

**Consultation
Response
Form**

Your name:

Desmond Kitto

Organisation (if applicable):

**Board and Community Health
Councils in Wales**

email / telephone number:

02920 235558

Your address:

**Board of Community Health Councils
in Wales**

33 – 35 Cathedral Road

Cardiff

CF11 9HB

1: Is it clear who this bereavement framework is for and why it has been developed?

Yes

If the answer is no please tell us below what can we do to achieve this?

Community Health Council (CHCs) who considered the document agreed that the Ministerial Foreword was clear and focused well on the aims and objectives framework.

CHCs agree that they understand why the framework has been developed.

Although the framework indicates the fact that every person's reaction to bereavement is unique, the scope provides an indication of who would be the principal group to take on a particular part of an overall bereavement service – e.g. mental health – primary care, loneliness – social care etc.

CHCs felt that to ensure a greater understanding by those needing/assessing bereavement services there should be an easy to read version available.

2. How can the provision of and access to bereavement services for people with protected characteristics (section 4) be improved?

Please provide your suggestions below

CHCs have identified a range of suggestions. These include:

- A standardised training programme for all commissioned services, that are measurable, that:
 - recognise cultural differences
 - are knowledgeable about death customs

- consider religious and ethnic knowledge and understanding
 - recognise diverse membership of service deliverers
 - provide multiple language documentation
 - identify methods of attracting local protected characteristic members
 - provide a broader exposure to bereavement services
- People with protected characteristics should be included in the preparation of the literature and promotion of the bereavement services available.
 - Barriers as to why people from protected characteristic groups are not currently accessing bereavement services should be identified and removed.
 - Continuous engagement should be undertaken with people from protected characteristic groups (or their representatives) within communities. This will ensure that they are aware of how to recognise symptoms of bereavement and how to access specialised bereavement support:
 - through review of process/procedures and gathering information from those affected
 - continual engagement with communities to understand their needs, beliefs and requirements.

The above suggestions should be part of any regular review of the overall service provided.

- Represents of **all** nine characteristics, as defined by the Equality Act (2010), should be present on the steering group.

3: Are there any other models / programmes of support (Section 6) which should be referenced in the Framework?

Is the framework clear in outlining responsibilities across all areas of health and social care for considering support needs and addressing gaps in bereavement provision?

No

Please provide details below:

- The framework is not clear in outlining **ALL** responsibilities across all areas of health and social care Section 1.2 only briefly documents commissioner responsibility:
 - it does not appear to explain how commissioners will be assessed on ensuring those in need of bereavement services are able to access the right service for them, in the right format, at the time they may need it.
 - it refers to the fact that commissioners 'should' ensure anyone experiencing a bereavement is provided with relevant information:
 - how will this be audited to ensure equity in services and professional standards are being delivered across Wales?
 - who are they responsible to?
- It was felt that further information is required on the following:
 - how is it ensured/monitored that 'The Three Component Models'/programmes of support translate into an equitable knowledge of, provision for and delivery of bereavement services?
 - where is the assessment of need?
 - how do carers and those at end of life, the grieving and bereaved, become informed of services

- there should be an extension of Registrar's role
 - there is also a need for an extension of the funeral directors' role
 - there is a need a "whole system approach" as discussed in 'A Healthier Wales'
 - there needs to be improvement of the Pyramid System: it presently lacks clarity, does not address the 'need' for support, and implies the potential for long delays
 - there is need to explain how commissioners/providers will ensure standards of service delivery, training, qualifications etc.
- The membership of the National Bereavement Steering Group includes CRUSE, SANDS etc. and annex 3 already lists existing and recognised bereavement models. It is not known if any other models/programs of support should be referenced in the Framework.

4: Does the Learning from Covid-19 section (Section 9) sufficiently cover the lessons learned during the pandemic, and the action that needs to be taken to make sure that high quality bereavement care and support is available to everyone who needs it in Wales?

No

If no, please tell us below how this could be made clearer and what else should be included.

The 'learning from Covid-19' section does briefly acknowledge that people may have experienced difficulties accessing support for reasons such as long waiting lists, etc.

The core elements of what has already been experienced and studied to date have been detailed in this section but both

lessons and actions may need to shift considerably following further studies/investigations and potentially after experiencing possible further Covid-19 related restrictions/outcomes.

It is known that in some areas there were already waiting lists to access bereavement services, prior to the pandemic. It may be worth considering therefore how this will be assessed, monitored and improved going forward. All those affected by bereavement should have access to timely, person-centered bereavement care to avoid causing additional distress.

Therefore, it is felt that there needs to be clearer guidance provided on bereavement support around aspects of the ongoing Covid-19 pandemic, particularly in relation to all four harms. There is also concern about health/social care services being aware of individuals' grief and bereavement status.

It is recognised that the pandemic has caused additional loneliness and isolation. Whilst recognising the reduction in face-to-face events, surely an affected user should have this option available to them, even if it does involve strict PPE requirements. The user should have the CHOICE.

It is not yet known what the full affect that Covid-19 will have on the wider community, but by listening and learning from what has been said, and ensuring services are accessible to everyone regardless of postcode or need, a positive step can be taken.

5: How can the provision of and access to bereavement services for Black, Asian and Minority Ethnic Communities be improved? (Section 10).

Please provide your suggestions below:

See also answers provided to question 2

This is an ongoing issue for all health and social care services and there needs to be absolute recognition that grief and bereavement affects everyone differently.

The framework suggests that tailored bereavement and mental health services are often needed to support people from Black, Asian and Minority Ethnic Communities. There should therefore be a co-productive and continuous process with people from Black, Asian and Minority Ethnic Communities in bereavement service design.

Other suggestions include:

- targeted action is needed to encourage a diverse workforce delivering bereavement services
- this should include a rigorous standardised training programme
- appropriate funding is needed
- there must be clear outcome measurement in place
- there is a need for further research into sensitivity into the importance of race, culture, beliefs, values, attitudes, religion and language, to improve benefits amongst culturally diverse groups

Regular engagement with appropriate representative groups and/or individuals appears to be the main way forward to ensure that the framework creates a service that is available to all.

6. Do you consider that the section on Training, Learning and Supervision for individuals providing bereavement support and for professionals who come into contact with people who are bereaved (Section 11) can be strengthened to address bereavement workforce, education and recruitment issues?

No

Please provide details below:

Recognising that each bereavement is unique, suggests that **FLEXIBILITY** is the keyword for training, learning and supervision. Therefore there must be a heavy reliance placed on quality training and evaluation against training standards to improve bereavement services.

Ideally, any user of bereavement services would have a dedicated 'support officer/key worker' throughout their pathway. This should not exclude the use of 'multi-agency' working/support

CHCs suggest that:

- commissioning bodies need to take responsibility for evaluation of their commissioning process and evaluate it effectively
- specialist areas of bereavement need specialist trained personnel
- quality-evaluated supervision support is required for the bereavement workforce. This should, where possible, include users in evaluation of bereavement services.

7: Does the section on referral pathways (section 12) provide sufficient information about the route people can take to access bereavement support?

No

If the answer is no, please provide details of how this can be achieved.

CHCs suggest that further information on the route people can take to access bereavement support in section 12 would be helpful.

- Firstly, it would be unrealistic to expect that those bereaved to be familiar with the 'NICE Three Component Model', which will possibly be clear only to professionals.
- There appears to be a lack of clarity regarding onward referrals and how will the service user be involved in discussion on these, this includes
 - how referral pathways will be accomplished?
 - how entry referrals will be made into the bereavement framework?
 - the effect of onward referrals in relation to time frames and/or potential delays
 - can people who are bereaved directly access services themselves, or do they need to be referred via the commissioner of the services?

This is all dependent on adequate publicity and timely support. There has been a culture of "signposting" and not "doing" historically. This can be unhelpful and ineffective. Overall, it was not clearly spelt out.

8: Are there other forms of self-management/self-care (section 13) that should be referenced in the framework?

Yes

If the answer is yes, please provide details of the approaches below:

The forms of self-management/self-care provided appear to be a reasonable baseline, but updates or amendments should be part of the regular review of the service.

CHCs agree that an element of self-management is central in assisting in the planning, design, and delivery of bereavement services. It was also felt that fully represented user involvement in the design of appropriate self-management materials is essential. The provision of further evidence on self-management care would have been helpful in clarifying its value and outcome.

CHCs agreed that a family/friend network could be useful in supporting bereaved people, especially post-Covid-19. The provision of guidance material could be considered. An online service for those able to connect could also be of help, particularly in relation to coping strategies.

9. Do the Bereavement Standards (Annex 1) set out what areas need to be addressed in order for bereavement support services to be both safe and effective in meeting the needs of bereaved people? Is it clear who is responsible for delivering these standards?

In general - Yes

If no, please provide details of how this can be achieved.

See answers provided to Question 3 above.

The visual clarity of the pyramid was commended and CHCs welcomed the inclusion of core standards in the framework. It was recognised that there is /will need to be a heavy reliance on quality skilled assessments of need. As indicated earlier, it was felt that evaluation of the service is essential and commissioners of bereavement services need to ensure that all 3 components of Nice guidance are geographically equitable.

However, it is not clear in the document how the public will be made aware of services? There is an absence of evidence regarding what support may be given to whom and from whom.

In the current system of bereavement support there is a heavy reliance on third sector delivery of bereavement services, some clarity of the continuance or cessation of this would be helpful.

Again, as indicated earlier, more information on the supervision and monitoring element of the service would be welcomed. This should include regular timeframe reporting and possible waiting times that may have been experienced by the bereaved person/created impact upon the provision of service.

Monitoring of the Framework:

It was suggested that there needs to be consideration of setting up a peer review system. The Framework could also be monitored in line with existing processes or by a separate external body.

Clarity needs to be provided on:

- who decides what is appropriate in section 1.1 which indicates - 'Commissioners should ensure 'appropriate standards of care and support can be provided'.
- is it for commissioners to decide what they feel is an appropriate standard of care?
- how will this be monitored and by who?

10. We are interested in your views on how the Welsh Government can ensure that the bereavement framework/standards are appropriately monitored and evaluated? Is it clear how the implementation of the framework will be monitored to see if it will have a practical effect on the provision of bereavement care in Wales?

Please provide your suggestions below:

CHCs agreed that:

- Recruitment of Welsh language speakers for bereavement support where necessary is essential
- Monitoring should, have to be subjective and not concentrate on 'bean counting'
- Any 'Performance Indicators' should be kept to a minimum
- More weight should be given to the views of service users. They have to feel satisfied with the services and support they receive

- commissioners of the service should report their evaluations of service users feedback to their Boards and Welsh Government
- service users have access to managers of these services in order that they can feel they can provide honest feedback.
- more clarity is needed on who will monitor service provision, or who will ensure that any learning from evaluation will be implemented to ensure continuous improvement of the services available
- there are routes available to share learning across networks and providers

11. We would like to know your views on the effects that the Draft National Framework for the Delivery of Bereavement Care in Wales would have on the Welsh language, specifically on opportunities for people to use Welsh and on treating the Welsh language no less favourably than English.

What effects do you think there would be? How positive effects could be increased, or negative effects be mitigated?

- The Draft National Framework does not change the statutory requirement as stated in the Welsh Language Standards. These require that all services provided must ensure that the Welsh Language is not be treated less favourably than the English language.
- Neither does it include any indication of changes to workforce planning to ensure sufficient Welsh speaking capacity to meet needs and provide an environment that encourages people to use Welsh.

12: Please also explain how you believe the proposed policy Draft National Framework for the Delivery of Bereavement Care in Wales could be formulated or changed so as to have positive effects or increased positive effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language, and no adverse effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language.

See above

13: We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, including on any missing actions/next steps that you think the National Bereavement Steering Group should take please use this space to report them:

No further comment