

Commissioning for Compassionate Community Bereavement Support

Identifying local needs and mapping support & gaps

This document is intended to help communities, providers and commissioners to identify levels of need for bereavement support in a local population, map the support that is available, identify gaps and consider how to fill these. It sets out three main types of activity.

- Involving bereaved people
- Using local data
- Mapping existing support and identifying gaps.

This guidance forms part of a suite of resources for commissioners and providers of bereavement services. These resources are intended to build on the opportunities in the Health and Care Act 2022 and the UK Commission on Bereavement. These provide new structures and ways of working for local people, communities and services to collaborate to set out a vision for bereavement support in the local area, and to work together to make this vision a reality.

Overall, these will help communities, providers and commissioners collaborate to ensure that the full range of bereavement support is in place and integrated, following expected and unexpected deaths across an Integrated Care System or place-based partnership.

To see the full suite of resources, visit

<https://nationalbereavementalliance.org.uk/ourpublications/commissioning/>

Involving bereaved people

It is crucial to involve bereaved people in identifying needs, mapping support and understanding more about gaps in the local area.

By building their participation in right from the start, you increase the likelihood of making sure that the vision of support for bereaved people locally is truly rooted in what bereaved people want and need.

Bereaved people want to be involved in research and service design (Cook et al 1995, Beck et al 2007). Participation can empower bereaved people and contribute to them finding meaning in their experience, which is known to help manage grief.

Resources for co-design

There are many resources available to help you design surveys, stakeholder workshops and other forms of consultation with bereaved people.

- [Statutory guidance](#) from NHS England supports effective partnership working with people and communities, and a ['how to' series](#) sets out core principles and practical tips
- Public Health England has set out a ['family of community centred approaches'](#) that draw on community assets to improve health and wellbeing
- The Coalition for Personalised Care has [information and resources about co-production](#)
- A [toolkit](#) for designing and planning locally-led VOICES end of life surveys (Hunt and Addington-Hall 2011) provides general guidance about surveys of bereaved people.

Prioritising under-served communities

It is crucial that you hear from groups that face particular difficulties in bereavement, and challenges in getting the support they need. Consider

- groups who are more likely to be bereaved because of patterns of mortality
- groups who are particularly affected by risk factors in bereavement (e.g. social isolation, poor physical health, previous experiences of trauma)
- groups who have previous poor experiences of health and other services because of racism, discrimination or other forms of exclusion and injustice
- groups whose bereavement can be overlooked or ignored
- groups who face particular barriers in accessing bereavement support.

It can be helpful to partner with community organisations, faith groups and community elders to improve your reach.

- The [Health Equity Assessment Tool \(HEAT\)](#) provides a framework to support systematic action on health inequalities and equities
- Kingston upon Thames, SW London ICS have produced a [case study](#) on developing bereavement services via community engagement (email england.palliativeandendoflife@nhs.net for access) including a discussion guide for focus groups that were run in partnership with local community groups.

What to ask?

Your involvement work should gather

- the experiences that people had before, around and after the death that impacted on their bereavement
- the support they needed and the support they got
- their suggestions for how support could be improved and extended in the local area.

Tips

- Consider involving bereaved people not just as participants but also in designing and delivering the tools you use to gather evidence, such as co-designing surveys and facilitating stakeholder workshops.
- If you want to quote from what people tell you in surveys, workshops or other events, make sure you have their consent to do this.

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- Think carefully about the support that people will need if you are asking them about their experiences of bereavement. If you are running a stakeholder workshop, make sure you have plenty of facilitators who can support participants if they become upset. Draw up a leaflet with sources of useful information and support.
- Consulting with members of the community about the support available and gaps can create an expectation that more support will soon be available. Make sure that you are clear about next steps with participants, and follow through on promises to keep them informed.

Using local data

The level of need for bereavement support varies across local areas. The key driver will be the number of people bereaved each year, but their needs will be affected by a range of protective and risk factors. These include the types of deaths experienced in the area, levels of social connection and volunteering, rates of poverty and disadvantage.

In considering the needs of bereaved people in your area, it is also helpful to think about the particular local priorities and challenges that are outlined in your Joint Strategic Needs Assessment and Joint Health and Wellbeing Strategy, along with local circumstances that might affect how you deliver services (for example, travel times across the area). Demographic data will give you information about the cultural, language and faith needs of the people you are aiming to serve.

Finding local data

The national public health datasets produced by the Office for Health Improvement and Disparities is a rich source of data at different levels on a wide variety of topics. These can be viewed and manipulated at <https://fingertips.phe.org.uk/>. Some of the most relevant datasets are outlined in the table below.

The [guidance page](#) explains how to select a theme and specific indicator, how to view this at a particular geographic level such as local authority or ICB, and how to benchmark against a regional or England average.

Theme	Relevant indicators
Mortality profile	<ul style="list-style-type: none"> • Premature mortality: under age 75 for all causes and leading causes of death • Leading causes of death • Preventable mortality • COVID-19 mortality • Other mortality including drug misuse, suicide, and road casualty
Palliative and end of life care profiles	<ul style="list-style-type: none"> • Percentage of all deaths that are of people of different ages • Place of death • Underlying cause of death • Needs assessment including proportion of households in fuel poverty, overcrowding and proportion of older people living alone

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[Public Health Outcomes Framework](#)

- Healthy life expectancy
- Wider determinants of health e.g. child poverty, employment rate, crime, homelessness, social isolation and loneliness
- Health improvement: child health, physical activity, health screening, self-reported wellbeing (including happiness and anxiety)
- Premature mortality from different causes
- Supporting information: deprivation score, percentage of population in different age groups and from minority ethnic communities

[Mental Health and Wellbeing JSNA](#)

- Estimated prevalence of common mental disorders
- Risk factors e.g. % of school children with
- Wellbeing e.g. % who have volunteered more than once in the last 12 months, % of >16 who feel like they belong in their neighbourhood
- Services e.g. % of people estimated to have anxiety/depression who access IAPT services

[National General Practice Profiles](#)

- Local demography
- % people with caring responsibility
- Satisfaction with care

Tips

- Attempts have been made to identify the number of bereaved people in a given area by multiplying the number of deaths by the number of people who might be affected. These estimates should be used with caution, for several reasons.
- There is no simple relationship between the number of deaths in an area and the number of bereaved people with a given set of needs. Commissioners and providers need to think carefully about the particular characteristics of their area and how these will affect people's experiences of bereavement. For example, bereaved people in an area of high social cohesion may be more likely to get the support they need from families and friends than those in an area with high rates of social isolation. People living in socio-economically disadvantaged areas are more likely to face significant financial stress following bereavement which can worsen the emotional impact of their grief.
- Estimates of what proportion of people need support at which level - including those in the NICE three-component model - are derived from studies of widowed people or 'key carers', generally focussing on one bereaved person per death (Aoun et al, 2015; Ward et al, 2004). These suggest that around 10% of those people needed component 3 support, 30-35% needed component 2 support, and the rest managed with component 1 support. Caution must be used when extrapolating levels of need from these sub-sets of bereaved people to the general population to avoid over-estimating rates of vulnerability
- Families and friends are often dispersed, meaning that many bereaved people do not live near the person who died. Commissioners and providers also need to consider the needs of people in their area who are affected by deaths in another area (for example, adult children who have been caring at a distance for an elderly parent).

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- A systems level approach to exploring need is likely to be too broad: this is better considered at place or even neighbourhood level. Taking too broad an area will mask some of the nuances that affect people's experiences.
- Bereavement is an underlying cause or contributor to other difficulties such as loneliness, financial crisis, housing difficulties, and incapacity for work. Our summary of how bereavement maps on to the Public Health Outcomes Framework sets out more information on this.

Case study: service use

A specialist palliative care bereavement service gave information to 800 key carers following the deaths of 693 people (1.2 bereaved people per death). 312 people accepted support, of whom:

- 240 (30% of those contacted) received supportive counselling from trained and supervised volunteer bereavement support workers (NICE component 2 services)
- 72 (9% of the 693) received therapeutic counselling from specialist bereavement counsellors (NICE component 3 services)

In practice the boundary between the work of specialist, trained volunteers and specialist counsellors is fluid. Many practitioners, including volunteers, work with people with degrees of complexity.

Mapping existing support and identifying gaps

This part of the exercise will help you find out what is already available in your local community, understand the gaps and pressures, and build up a picture of bereaved people's needs from the perspective of those already working with them.

Doing this part of the exercise thoroughly will bring a number of benefits. In particular, it can provide:

- a picture of current service provision, activity levels and plans for the future, which can be cross-referenced to the needs you have identified
- the building blocks for a directory of local services, if this does not already exist
- a concrete first task for a new local bereavement forum or network which can help to build trust and collaboration, and identify further opportunities for working together. See our guidance on [setting up a regional network](#).
- the perspective of service providers on gaps in provision and how these could be filled.

Who to involve

A good starting point is to draw up a list of all those agencies who are concerned with end of life or bereavement support provision, as well as those agencies who may – directly or indirectly – come into contact with bereaved people. This will include

- organisations providing direct bereavement support as their sole role (such as a Cruse Bereavement Support area, suicide postvention service, or peer support group for bereaved children)
- organisations providing services to bereaved people as part of their wider role (such as a local registry office, NHS Talking Therapies service, or hospice)

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It may also be helpful to involve organisations that do not provide specific support targeted to bereaved people, but who have a number of bereaved people among their service users, such as lunch clubs, befriending projects and Citizens Advice).

See the 'membership' section of our [guide to setting up and running regional bereavement networks](#) for more ideas.

How to organise the mapping and consultations

Much of the relevant information can be gathered through desk research, followed up by

- an online questionnaire
- short phone or video interviews
- site visits.

You could also organise a stakeholder workshop. Make sure this is properly inclusive, and remember that some organisations may not feel comfortable sharing all the information you need (such as their financial position and sustainability) in a group setting.

What to ask

It is helpful to consider the following aspects of service provision as part of your mapping.

Theme	Relevant indicators
What do they provide?	<ul style="list-style-type: none">• Current provision: what is offered (e.g. groups, 1:1 support, practical assistance), to which groups of bereaved people, at what level, in what mode (e.g. in-person, telephone) and in which languages?• Assessment including risk assessment: how does the service tailor support to identified needs? What is the service's approach to managing the risks and vulnerabilities of people using their support?• Activity levels and waiting lists: how many people do they start supporting each year? Roughly how long do they support people for? How long do people have to wait for the service?• Referral routes (inbound and outbound): how do people hear about the service, where might they be referred on and in what circumstances?
How do they know it is needed? How do they know it is effective?	<ul style="list-style-type: none">• See our guide to assessment and evaluation for more details.
What more do they think bereaved people in the area need?	<ul style="list-style-type: none">• Inequities: which groups has the service identified as having poor access to support? How are they tackling this?• Community capacity building approaches: what is the service doing to build the capacity of the local community to support one another better?• Perceived other gaps: what does the service see as the key gaps in provision affecting bereaved families?•

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What more do they need to provide their support?

- **Partnerships:** what are the key partnerships that the service has or wants to build in the interests of bereaved people?
 - **Development:** what plans does the service have in the short to medium term? What is their wish list?
 - **Funding and sustainability:** what is the current funding mix for the service and what trends are the noticing in income? How sustainable are they?
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Tips

- Mappings and gap analyses are sometimes carried out and then forgotten. If you are initiating one, check to see if there is an earlier one available for your area which you can build on.
- Consider visiting stakeholders and potential service users rather than sending out a questionnaire – this can have a higher response rate.
- Although the mapping and gap analysis is useful in itself, it is important that this is part of a wider piece of work and not an end in itself. People who participate in the mapping need to see some sort of next step or plan for meeting the gaps that have been identified.
- A directory of services will go out of date surprisingly quickly. Try and build in some capacity to keep any publications updated.

Next steps

With all this information, you should have a clearer idea of what kind of provision is already out there and what more is needed to meet the needs of bereaved people in your community.

This will help you to set out a vision for support and begin to clarify how this can be provided and funded.

See our additional guides and resources, including how to make the case for support locally, at <https://nationalbereavementalliance.org.uk/ourpublications/commissioning/>

References

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www.nationalbereavementalliance.org.uk

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