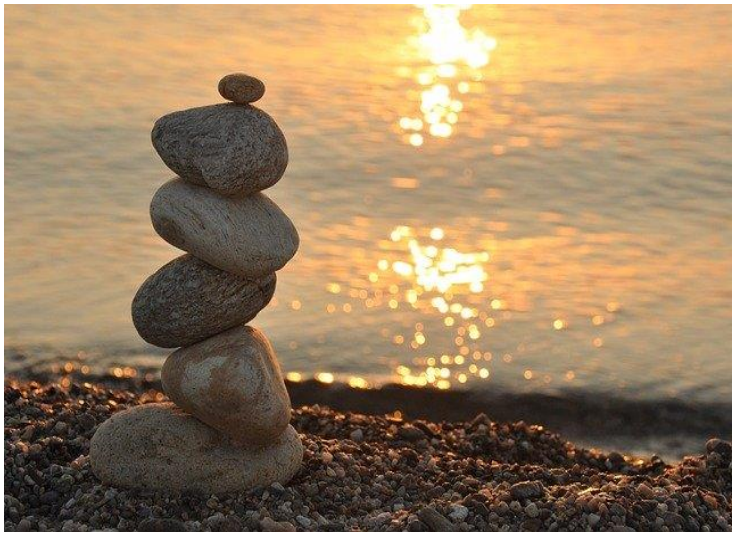

A Scoping Survey of Bereavement Services in Wales

END OF STUDY REPORT

December 2019

Writing team

Dr. Cynthia Ochieng
Research Associate
Marie Curie Palliative Care Research Centre
Cardiff University School of Medicine
8th Floor, Neuadd Meirionnydd
Heath Park, Cardiff CF14 4YS
Email: OchiengC@cardiff.ac.uk
Tel: 02920687211

Mrs. Alison Evans
Project Officer
Marie Curie Palliative Care Research Centre
Cardiff University School of Medicine
8th Floor, Neuadd Meirionnydd
Heath Park, Cardiff CF14 4YS
evansa73@cardiff.ac.uk

Dr. Emily Harrop
Research associate
Marie Curie Palliative Care Research Centre
Cardiff University School of Medicine
8th Floor, Neuadd Meirionnydd
Heath Park, Cardiff CF14 4YS
Email: HarropE@cardiff.ac.uk

Ms. Alisha Newman
Research Associate
Marie Curie Palliative Care Research Centre
Cardiff University School of Medicine
8th Floor, Neuadd Meirionnydd
Heath Park, Cardiff CF14 4YS
NewmanA3@cardiff.ac.uk

Dr Kathy Seddon FRSA FLS CF
Patient and Public Involvement representative
Marie Curie, Research Expert Voice
Wales Cancer Research Centre RP
eLearning Specialist

Prof. Anthony Byrne
Clinical Director
Marie Curie Palliative Care Research Centre
Cardiff University School of Medicine
8th Floor, Neuadd Meirionnydd
Heath Park, Cardiff CF14 4YS
E mail: anthony.byrne2@wales.nhs.uk

Prof. Annmarie Nelson
Scientific Director Marie Curie
Palliative Care Research Centre
Cardiff University School of Medicine
8th Floor, Neuadd Meirionnydd
Heath Park, Cardiff CF14 4YS
Tel: 029 2068 7473

Coordinating Centre

Marie Curie Palliative Care Research Centre
Cardiff University School of Medicine
8th Floor, Neuadd Meirionnydd
Heath Park, Cardiff CF14 4YS

Tel: 02920687175
Fax: 029 2068 7501
Email: mariecuriecentre@cardiff.ac.uk
Website: http://www.mariecurie.org.uk/en-GB/research/research-facilities/palliative-care-research-centre-cardiff-wales/

This report presents the results of a bereavement service scoping exercise in Wales commissioned by the End of Life Care Board and conducted in 2019.

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EXECUTIVE SUMMARY

Support following the loss of a loved one can reduce the emotional, physical and mental impact of grief. It is widely acknowledged that bereavement care services should be accessible to those in need of support. Three components of bereavement support have been described by the National Institute for Health and Clinical Excellence (NICE) encompassing:

- Component 1: where information is offered regarding the experience of bereavement and people are sign-posted towards further support
- Component 2: which makes provision for people to access formal opportunities to reflect upon their grief, and may involve individual or group sessions
- Component 3: which encompasses specialist interventions that may involve mental health services, psychological support and specialist counselling

It is argued that adequate bereavement care requires a balance in access to all three NICE Components. Part of providing that access involves having a comprehensive knowledge of the services available within local areas, which may differ in focus and funding streams. In 2018 the End of Life Care Board (EOLB) in Wales commissioned a scoping review that aimed to gather this knowledge by conducting a survey of structured bereavement providers across Wales. The survey content was developed through a combination of literature review of other bereavement scoping studies and relevant surveys as well as consultation with bereavement care experts, healthcare professionals and academics with an interest in bereavement care. The quantitative data presented in this report was analysed using descriptive statistics, and the free text data was analysed using a thematic approach.

We received 256 individual responses to the survey comprising of: Charity/Not for profit (n=64), Councils (n=13), Private Practitioners (n=2), Schools (n=1), Criminal Justice/Prisons (n=8), GP Practices (n=90), Hospices (n=13), NHS including Hospitals (n=58) and others (n=7). Of the respondents, 74 identified themselves as directly providing bereavement care, whilst the other respondents either refer to these services or care for those likely to be affected by bereavement.

The results of the survey identified that more bereavement services were available in the South East of Wales, with the least number being available in the North and West of Wales. The findings also showed that across Wales, there were more bereavement services available to support bereavement following adult deaths, compared to bereavement following the loss of children, infants and in pregnancy, with no or extremely low levels of support relating to pregnancy loss and stillbirth in some areas. When considered according to the NICE components of bereavement support, there was a mix

of all three available across all areas of Wales. The highest number of bereavement services across Wales were for NICE Component 1, followed by Component 2 support and the least numbers of bereavement support were for specialist Component 3 support. Of the survey respondents, registered charities were reported to fund the highest number of bereavement services (nearly half of all bereavement services). Approximately half of the bereavement services reported that they were externally assessed, and health boards were identified as assessing the highest number of bereavement services.

Respondents described a number of gaps and challenges in bereavement service provision. They resonate with those found in other recent UK and European surveys. Many appeared to relate to the lack of a clear framework for the commissioning and delivery of bereavement services and included non-prioritisation of bereavement care within organisations, lack of access to funding and restricted access to training and appropriate facilities. They also described specific challenges in relation to the accessibility of services such as access to specialist support, waiting lists and inability to meet demand, restrictive eligibility criteria, unclear referral pathways and the challenges of rurality and geographical access.

A key consideration from the results therefore is the development of a national framework for bereavement care. This in turn could facilitate increased prioritisation of bereavement support at organisational and regional level and equity and access to appropriate types and levels of support across Wales. The establishment of clear referral pathways and approaches to needs assessment, as well as the development and maintenance of a directory of available bereavement support would create a more seamless and sustainable service model. Improved access to training for staff and volunteers and improvements in how services are evaluated and assessed will be important to the ongoing development of a sustainable and motivated workforce and the effective and efficient delivery of bereavement support in Wales.

ABBREVIATIONS AND GLOSSARY

CI	Chief Investigator
MCPCRC	Marie Curie Palliative Care Research Centre
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
GP	General Practitioner
PPI	Patient and Public involvement
EOLB	End of Life Care Board in Wales
SANDS	Stillbirth and Neonatal Death Society
SOMREC	School of Medicine Research Ethics Committee for Cardiff University
ABUHB	Aneurin Bevan University Health Board
CTUHB	Cwm Taf Morgannwg University Health Board
CVUHB	Cardiff and Vale University Health Board
HDUHB	Hywel Dda University Health Board
PTHB	Powys Teaching Health Board
BCUHB	Betsi Cadwaladr University Health Board
SBUHB	Swansea Bay University Health Board
UHB	University Health Board

INTRODUCTION

1.1 BACKGROUND AND RATIONALE

Bereavement care involves the provision of services to help an individual cope practically and emotionally following the loss of a loved one [1]. Bereavement is associated with elevated risks to mental health, morbidity and mortality and as such services that provide bereavement support can be vital in managing these risks [2]. In Wales, the End of Life Care Board (EOLB) acknowledges that good care at the end of life ought to include bereavement support for both adults and children to facilitate a healthy grieving process [3, 4]. It has been identified as a priority area strategically and the Board is also supporting projects promoting awareness and online resources aimed at facilitating societal discussions on death and bereavement.

NICE has detailed three components of bereavement support [5]. Component 1 involves signposting towards support and providing information on grieving. Component 2 encompasses opportunities for reflection and talking about grief, while Component 3 incorporates specialist interventions including mental health services, psychological support and specialist bereavement counselling. These closely map to the three-tiered Public Health model, which advocates for universal, selective and indicated levels of provision, depending on the needs of the bereaved person [6]. In both models it is argued that adequate bereavement care requires a balance in access to all three components, with access to specialist support targeted at those assessed as having high level risk of prolonged grief disorder [5, 6]. It is estimated that 10 to 20% of bereaved people experience such difficulties, and would benefit from specialist professional intervention [6, 7, 8]. Variations in these proportions by type of bereavement are also observed, with unexpected or 'resisted' loss of a child or younger spouse considered more likely to lead to prolonged grief disorder than other types of losses [7].

Considerable work has been done to standardize and improve the quality of bereavement care provided in the UK and internationally, with the development and publication of the Bereavement Care Service Standards [9], Guidelines for Good Practice in Child Bereavement Services [10] and recently, the Bereavement Support Standards and Bereavement Care Pathway for quality palliative care [11]. However, the extent to which these standards are applied by providers in Wales is unknown. Many community bereavement services are provided by the voluntary sector. It has been noted that lack of coordination between different statutory and voluntary bereavement support providers can result in difficulty knowing the services available, who provides support, at what stage and how referral is conducted [1]. A survey of European palliative care providers also identified issues relating

to the non-prioritisation of bereavement support as a core part of care, inadequate training of staff, limited formal risk assessment practices and adherence to formal policies or guidelines [12].

One of the priorities of the EOLB 2017-2020 is for health boards to review the settings and capacities of their bereavement services with an aim that the needs of the bereaved are met [3]. A challenge identified by health boards is the facilitation of a healthy grieving process through responsive and effective bereavement services. This has led to the Welsh Government promoting bereavement support in acute hospitals as well as funding studies such as this one [13]. It is also argued that due to the varied nature of bereavement support, further knowledge is required to inform service planning and delivery [14]. This scoping review aimed to collate this information thereby improving knowledge of bereavement services in Wales.

1.2 AIM AND OBJECTIVES

This study aimed to identify and gather information on bereavement services available in Wales. The specific questions for the review were:

- Are there regional variations in bereavement support across Wales?
- Which groups of bereaved people are supported by these bereavement services?
- Which of the NICE Components of bereavement support are provided by these services?
- How are bereavement services assessed and what performance indicators are used?
- What are the gaps and challenges in bereavement support provision in Wales?

2 METHODS

2.1 SURVEY DEVELOPMENT

At the start of the project meetings were held with the funder, a Welsh Government representative and the study team in order to agree on the main review question and scope of the study. A literature review was conducted including similar scoping and evaluation studies that had been conducted in the UK and Europe. Based on discussions with the funder, academics with an interest in bereavement and the findings of the literature review, a logic model was designed to outline the scoping review. The protocol for the scoping exercise was written based on the agreed parameters resulting from these discussions.

Several themes were identified in the literature review that were of relevance to this scoping exercise. Previous questionnaires that had been used in similar studies on bereavement [15, 16] also suggested key domains for inclusion in the survey. A draft survey was then developed in line with the aims of the scoping exercise, with further revisions made following review by colleagues and discussion with the study team, the Welsh Government and the EOLB. The questions in the survey sought information on the domains of: service description and location, service user description, management, assessment and funding, and perceived gaps and challenges in service provision. The survey included categorical responses using Likert scales, and free text boxes to gain further detail and perceptions.

The survey was reviewed by a number of key stakeholders within the field of bereavement support. The electronic version of the survey was tested among colleagues at Cardiff University and a member of the Patient and Public Involvement panel (PPI) prior to being finalised and sent to the funder for final approval. A copy of the survey is attached as Appendix 3 at the end of this report.

2.2 ETHICAL APPROVAL

Following advice from Cardiff University School of Medicine Research Ethics Committee (SoMREC), permission was granted to conduct the survey as a scoping exercise of bereavement care without the need for University ethical approval. That notwithstanding, the scoping exercise was designed and conducted under strict ethical principles and the tenets of good research practice. Through project documentation all participants were informed of the aims of the study, the processes involved and any risks of participation as well as being informed of the usage and strict confidentiality that would be applied to managing their data.

2.3 SAMPLE SELECTION

The scoping survey was targeted at services identified as providing structured bereavement support in Wales. While it is appreciated that unstructured support following bereavement, such as social gatherings, are valuable in providing Component 1 of NICE bereavement support, identifying all such endeavours was anticipated to be unattainable within this study. Services that provide health and social care to bereaved populations, including GP practices, local authorities, peri-natal services and paediatric and adult palliative care services were also targeted in the survey.

A database of bereavement service providers was collated from detailed online and database searches. Resources used included: Dewis Cymru, the Childhood Bereavement Network and NHS Direct Wales. These searches yielded 60 bereavement services in the third sector, government funded and privately owned organisations. A list of 583 GP practices and 90 hospitals was collated from the NHS Direct Wales website, although seven of these hospitals had been permanently closed at the point of data collection. All hospices in Wales were also identified via the EOLB and available databases.

A letter of introduction from the Deputy Chief Medical Officer (Wales) underpinning the importance of the study was sent out via e-mail with an electronic link to the online survey. The survey was sent to all hospices and other charities identified as providing bereavement support in Wales, as well as national organisations (including those based in England) that were available to Welsh residents. The study team also contacted (via telephone) all hospitals in Wales to introduce the review and obtain contact details for those responsible for bereavement support at each hospital, prior to sending them the survey. Recruitment in hospitals was challenging, with many hospitals either not being able to identify a single person/ department responsible for bereavement care or otherwise not receiving our recruitment telephone call. We also undertook survey dissemination through health boards and promotion of the survey via the GP One website. GP practices were sent the survey electronically via University Health Board (UHB) communication departments or primary care leads within the different health boards, with the remainder contacted via telephone to obtain e-mail addresses. Paper copies were available where requested.

Non-respondents were followed up via telephone calls and emails five weeks after the initial invitation to the survey. Snow-ball sampling was also conducted from the survey responses, and any new organisations identified from the survey were invited to participate. Further recruitment

opportunities were sought through professional networks of bereavement and neonatal nurses, councils, prisons, and twitter.

The survey was open for five months; data collection began on the 18th of March 2019 and closed on 23rd August 2019. The table below shows the different organisations that we invited to take part in the survey as well as the total number that completed the survey from each sector. Please note that aside from the participants we invited, the survey was also disseminated through other channels (as listed above) from which we are not able to ascertain specific figures on response rate.

Numbers of organisations approached and survey responses

Organisations	**Invited**	**Survey completed**
Charities	134	64
Hospices	20	13
Hospitals	84	58
GPs	583	90
Councils	22	13
School		1
Prisons and criminal justice organisations	5	8
Private practitioners	11	2
Others		7

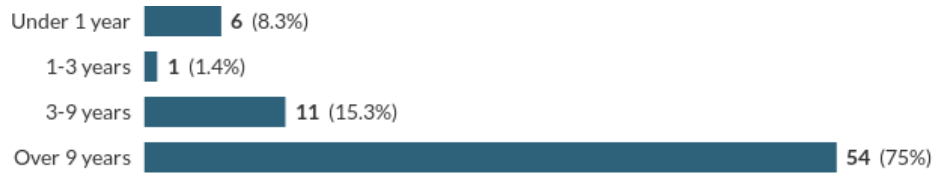
2.4 DATA ANALYSIS

Quantitative data from the survey responses were collated and analysed in Excel using descriptive statistics. Free text responses were analysed for key themes using Nvivo 10 software. Geographic mapping of the resultant data was then conducted through a tool developed by the Wales Institute of Social and Economic Research, Data and Methods (WISERD https://data.wiserd.ac.uk/) as well as in Publisher.

3 RESULTS

In total 256 respondents completed the survey including: charities (n=64), local councils (n=13), private practitioners (n=2), schools (n=1), criminal justice/prisons (n=8), GP practices (n=90), hospices (n=13), NHS including hospitals (n=58) and others (n=7). Out of these, 74 (28.9%) respondents reported either providing bereavement care within Wales or providing bereavement services in England but available to Welsh residents. Other respondents identified themselves as providing referrals for bereavement services but not directly providing support themselves. These respondents completed a short version of the questionnaire and their responses are only reported in sections *3.7 (Medical Examiners Process)* and *3.8 (Gaps and Challenges)* of this report. The length of time in service ranged between eight weeks and 40 years for bereavement service providers. The vast majority had over 9 years of direct service provision. This is shown in the graph below:

Number of service providers per age of service

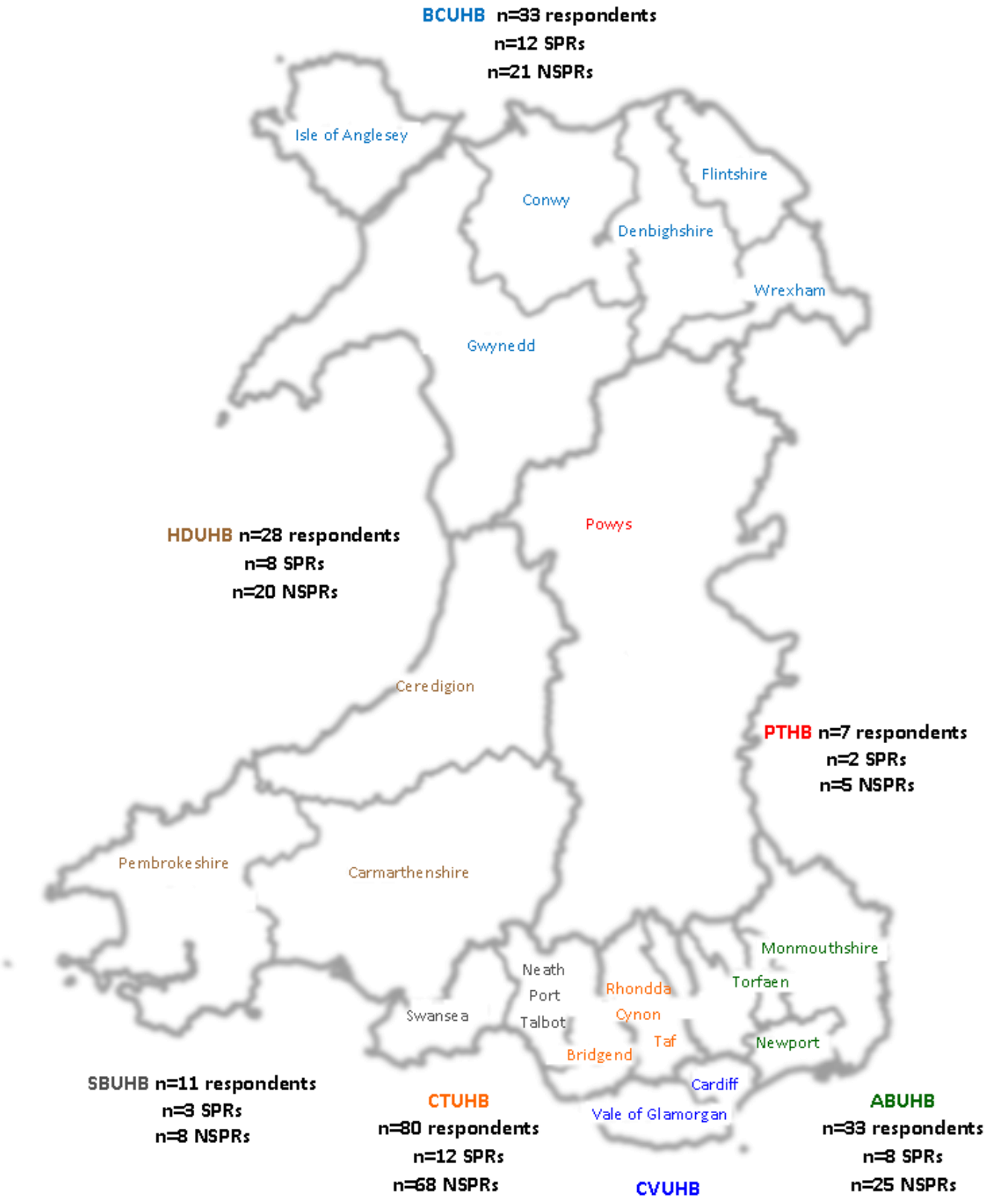


3.1 SUPPORT AVAILABLE IN DIFFERENT REGIONS OF WALES

The service provider respondents described different elements of the various bereavement services that they provided. This sub-section reports on the geographical location of the services described in the survey.

The map and table overleaf shows the number and type of respondents physically located within the seven health boards in Wales. Twenty other services responded that were not based in Wales but provided support either nationally across the UK or cross-border (based in England but available to Welsh residents within close proximity to the border). These respondents are not detailed on this map or subsequent table. It should also be noted that some of these services had catchments beyond their local authority or health board areas. Breakdown of services by catchment areas is reported separately in the report.

Number and type of respondents per Health Board



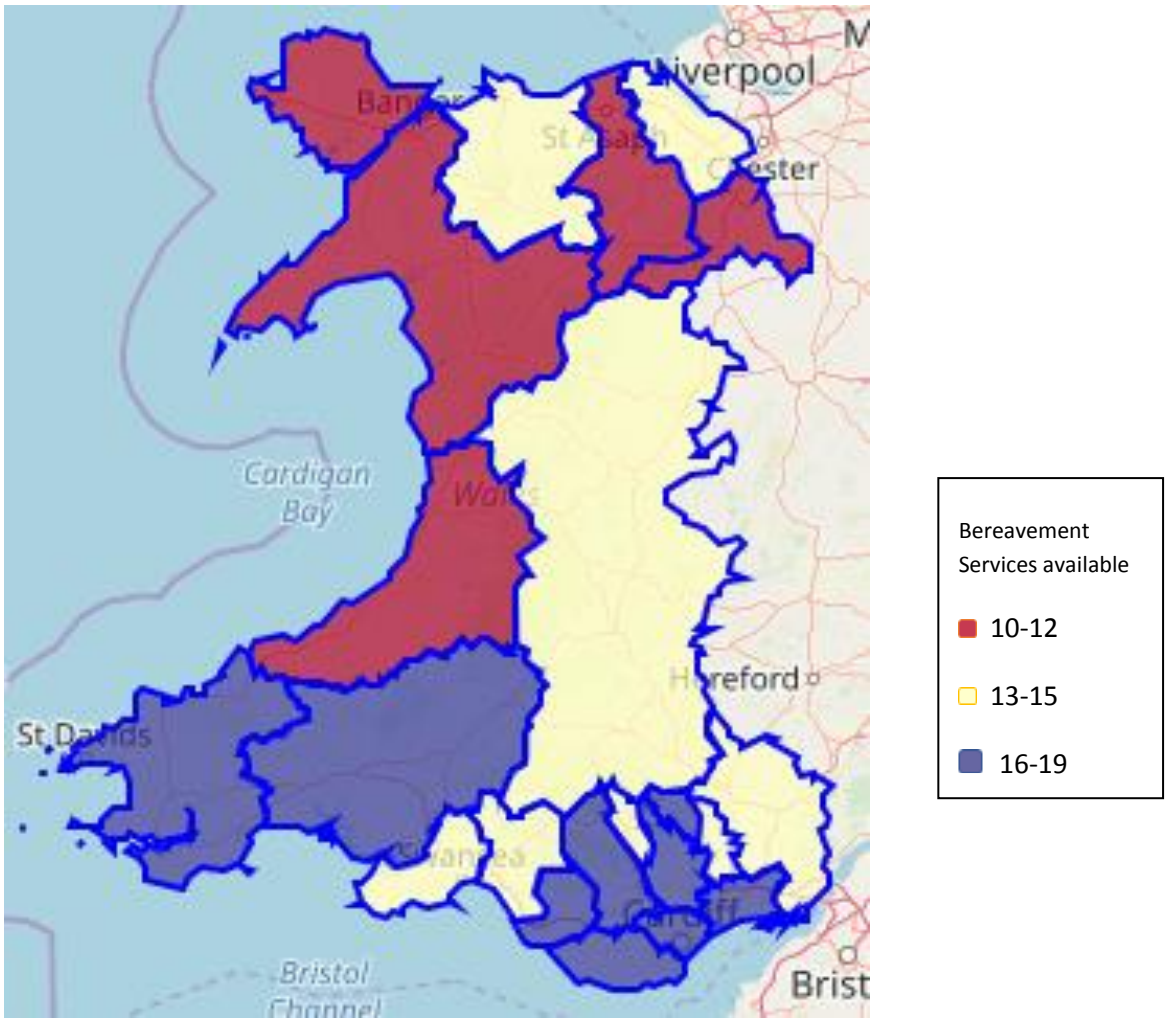
Key:
SPRs – Service Provider Respondents
NSPRs – Non-Service Provider Respondents

Types of SPRs by UHBs

Bereavement Service Provider	ABUHB	BCUHB	CTUHB	CVUHB	HDUHB	PTHB	SBUHB
NHS inc Hospitals	1	2	7	10	3	0	2
Charity/Not-profit	4	4	4	6	3	1	1
Hospice	2	2	1	2	1	0	0
Private	1	1	0	0	0	0	0
Council	0	2	0	0	0	0	0
GP Practices	0	1	0	1	1	1	0

The following map illustrates the number of bereavement service providers per their self-identified catchment areas, within local authorities in Wales. A table with this data is also attached as Appendix 1a at the end of this report.

Number of bereavement services mapped onto catchment areas as per Welsh local authorities

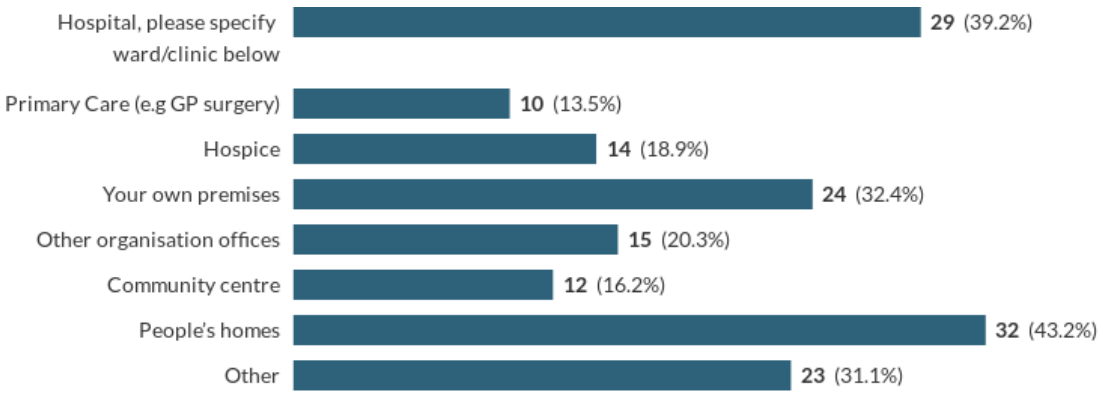


The highest number of services identified in the survey were available in Cardiff (n=19), Rhonddha Cynon Taf (n=19), Newport (n=18), and the Vale of Glamorgan (n=18) while the least number of services were available in Gwynedd (n=10) and the Isle of Anglesey (n=11).

It is important to note that although service density would appear to reflect population density when broken down by localities, it also highlights likely gaps for mid, west and north Wales in terms of geographical distance for service coverage and associated challenges of rurality. A breakdown of population data for the Health Boards and their respective local authorities is attached as Appendix 2b at the end of this report.

When asked the specific location of service provision, 42.3% (n=32) of those respondents provided a bereavement service in people's homes, while 39.2% (n=29) provided the support in hospitals. The least provision was at GP surgeries (13.3%, n=10). Below is a graph showing this data on the physical locations of bereavement support:

Numbers of services per location of service provision



Other locations for bereavement support identified in this survey included: churches (n=1), council offices (n=1), schools (n=15) and remotely through telephone.

3.2 SUPPORT FOR DIFFERENT GROUPS AND TYPES OF BEREAVEMENT

This section describes the support available for different groups of bereaved populations and types of bereavement, as identified through the survey responses. As shown in the graph below, bereavement support providers in our survey catered to: bereaved children and young people (n=48), bereaved parents following the loss of a child (n=53) and bereaved adults (n=59), with many services providing support to more than one of these groups.

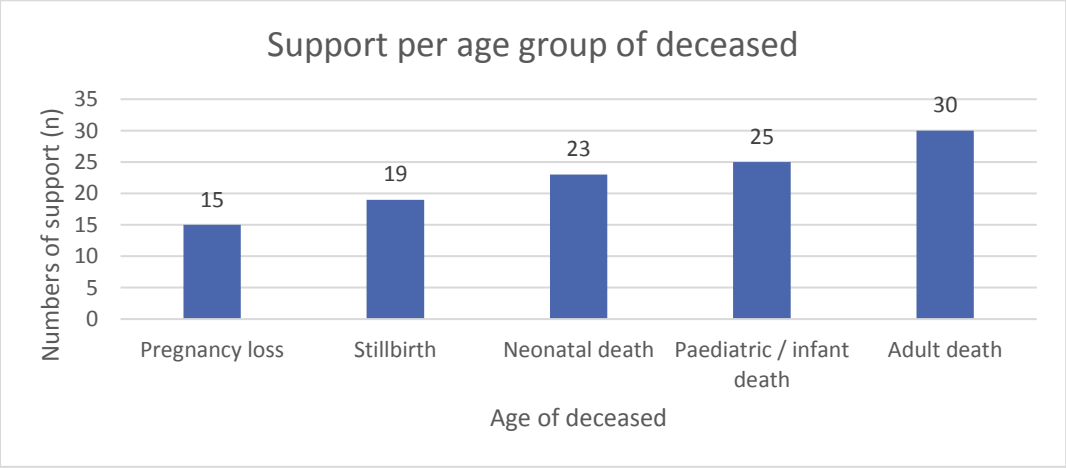
Numbers of services per type of people served

In addition, 30 of the 74 respondents that provided bereavement support reported that their service was restricted to people already known to their organisation (eg family members of deceased patients). Five services also identified as being restricted to other groups of people (such as farmers, cancer patients and particular age groups).

Services were also categorised according to the type(s) of bereavement that they supported in terms of the age group of the deceased (eg pregnancy loss, neonatal, adult) and type of death (eg expected, sudden, suicide). With regards to specific support provided in relation to the age group of the deceased, the largest amount of support reported was for adult death (n=30), with the least amount of support overall being for pregnancy loss (n=15).

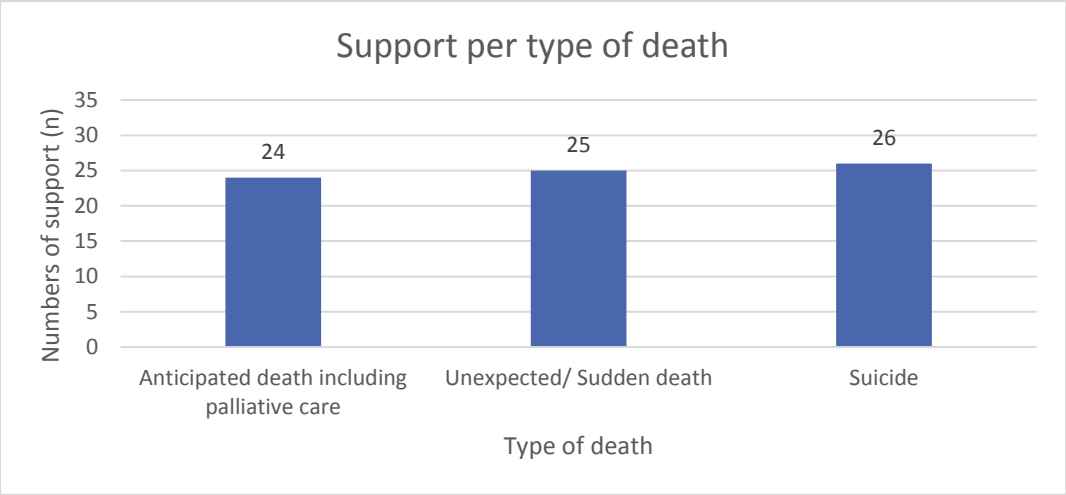
Below is a graph representing the number of bereavement services reported as per the age group of the deceased:

Numbers of services per age group of deceased



When categorised by the type of death, there was little difference between categories, as demonstrated in the next graph:

Numbers of services per type of death



The data on the numbers of specific support services available in each Welsh local authority for the different age groups of deceased are detailed in the table below. The lowest two frequencies for each category of support are highlighted in red:

Numbers of services per local authority and age group of deceased

What is your catchment area?	Pregnancy loss	Neonatal death	Stillbirth	Paediatric / infant death	Adult death
Blaenau Gwent	4	9	6	11	9
Bridgend	2	7	4	9	8
Caerphilly	6	11	8	10	9
Cardiff	4	9	6	8	9
Carmarthenshire	0	6	3	8	7
Ceredigion	0	5	3	6	4
Conwy	3	6	5	7	6
Denbighshire	2	5	4	6	5
Flintshire	3	6	5	7	6
Gwynedd	1	4	3	5	4
Isle of Anglesey	1	4	3	5	4
Merthyr Tydfil	2	7	4	9	7
Monmouthshire	4	9	6	10	8
Neath Port Talbot	2	7	4	8	7
Newport	6	11	8	11	10
Pembrokeshire	0	5	2	9	7
Powys	1	5	3	6	7
Rhondda Cynon Taf	3	8	5	8	10
Swansea	2	6	3	7	7
Torfaen	4	8	6	8	6
Vale of Glamorgan	3	8	5	9	10
Wrexham	2	5	4	6	5

The data on numbers of specific support available in each Welsh local authority for the different types of death are detailed in the table below. The lowest two frequencies for each category of support are again highlighted in red:

Numbers of services per local authority and type of death

What is your catchment area?	Anticipated death including palliative care	Unexpected/Sudden death	Suicide
Blaenau Gwent	5	10	7
Bridgend	5	9	7
Caerphilly	5	9	8
Cardiff	5	9	8
Carmarthenshire	4	8	7
Ceredigion	3	5	5
Conwy	4	7	7
Denbighshire	3	6	6
Flintshire	5	8	8
Gwynedd	2	5	5
Isle of Anglesey	2	5	5
Merthyr Tydfil	5	7	5
Monmouthshire	5	9	7
Neath Port Talbot	4	8	6
Newport	5	10	9
Pembrokeshire	3	6	8
Powys	6	7	6
Rhondda Cynon Taf	7	8	8
Swansea	4	8	6
Torfaen	4	7	6
Vale of Glamorgan	7	10	7
Wrexham	4	7	7

Key observations regarding the lowest levels of provision in these two tables include:

- The absence of support specifically relating to pregnancy loss in Ceredigion, Carmarthenshire and Pembrokeshire, and only one provider of this support in Gwynedd, Anglesey and Powys.
- Low levels of support specifically relating to stillbirth in Pembrokeshire (n=2), Carmarthenshire (n=3), Ceredigion (n=3), Gwynedd (n=3), Anglesey (n=3), Powys and Swansea (n=3).
- Consistently lowest levels of provision across all categories of support in Ceredigion, Gwynedd and Anglesey.

The most prevalent levels of provision detailed in the above tables include:

- Support for neonatal death in Caerphilly (n=11) and Newport (n=11).
- Support relating to paediatric and infant deaths in Blaenau Gwent (n=11), Caerphilly (n=10), Monmouthshire (n=10) and Newport (n=11).
- Support relating to adult deaths in Newport (n=10), Rhondda Cynon Taf (n=10) and the Vale of Glamorgan (n=10).
- Support available for unexpected or sudden death in Blaenau Gwent (n=10), Newport (n=10) and the Vale of Glamorgan (n=10).

Responses from 8 prisons in Wales indicated that there was little bereavement support available to prisoners in custody, aside from general support such as that of the chaplaincy. One respondent wrote: *'Men in custody have limited contact to Bereavement service although we have a chaplaincy service who offer immediate support if a man suffers a loss'* (Large prison 1).

It is important to note here that these results are limited to the responses we received from our survey. It is therefore likely that there are additional bereavement services available that may not have been captured in the survey results.

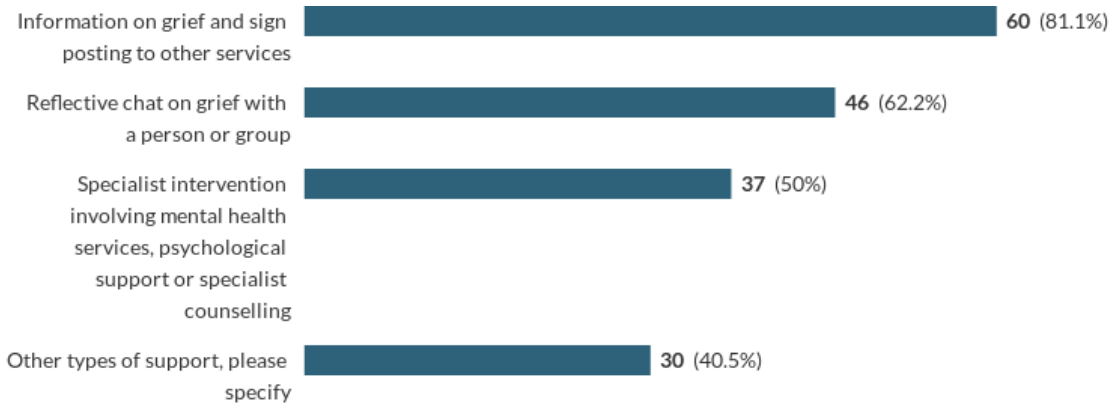
3.3 TYPES OF SERVICES OFFERED

The previous sections have reported on the location of bereavement services in Wales and the groups of bereaved people supported by these services. This section reports on the specific characteristics and features of the bereavement support offered, including their alignment with the NICE components of bereavement support. Out of 74 service provider respondents, 69 confirmed that they aligned with at least one of the NICE Components whilst 5 indicated that they only provided 'other' types of support.

3.3.1 PROVISION OF NICE COMPONENTS OF SUPPORT

In line with the NICE guidance which identifies three components of bereavement support [5], respondents categorised their bereavement support in the following proportions:

Numbers of services offered per NICE components



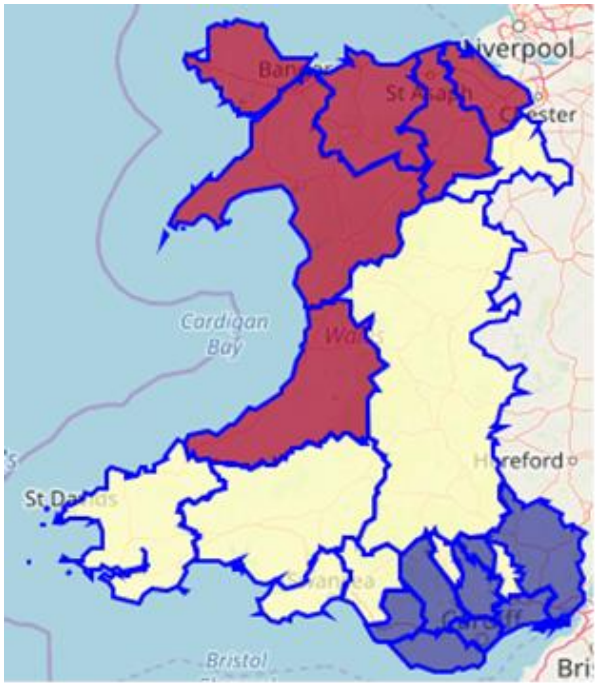
The majority of those who provided bereavement care (81.1%, n=60) considered that they provided NICE Component 1 support which encompasses providing information on grief and sign-posting to other support services. 62.2% (n=46) provided NICE Component 2 support which is defined as support involving reflective discussions on grief with a person or group. 50% (n=37) responded that they provided NICE Component 3 support which involves specialist intervention involving mental health services, psychological support and specialist counselling. Interestingly, in a subsequent question on service delivery only seven respondents considered that they offered specialist mental health support, suggesting that other types of Component 3 support (e.g grief counselling) were more commonly provided. Approximately a half of providers (n=35) reported that they provided more than one component of support. These combinations are displayed in the table below:

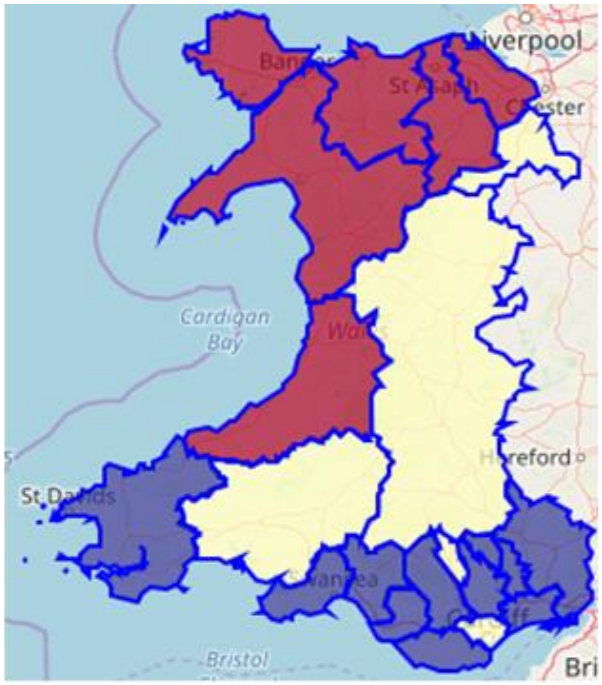
Number of service providers providing combinations of NICE Components of support:

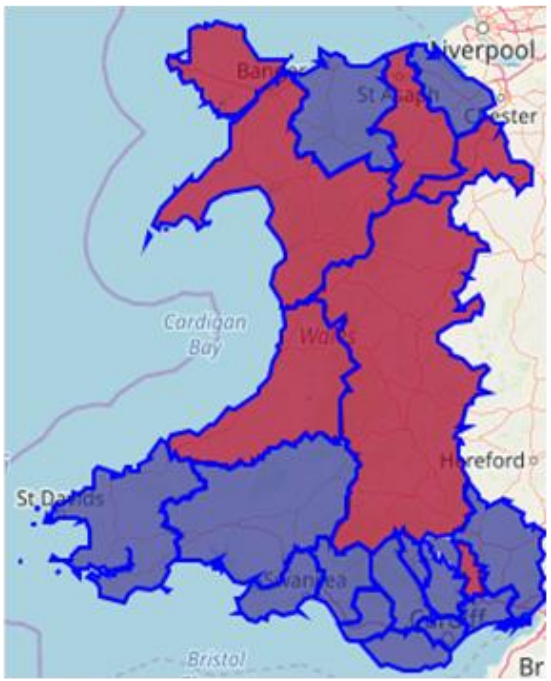
NICE 1+2	NICE 1+3	NICE 2+3	NICE 1+other	NICE 2+other	NICE 1+2+other	NICE 1+3+other
12	4	1	5	2	8	3

These three components of bereavement support are mapped overleaf. Each map shows the different components of support services that were reported as available in different local authorities.

Maps displaying the prevalence of NICE Components 1, 2 and 3 support across Welsh local authorities



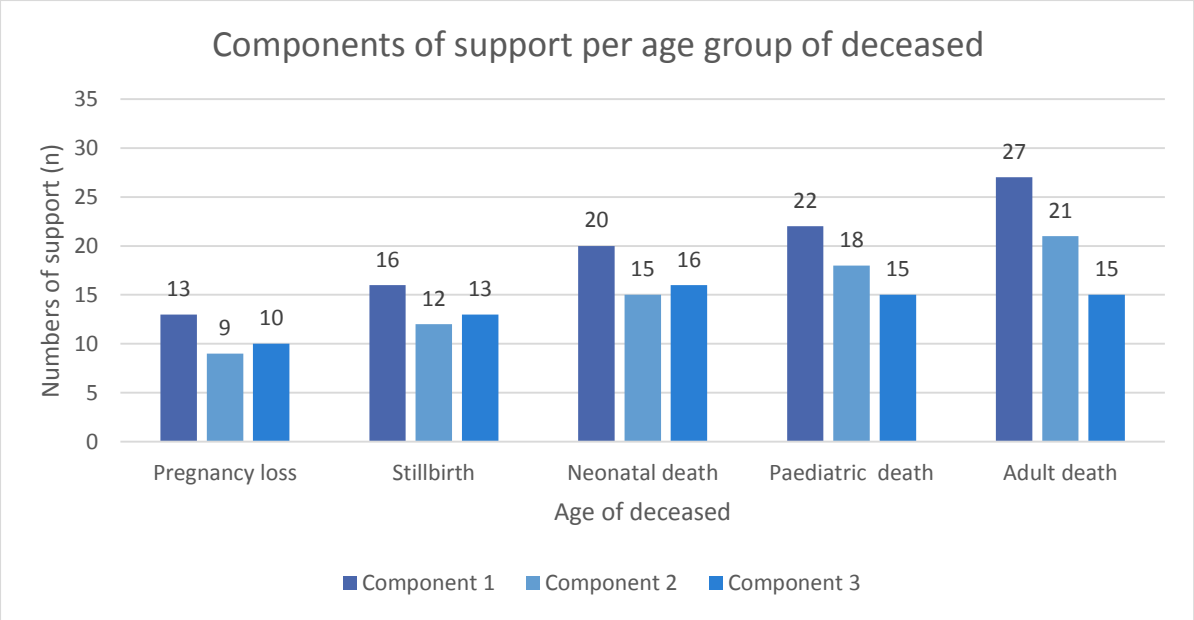




As illustrated in these maps, the highest number of services providing Component 1 support were available in the South East of Wales and the least numbers were available in the West, North and North West. For Component 2 support the majority of the services were available in the South, South East and South West of Wales while the least number were reported in the West, North and North West of Wales. For Component 3 support there was less variation although the lowest numbers were reported in mid and North West Wales and there was also variability in the distribution in some local authorities in the North and North East of Wales. South Wales again appeared to have higher numbers of this component of specialist support. A table showing responses for all three components against local authorities in Wales is attached as appendix 1b at the end of this report.

The numbers of services providing each NICE Component of support in relation to the age group of the deceased is displayed in the graph overleaf. As would be expected, Component 1 support was most commonly provided for each of these groups, followed by Component 2 and then Component 3 for paediatric and adult deaths. It is interesting to note that Component 2 and Component 3 support were provided at a similar level for neonatal death, stillbirth and pregnancy loss.

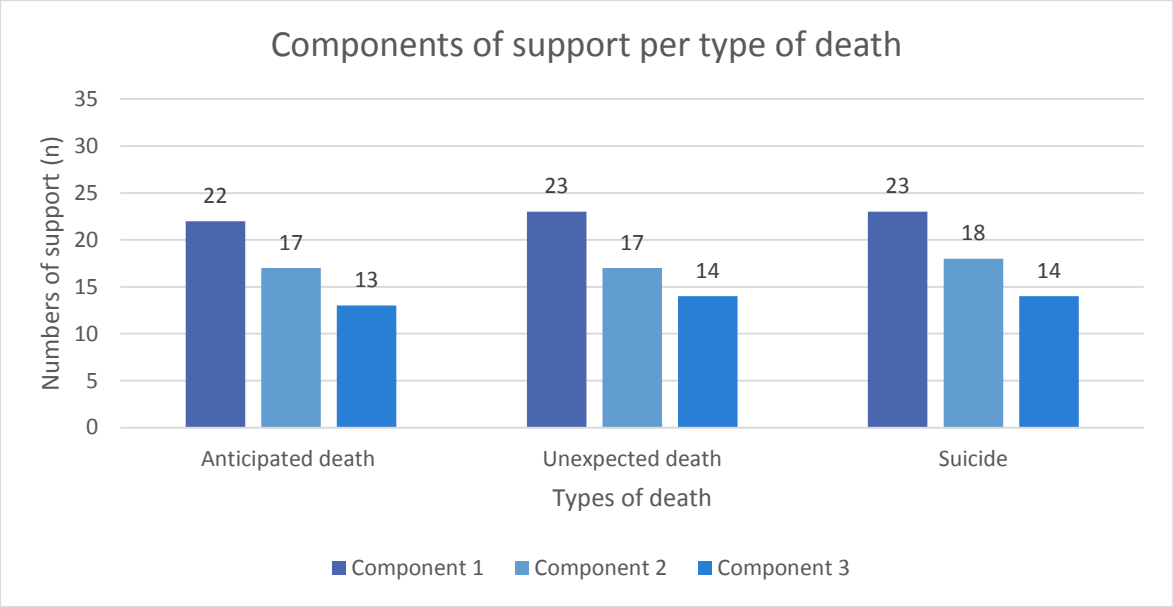
Numbers of services providing care each component of support per age group of deceased



The numbers of services providing each NICE Component of support against type of death (anticipated, unexpected and suicide) is shown in the graph below, with cross-tabulated data relating to other types of death reported in appendix 2a. Services providing Component 1 support were again most frequent for each of the types of death, followed by those providing Component 2 and then

Component 3 support. It is also interesting to note the broadly similar numbers reported across the three categories for the different components of support.

Numbers of services providing care each component of support per type of death



Using free text responses, some participants also described bereavement support which they did not categorise into the three NICE Components of bereavement support. Much of this support was provided immediately after the death of a loved one including:

- Help with administration such as death registration and funeral arrangements.

  All aspects of death administration ie MCCD [Medical Certificate of Cause of Death form]/Cremation Forms/ Coroners' Postmortems/Hospital Financed Funerals/Registration of Deaths/ etc etc. (Hospital 1 North Wales)

  Respond to a child death within one hour, transfer child to bereavement suites, organise viewings, assist with registering death, liaise with coroners, police, funeral directors, work with family intensely in first weeks, and then offer longer term support through a range of interventions according to family need. (Hospital 2 North Wales cross-border)

- Memory boxes and opportunity for photography and cuddle cots particularly in peri-natal death.

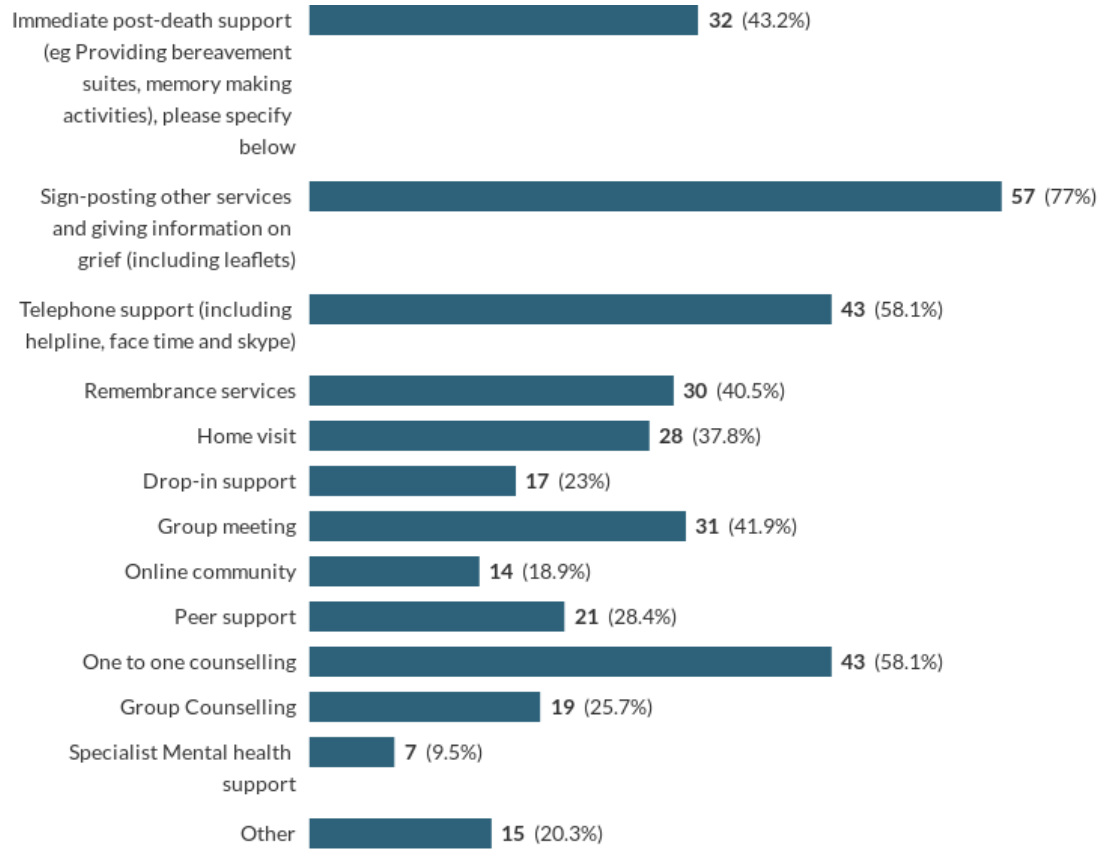
  We have funded memory boxes, training for midwives in photography, bereavement suites, cold and cuddle cots etc (Baby loss national charity 1)

  We have two bereavement suites where children can rest for 7 to 10 days giving families more time to continue to make memories (Children's hospice cross-border 1)

3.3.2 SERVICE DELIVERY AND IMPLEMENTATION

Respondents were asked about the different ways in which bereavement support was delivered. The graph below shows the numbers of respondents providing the different types of bereavement support activities listed:

Numbers of respondents providing different types of bereavement support



This data demonstrated that the majority of provider respondents provided information on grief and sign-posting to other services (77%, n=57), with the least numbers providing specialist mental health support (9.5%, n=7). Just under a half, 43.2% (n=32) of respondents offered immediate post-death support, such as memory making activities and bereavement suites in hospitals. A large proportion of respondents also offered bereavement support through one-to-one counselling (58.1%, n=43) and telephone support including helpline and skype (58.1%, n=43). When asked about the provision of written material/ multimedia resources to service users, respondents reported providing leaflets (n=59), websites (n=37), social media (n=16), DVD (n=4) and audio recordings (n=3).

33 (44.6%) service provider respondents reported that their support was time limited, whilst others stated that the length of support was based on the service user's need or available funding. 36 respondents specified the amount of support that they typically provide.

The number of sessions of support reported were as follows:

Numbers of support sessions provided by bereavement services

Number of sessions	Frequency (n of respondents)
1-4	3
5-9	13
10-14	1
15-19	2

There was significant variation with regards to when support was provided, ranging from 6 weeks to over a year post-bereavement.

> *Varies some are 6 weeks some 2 years or more average 12 weeks (Therapist 1 South East Wales)*
>
> *Varies a lot - anything from weeks to years after the bereavement. (Large bereavement charity 2 North Wales)*

Overall the majority of provider respondents (62.2%, n=46) did not have a waiting list for the service. These proportions were similar across our main categories of support, although it is noteworthy that the largest number of services with a waiting list were those providing specialist Component 3 support. Approximately 30% of services providing Component 1 and 2 support had a waiting list, compared with 50% of those providing Component 3 support.

3.4 REFERRAL AND RISK ASSESSMENT

The previous section reported data relating to the types of bereavement services provided. This section describes information collected on referral processes and risk/needs assessment practices amongst bereavement service providers.

3.4.1 REFERRAL PATHWAYS

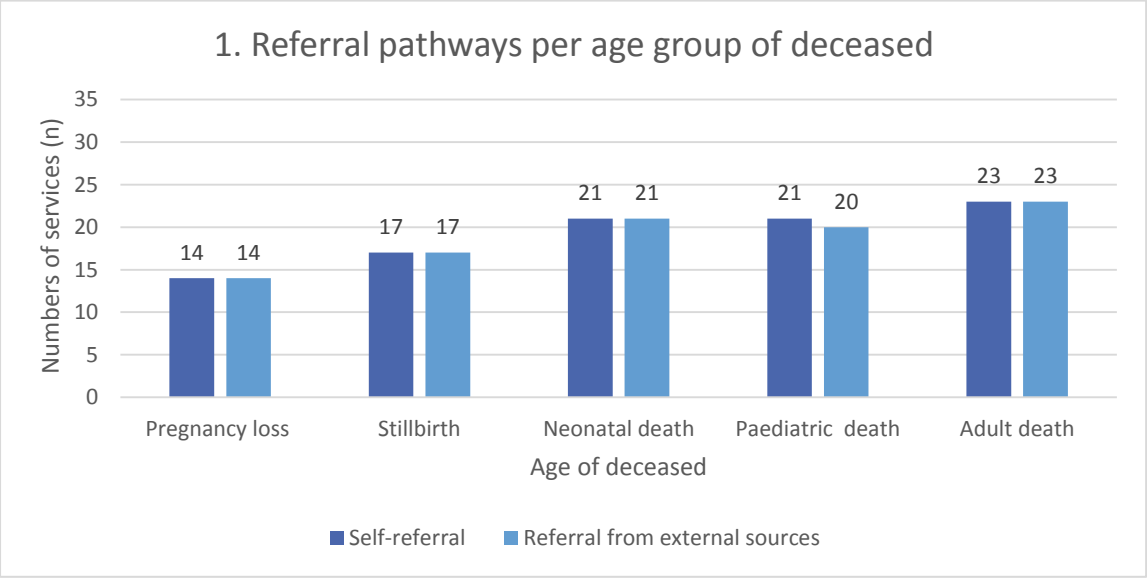
Of those who responded to a question on referral pathways, referrals to their support were commonly through self-referral (73%, n=54) and external referral (74.3%, n=55). Most services accepted both types of referrals, with only 8 reporting to accept external referrals only. However, it should also be noted that approximately 40% of these respondents only provided support to people already known to their organisation, indicating that 'self-referral' may not always imply an 'open door' approach. The proportions of services accepting self and external referrals was similar for different categories of death and for each NICE component of bereavement support, as reported in the tables below:

Numbers of services per referral modes for different components of support

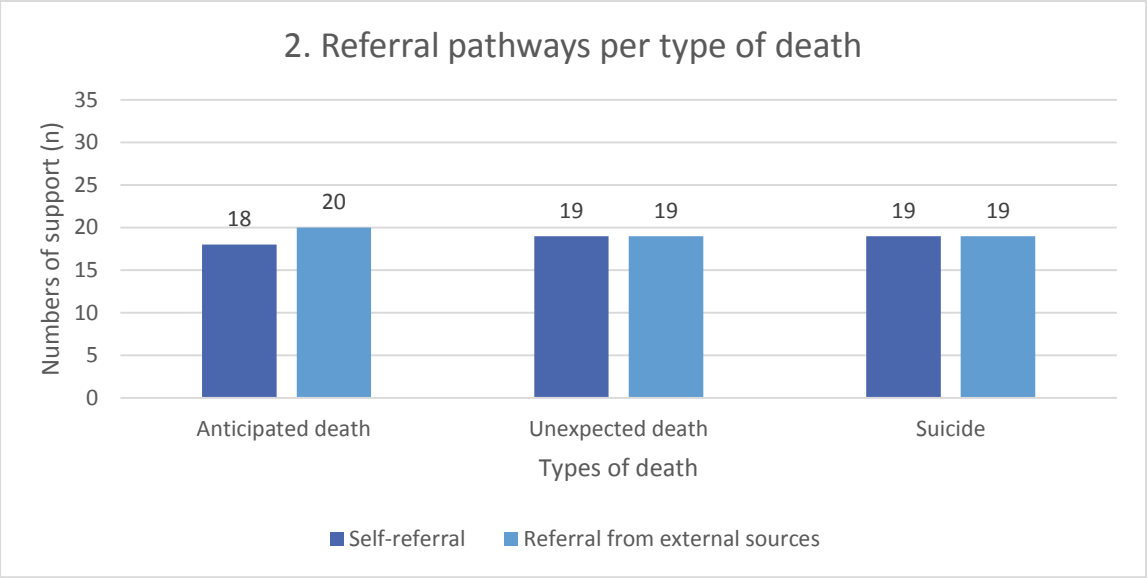
How do service users access your service?	**Component 1 support**	**Component 2 support**	**Component 3 support**
Self-referral	47	36	28
Referral from external sources	44	34	34

The following two graphs represent the referral pathways of provider respondents, according to support relating to 1) the age group of the deceased and 2) type of death.

Numbers of services per referral pathways and age group of deceased



Numbers of services per referral pathways and type of death



The data from these two graphs shows that the proportions of services accepting self-referrals and external referrals were evenly split for support relating to neonatal death, adult death, unexpected deaths and suicide, with only slight differences for support relating to anticipated and paediatric deaths. It is also interesting to note that out of 47 services that responded to a question on uptake of referrals, 14 stated that less than 50% of those referred to them take up the service. This raises possible questions over the length of waiting lists and the timeliness of support at the point of eventual access.

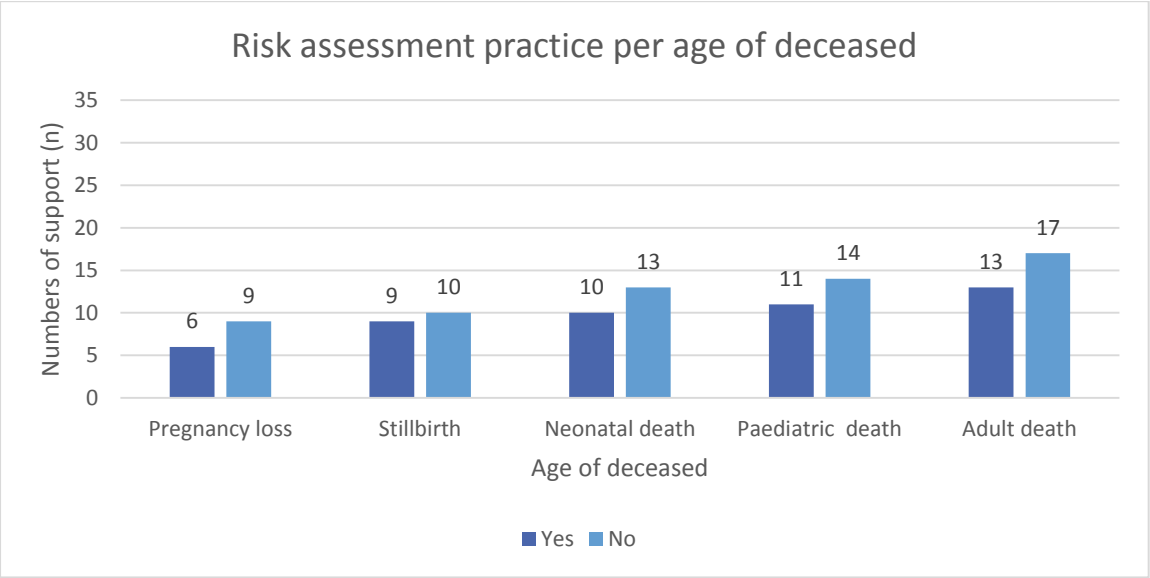
In terms of uptake of support, 33 out of the 74 provider respondents reported supporting more than 100 new users each year. Nine bereavement services reported 51-100 new users per year, eight reported 21-50 new users and six services reported 20 new users or less.

3.4.2 BEREAVEMENT RISK AND NEEDS ASSESSMENTS

Of the respondents that provided bereavement support, 44.6% (n=33) reported to use a risk or needs assessment tool, compared with 50% (n=37) that did not and four (5.4%) that did not know. As would be expected, when broken down according to the NICE components of support provided by these services there was variation in these proportions. Roughly twice as many providers of Component 3 support used risk assessment tools than did not (yes=23, no=12). This compared with more even proportions for providers of Component 2 support (yes=20, no=23), and higher numbers of providers of Component 1 support reporting that they do not use risk assessment tools (yes=25, no=33).

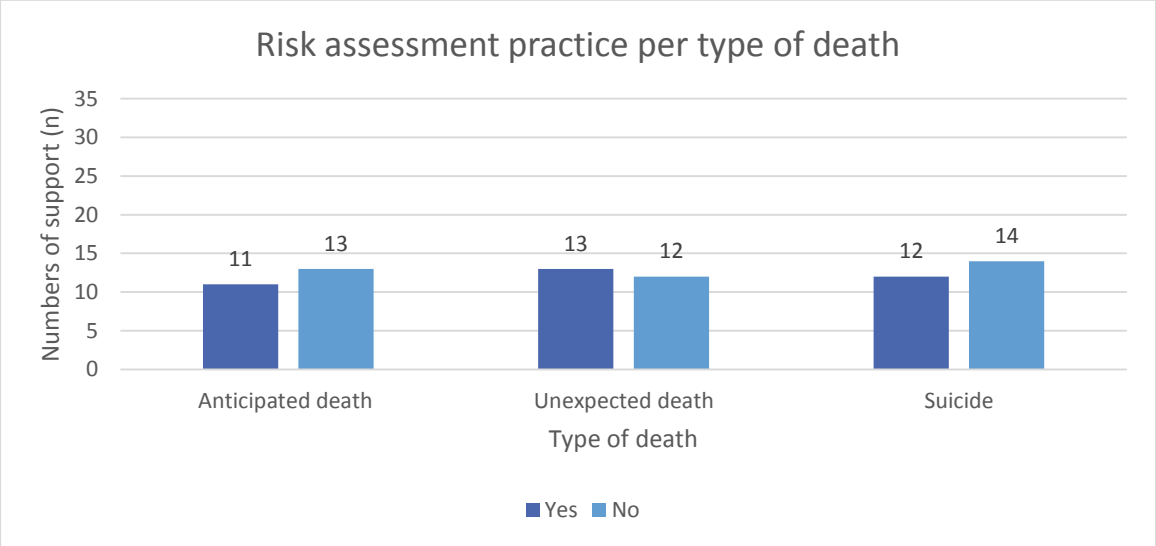
The following graphs compare the use of risk assessment tools for support relating to the different death categories:

Numbers of services with risk assessments per age of deceased



Across all of the age group categories (above) slightly higher proportions of providers stated that they did not use a risk/needs assessment tool. In the graph below, which compares anticipated death, unexpected death and suicide, the proportions were more evenly split across the three categories.

Numbers of services with risk assessments per type of death



3.5 FUNDING AND ASSESSMENT OF SERVICES

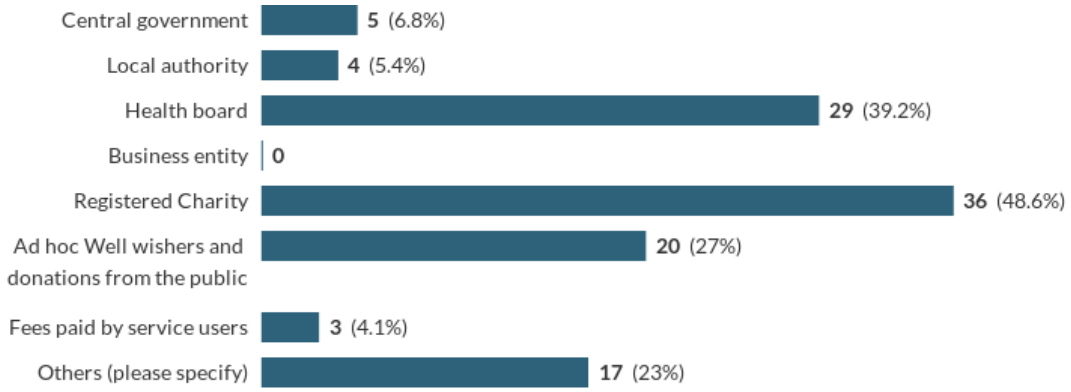
The previous section reported on the referral pathways and risks assessment practices described by respondents. This section discusses the information provided on the funding and assessment of bereavement services.

3.5.1 FUNDING OF SERVICES

94.6% (n=70) of those who provide bereavement care did not charge for the bereavement support they offered. The services that reported requiring service users to pay their own fees included three services that offered support for pregnancy loss, neonatal death, stillbirth, adult death and suicide. Of those that charged the prices ranged from £22 to £150.

The number of bereavement services and their funding sources were described as follows:

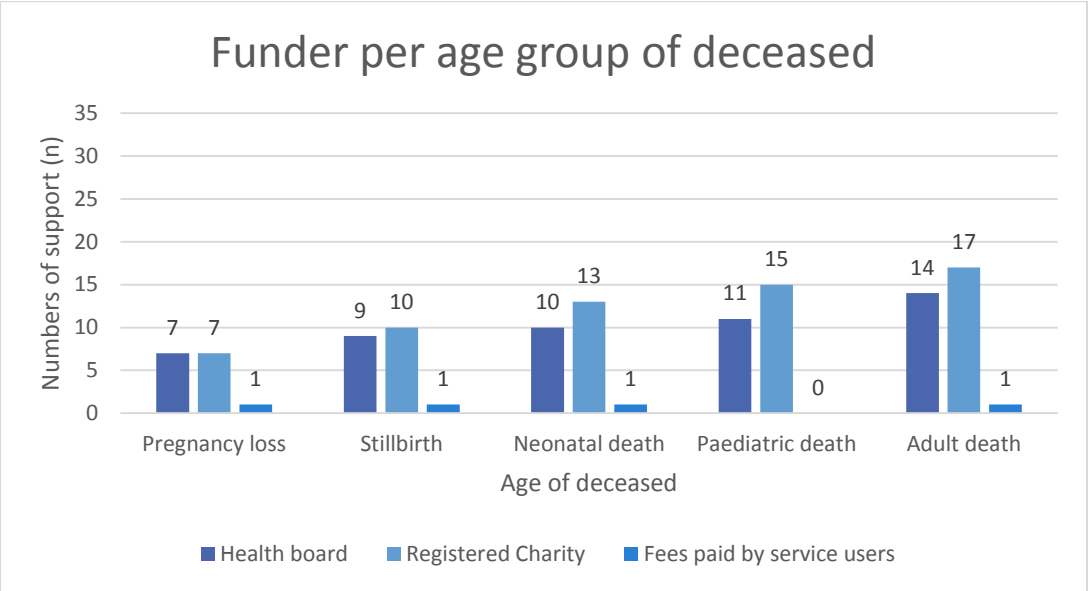
Numbers of services per funder



The largest funders overall were registered charities (48.6%, n=36) and health boards (39.2%, n=29), and this was also the case across all the main categories of death specific bereavement support.

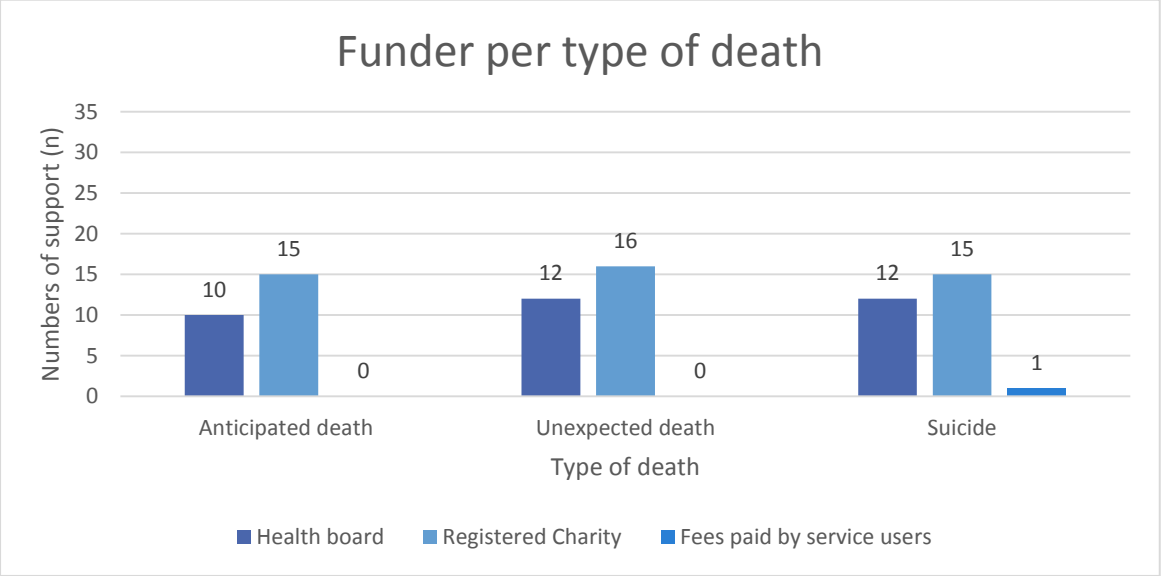
The data on funding by age group of deceased is shown in the following graph:

Numbers of services per funder and age group of deceased



Bereavement support for neonatal, paediatric and adult death was therefore more frequently funded by charities than by health boards, whilst support relating to pregnancy loss and stillbirth reported more equal proportions of funding from charities and health boards. The data was similar for anticipated death, unexpected death and suicide, with charities being the most frequently indicated source of funding. The data on funding per type of death is shown in the following graph:

Numbers of services per funder and type of death



When funding was compared across the three NICE Components of bereavement support, the majority of the services reported that their funding came from a registered charity, with funding also commonly received from health boards (see table below):

Numbers of services per funder and components of support

Who funds the service?	**Component 1 support**	**Component 2 support**	**Component 3 support**
Health board	23	16	15
Registered Charity	31	29	20
Fees paid by service users	2	1	2

3.5.2 SERVICE ASSESSMENT

Service provider respondents were asked if and how their services were assessed. 38 (51.4%) respondents stated that their organisation was externally assessed, 21 providers (28.4%) reported that they were not externally assessed and 15 (20.3%) did not know. Across the different categories of death specific support, the responses suggested that more bereavement services were externally assessed than those that were not. Likewise, when responses were broken down across the NICE Components of support, more organisations stated that they were externally assessed than those that were not (see table below):

Numbers of services based on assessment practices and components of support

Is your organisation externally assessed and/or inspected?	**Component 1**	**Component 2**	**Component 3**
Yes	32	24	24
No	16	11	9
Don't know	12	11	4

Overall 35 respondents reported statutory body assessments, most commonly from health boards (n=24), Welsh Government/Health Inspectorate Wales (n=5) and local authorities (n=3). Health boards were most widely reported to assess services providing bereavement support relating to all the different categories of death, and across the three NICE components of support. Other modes of assessment mentioned in the free text data included professional bodies such as the National Counselling Society, the British Association of Counselling and Psychotherapy (BACP) code of ethics, individual charities, boards of directors, independent auditors/external evaluators.

Two respondents reported to conduct service audits using the *Bereavement Care Service Standards*, and another used the *Macmillan Environmental Standard* and *Health Care Standards*. A large number of respondents also reported to collect service user feedback using their own evaluation forms and questionnaires, or in one case using the Childhood Bereavement Network Evaluation Forms.

3.6 STAFF AND VOLUNTEERS

This section focuses on the data obtained on the staffing of the bereavement services. There was considerable variation in the number of paid staff and volunteers per organisation. Most commonly, organisations employed under ten paid staff (n=42), although 3 providers employed over 60 staff members. Just under a half of services used volunteers (n=37), with 8 reporting to provide support through volunteers alone. These frequencies are detailed below:

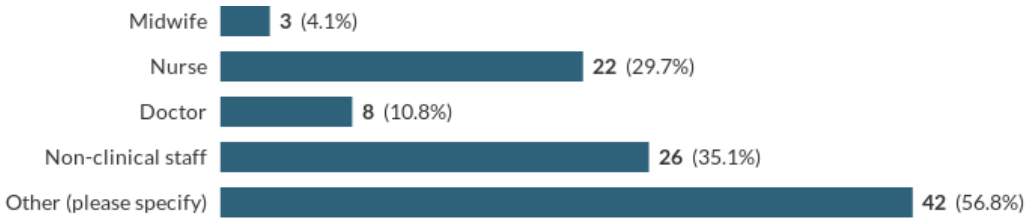
Numbers of staff and volunteers providing bereavement support per organisation

Estimated numbers of staff/volunteers	**N of services (staff)**	**N of services (volunteers)**
1-10	42	19
11-20	11	7
21-40	3	6
41-60	1	0
Over 60	3	1
Don't know/not quantified	6	4

There was also variation in the training and qualifications of staff and volunteers providing bereavement care. Just under half of services with paid staff reported that all of their staff had relevant qualifications (n=29) while only 10 services reported that all of their volunteers had relevant qualifications. By contrast 6 services stated that none of their paid staff had relevant qualifications while 3 stated the same for their volunteers. 10 services stated that they did not know about the qualifications of their paid staff and 9 services did not know about the qualifications of their volunteers.

Respondents were also asked to identify who provided bereavement care in their organisations. Various professionals were identified, as illustrated below:

Professional groups involved in delivery of bereavement care (n=respondents)

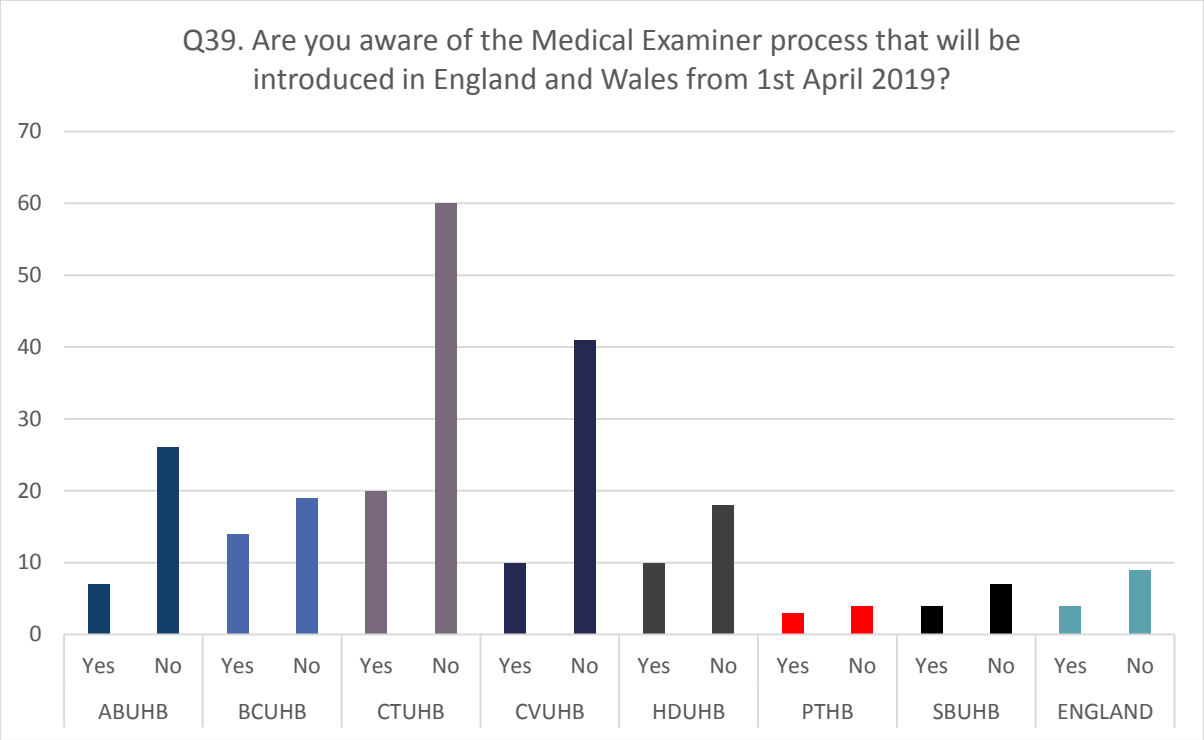


Doctors were reported to provide support in relation to adult death (n=2), anticipated death including palliative care (n=2) and death related to dementia (n=1). Midwives were reported to provide support for pregnancy loss (n=3), neo-natal death (n=3) and stillbirth (n=3). Nurses were identified as providing support across all categories of death with the largest number of respondents providing support for adult death (n=11). However, across all the categories of death, non-clinical staff were identified as providing more bereavement support. From the free text responses, other people noted to provide bereavement care included: volunteers, psychotherapist, counsellors, bereavement coordinators, play therapists, complementary therapists, teachers, social workers, youth workers, chaplains, clinical psychologists, administration staff, suicide prevention advisors and welfare rights advisors.

3.7 MEDICAL EXAMINER PROCESS

This section describes awareness of the newly introduced medical examiner (ME) process, and perceived implications for practice among respondents to the survey. Overall, awareness of the change was very low, with 72% (n=184) of the respondents not being aware of the process and 79 % (n=180) being unsure of whether this would affect their service provision. As demonstrated in the graph on the following page, there was some variation across the seven health boards with roughly equal numbers of respondents reporting awareness/lack of awareness in Powys and Betsi Cadwaladr Health Boards, compared to much higher proportions of services reporting 'no awareness' in the other five health boards.

Numbers of respondents aware of ME process per health board



It is important to note, however, that not all types of respondents would be expected to have knowledge of the new process, which is of most relevance to health care professionals involved around the time of death. When the data was divided according to respondents' organisations, the results were as follows:

Numbers of respondents aware of ME process per type of organisation

Category of respondents	**Yes**	**No**
GP Practices	24	66
NHS inc Hospitals	24	34
Hospices	7	6
Charities/not-profit	13	51
Private practitioner	1	1
Local councils	1	12
School	0	1
Prisons/criminal justice organisations	0	8
Other	2	5

When asked if they envisaged the ME process affecting how any of their services were provided, only a small minority of organisations thought the ME would affect their service provision while the majority of respondents were not sure. While it might be expected that many bereavement charities would be unaware of the process it was surprising that only a small minority of healthcare provider respondents (eg GPs, Hospitals, Hospices) recognised its introduction and likely impact. This data is shown below:

Numbers of respondents per organisation envisaging an impact from ME process

Category of respondents	Yes	No	Not sure
GP Practices	3	6	69
NHS inc Hospitals	4	6	44
Hospices	1	5	6
Charities	2	16	39
Private practitioner	0	1	1
Local councils	0	3	9
Prisons/criminal justice organisations	0	0	8
Other	0	3	4

The survey also included a question on assessment and planning undertaken in preparation for the ME process. The majority of the respondents (87.8%, n=225) did not answer this question. The following comments were made in free text responses to this question:

- 10 respondents stated that they had not undertaken any preparation/ assessments for the ME process.
- One hospital responded that the clinical director was preparing for the new process. A bereavement specialist midwife from a different hospital stated that they were not aware of the process being rolled out in Wales, while a hospital counselling psychology service at another hospital was aware of the process and attended the health board planning group.
- A palliative care consultant at a hospital and hospice stated that they had been in discussion with the lead for the ME introduction, and a further staff member there stated that doctors were aware and planning for it.
- A GP reported that they understood it was to be rolled out in hospitals first and had therefore not made any changes. Three GP practices further stated that although they knew of the ME introduction, they had not had any communication to explain the process and its impact on general practice. Another GP practice stated that a colleague had attended meetings about the ME process and they were awaiting advice.

- A child bereavement charity stated that they were '*educating helpline staff to make sure they are aware of the changes'.*

3.8 CHALLENGES AND GAPS IN BEREAVEMENT SUPPORT

This final section of results describes the challenges and gaps identified by all survey respondents relating to bereavement support in Wales.

The main challenges reported in the survey amongst all respondents (including those who do not provide direct bereavement support) are shown in the graph below:

Numbers of respondents reporting different gaps in bereavement support

Access to specialist support was identified as a gap in service provision amongst the majority of respondents. However, among those who stated that they provided bereavement support the largest challenge across all the categories of death and across all three NICE Components of support was the lack of access to funding. The second highest challenge reported among those who provide bereavement support was an inability to meet demand for services.

Data from open questions (the free text responses of the survey) provided greater understanding of the gaps and challenges that respondents thought existed in bereavement support provision in Wales. A number of gaps were identified within individual services, as well as locally and across Wales. These included:

- Challenges with death administration and funeral arrangements
- Lack of prioritisation of bereavement care within organisations
- Lack of resources including trained staff
- No clear referral pathways for support
- Long waiting times
- Strict eligibility criteria and lack of support for some groups
- Geographical access issues

3.8.1 CHALLENGES WITH DEATH ADMINISTRATION AND FUNERAL ARRANGEMENTS

Respondents described challenges such as delays with the administrative components immediately after death such as death registration and the accommodation of the deceased. A respondent from a mental health charity cited delays with the coroner's process as causing distress to bereaved families. Other respondents also described issues for bereaved people needing assistance with funeral/gravestone costs, and the particular distress experienced by families that had lost babies or children when these needs could not be met.

> *Significant delays for registration of deaths and storage of bodies (Hospital 1 North Wales)*
>
> *Many people come to us looking for help with funeral costs (including gravestones). Not all funds help with this kind of cost and some people aren't eligible for any fund. Also the amount a charity can provide for funeral expenses will often fall below the total costs. Because of a need to arrange a funeral soon after someone dies, some funds can't respond quickly enough or people pay for the funeral and then try to find a grant to cover the costs. Many funds won't pay for costs that have already been paid. Being unable to pay for a headstone can cause bereaved people great distress, yet very few charitable funds would pay for this type of cost. This is particularly true of parents of children who have died/still born children (Poverty Charity 1 national).*
>
> *Coroner service takes too long to hear cases. leaving families without a death cert. this causes no end of issues as well as expecting the bereaved to revisit the trauma of a death (Mental health charity 1 Wales).*

3.8.2 LACK OF PRIORITISATION AND SERVICE FRAMEWORK

A number of respondents (in particular from the NHS) considered that their organisations did not prioritise bereavement support. This was linked to a lack of a framework for bereavement support in the structure of the organisation. These challenges were partly understood by some as being the result of a large workload within the hospitals which prevented them from providing the extra service of bereavement support.

> *Management do not recognise that bereavement support should be part of ongoing care. Palliative care includes the family as well as the patient, surely their needs continue after a death (Hospital 1 Central Wales).*
>
> *There is a lack of a framework to provide the appropriate support. Leading to inconsistencies in the services that bereaved individuals and families receive (NHS Public body 1 South East).*
>
> *Our service I feel should be providing both pre and post bereavement support but workload pressures mean that we are only able to offer people a bereavement phone call post death and then signpost to the limited options in our area. We are involved with families at the most intense times and then all our support and services are withdrawn when the patient dies; sometimes i feel this can compound the grief and loss that families feel (Hospital 3 North Wales).*
>
> *Perception that this is not a priority for other areas of health and social care (Hospital 1 North West Wales).*

3.8.3 LACK OF CLEAR REFERRAL PATHWAYS FOR SUPPORT

A number of respondents, from different types of organisations, stated that clear referral pathways to bereavement support were lacking. They also commented on a lack of information on which services were available and suggested that more guidance and promotion of available bereavement support was needed.

> *No clear referral pathways. No clarity on specific bereavement pathways e.g. death of parent, death of child, unexpected etc (GP 1 South East Wales)*
>
> *Sometimes it is very difficult to know where to refer on when a chaplain has been supporting a patient or family (Hospital 2 South East Wales).*
>
> *Lack of clear guidance as to what should be provided - and by whom? (Hospice 2 South East Wales)*
>
> *Not enough services & knowledge of services due to lack of advertising (Disability charity 1 national).*
>
> *There is a lack of awareness regards the menu of models to provide support other than specialist counselling. There is also a general lack of awareness regarding the damage unresolved grief has in developing children and young people (Child bereavement charity 1 South West Wales).*
>
> *No directory or central resource that I know of (Large Hospital 1 palliative South East Wales)*
>
> *Unaware of other agencies available in Wales to refer clients to (Hospital 3 South East Wales)*

One respondent proposed the need for the "*development and implementation of a National Bereavement Care Pathway".* Another respondent also recalled a '*Help is at Hand*' publication that they had previously used to identify locally available services, but was no longer available.

3.8.4 LACK OF TRAINED STAFF AND PROVISION WITHIN THE WIDER COMMUNITY

As indicated in the previous section on staff and volunteers, many respondents described how they lacked specially trained staff to provide bereavement support. Interestingly, some GPs stated that they provided bereavement support while others stated that they did not provide the service. Of those that provided the support, their perspective was that not only were they not trained to handle bereavement care but they did not have ample time within the GP consultation to provide the support needed. One GP explained that grief was a natural process and considered that most bereavement support needed to be provided in the community, rather than by GPs or mental health services.

> *We cannot address everything in a 10 min GP appointment and need services to refer to but sometimes the referral to [large bereavement service] is shut as they cannot meet demands (GP 1 North Wales).*
>
> *Generally staff in primary care aren't specifically trained in bereavement care (GP 2 North Wales)*
>
> *As a GP i see a lot of Mental distress caused by Bereavement. It is a normal part of the human condition but is now seen as a MH issue. The current MH service cannot cope with this influx of ''normal '' mental stress and cannot provide a service -the community is based placed for this in the form of local*

bereavement groups of counsellors… the problem with grieving pts is that there isnt a good immediate service [apart from very expensive , busy GP] and by the time they see a [large bereavement service] member the immediate crisis has passed. we need an immediate SERVICE working along side GPs in practice or in the community-NOT in a psychiatric unit (GP 2 South Wales)

There were also arguments made in favour of a non-medical approach to bereavement support. The use of social prescribing and utilisation of principles of compassionate communities were highlighted as potentially sustainable ways of bereavement support provision. One respondent made reference to social prescribing activities in Frome and *Life Rooms Liverpool* as examples of good practice in England that could be replicated in Wales. Additionally, another respondent highlighted an opportunity linked to 'compassionate communities', which could be used to enhance bereavement support through education in schools and workshops in community cafes and workplaces.

3.8.5 LONG WAITING TIMES

Respondents repeatedly stated that there were long waiting times for service users to access bereavement support. These resulted in services not being able to meet demand, and as noted above also meant that people in crisis were not being supported at their point of most need.

[Large bereavement Service] is the only service we use and the process is long winded and not fit for purpose - we need one to one counseling and you have to attend a group meeting and at that are discouraged from one to one support due to their availability (Community charity 2 South East Wales)

We have many calls to the CVC looking to access bereavement support and refer to [large bereavement service] who reported they have waiting lists of a few months in some boroughs. Also there are competing demands to recruit volunteers from third sector and the NHS which makes finding the capacity to deliver difficult. It takes a while to train people appropriately (Community charity 3 South East Wales).

Limited provision, lengthy waiting lists to access. Continuity of throughcare support (Prison 2 South East Wales).

Long waiting times for specialist bereavement services (GP 4-community primary care South East Wales)

3.8.6 RESTRICTIVE ELIGIBILITY CRITERIA

Respondents stated that some support services had restrictive eligibility criteria, and lacked services for particular groups of people. Those groups mentioned included bereaved children and young people following an unexpected death, people with learning disability and people struggling with grief beyond the initial bereavement phase (eg 6 months post death).

There is a severe shortage of organisations that offer specialist bereavement support for children and young people who are bereaved by the death of a parent or grandparent especially if they died through suicide or in unexpected circumstance (Children hospice 2 North cross-border).

No bereavement services at all in [large Welsh city] for people with learning disability (Disability charity 2 South East Wales).

We have found that there is quite a lot of help and support for people just after their bereavement however long term people often say that 3 to 6 months after their loss the world goes back to normal and they are expected to do so also. In reality this is far from the case and they need that on going support for many more months. Its not an overnight fix (Family support charity 1 national).

These gaps are again noted in the comments from a hospice in South East Wales, which responded by opening up their adult and child services to anyone needing support relating to an adult death.

There can be long delays and more restrictive eligibility criteria (e.g. how recent the death was) in some bereavement services other than that of our hospice within this locality which results in people waiting for services unless they get referred to us - sometimes by those agencies themselves. As a result we have widened our adult and child services so that they are open to anyone needing help with the death of an adult (Hospice 1, South East).

3.8.7 GEOGRAPHICAL ACCESS AND INEQUITY IN PROVISION

Respondents in certain regions of Wales reported that some bereavement charities were not available within their localities, whilst others reflected on a more generalised inequity relating to the absence of a coordinated and cohesive national framework or service model.

Bereavement services do not have equity across Wales. They also do not have an accepted professional model (hospice 1 south West Wales).

There is no comprehensive or cohesive bereavement support response across Wales (Hospital 2 South Wales).

Particular challenges with access in rural areas were also identified, as indicated in the statistical data reported earlier.

Some of the bigger grief organisations such as [Charity R, Charity P) etc do not hold groups in our area and people who want to access this support have to visit a city to do so, which is not an option for everyone (Hospice 1 North Wales).

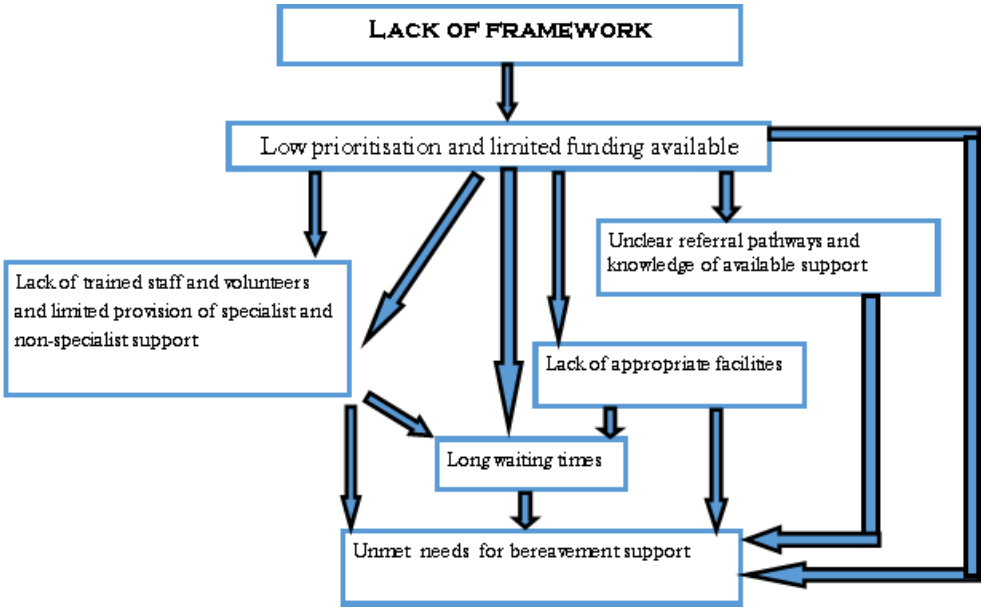
Lack of services that cover the rural areas across Wales, most support is concentrated in the populated areas and therefore others have to travel extensive distances to get the help they need (Large bereavement charity 1 National).

The challenge is the sheer size and remoteness of the North Wales area. Getting the information about the service to everyone who needs it can prove a difficulty also (Large bereavement charity 2 North Wales).

These gaps and challenges are clearly inter-connected. For example, it follows that services will not be able to offer a mix of specialist/ non-specialist support without suitably trained staff or volunteers or appropriate facilities. This in turn results in long waiting lists to access services and inability to meet

the demand for support. Likewise, lack of knowledge of services or referral pathways and limited risk assessment activities could lead to potential under-utilization of non-specialist community-based support (considered more appropriate for those with 'moderate' risk level and needs [6]), and further pressure placed on more limited specialist services. This is illustrated in the diagram below:

The challenges of bereavement support provision in Wales



4 DISCUSSSION

The results of this scoping review have taken a first step towards mapping the different types and characteristics of bereavement care available in different parts of Wales. Informed by a public health approach and the NICE three component model of support [5,6], the availability of specialist and non-specialist support in relation to specific groups of bereaved people and types of bereavement has been investigated. The results of the survey have been used to identify parts of Wales that may be experiencing gaps in structured bereavement care services, as well as gaps and challenges in the provision of comprehensive bereavement support across Wales.

The results of this survey revealed that the largest number of bereavement services were available in the South East of Wales and the least number of services were available in the North and West of Wales, with consistently lowest levels of provision across all categories and components of support in Ceredigion, Gwynedd and Anglesey. The survey also found that across Wales there were more bereavement services specifically available following adult death than for any of the other main categories of death, with the least support available for pregnancy loss, followed by stillbirth. No specific support was identified for pregnancy loss in Ceredigion, Carmarthenshire and Pembrokeshire, and only one provider was identified in Gwynedd, Anglesey and Powys.

Overall the highest proportion of bereavement services across Wales provided NICE Component 1 support, followed by Component 2 support and then Component 3 support [5]. This is expected and broadly fits with public health approaches which recommend universal access to information based support and usual support networks (Component 1), selective access to non-specialist support for those with moderate needs (Component 2) and indicated access to specialist mental health and psychotherapy services (Component 3) [5,6]. The exceptions here concerned support relating to neonatal, stillbirth and pregnancy loss which was more evenly divided between Component 2 and 3 support, suggesting either a relatively higher proportion of specialist support or relatively lower proportions of non-specialist provision. Whilst the survey results demonstrate coverage of all NICE Components of support across Wales, in roughly anticipated proportions, the data on waiting lists, perceived inability to meet demand for services and lack of access to specialist support, would suggest inadequacies in the current level of provision. The fact that only a half of services reported that they conduct formal risk or needs assessments, as specified in the NICE/Public Health models, BCSS and other guidelines [2,5,6,9], would suggest that there may also be challenges to address in the consistency with which support is being offered.

A number of additional gaps and challenges were identified in the survey. Many of these were similar to those identified in surveys of UK and European palliative care providers [12,15], which included the non-prioritisation of bereavement support at an organisational level, inadequate training of staff/volunteers, limited formal risk assessment practices or adherence to formal policies or guidelines and limited access to specialist mental health support for onward referral of more complex cases [12, 15]. Lack of funding was the most commonly identified barrier for service providers in this survey. Other problems included those relating to the accessibility of services such as unclear referral pathways, restrictive eligibility criteria and rurality. There were also issues impacting upon service delivery such as access to training and trained staff/volunteers, access to appropriate facilities, and the non-prioritisation and lack of a framework for bereavement care within organisations. The fact that available bereavement service standards [eg 9,10] were rarely mentioned by providers when asked about service assessment, also raises questions over the status and implementation of established standards amongst bereavement care providers in Wales. The finding that nearly half of all services were funded by charities, and only a half were externally assessed, would also indicate lack of prioritisation or frameworks at regional and national levels.

4.1 CONSIDERATIONS FOR SERVICE DEVELOPMENT

As discussed above, this scoping exercise identified several gaps and challenges within bereavement care provision in Wales. Based on these observations several considerations for service improvement and development are identified in the table overleaf. These are contextualised with reference to the core principles underpinning “A Healthier Wales: our plan for health and social care” [17], as summarised below the table.

Considerations and their relevance to the principles of Healthier Wales:

Key considerations:	**Relevance to "A Healthier Wales" [17]**
A National Framework: The development of a national framework for the delivery of bereavement care in Wales. This would in turn facilitate:	1
Prioritisation of bereavement care: The prioritisation of bereavement support at organisational and regional levels.	1
Equity and access to appropriate support: *A*vailability of appropriate types and levels of support which are responsive to local needs and comprise an effective balance of non-specialist community-based provision and specialist professional intervention.	1,2
Referral and risk assessment: The establishment of clear referral pathways and approaches to risk/ needs assessment. The development and maintenance of a directory of available bereavement provision could improve signposting, referrals and access to appropriate local support.	1,2
Training and learning: Improved access to training for staff and volunteers and sharing of expertise and good practice between local service providers.	1,4
Evaluation and assessment: Improvements in how services are evaluated and assessed, with implications identifiable for service improvement and investment. Appropriate sets of standards could be considered for use as audit and quality improvement tools and suitable measures and methods identified for evaluating the impact of services on service users.	1,3

Summary of principles from *A Healthier Wales: our plan for health and social care* [17]

1. The health and social care system working together across Wales, including sharing good practice and expertise.
2. Shifting services out of hospital to communities, with a focus on earlier detection and prevention of illness.
3. Improving how services and treatments are evaluated, to enable identification of those that work well and those that do not.
4. Supporting healthy and productive workplaces in health and social care, with investment in training and skills for staff and volunteers.

4.2 STUDY LIMITATIONS AND IMPLICATIONS FOR FURTHER RESEARCH

Although extensive effort was made to collect data from all bereavement service providers in Wales, not all service providers that were sent the survey completed it and it is possible that others may not have been identified, despite the extensive searching, promotional and snowballing techniques described in the methods section. The research team made extensive efforts to maximise the response rate by sending the survey directly to organisations, sending email reminders and telephoning potential respondent organisations to encourage survey participation. The research team also found that it was unclear who should complete the questionnaire in some organisations. This was as a result of some organisations not being able to identify a single person/department/job role tasked with bereavement care. This limitation means that our data set and results may only partially represent the extent and nature of bereavement service provision in Wales and should be seen as indicative rather than exhaustive and conclusive.

The need to design a survey which could capture information relevant to the broad spectrum of bereavement care in Wales also presented a challenge and the possibility of subjectivity and variability in how question items were interpreted and responded to by different types of respondents. The research team tried to mitigate this risk by designing a focused questionnaire, validating it among stakeholders in the field of bereavement in the UK, and piloting it to further enhance its validity and reliability.

This study has also only captured an overview of structured bereavement support in Wales. Further work would be required to determine the less formal types of bereavement support available (e.g. social ventures like coffee mornings), and the perceived impact and value of such provision, as fits with the NICE and Public Health models of bereavement care already discussed [5,6]. Local needs assessments, incorporating the views of the bereaved/members of the public could also help to determine the key gaps and priorities for future service development in this area.

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For further details please contact Cynthia Ochieng, Research Associate by telephone on 02920687211 or by email at OchiengC@cardiff.ac.uk.

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APPENDICES

APPENDIX 1A

Number of responses offering bereavement support in each Welsh local authority

Local authority	Number of responses offering bereavement care in the authority
Blaenau Gwent	16
Bridgend	17
Caerphilly	17
Cardiff	19
Carmarthenshire	17
Ceredigion	12
Conwy	14
Denbighshire	12
Flintshire	13
Gwynedd	10
Isle of Anglesey	11
Merthyr Tydfil	14
Monmouthshire	15
Neath Port Talbot	14
Newport	18
Pembrokeshire	16
Powys	13
Rhondda Cynon Taf	19
Swansea	14
Torfaen	14
The Vale of Glamorgan	18
Wrexham	12

APPENDIX 1B

Numbers of services providing each component of support per Welsh local authority

Unitary authority	**NICE Components of support**		
	Component 1	Component 2	Component 3
Blaenau Gwent	15	12	9
Bridgend	15	12	9
Caerphilly	16	12	9
Cardiff	17	10	8
Carmarthenshire	13	10	10
Ceredigion	9	8	7
Conwy	8	8	8
Denbighshire	8	7	6
Flintshire	9	8	8
Gwynedd	6	7	6
Isle of Anglesey	7	7	7
Merthyr Tydfil	13	10	8
Monmouthshire	14	11	8
Neath Port Talbot	13	11	8
Newport	17	13	9
Pembrokeshire	13	13	8
Powys	12	10	7
Rhondda Cynon Taf	18	13	8
Swansea	13	11	8
Torfaen	13	11	7
The Vale of Glamorgan	17	13	8
Wrexham	10	9	7
Other (cross border)	19	13	9

APPENDIX 1A

Numbers of services providing each component of support per different categories of death

	Component 1	**Component 2**	**Component 3**
Pregnancy loss (Including Miscarriage, Ectopic/Molar Pregnancy, Termination of Pregnancy for Foetal Anomaly)	13	9	10
Neonatal death	20	15	16
Stillbirth	16	12	13
Paediatric / infant death	22	18	15
Adult death	27	21	15
Anticipated death including palliative care	22	17	13
Accidental death	20	16	13
Unexpected/ Sudden death	23	17	14
Suicide	23	18	14
Homicide	17	14	12
Dementia related death	15	12	8
Negligence or corporate manslaughter	14	11	9

APPENDIX 2B: POPULATION DATA BY HEALTH BOARDS AND LOCAL AUTHORITIES

Health Board/Local Authority	**Population Data**
ABUHB	**591225**
Caerphilly	181,019
Blaenau Gwent	69,713
Monmouthshire	93,049
Newport	94,142
Torfaen	153,302
BCUHB	**698369**
Isle of Anglesey	69,961
Gwynedd	124,178
Conwy	117,181
Denbighshire	95,330
Flintshire	155,593
Wrexham	136,126
CTUHB	**445190**
Rhondda Cynon Taf	240,131
Merthyr Tydfil	60,183
Bridgend	144,876
CVUHB	**496413**
Vale of Glamorgan	132,165
Cardiff	364,248
HDUHB	**385615**
Ceredigion	72,992
Pembrokeshire	125,055
Carmarthenshire	187,568
PTHB	**132,447**
Powys	132,447
SBUHB	**389372**
Swansea	246,466
Neath Port Talbot	142,906

Source: Office for National Statistics (ONS)

APPENDIX 3

A survey to scope Bereavement services in Wales

Part 1: About the survey

Background: Bereavement is associated with increased risks to mental and physical health. Appropriate support following bereavement can reduce these challenges. Bereavement care involves the provision of services to help an individual cope practically and emotionally following the loss of a loved one. In Wales, the government acknowledges that good care at the end of life, including sudden deaths, ought to include bereavement support for both adults and children to facilitate a healthy grieving process. To that end it is important to understand the different types of bereavement service available in each locality, to ensure an integrated mix of support services for all groups of bereaved people, and to provide accurate information on what support is available.

Purpose: The Welsh government has funded this project to produce a map of structured bereavement support offered in different areas within Wales. The findings from this survey will inform that process.

We are grateful for your time in completing the questionnaire as the accuracy of the survey in terms of breadth and depth of service provision is dependent on your engagement.

Part 2: Data Protection

Before you decide whether to consent to participate, please read through this page:

Voluntary participation: Participation in this survey is voluntary, and you may choose not to answer some or any of the survey questions. If you decide to withdraw at any stage, you do not have to give a reason why.

Confidentiality: The full survey results will only be seen by the project staff who are undertaking this survey. Any information we publish that might identify you, or others, will be anonymised.

Data protection and usage: All data collected in this survey will be held securely at Cardiff University in accordance with the General Data Protection Regulations (GDPR; EU 2016/679). For more information on data protection, please follow the link: General Data Protection Regulation (GDPR; EU 2016/679). Cookies, personal data stored by your web browser, are not used in this survey.

By participating in this survey, you are agreeing that your survey responses and anonymised extracts of text may be included in future reports, professional journals and future research. The results will be appropriately disseminated through the Welsh government and may be published in peer-reviewed journals, secondary analysis of the data, presentation in national and international conferences, or use for educational purposes. Your data will be kept securely for 15 years after the scoping exercise is completed in line with Cardiff University policies in addition to GDPR.

Risks and benefits: When using the internet, there can be a risk of compromising privacy, confidentiality and/or anonymity. We have taken the precaution of using a secure platform to conduct the survey in order to minimise these risks. By completing this survey, you are helping the Welsh government establish a map of the bereavement support available in different locations in Wales.

Contact information: If you have any concerns or questions relating to this questionnaire, please contact Dr. Cynthia Ochieng, Research Associate at OchiengC@cardiff.ac.uk or 02920 687211. Additionally, if you have a complaint or other queries, contact Professor Anthony Byrne on 02920 687175 or mariecuriecentre@cardiff.ac.uk, Marie Curie Palliative Care Research Centre, Cardiff University, 8th Floor Neuadd Meirionnydd, Heath Park, Cardiff, CF14 4YS.

This study is funded by the Welsh Government.

Part 3: Instructions for completion

- The survey should take about 10-20 minutes to complete.
- Please add any comments in the blank boxes that you feel are relevant or important.

Please bear in mind that the survey is designed to capture information on many different types of services. Therefore some questions may appear less relevant to you than others, but we would be grateful if you could please try to answer all questions that apply.

If you would like to request a Welsh version of the survey, please contact me on OchiengC@cardiff.ac.uk or 02920 687211.

Part 4: Consent

By agreeing to participate in this survey, you imply that you have read and understood the information above and that you are aged 18 or over.

Thank you for supporting the review by completing this survey.

I consent to participate in this survey and I agree that I have read and understood the information provided above.

- o Yes
- o No

Part 5: Demographics

Name of organisation:_____ Name of department/Ward:_____ Address: _____ Job title:_____ Name:_____ Length of service :_____
Part 6: The survey 1. Do you provide a bereavement service? a) Yes b) No **If no please skip to Section 6 (question 25).**
Section 1: Service description

2. Where is your service located? Tick all that apply

a)	Blaenau Gwent	b)	Bridgend	c)	Caerphilly	d)	Cardiff	e)	Carmarthenshire
f)	Ceredigion	g)	Conwy	h)	Denbighshire	i)	Flintshire	j)	Gwynedd
k)	Isle of Anglesey	l)	Merthyr Tydfil	m)	Monmouthshire	n)	Neath Port Talbot	o)	Newport
p)	Pembrokeshire	q)	Powys	r)	Rhondda Cynon Taff	s)	Swansea	t)	Torfaen
u)	Vale of Glamorgan	V)	Wrexham	W)	Other cross border (please specify)				

- If you provide bereavement support at any other sites other than the address listed above in demographics, please provide names of these sites here:
  _____

3. What is your catchment area? Tick all that apply

a)	Blaenau Gwent	b)	Bridgend	c)	Caerphilly	d)	Cardiff	e)	Carmarthenshire
f)	Ceredigion	g)	Conwy	h)	Denbighshire	i)	Flintshire	j)	Gwynedd
k)	Isle of Anglesey	l)	Merthyr Tydfil	m)	Monmouthshire	n)	Neath Port Talbot	o)	Newport
p)	Pembrokeshire	q)	Powys	r)	Rhondda Cynon Taff	s)	Swansea	t)	Torfaen
u)	Vale of Glamorgan	v)	Wrexham	w)	Other cross-border (please specify)				

- Does your catchment area cross University Health Board boundaries?

a) Yes
b) No
If yes how many? _____

4. How long has your service been in operation?
   a) Under 1 year
   b) 1-3 years
   c) 3-9 years
   d) Over 9 years

5. To whom do you provide the service? Tick all that apply
   a) Bereaved children and young people
   b) Bereaved adults
   c) Bereaved parents

6. Is the support that you offer restricted to people already known to your organisation? (eg family members of deceased patients)
   a) Yes
   b) No

7. Is the support that you offer restricted to any other group of people not listed above? (eg members of particular religious/cultural group, particular society or institution etc)

   a)Yes, please specify_____
   b)No

8. Do you specialise in providing support for specific categories of deaths?
   a) Yes
   b) No

- If you specialise, tick all that apply:

a) Pregnancy loss (including miscarriage, Ectopic/ Molar Pregnancy, Termination of Pregnancy for Foetal Anomaly)
b) Neonatal death
c) Stillbirth
d) Paediatric/infant death
e) Adult death
f) Anticipated death including palliative care
g) Accidental death
h) Unexpected death/Sudden death
i) Suicide
j) Homicide
k) Dementia related death
l) Negligence or corporate manslaughter
m) Other (please specify) _____

9. Which of the following types of support do you provide? (See question 8 for list of services provided). Tick all that apply
   a) Information on grief and sign posting to other services
   b) Reflective chat on grief with a person or group
   c) Specialist intervention involving mental health services, psychological support or specialist counselling
   d) Other type of support, please specify_____

Section 2: Service details

10. If known please tell us the approximate proportions of your service users requiring the following types of support:

- Information on grief and sign posting
   a) 0-25%
   b) 26-50%
   c) 51-75%
   d) 76-100%
   e) Information not available

- Reflective chat on grief with a person or group
   a) 0-25%
   b) 26-50%
   c) 51-75%
   d) 76-100%
   e) Information not available

- Specialist intervention involving mental health services, psychological support or specialist counselling
   a) 0-25%
   b) 26-50%
   c) 51-75%

d) 76-100%
e) Information not available

- Any other type (s) of support, please specify and give rough proportions of service users that take up this type of support _____

11. How do you provide your bereavement service? Tick all that apply
    - Immediate post-death support (eg Providing bereavement suites, memory making activities), please specify_____
    - Sign-posting to other services and giving information on grief (including leaflets)
    - Telephone support (including helpline, face time and skype)
    - Home visit
    - Remembrance services
    - Drop-in support
    - Group meeting
    - Online community
    - Peer support
    - One to one counselling
    - Group counselling
    - Specialist Mental health support
    - Other (Please specify) _____

12. Do you provide any written material/ multimedia resources to service users?
    a) Yes
    b) No

- What does this resource look like?
    a) Pamphlets/leaflets
    b) Websites
    c) Social media
    d) DVD
    e) Audio recording
    f) Other (please specify) _____

13. Where is the bereavement service provided? Tick all that apply
    a) Hospital, please specify which ward/clinic_____
    b) Primary Care (e.g. GP surgery)
    c) Hospice
    d) Your own premises
    e) Other organisation offices
    f) Community centre
    g) People's homes
    h) Other (please specify)_____

Section 3: Service users description

14. If known, approximately how many new users take up your service each year?
    a) 0-20
    b) 21-50
    c) 51-100
    d) Over 100
    e) Not known

15. How do service users access your service?
    a) Self-referral
    b) Referral from external sources (please specify) _____

16. If known, roughly what proportion of the total referred people take up your bereavement service?

a) 0-25%
b) 26-50%
c) 51-75%
d) 76-100%
e) Information not available

17. If known, on average how soon after bereavement do your service users get support?_____
18. Is your bereavement support time limited?
    f) Yes
    g) No
    - If yes please specify_____
19. Are service users charged to access your bereavement service?
    a) Yes
    b) No
    - If you charge, roughly how much per session?_____
20. Is there a waiting list for people to access your bereavement services?
    a) Yes
    b) No
- If known, on average how long does it take to access the service? _____
21. Do you use a risk or needs assessment tool to help you provide the right level of support?
    h) Yes
    i) No
    j) Don't know
- If yes, which risk/ needs assessment tool does your service use?

  _____

Section 4: Funding and management of the service

22. Who funds the service? Tick all that apply

a) Central government
b) Local authority
c) Health board
d) Business entity
e) Registered Charity
f) Ad hoc Well wishers and donations from the public
g) Fees paid by service users
h) Others (please specify) _____

23. Your Team	Volunteers	Paid staff
a. How many volunteers and paid staff provide bereavement care in your service? (estimate if not known)		
b. If known, roughly what proportion of your volunteers and paid staff have bereavement related qualifications or are working towards these qualifications (e.g counselling, social work)	a) All b) Over 50% c) Less than 50% d) None e) Don't know	a) All b) Over 50% c) Less than 50% d) None e) Don't know
c. Please give examples of types of relevant qualifications held _____ _____		

24. Who provides your bereavement service? Tick all that apply
    k) Midwife

l) Nurse
m) Doctor
n) Non-clinical staff
o) Other (please specify)

25. Please give examples of the types of training and support available to staff and volunteers:
_____

Section 5: Service assessment

26. Is your organisation externally assessed and/or inspected?
a) Yes
b) No

- If yes, specify assessing organisation:
a) Health board
b) Local authority
c) Social care
d) Other (please specify) _____

27. Are there any other ways in which your service is evaluated?
a) Yes
b) No
c) Don't know

- If yes, please describe _____

Section 6: External referral and Medical examiners

28. Do you refer services users to other support?
p) Yes
q) No

- If yes, what type of services do you refer on to: _____

Type of support	Name of provider
a) Group meetings	
b) Counselling	
c) Specialist Mental health support	
d) Other (please specify)_____	

29. Are you aware of the Medical Examiner process that will be introduced in England and Wales from 1st April 2019?
a) Yes
b) No

30. Do you envisage this affecting how any of your services are provided?
r) Yes
s) No
t) Not sure….

31. If yes, what assessment/planning have you undertaken in preparation for the introduction of Medical Examiner process?
_____

Section 7: Gaps and challenges of service provision

32. What challenges regarding bereavement support do you face in service delivery?
a) Access to training

b) Access to funding
c) Access to specialist support
d) Access to appropriate facilities
e) Unable to meet demand for service

33. Please describe any further gaps or challenges in bereavement support that that you experience or perceive;

- Within your service

- Within your locality

- Within Wales

Thank you for completing the survey. If you have any questions please contact the Research Associate at OchiengC@cardiff.ac.uk or 02920687211