75
Q6: Problems with memory, concentration, making decisions, speech	75
Q7: Accessing practical support if needed	75
Q5: Regulation and control of feelings and behaviours	73
Q6: Related physical symptoms (e.g. pain or sickness)	73
Q4: Intensity of grief experienced around time of death	71
Q6: Paranoia or obsessive thoughts	70
Q5: Financial security and material wellbeing	68
Q7: Feeling understood by and connected with other bereaved people	68
Q6: Tiredness and fatigue	67
Q7: Accessing financial/material support if needed	67
Q6: Irritation and bad mood	65
Q4: Feelings of shame and/or stigma	64
Q5: Involvement in home management and housework	64
Q6: Use of health care services	64
Q6: General health problems (e.g. infections, blood pressure, loss of sex drive, other illness)	62

Q4: Hallucinations about the deceased person	60
Q6: Hyperactivity and inability to slow down	60
Q4: Avoidance of reminders of the deceased person	59
Q7: Relationships with health and social care professional(s)	59
Q6: Symptoms of phobias	54
Q5: Satisfaction with home, neighbourhood and community environment	52
Q7: Finding comfort, meaning or strength in religious or spiritual beliefs	49

Results from the second Delphi Survey (Delphi Two)

The tables below detail the percentage of respondents that rated the outcome or outcome dimension important or very important (as listed in the Delphi Survey). We have listed the results for the sample overall and for the service user subgroup.

Outcomes

	The all sample (%)	Service Users (%)
Identity and belief systems	62	60
Self-esteem	62	73

Outcome Dimensions

	The all sample (%)
Q7: Accessing financial/material support if needed	79
Q6: Tiredness and fatigue	79
Q5: Financial security and material wellbeing	75
Q6: Use of health care services	72
Q6: General health problems (e.g. infections, blood pressure, loss of sex drive, other illness)	72
Q7: Feeling understood by and connected with other bereaved people	70
Q6: Paranoia or obsessive thoughts	69
Q4: Feelings of shame and/or stigma	67
Q6: Hyperactivity and inability to slow down	66
Q4: Avoidance of reminders of the deceased person	54
Q7: Relationships with health and social care professional(s)	53
Q5: Involvement in home management and housework	52
Q4: Hallucinations about the deceased person	48
Q7: Finding comfort, meaning or strength in religious or spiritual beliefs	47

Q5: Satisfaction with home, neighbourhood and community environment	43
Q6: Symptoms of phobias	38
Q6: Irritation and bad mood	22

	Service User only sample (%)
Q6: Tiredness and fatigue	87
Q7: Feeling understood by and connected with other bereaved people	83
Q7: Accessing financial/material support if needed	80
Q6: General health problems (e.g. infections, blood pressure, loss of sex drive, other illness)	80
Q6: Paranoia or obsessive thoughts	77
Q5: Financial security and material wellbeing	73
Q6: Use of health care services	73
Q6: Hyperactivity and inability to slow down	73
Q5: Involvement in home management and housework	67
Q4: Feelings of shame and/or stigma	63
Q7: Relationships with health and social care professional(s)	63
Q5: Satisfaction with home, neighbourhood and community environment	63
Q4: Avoidance of reminders of the deceased person	57
Q6: Symptoms of phobias	50
Q4: Hallucinations about the deceased person	47
Q7: Finding comfort, meaning or strength in religious or spiritual beliefs	43
Q6: Irritation and bad mood	37