

STUDY TITLE: Bereavement scoping study in Wales

INTERIM STUDY REPORT

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This report is written as an interim description of the bereavement scoping in Wales exercise commissioned by the End of Life Care Board and conducted in 2019.

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SUMMARY

Support following the loss of a loved one can reduce the emotional, physical and mental impact of grief. It is therefore acknowledged by various organisations that bereavement care services should be accessible to those in need of it. Three components of bereavement support have been described by 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 the provision of all the 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. The proposed scoping review will aim to gather this knowledge through conducting a survey of all structured bereavement providers identified across Wales. The survey was developed through a literature review of other bereavement scoping studies and relevant surveys as well as consultation with bereavement care experts, healthcare professionals and academics. Data presented here has been analysed using descriptive statistics; analysis of the free text data will be conducted via thematic qualitative analysis.

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

1 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 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]. Good quality end of life care as well as good communication between professionals and patients and their loved ones has been reported to help families cope with bereavement [6]. The Welsh Government are therefore supporting projects promoting awareness and online resources aimed at facilitating societal discussions on death and bereavement [4]. Many community bereavement services are provided by the voluntary sector and 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]. Given that bereavement support is provided through different sectors in Wales, the current scoping exercise will help outline the proportion of different sectors providing different types of bereavement support, as well as their integration in service delivery in different areas. One of the priorities of the End of Life Board in Wales (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 healthy grieving process through responsive and effective bereavement services, which has led to the Welsh Government promoting bereavement support in acute hospitals as well as funding studies such as this one [5]. It is also argued that due to the varied nature of bereavement support, further knowledge is required to inform service planning and delivery [6]. This scoping review aims to collate this information thereby improving knowledge of and by extension access to bereavement services in Wales.

1.1.1 AIM AND OBJECTIVES

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

- What bereavement support is available in different areas in Wales?
- For whom are these bereavement services available?
- Which of the NICE components for bereavement support do the services offer?

- Which performance indicators do bereavement services use?
- What are the gaps in bereavement support in different parts of Wales?

2 STUDY DESIGN

2.1 SURVEY DEVELOPMENT

Meetings were held with the funder, a Welsh Government representative and the study team in order to agree on a review question and the scope of the study. A literature review was conducted including similar studies that had been conducted in the UK (and EU that included UK), of scoping or evaluation of bereavement services. From the review, key themes were identified that were deemed useful for this scoping exercise. Also identified from the review were previous questionnaires that had been used in similar studies on bereavement, which aided the development of the survey [7, 8]. Based on discussions with the funder, fellow academics and the findings of the literature review, a logic model was designed to outline the scoping review. The protocol for the scoping exercise was then written based on the agreed parameters resulting from the discussions with the EOLB, the Welsh government and academics from Cardiff University.

A draft survey was then developed in line with the aims of the scoping exercise, with further revisions made following peer review and discussion with the study team, the Welsh Government and the EOLB. The questions in the survey seek information on: service description and location, service user description, management, assessment and funding. The survey also includes categorical responses using Likert scales, and free text boxes for further detail and perceptions.

The survey was then reviewed for validation with a number of key stakeholders within the field of bereavement support (including GPs, Hospice of the Valleys, 2 Wish Upon a Star, Tommys, SANDS, Bliss among others). The electronic version of the survey was also 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.

2.2 ETHICAL APPROVAL

Following advice from Cardiff University SoMREC, permission was granted to conduct the survey without the need for University ethical approval. This was on the basis of the survey not being a traditional research project but rather a scoping exercise which would not require formal Ethical approval. That notwithstanding, the scoping exercise was designed and is being conducted under strict Ethical principles. Through project documentation, all participants have been 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 will be applied to managing their data. This scoping exercise is being conducted according to the principles of good research practice (including proper and appropriate conduct of research, professional integrity, honesty, statistical methods, use of data, interpretation of data, non-plagiarism) and the Research Governance Framework for Health and Social Care [9] as well as GDPR [10].

2.3 SAMPLE SELECTION

The review was carried out at sites providing bereavement support in Wales. While it is appreciated that unstructured support following bereavement such as social gatherings are valuable in providing component one of NICE bereavement support, identifying all such endeavours is anticipated to be unattainable within this study. However, effort is being made to include as much bereavement support as is identifiable.

A database of bereavement service providers was collated from a detailed online and database searches. Resources used include Dewis Cymru, the Childhood Bereavement Network, NHS Direct Wales, and Cardiff Bereavement Services which yielded 60 bereavement services in the third sector, government funded and privately owned organisations. A list of 583 GP practices in Wales (via NHS direct Wales website) including their practice managers was also collated. A further list from the NHS website was made of 90 hospitals (following further research 7 of these were found to have been permanently closed at the point of data collection). All hospices in Wales were also identified via the End of Life Board and a search of available databases.

A cover letter of introduction from the Deputy Chief Medical Officer (Wales) underpinning the importance of the study was used as an introduction for the study and sent out via e-mail with an electronic link to the on-line survey. The survey was sent to all hospices and other charities identified as providing bereavement support in Wales, as well as those across the border which are 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.

There were a number of challenges faced in identifying contact email addresses for recruitment. Particular challenges were met in trying to identify email addresses associated with the 583 GP

practices in Wales. Most of these GP practices did not have an external facing email address. A number of strategies were therefore utilised to try and reach the GPs including:

- Cold calling GP surgeries
- Extensive internet searches of GP contact details
- Emailing GP practices with external facing email addresses
- Introducing the survey through GP contact forms online
- Approaching Health Boards to request them to disseminate the survey to GP in their health boards
- Requesting the survey to be posted in different GP forums such as GP One newsletters and mailing lists
- Having the survey disseminated by a representative from the Welsh Assembly
- Efforts were also made to seek email contacts of GPs from the Deanery, Health and Care Research Wales and the Primary Care Research team at Cardiff University.

Recruitment in hospitals was also 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. Some hospitals also referred the study team to their Chaplaincy service.

Efforts to enhance recruitment in hospitals and among charities included:

- Dedicated cold calling of the hospitals
- Disseminating the survey through health boards in Wales
- Publicising of the survey through the Welsh government to hospitals, charities and other stakeholders (councils, community psychologists)

Non-respondents were followed up with telephone calls and emails five weeks after the initial launch of the survey. Snow ball sampling is also being conducted from the survey responses, and any new organisations identified from the survey are currently being invited to participate.

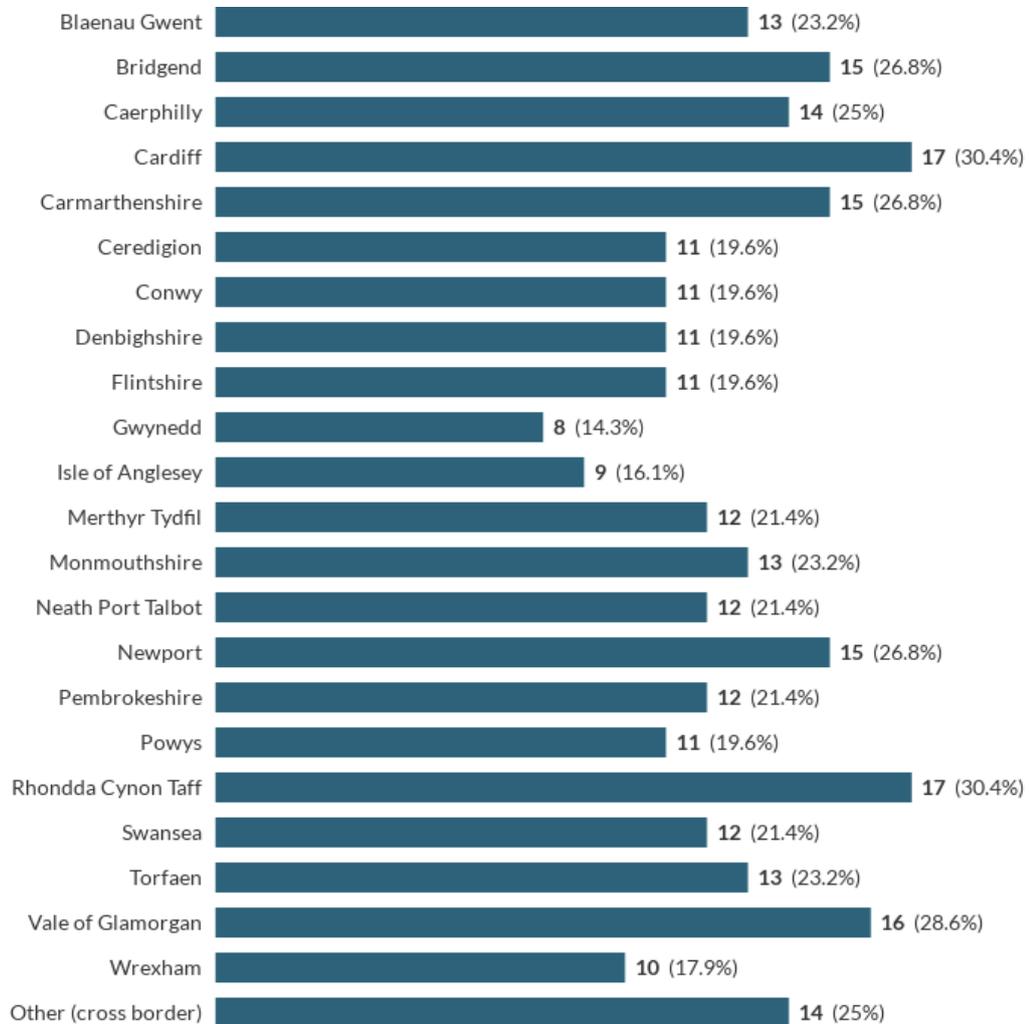
Opportunities for recruitment will also be sought through professional networks of bereavement and neonatal nurses; councils, prisons, and through twitter.

3 PRELIMINARY RESULTS

As of the 14th of May 2019, the survey comprised of data from 210 respondents including: health boards (7), hospitals (49), hospices (8), GP practices (76), psychological and social care workers (3), councils (13), charities (57) and others (4). These respondents either provided bereavement care within Wales, provided referrals for bereavement services or provided bereavement services nationally but available to Welsh residents. 26.7% (n=56) of these respondents provided bereavement support.

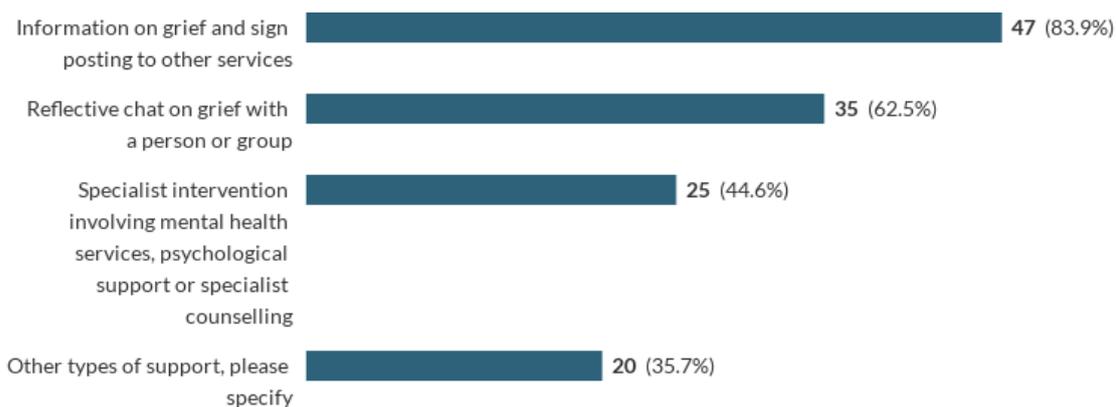
3.1 AREA COVERED

The catchment area for the bereavement care described was represented in the graph below (n (%)):

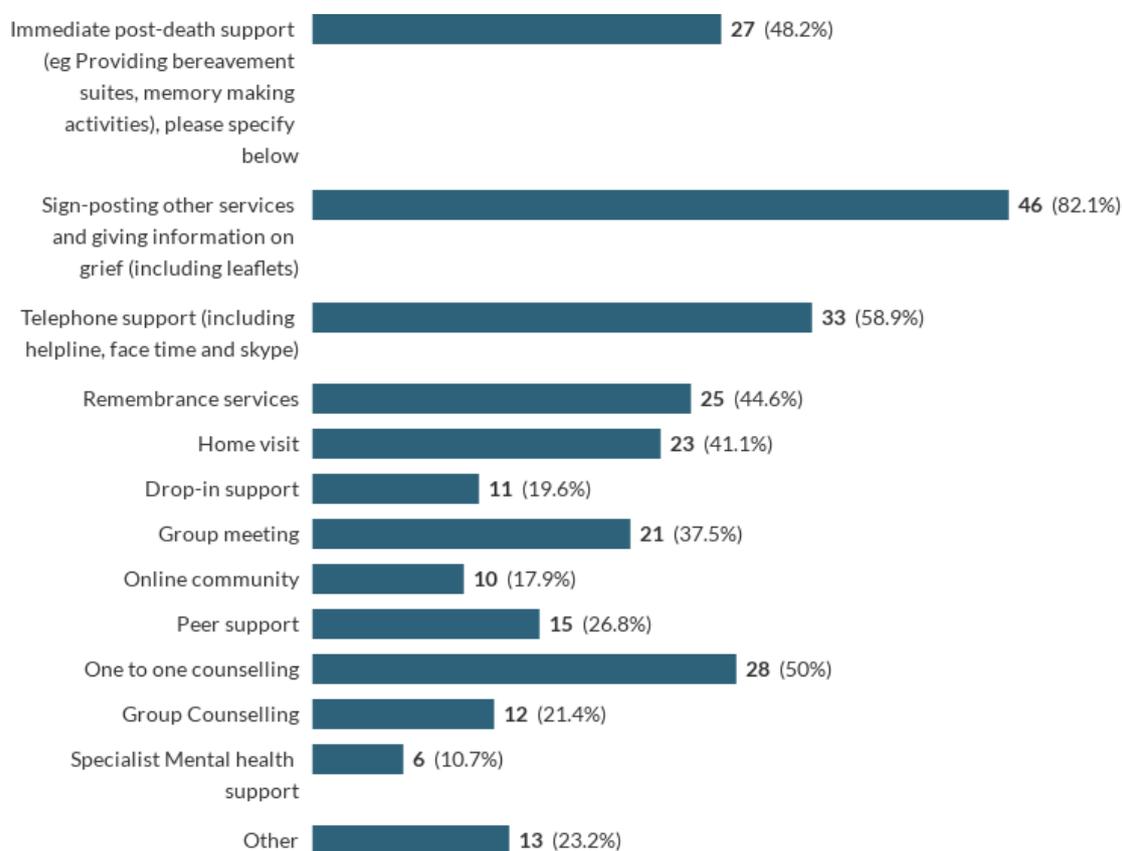


3.2 SERVICES PROVIDED

Based on the NICE guidance, the survey revealed that the following bereavement care components were provided by respondents:

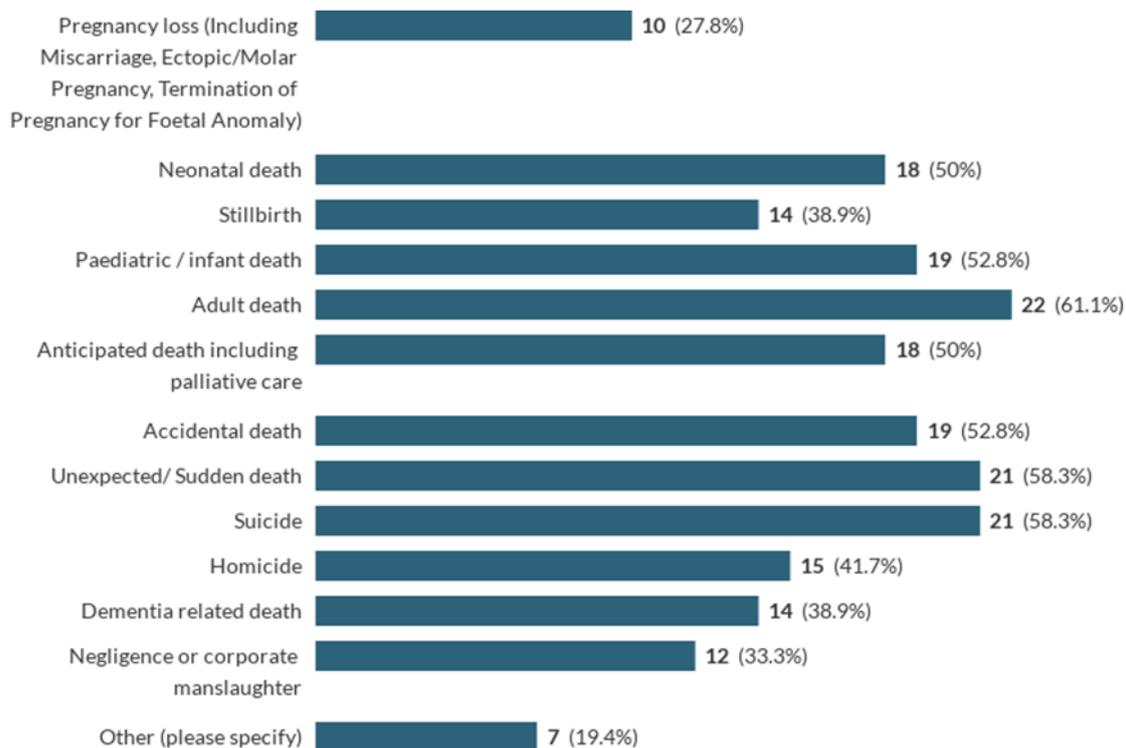


The specific bereavement care was provided as follows:



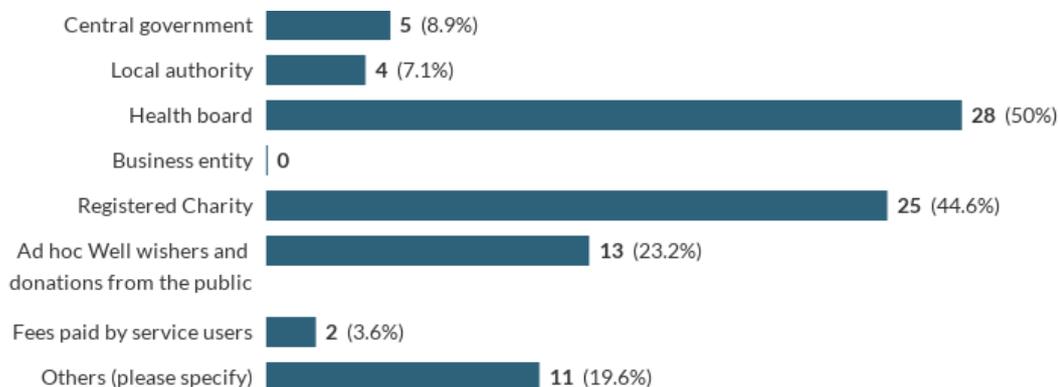
3.3 SPECIALITIES

The bereavement services were distributed as follows: bereaved children and young people (n=36), bereaved parents (n=40), bereaved adults (n=46). Additionally, the bereavement services described covered the following categories of death:



3.4 FUNDING AND REFERRAL

94.6% (n=53) of those who provide bereavement care did not charge for the bereavement support they offered. Funding for the service was provided as follows:



91% (n=191) of the total respondents referred their service users to other bereavement support. Referral to the support was mainly through self-referral (67.9%, n=38) and external referral (69.6%, n=39). Additionally, 69.6% (n= 39) did not have a waiting list for the service.

3.5 RISK ASSESSMENT

50% (n=28) used a risk assessment tool, while 44.6% (n=25) did not. 53.6% (n=30) had their service externally assessed.

3.6 MEDICAL EXAMINER

71.9% (n=151) of the respondents were not aware of the newly introduced medical examiner role with 79.7% (n=149) being unsure of whether this would affect their service provision.

3.7 CHALLENGES OF SERVICE PROVISION

The main challenges faced by service providers were:



4 NEXT STEPS

Data collection is on-going with 30th June 2019 being the anticipated closure date for the survey. Preliminary analysis of the data has begun with the production of this interim report, a more exhaustive analysis of the entire data set will be conducted after the completion of data collection. This will be reported in full at the end of study, this final report is due in October 2019.

COLLABORATIONS

The scoping review has been developed in collaboration with the End of life Care board in Wales, the Welsh Government, Cardiff University, Marie Curie Palliative Care researchers, SANDS, Bliss, 2 Wish Upon a Star, Tommys, Hospice of the Valleys, Cruise bereavement among others. Their involvement was greatly appreciated. Support for this project from Alison Evans and Alisha Newman is also appreciated.

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