Healthwatch Kingston
in collaboration with
Kingston Voluntary Action

Bereavement Services and Support in Kingston - Community Engagement Report

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Kingston upon Thames

Contents

1. Introduction

"Compassionate Communities recognise that all natural cycles of sickness and health, birth and death, and love and loss occur every day within the orbits of its institutions and regular activities. A compassionate community recognises that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone's responsibility."
A. Kellehear

The Covid-19 pandemic has highlighted the need to improve support for bereaved people. Plus, it is predicted that circumstances related to the pandemic will increase the numbers of people at risk of complicated grieving. Hence our review and dialogue with the community.

Grief is a normal reaction to bereavement and many people find that their inner resources, combined with support from family and friends, are sufficient to help them manage their distress and the life changes and adjustments triggered by loss. However, general awareness and understanding of grief is often lacking, which can leave bereaved people feeling lost and misunderstood. Additionally, bereavement is associated with risks to health and wellbeing and can give rise to a wide range of needs. Services that can help people manage their grief range from the provision of information through health promoting community-based resources to more intensive, specialist help for those whose reactions are complex or prolonged, and affect their ability to manage everyday life. The number of bereaved people is growing and ONS data suggested that alongside increases in the population, by 2040, it has been estimated that annual deaths in England and Wales are projected to rise by 25.4%.

The National Bereavement Alliance, ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 states that any 'commissioning plans must encompass good bereavement and pre-bereavement care, including care for children and young people'. Bereavement support is a core part of health and social care provision and is of heightened importance at times of mass bereavement. Public health approaches to bereavement care recognise the differing needs of bereaved people and recommend a tiered approach to support.

- The first-tier includes universal access to information on grief and available support, recognising that (in pre-pandemic times) c.60% of bereaved people cope without formal intervention, supported by existing social networks.
- The second-tier includes structured, reflective support, beneficial for those with moderate needs, estimated at c.30% of the bereaved population.

- Third-tier support, including specialist grief, mental health and psychological interventions, should be targeted at the small minority of people estimated at c.10% of the bereaved population.

Bereavement can have significant impacts on physical and mental health which have been shown to be related to social networks, circumstances surrounding the death and the length of time since the death.

In order to build a more comprehensive picture of the impact of bereavement on our local population, and to gather further insight into views on our current service provision, Healthwatch Kingston (HWK) and Kingston Voluntary Action (KVA) were commissioned by South West London Clinical Commissioning Group (SWL CCG) to undertake a pilot research project into people's experiences of bereavement services and support.

The local CCG had previously completed a mapping exercise on bereavement support and services. This initial work for SWL residents, seeks to build on London-wide mapping of bereavement support and services and in August 2021 HWK and KVA hosted a 'Let's Talk About Bereavement' consultation with Kingston residents and service users. Learning from both of these identified gaps and confirmed the need to further understand the experiences of people with under-served needs and those from under-served communities, such as BAME communities, children and young people, and people with learning disabilities.

This research aimed to initiate more in-depth discussion on specific issues that were identified during the consultation with local people. We undertook the research in 2021-2022 to support the South West London CCG's programme aim to: 'Improve awareness of, access to, and the quality of bereavement services and support for under-served communities' in Kingston.

We adopted a community engagement approach and explored the lived experience of those accessing bereavement services/support, what mattered most when grieving and the intersection with culture, faith and language barriers.

Three online surveys were designed collaboratively by the 'Think Tank' made up of representatives from HWK, KVA, SWL CCG/ICB, faith leaders, hospital chaplaincy teams, primary care teams, local bereavement services, funeral directors, local residents, Princess Alice Hospice, Royal Borough of Kingston (RBK) and Public Health teams, SWL EOLC (End of Life Care) and bereavement commissioning team, Staywell and Your Healthcare.

These surveys were shared across the Kingston communities via the communications teams associated with the membership of the group and by the Royal Borough of Kingston communications and engagement team and local media channels. We also ran 9 focus groups following a request for expressions of interest from community groups in Kingston, representing a variety of faiths, ethnicities, disabilities and ages.

This was a pilot project in Kingston on behalf of SWL CCG and we recognised that due to the challenges of getting people together during the pandemic for focus groups, there would be gaps. With the planned scaling of the model across SWL, we should be able to identify these gaps, for example veterans, gypsies and travellers. We also recognise that several major faiths and ethnic groups are missing from our data, but may have greater representation in other London boroughs. We will continue to build on this learning when scaling across South West London.

2. Executive summary

Dialogue between people who have been bereaved and the providers of support and services, including emotional support, funeral arrangements and death registration, is vital to identify what is working well, what needs to be improved, and unmet needs. This dialogue should include a focus on faith and cultural needs.

Death is a culturally significant event and honouring the dead with mourning and an appropriate funeral is crucial. It is important that when people have strong traditions and rituals that these are recognised and provided for, including provision for culturally sensitive rapid burial or cremation.

People are often struggling with grief and bereavement at the same time as they need to complete challenging administrative tasks that they may have not encountered before. These include registration of the death, funeral arrangements and notifying a wide range of organisations. It is important to have a clear, easily accessible guide on how to do this. Funeral directors were valued as a source of practical advice, and funeral poverty is a growing issue.

There are particular issues where the deceased person undertook all the ‘life admin’, especially if English was not the family’s first language and digital literacy is a problem. Age UK has estimated that 40% of people over 75 do not use the internet and the Digital Poverty Alliance is calling for greater help for the estimated 11 million UK citizens who lack digital life skills. It is important to ensure that people in this vulnerable situation are identified and supported.

Most support was provided by family and friends; people at risk of isolation need to be identified. A wide range of organisations also provided support such as Kingston Bereavement Services and religious organisations. However, there were often waiting lists for counselling and perhaps it should be clarified what support GPs can provide. Some people may find counselling more useful later in the bereavement process.

The results from our research suggest that some people find counselling is helpful when provided face to face. However, bereavement care and support should be assessed and adapted to meet the unique needs of each bereaved person. Not all support will require formal counselling with a trained practitioner face to face. The aim should be to resource those most in need (those less resilient and more vulnerable in their grief requiring therapeutic support from limited resources or finances). The type of bereavement experienced will require a level of understanding specific to the physiological and psychological symptoms being experienced. Bereavement care and support however provided, should be mindful of a person's faith, belief and lifestyle choices and delivered with kindness and empathy by the carer or practitioner and in the native language of the bereaved person. Speaking about death is still a taboo in some cultures.

The Covid 19 pandemic has had a large impact, on people who were bereaved and whose relatives were not able to achieve a ‘good death’ and culturally appropriate burial, and on staff who worked under enormous pressure and saw a great amount of death at first hand.

It is well recognised that the experience of a bereavement often has a major impact on both our emotional and physical health and our overall wellbeing. Dealing with the aftermath of the loss of someone important to you can be devastating, stressful and overwhelming. It is also acknowledged that good support, advice, up to date and relevant information and loving care for the bereaved is an important aspect of coming to terms with loss, but the range of services tends to be ad hoc and dependent on what resources are available to fund them, or indeed what community/peer led support there is - aside from friends and families.

Bereavement services can be offered through a range of individuals and providers, including those in the NHS, charity and voluntary organisations, through communities and other peer-led organisations, and in some circumstances, legal and corporate services (including probate firms and funeral providers). In the report we refer to bereavement counselling, in some instances, this is counselling provided by a qualified counsellor, however, this also encompasses other trained listening and supportive services provided by a variety of the organisations listed above. However, finding out what is available when in a state of shock and grief can be a difficult task, and may seem overwhelming.

The support needs of bereaved people with disabilities, children and young people, and people who have lost a child or pregnancy, for example, need further investigation. We have also identified that more research should be undertaken into bereavement support for our veterans and their families.

3. Recommendations

The following recommendations are derived from the Kingston community engagement pilot; however, they should be contextualised within the four pillars of the Compassionate Communities programme of work being delivered through the South West London Integrated Care System (ICS):

1. Primary Care Quality Improvement - improve coding of ethnicity, cultural/spiritual needs, bereavement status
2. Community development - baseline mapping, gap analysis, community dialogue, service reach vs needs, enhancing networks
3. Acute transformation - improve coding/information
4. Compassionate community charter - leadership to enable cultural change and support.

For the attention of ICS/Place leaders

1. ENSURE actions taken in response to the Kingston community engagement pilot recommendations align with the South West London End of Life Care action plans, other relevant strategies, and support the life-long approach (Start Well, Live Well, Age Well) set out in South West London local Health and Care Plans.

For the attention of Council Senior Leadership Team/Place Leaders

2. ENCOURAGE collaborative working between the borough bereavement officer, responsible for the local council funeral service, and organisations within Place.

3. PROVIDE bereavement services, crematoria and burial sites to meet the needs for all faiths, beliefs, and life philosophies, being mindful of community demand for culturally sensitive rapid burials or cremations.

4. ESTABLISH an RBK funeral service (offering a clear, transparent, set-price funeral arrangement which the bereaved can choose if they wish to) to address funeral poverty.

5. CREATE a multi-agency task and finish group to develop services, and a set of agreed bereavement service standards in consultation with local community groups. The Task Group should also monitor the uptake of bereavement services by different groups in order to measure the effectiveness of any changes and new services.

For the attention of Commissioners/Providers/Community leaders

Information

6. CO-PRODUCE a multi-cultural leaflet/document that is available to print and accessible digitally, of the practical steps on how to arrange a cremation or burial service, and how to access support services

7. MAKE all information about bereavement services and support accessible through *Connected Kingston* as the digital hub for the borough, to raise awareness of the local offer. Ensure information about end-of-life care, making funeral arrangements, and bereavement care and support is fully accessible to all residents.

8. CO-COMMISSION short educational films and other media to remove the fear of the unknown and stigma related to death and bereavement in a range of community languages, and upload to Connected Kingston so that other stakeholders can signpost to these, and maintain up-to-date links to a centralised point of current information.

Services

9. IDENTIFY what bereavement services and support networks are available for people with varying capacity to engage (such as with learning disabilities) and address any gaps in provision.

10. IDENTIFY what bereavement services and support networks are available for children and young people in education (including educational psychology) and address any gaps in provision.

11. REDUCE waiting lists for access to bereavement services and support. Design bereavement services which are inclusive of all kinds of loss and support that meet the diverse needs of individuals within our communities and explore different delivery models, including a tiered model.

12. INTRODUCE voluntary bereavement champions within the community to connect communities with bereavement services and support.

Frontline staff

13. UNDERSTAND the development needs of frontline staff and community volunteers to support culturally sensitive services and develop workforce learning plans.

14. PROVIDE pandemic specific support for frontline staff and residents/community members (such as care home staff and domiciliary care workers) who may have experienced trauma due to individual or multiple losses including social isolation, employment, and financial security.

Pre-Bereavement Care

15. OFFER all individuals who are experiencing a terminal illness (including their families, friends, and other carers), diverse and culturally appropriate, accessible information and support to assist in making pre-death funeral arrangements.

16. INCREASE identification of people who may be anticipating grief (for example in a care-giving role) as well as people experiencing grief following a loss and signpost more people with bereavement needs to bereavement services and support.

17. OFFER families, friends, carers, and others involved in pre-death care who are affected by the death, practical and emotional bereavement support, ensuring this continues as required after the funeral, including access to their pre-existing care support networks.

4. Research methods

In response to the Covid-19 pandemic and to support bereaved people across South West London, the South West London Clinical Commissioning Group (SWL CCG) had previously completed a mapping exercise on bereavement support and services. Following this, Healthwatch Kingston (HWK) and Kingston Voluntary Action (KVA) were commissioned by SWL CCG to undertake a more in-depth research project into people's experiences of bereavement services in the borough. This included how the Covid-19 pandemic had impacted our local residents and had affected the provision of bereavement services and support in Kingston.

Several priority areas suggested by the UK Commission on Bereavement were included in the discussions:

- Understanding what new challenges emerged as a result of the pandemic, and how it exacerbated existing problems
- Understanding how different social groups – including BAME communities, and people living in poverty - can be affected differently when bereaved
- Lessons that have been learned about the experience of bereavement during a mass bereavement event like Covid-19
- What recommendations should be made to different decision makers about how support for bereaved people could be improved, both now and in the long term.

In August 2021, HWK and KVA hosted a 'Let's talk about Bereavement Services' session at the HWK Open Meeting attended by 25 people. We explored:

- How could we work collaboratively (as a community) and engage with Kingston residents about Bereavement Services?
- What are the best methods for engagement?
- How do we best address issues around culture, faith, practice and beliefs?

The research covered experiences of bereavement before and during the Covid-19 pandemic and is part of a wider initiative at national level that aims to improve end-of-life and bereavement services and support. It provides examples of local people's experiences that they shared and covers the perspectives of community groups, bereavement services and health professionals on local provision.

We were delighted with the collaborative approach to this research, and the valuable participation of respondents and of our partners in the NHS, charity and voluntary sectors and the community support we experienced. A final report will be published by the UK Commission on Bereavement in 2022, and it is anticipated that our HWK/KVA local research will add depth, richness and value to those findings.

This report covers research conducted from August 2021 to February 2022. Methods used to collect data included:

- Survey (including Easy Read versions) for individual residents
- Survey for staff managing and providing bereavement services within the voluntary and community sector and the health service
- One to one case studies
- Focus group with Kingston community groups
- Focus group for faith, beliefs and life philosophy communities
- Engagement through the HWK website, email and voicemail and open meetings

A number of community groups applied to be part of this research with successful applicants awarded a small grant of £500 each to arrange community focus groups and contribute notes and one to one case studies. The groups were MILAAP (Multicultural Day Centre), the Korean Culture and Arts UK CIC, the Kingston Chinese Association, Kingston Carers Network, KAG Advocacy, Kingston Centre for Independent Living (KCIL), the Migrant Advisory Service, Tamil Information Centre and Oxygen (a charity for young people).

Members met in focus groups in January and February 2022, either virtually or face to face with the option for one to one discussions if preferred. A further inter-faith focus group was held in January 2022 that involved members of Christian, Hindu, Muslim, Buddhist, Jewish and Humanist organisations and faith groups in Kingston.

Two-hour sessions were conducted, supported by a short guide prepared by KVA, with questions to inform the discussions about experiences of bereavement in the borough. As these were scheduled during one of the virtual lockdowns, many were hosted via virtual platforms and follow up one to one calls. Some of the organisations ran two or three sessions in order to hear from as many members of their community as possible.

A survey was completed by 59 bereavement service providers and staff in health and other services, including 7 RBK staff, 17 staff from spiritual and pastoral support at Kingston Hospital, plus 11 people representing spiritual and pastoral support outside the hospital, 2 GPs, 19 health staff from Kingston Hospital, 2 staff from end-of-life services and one care home staff member. In addition, 9 VCSE leaders also completed the survey.

In summary:

- Three online surveys were designed collaboratively by the Think Tank. These were shared across the Kingston communities via the communications teams associated with the membership of the group and by the Kingston borough communications and engagement team and local media channels
- Public survey (128 respondents)
- Provider and health and social care professionals survey (59 respondents)
- VCSE organisations CEOs/Managers survey (9 respondents)
- Focus groups and one to one sessions (122 attendees)
- HWK Open Meeting, emails and telephone conversations (30 local residents)
- This report therefore was informed by 348 responses.

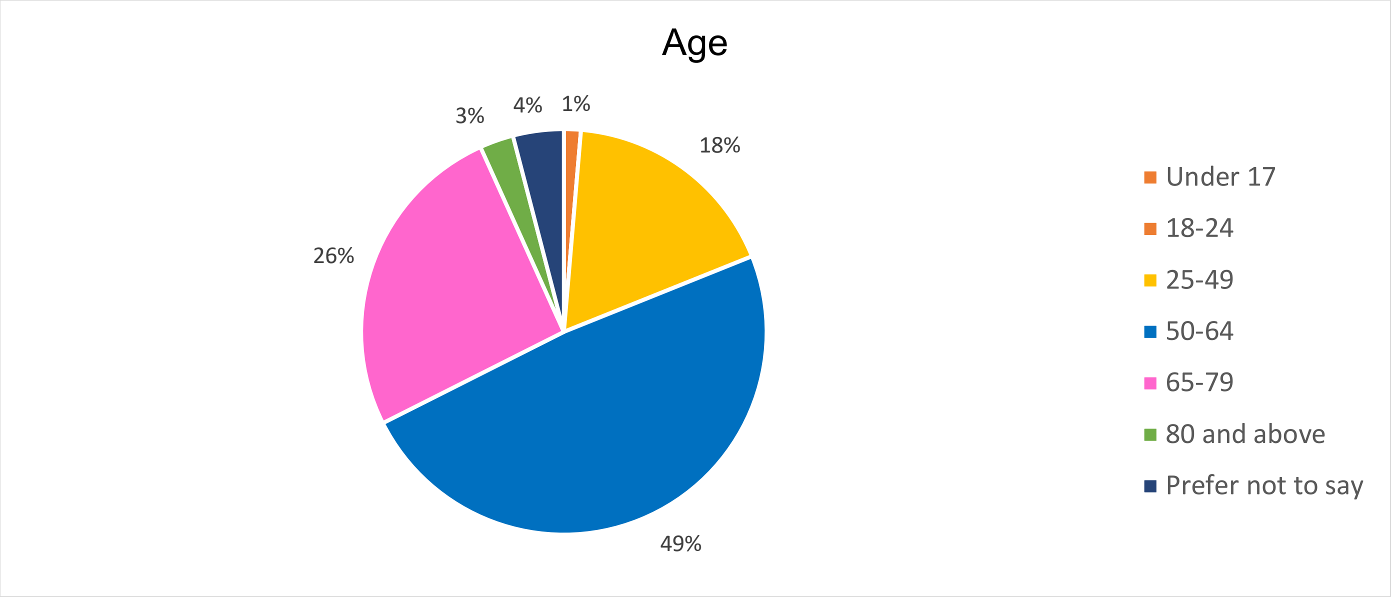
We recognise the methodological limitations in online surveys, but we were delighted with the number of responses, and the rich data from our focus groups and one to one interviews added real depth and value to our overall findings. As noted in previous surveys undertaken by HWK, it is acknowledged that they are a useful tool in gathering information in a timely fashion and for providing us with a snapshot of views and experiences at the time of the community engagement. The full quantitative dataset can be available upon request from Healthwatch Kingston – info@healthwatchkingston.org.uk

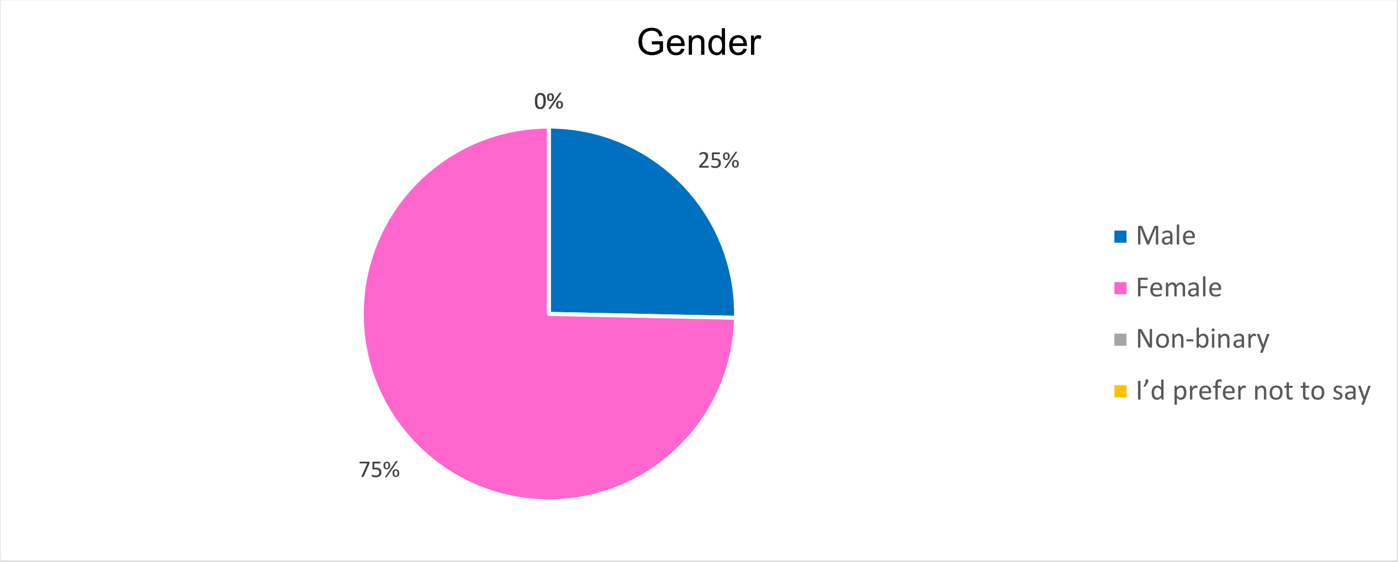
5. Summary of the online survey demographics

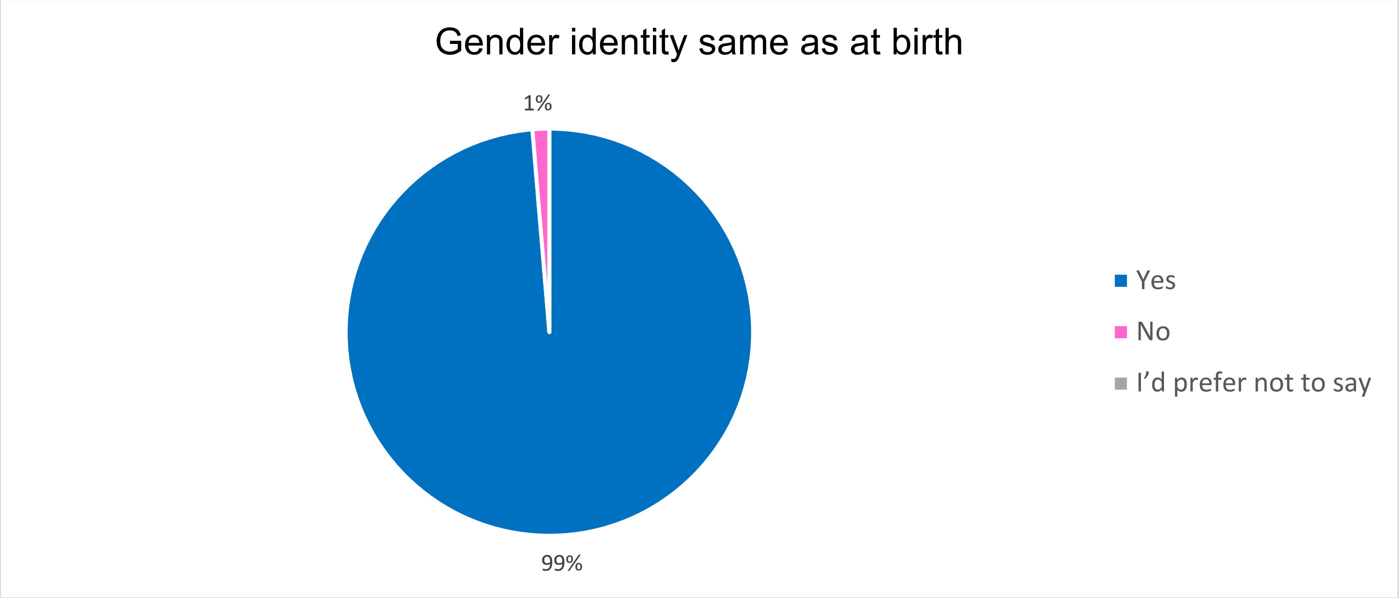
Both surveys had a larger representation from female respondents (frontline staff survey: 61% females, 37% males and 3% preferred not to say / public survey: 75% females, 25% males). Both surveys had the highest representation from people aged between 50-64 (frontline staff survey: 47% / public survey: 49%). There were more respondents from the public survey who were aged between 65-79 (26%) than the frontline staff survey (16%). This is likely to be due to fewer people aged between 65-79 currently working in bereavement services. 26% of the respondents to the frontline staff survey were aged between 25-49 whereas the public survey had fewer respondents aged between 25-49 (18%).

It is significant to note that the methodologies used to create these surveys, and the partnership work between HWK, KVA, Kingston VCSE and faith, beliefs and life philosophy groups, meant that this project benefited from a wealth of multi-cultural input. According to Government data, in Kingston 33.1% of the population are from the BAME community. Although we have used slightly different categories for the people that responded to our public survey, 30% said they were from a non-white background.

Demographics for service users from the public survey




Gender
0%
25%
75%
Male
Female
Non-binary
I'd prefer not to say


Gender identity same as at birth
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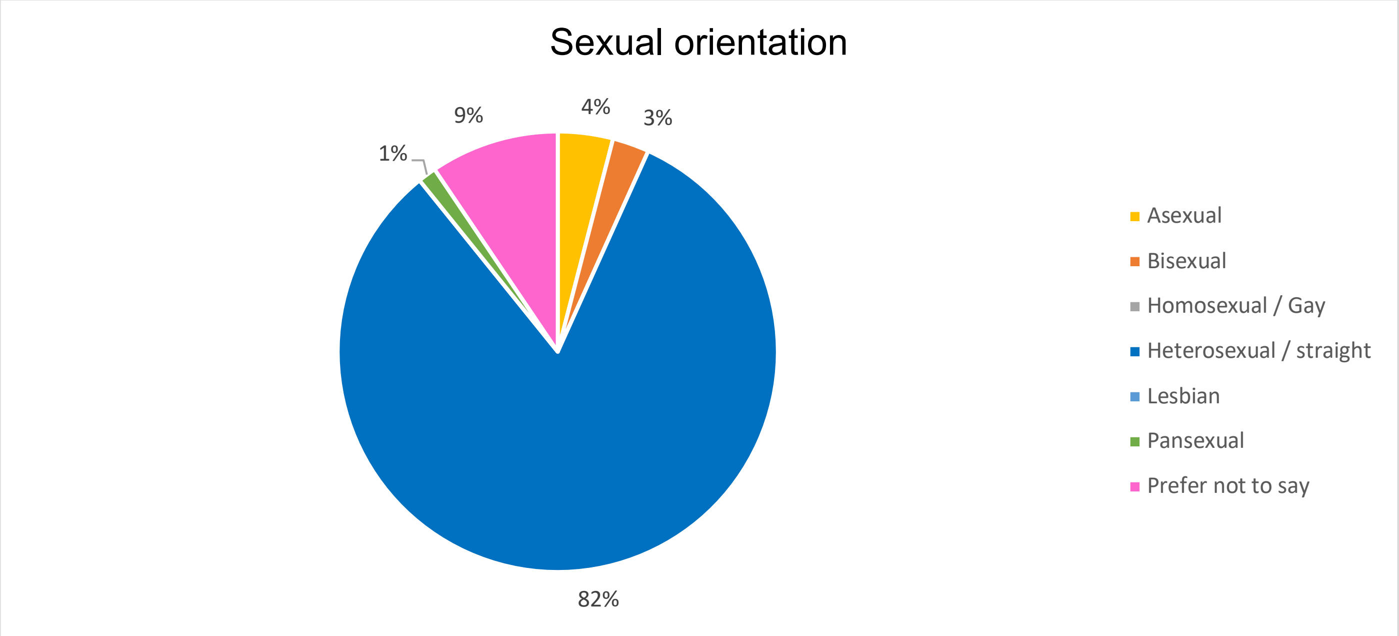
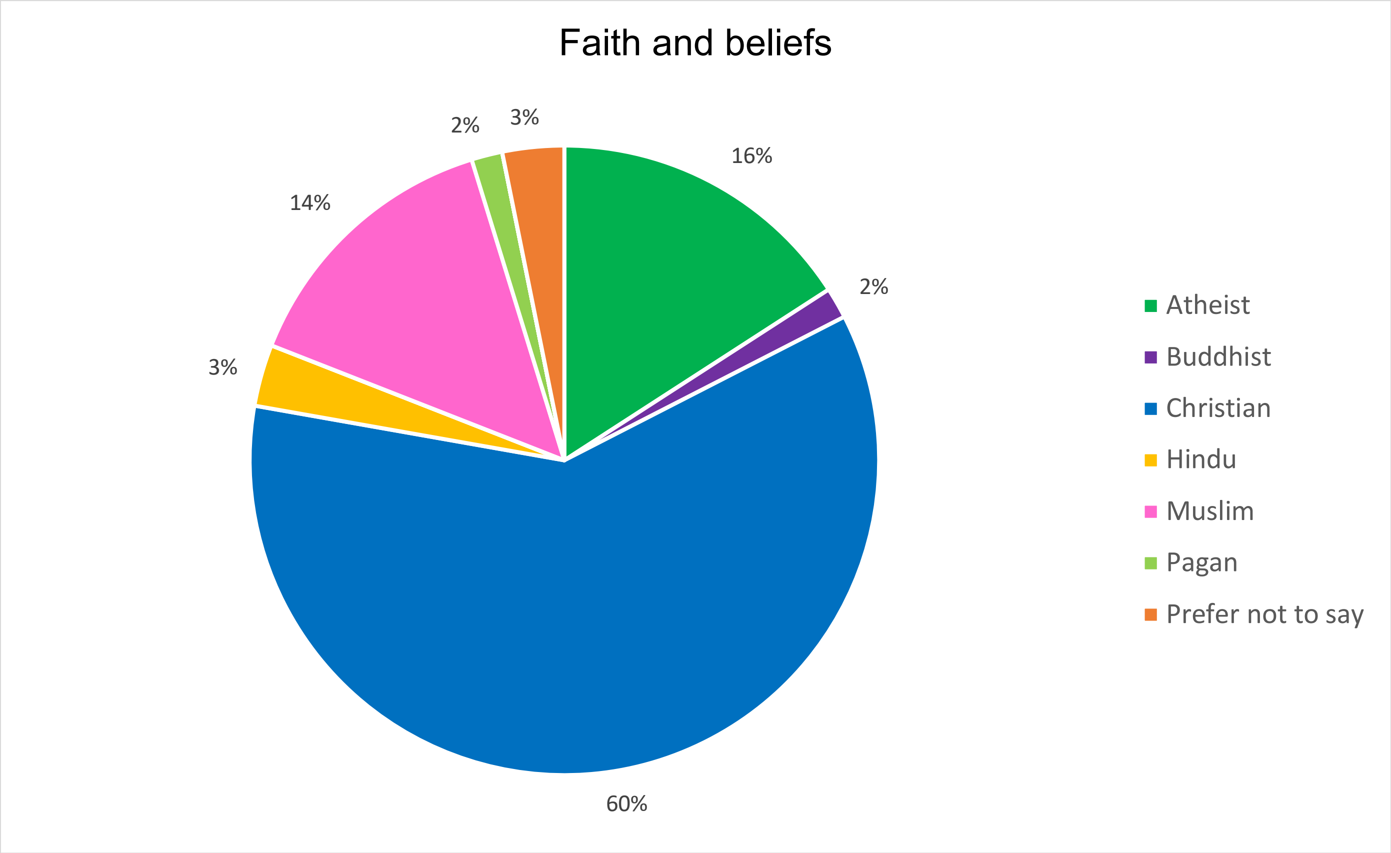
99%
Yes
No
I'd prefer not to say


Sexual orientation
9%
4%
3%
1%
82%
Asexual
Bisexual
Homosexual / Gay
Heterosexual / straight
Lesbian
Pansexual
Prefer not to say


Faith and beliefs
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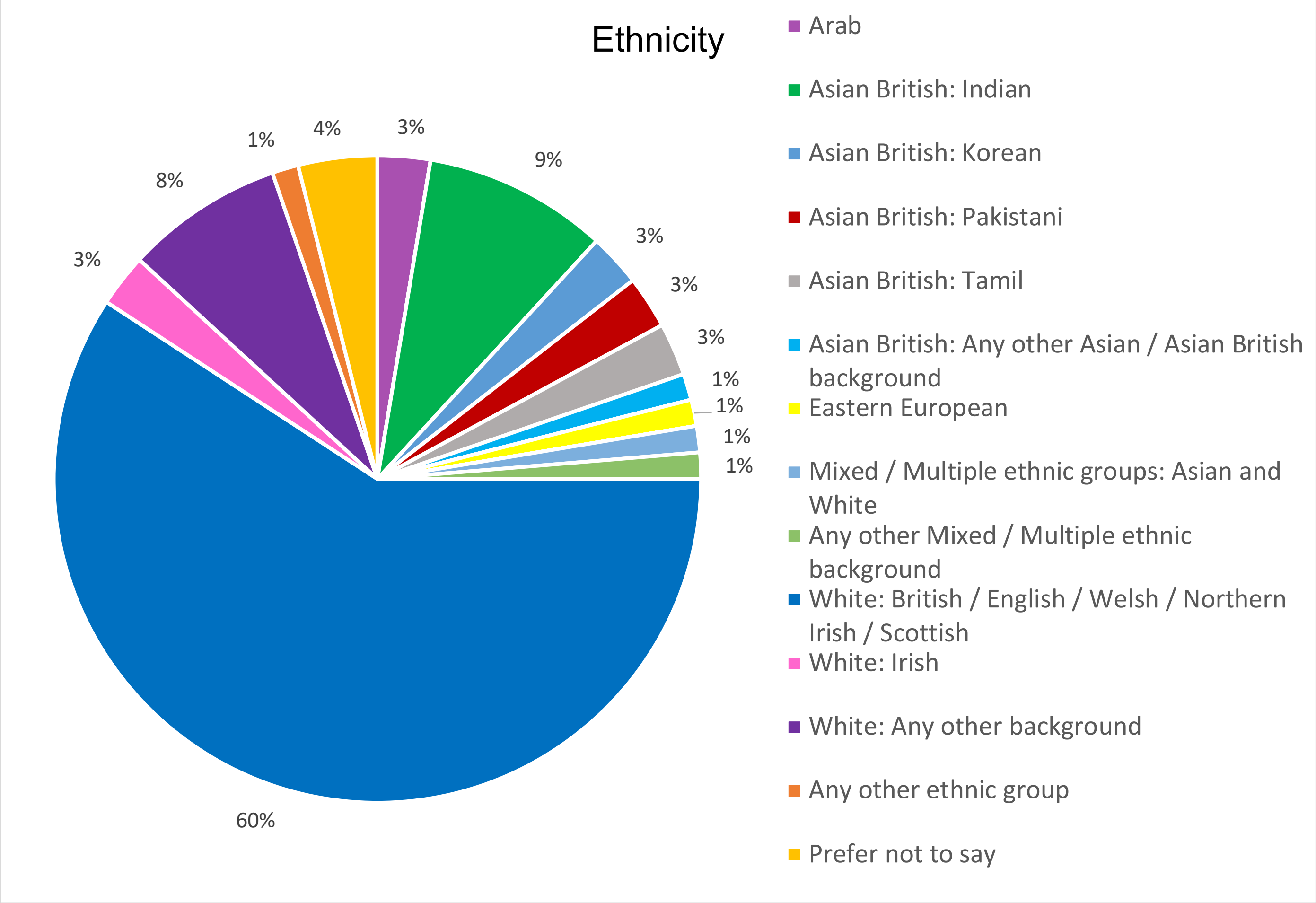
2%
60%
3%
14%
2%
3%
Atheist
Buddhist
Christian
Hindu
Muslim
Pagan
Prefer not to say


Ethnicity
3%
9%
3%
3%
3%
1%
1%
1%
1%
60%
3%
8%
1%
4%
Arab
Asian British: Indian
Asian British: Korean
Asian British: Pakistani
Asian British: Tamil
Asian British: Any other Asian / Asian British background
Eastern European
Mixed / Multiple ethnic groups: Asian and White
Any other Mixed / Multiple ethnic background
White: British / English / Welsh / Northern Irish / Scottish
White: Irish
White: Any other background
Any other ethnic group
Prefer not to say

6. Overview of community engagement findings

The following sections include responses provided by respondents across the various research methods used and provides a rich insight into the experience and feedback of our local population.

6.1 What we were told about bereavement

The experience of a bereavement varied widely in the responses, but the common themes were those of loss, sadness, shock, depression, isolation and the need for practical and emotional support. 62% of respondents said that bereavement had affected their mental health and 45% said that it had affected their physical health.

“Initially I felt angry and emotional, feeling depressed and sad. Sometimes people seem distant and not in the room, like their thoughts are somewhere else.”

“I just didn’t feel able to participate as the sadness was overwhelming.”

“I have had friends who have become a bit aggressive or don't seem to care about anything or themselves. They do things which are not them, out of character. It can tear families apart because the person they have lost has been holding them together. It can also bring people closer because they realise how much they need each other.”

“It can make relationships more tense but also deeper. Someone who has experienced bereavement can be more understanding and reliable as they have thought about life on a deeper level.”

6.2 What matters most when grieving

There were a wide variety of responses which, when summarised, included:

- Recognising the importance of faith and culture
- Ensuring that someone is available to listen and talk to, in the same language
- Providing empathy and compassion
- Sharing similar experiences with others who have experienced bereavement
- Providing ongoing and timely support

- Knowing what to do – practical advice and legal support when necessary
- Giving oneself time to heal and reflect
- Getting support from family and friends
- Making sure you get time to yourself
- Finding people to continue to talk to about the person you lost
- Feeling safe when emotions are overwhelming
- Needing a dedicated place to go
- Ensuring you make time for the children

Others may not know what to say and do. The worst possible thing is to say nothing. Fear of getting it wrong creates a greater wrong, which is not to say anything. Ignoring bereavement is not helpful.”

When grieving, it is important to have people to support you, but because I lost my entire family ... I did not have the support, I was on my own. I was unable to reach out for support anyway because I felt too overwhelmed with losing my family.”

6.3 Bereavement services

Respondents were asked, ‘in your experience what does good bereavement support look like for you and those close to you’. Respondents indicated that good bereavement support is based on skilled listening that is non-judgmental and confidential, coupled with practical support which should be flexible and easy to access. Help with aspects of everyday living soon after a bereavement is valuable, as is accurate information and advice about what to do when someone dies, in a concise and simple format. An A-Z of bereavement support in the borough would be very helpful, available in different languages. Responses varied but there were common themes throughout the feedback which resonated across a range of communities and abilities. For example:

Being there at the right moment when they lose a loved one. Be gentle and kind, share their feelings with the loss, accommodate their emotions, let them speak and listen attentively, support by helping with the chores like school runs, shopping, cooking, and helping with important admin work that comes through. Basically, looking at whatever they need at the time, and accommodating their needs.”

Good support is where people listen to your struggles and the pain that you are facing. They make you feel like you are not alone in your experience. I believe that if I had counselling support from professionals, or someone who was able to check on me every day who I could have talked to about my feelings this would have made me feel that I was not alone."

An example of what was not helpful:

I was contacted by a bereavement service soon after the death of my mum. It was very shortly after the death, far too close for it to be of use to me. They also didn't offer any support to my family members some of whom were very deeply affected. Bereavement support should be offered more than on a 'once only' basis. It can take a long time for the impact of the loss to sink in. It would be very good to have received some follow-up every month or so afterwards and certainly to have been asked about the emotions of other close family members who were affected far worse than I was."

In the online survey, 68% of respondents said they received the help they needed, although this did not distinguish between types of support and whether it came from family and friends, bereavement services or healthcare professionals. Respondents also indicated that when support was available it was most commonly provided by partners, sympathetic employers, friends and family. However, it was not merely a case of either support from family or friends or external agencies, but both.

Respondents said that they received support from a range of organisations, including the hospital chaplaincy service, bereavement counsellors, Kingston Bereavement Service, a hospice, Kingston Mosque, their local church, community organisations such as Korean Culture and Arts, and Winston's Wish. Most people found out about bereavement support services through word of mouth and in their local community. Other sources of information were GPs and healthcare providers, and relevant websites.

Some people reported that health service advice and information was out of date and fragmented and many people did not understand the significance of the procedures involved when someone dies, particularly how one registers a death and the role of the coroner.

Counselling services were valued by all groups and one-to-one counselling and support from faith communities was particularly valued but there was concern about the long waiting lists for this service. For some this was an alternative to support from family and friends, for others it was a key source of additional support. It can be easier to share with a skilled, trained stranger rather than friends or family when they too are experiencing their own bereavement. The majority of people who do not experience more complex grief responses were looking for normalisation of their grief, peer support and community activity and events. However, it is now evident that, during and since Covid-19, there is a large increase in more complex grief responses and these individuals require specialist support and one-to-one therapeutic interventions and group support sessions.

It is recognised that GP services, in Kingston as elsewhere, have been under particular pressures. For some respondents, accessing a GP for counselling support had not been particularly helpful. The support offered by local GPs tended to be related to signposting and referrals and clinical interventions, and some patients were disappointed that GPs were unable to provide more listening support too. Others commented that they expected a GP’s role to focus on medical interventions and physical health and to refer to appropriate services for other kinds of support. One GP commented on the development of bereavement services:

“*If this is to be a priority, we will need much greater resources to actually do this effectively. Better to put those resources elsewhere and allow us to signpost in.”*

End of life care:

Some people also reported that there is a need for pre-bereavement services and support – preparing people for their own bereavement and those around them. End of life care within hospital before someone dies was valued. People of different faiths welcomed the opportunity for a room to be made available for them, including a private space to pray or have time for reflection. Key themes identified from a 2019 Healthwatch Kingston report on death and care homes were; knowing the person who was providing the care; continuity of care; choice; quality of care and uncertainty about when the death would occur. Carers’ comments included:

“*A good death – gentle into that good night”*

“*I had thought the last weeks would be serene, but it was busy. And with all the machines you forget to give your wife a cuddle”*

“I wasn’t there to say things while she was still conscious”

“A member of staff stayed with her all the time. A very dignified parting”

“Once she went downhill I knew this is how it’s going to end. She’s going to slip away slowly”

“It’s difficult to tell how long someone’s got. I got there before she died but my sons didn’t.”

“In the end it was quick- just five days from a chest infection. Quite a shock, even for the staff’

“I wouldn’t have known that night was going to be the night she died”

Most respondents agreed that the ideal death should be peaceful, and we should not die alone. People who are important to us, should be with us, and we should have the chance to say good-bye, but this obviously depends on carers, loved ones and those important to them, knowing when the time has come. These expectations about a good death were in many instances over-turned during the early stages of the pandemic, when patients died in isolation and funerals were severely restricted. See section 6.6 Impact of the Covid-19 pandemic.

Hospital bereavement care:

Spiritual and pastoral service providers have much experience in dealing with bereavement, and respondents in Kingston Hospital suggested that what matters most to bereaved people included the following:

- The importance of ensuring that people who have been bereaved are networked into a good community with meaningful relationships
- That bereaved people need to get support and comfort from sharing with those in similar situations which highlights the importance of creating peer groups
- Offering face to face contact and support is far better and that ideally, bereavement support happens within a wider context of family, friends, and the local community
- Bereaved people need advice and information from the hospital
- Training in dealing with trauma is helpful

Kingston Hospital staff comments included:

“It would be helpful to have an onsite bereavement person who could follow up relatives in the community.”

“An identified person/department should be identifying bereaved people and assessing the risk of the bereaved.”

“With the right resources, ie. personnel, the Chaplaincy service could do more bereavement support, particularly for discharged patients.”

“There is a need for ongoing support in the later months after bereavement. Bereaved people suffer from the immediate shock of losing a family member, but also need longer term support and care to cope with feelings of loss.”

In summary:

Respondents indicated that when support was available it was most commonly provided by partners, sympathetic employers and friends and family. In addition to this support:

- The role of services is understood as supplementary and not as an alternative to personal networks
- One-to-one counselling and support from faith communities were valued, but there was concern about the long waiting lists for counselling support
- Practical advice is necessary
- GPs support related to signposting, referrals and clinical interventions, although some patients expected GPs to provide listening support too
- Health service advice and information was often out of date and fragmented
- Support is often provided by family and friends and faith, belief and life philosophy organisations and groups that reflect the bereaved person’s culture
- Respondents indicated that what matters most after a bereavement is having someone available to listen and to talk to who has empathy and compassion and access to practical advice and information
- Help should be offered in a timely way when a bereaved person has had time to reflect and heal. Support immediately after a bereavement is sometimes of help, but this can be

a difficult time when it is especially hard to absorb new information and to recognise and fully understand what kind of help one needs

6.4 Under-served communities

A principle aim of the research was to improve awareness of, access to, and the quality of bereavement services and support for a diverse population and “under-served” communities in Kingston.

Cultural and religious factors:

When analysing the responses it became clear that the needs of different faith groups, their beliefs and life philosophies need to be met in a more proactive and respectful manner. For example, for those who are Hindu, Jewish, Buddhist or Muslim a swift burial or cremation is very important. This means that it is imperative that death certificates can be provided as quickly as possible and that the proceedings of the coroner can be expedited when relevant. Muslim respondents commented that more needs to be done to provide suitable places for burial in the borough and some have had to look outside the borough to find this.

Support may also be needed to access funds to provide for burial, particularly if the sole bank account was in the name of the deceased person. Examples were given of the mosque forgoing payment for the funeral until probate was granted and funds were released. It was also noted that it was important not to make assumptions about faith, beliefs and cultures and to recognise the complexities within many families.

One local network of Muslims were very clear on what constituted a good service and had developed a support group linked to their mosque. This kind of support, offered immediately after a death, was reflected in the help offered by other faith, belief, and life philosophy groups.

People with a Hindu faith had similar experiences and some were unable to access suitably qualified religious leaders to conduct funeral services. They also suggested that supporting people to help them know what to do after someone dies and the offer of practical support such as legal advice or the offer of meals was important. Members of the Kingston Hindu community commented that older women can be particularly isolated when their husband dies, and have little awareness of what is available to them, nor indeed how to access services:

Bereavement can be complicated if the person who dies is your lifelong partner who you depended on for much of your everyday life."

30% of respondents said that bereavement had affected their ability to cope with finances, housing or employment. These problems could be even greater for women who have limited (English) language skills, who had partners who did all the banking and other tasks that require conversations or using IT skills. For women who have no family in this country and have limited friends of their own, it could be catastrophic. Further review is needed on what bereavement support is available to them and whether providers have adequate training.

Some Korean people reported a struggle with practical issues in the UK. They did not necessarily speak English and some did not know how to make funeral arrangements. Christianity and Buddhism are the two main religions in the Korean community and Korean Buddhist ceremonies, often cremations, are expected to happen shortly after death.

There was clear recognition that if counselling is offered, it needs to be provided by someone from the Korean community, and that members of both North and South Korean communities need to be involved in service development. A Korean respondent found that administrative processes at the time of dealing with the death of someone close, made the experience overwhelming and expensive.

The support of community and faith groups was acknowledged to be very helpful immediately after death. However, several people mentioned that after the initial weeks following a bereavement "others return to their usual routine", and often this is when the grieving really starts, and the loss is keenly felt. In some communities, death is a taboo subject, and some members can feel isolated and unable to share their grief with people they know.

Most likely, a service that would allow me to speak to someone who had experience with dealing with grief of a loved one. But I feel what is important is having someone who had a similar ethnic background to me, who would have had an understanding of what it is like to experience grief in a culture that frowns on the awareness of mental health."

I feel that because I had my siblings to relate to about my loss, I did not feel the need to reach out for professional help. Also, I am from a culture where it is difficult to reach out for professional support for your mental health because it is not normal for a man to open up about his emotions. In fact, it is frowned upon, that is why sometimes I tend to bottle my emotions and not talk to people about it."

Different cultural and religious communities are often keen to offer support to someone recently bereaved and offer food and listening and practical support. Nevertheless, someone who has no immediate family can still feel very isolated.

In some communities, family members may not live in the UK and are not able to support someone living here."

I feel that it would have helped me to be more communicative about my feelings to other people, as this is something I still struggle with.... Opening up to someone who has experience with talking to lots of different people going through similar experiences as me would make me feel like I am in the right hands and that I can trust them to not judge me based on my difficult times."

Some participants mentioned that they had been offered support but waiting lists were very long, help was not provided until months later, or service providers promised to contact them, but this was not followed up. Similarly, on some occasions, support was offered immediately after death, when the bereft person was not ready for it, and there was no follow up later on.

A member of the Tamil community commented that people:

Most people get support from family and friends – it's those who have little support and are more isolated that need help."

don't like to talk about death before it happens. There is a lack of awareness of services due to language barriers. Translated practical support for organisations to share with service users after death, as well as emotional support would be helpful."

There is a role for community leaders in making sure a resource is promoted. Be aware of the danger in covering everyone with one blanket - Different faiths/different needs."

It was suggested by some respondents that the Royal Borough of Kingston could provide counselling, advice and information. GPs, schools and other comparable services should also have a staff member responsible for bereavement. There are support groups available, but local people may not know about them.

Other suggestions were that good bereavement services should have:

- a central point where services and performance are monitored and reviewed
- one to one and peer support groups, in addition to support from family and friends
- safe spaces in relevant services
- holistic and person-centred approaches
- practical support
- information at all levels – pre-death, immediately after, and further down the line

And as one respondent succinctly stated:

To be ready to talk about death in our daily life"

People with special needs and disabilities:

Is there guidance to support children with special needs such as ADHD or Asperger's? It is hard for them as they don't show their emotions like others and they can find it hard to process them."

In addition, it was recognised that some children or adults may have peers who have life limiting conditions and they may therefore encounter bereavement more frequently. 24% of people completing the online survey (18 people) stated that they had a disability and 41% said they had a long-term medical condition. People living with disabilities were asked where they would go for advice and information following a bereavement, and whether they had actually received relevant advice. Responses included:

“I wouldn’t know where to go for help”

“If it happened again, I would go to my GP first”

“Advice and information would have been helpful at the time but it wasn’t offered . No support was offered so I just had to deal with it.”

“Information and advice on how to prepare a will needs to be readily available.”

Respondents identified that a good service for people living with disabilities includes making sure bereavement information, advice and support is accessible to disabled people and those with sensory impairments who may struggle with online services and support, with information being in an accessible format. The Accessible Information Standard gives disabled people and people with sensory loss the right to get healthcare information they can understand and communications support if needed. Healthwatch England ran a ‘Your Care Your Way’ campaign in the Spring 2022, and their findings also confirm the need for organisations to meet the accessible information standard.

Bereavement services for children and young people:

“Someone to talk to. Having the opportunity to express your feelings, especially when you are low. Having a support network of people you can relate to. Knowing that people know what you have gone through.”

“Friends around you who can give support and know when to talk about it and when to distract you from thinking about it. Feeling that there are people around you can trust.”

“In a family there is always someone you can talk to, and they know you better than most. They can also be annoying as well!”

“An organisation that has a range of projects/programmes or services that might be available is reassuring because they are more likely to have the capability to respond in some way.”

“Knowing that someone has been trained to deal with bereavement and support young people would help. Having someone available or knowing when they are free to talk.”

“Buddy systems help both the person in need but also the young person helping.”

Bereaved carers:

40% of respondents to the public online survey stated that they were carers. The support that carers need is not always recognised. They not only lose the person they cared for, but a significant role in their life:

“You’ve lost not only your partner but also your purpose and caring role of recent years has been taken away too.”

Respondents emphasised that the loss they experienced as a carer differed to other deaths in their lives. They explained that the complex relationship that they had developed, which involved dependency and responsibility suddenly ending was an especially difficult experience. They described caring as giving them a purpose and when that went away, they had to deal with the grief for the person and the loss of their own identity. Awareness of, and access to relevant support services would have helped enormously.

A positive example included a British Asian carer who went along to a bereavement café held in a church nearly a year after the death of her husband:

“I resisted but when I went, it was the turning point. You can’t tell family and friends how you feel, but these people were trained to listen. It was a chance to say how you felt and it was near the cemetery where my husband is, so I could visit him afterwards. The church had other things and I joined in the other activities.”

The need for further support for bereaved carers has also been identified in the forthcoming All Age Kingston Carers Strategy 2022-2027, due for publication October 2022. Their research found that:

“Carers have told us about the challenges they experience when the person they care for passes away and that difficult transition period into not being a carer any longer. There can be a loss of identity and life purpose as well as going through grief and bereavement. Loneliness post bereavement is a significant issue. It is essential services continue to support carers post bereavement and beyond their caring role.”

The loss of a child:

“*If it is a child that has died, what matters most is to have someone re-iterating that it was nobody’s fault especially not the parent. Many parents take the blame even if there was nothing they could do and wish that it would be them as it is not right for a parent to outlive a child.”*

Easy access to information about what is available to support them would have been essential in order for them to get the correct information and support required. The bereavement midwife was mentioned several times, and some respondents were aware of the Saying Goodbye Project which supports Children and Young People through bereavements.

“*NHS professional counselling support in the community have a 3 to 4 months waiting list which is outrageous. We really need a professional counsellor/clinical psychologist in the trust for bereaved parents.”*

“*We need a psychologist for families who have lost a baby child beyond the neonatal period.”*

“*I wasn’t offered any support but was given the SANDS (Stillbirth and Neonatal Death Society) telephone number to call. A human being would have been better.”*

6.5 Accessing information and advice

Respondents to the online survey were asked about information and advice services following a bereavement, what they felt was important for them to access, who they thought should provide it, and where they could go to get this information.

We asked people 'how helpful was the information and support you were offered by a healthcare provider *immediately* after the death occurred?'. 74 people responded to the question, 36.5% said that the information was helpful, 12% said it was neither helpful or unhelpful, 5.5% said it was unhelpful, 18% said that they did not need information and support however, 28% shared that they did need information and support, but it was not provided.

The following question asked about further bereavement support and services and 45% of people shared that they were not informed about further bereavement services from the healthcare provider.

We asked people if they received support from bereavement services in Kingston, 81 people responded to this question. 27% said that they did receive support. 32% said that they did not need support and 41% told us that they needed support, but did not receive it.

Of those who did receive support they told us that currently, support, advice and information is available from Kington Bereavement Service, bereavement counsellors, the Samaritans, faith groups, Kingston iCope, Macmillan and Winston's Wish. There is some information available on the Royal Borough of Kingston Council website and on the Connected Kingston platform, but the level of awareness about these sources of information was not high and it was unclear if health professionals and other bereavement services were signposting people who had been bereaved, to these services. It was also noted that the support available to people with complex or multiple bereavements is a limited resource, and relevant services have a long waiting list.

There were positive comments about funeral directors who were described as good sources of information and advice on what to do after a death and were very good at giving practical advice. However, some respondents were cautious about any cost implications if they asked them for help or support. Funeral costs are not always transparent and some felt that funeral directors need to be regulated as funeral poverty is a major issue for those on low incomes. There was also a sense that people pay too much because they feel pressure to give someone a 'good send-off’. Local authorities already have a statutory duty to make basic funeral arrangements if a person does not qualify for a contribution from the Department of Work and Pensions (DWP). RBK’s Crematorium and Cemetery Service is a member of a Charter for the Bereaved and can offer impartial and unbiased advice on how to arrange a funeral.

Some elderly bereaved people struggled to register deaths without family support. They often just needed someone to book the appointment, check they had all the information they needed, or maybe sit with them while they registered the death.

It was also suggested that people who experienced someone dying in hospital could be offered a low-key assessment of their needs immediately following bereavement. Some respondents suggested that volunteers would be helpful within the hospital to help people with information, advice and support on how to access relevant services. Hospital guidance booklets in different languages were also considered helpful.

“On the majority of occasions the Hospital Bereavement Booklet was not provided ~ the issue of sudden death (Coroners) is a cause for concern ~ there was not visible and sustained support.”

“Whatever their faith or cultural background, thinking about death and preparing to die can be difficult. We need to encourage patients to talk to loved ones about their wishes for their will and inheritance, funeral arrangements or a memorial service, and explain the role of a power of attorney, the death certificate and the coroner.”

“I was supported by church members. They visited me regularly and helped financially with the funeral and gave me the information what to do after my husband’s death.”

“A lot of information is available online but sometimes you just want to hear it from a person.”

“Some people will not have access to online information or feel unable to use it, particularly if they need IT training or their first language is not English.”

Respondents suggested that existing services should be more joined up and connected to one place where they can go for information and signposting. It was widely agreed that it would be helpful to have one central source of information and advice, a ‘hub,’ available immediately after bereavement and beyond.

It was suggested that there needs to be information on the council website about the procedures regarding finances, death certificates and where the Registry Office is, whether a post-mortem is necessary, how to arrange the funeral and where Citizens Advice is located. The Tell Us Once service should also be publicised along with additional information on other local charities that can help to provide specific sort of support (e.g. Macmillan).

Providers of emotional support should also be on the RBK website. Some of those consulted were aware of the Born Too Soon services and support offered by Cruse. One person noted that there is a hospital guide, but it is not well-known. Macmillan also provides advice and information material; however, the information available is not always up to date.

In addition to the support provided by family and friends, respondents suggested that the best places to access information about bereavement support and services are GPs, faith, belief and life philosophy groups, hospitals, funeral directors and community organisations. Health care and other professionals also suggested more practical recommendations for access and information, for example registrars stated:

I feel it is important to clearly explain what that particular person needs to do in order to register the death. It is very helpful if they are told what the process will be, so they are prepared when they come to do the registration. It is also important to finish the registration clearly explaining what they need to do next.

Telephone registration is the way forward, it's much safer and quicker for us and more convenient for the bereaved than having to register face to face. We've had a lot of problems with MCCDs (medical certificate of cause of death) not being completed properly by doctors in GP surgeries. If they miss info or don't write clearly, we have to delay setting up the registration appointment while we sort that out, I think they need better quality control. Bereaved people are often in a hurry to register a death so any delay due to sloppy admin is unwanted.”

Digitisation of processes permanently would be beneficial for everyone involved in the bereavement ...”

Specific recommendations included the need for:

- Details about bereavement counselling
- Relevant information leaflets with up-to-date information on available services
- Information on where to access bereavement services
- How to arrange a funeral and the costs
- Advice on the agencies that need to be informed
- Arranging for a death certificate
- Dealing with the coroner
- Where to access a solicitor and the process of probate
- Culturally appropriate literature and seminars in different languages
- A guide on ‘how to have a funeral in the UK.’
- Banking advice, including what happens to the finances of the person
- How to activate power of attorney
- What to do if you are a friend of someone that has died and you are trying to reach family overseas

In summary:

It was agreed by most respondents consulted that it would be helpful to have one central source of information and advice, using technology more efficiently and connected to one place where they can go for information and signposting. It was also suggested that having comprehensive bereavement service provision could save the council resources further down the line, for example, people could be prevented from falling into debt, or developing mental health issues and needing further support.

6.6 Impact of the Covid-19 pandemic

A report (British Medical Journal 2021) found that:

“The pandemic has created major challenges for the support of bereaved people, increased needs for bereavement care, transition to remote forms of support and the stresses experienced by practitioners, among others. The extent to which services are able to adapt, and

meet the escalating level of need and help to prevent a 'tsunami of grief' remains to be seen. The pandemic has highlighted the need for bereavement care to be considered an integral part of health and social care provision."

This local research in Kingston has comparable findings, with many of the qualitative responses reflecting those challenges for bereaved people in our communities. Some of the statistics illustrated the impact of Covid-19, for example:

- 21 people who took the survey referenced Covid-19 related issues in their feedback
- 14 out of a total of 128 bereavement experiences noted Covid-19 as the cause of death (either as the main cause or part of contributing factors to the cause). 1 person stated the Covid vaccine as the cause
- People told us about Covid related issues which included lack of face to face contact, the impact of the pandemic and feelings of isolation
- 57% of people who completed the online survey had experience of bereavement services in the last 2 years (during the pandemic)

Residents' experiences:

The 2019 HWK report on end of life care highlighted several features of a "good death". However, during the pandemic, respondents found that there was little or no time to prepare for someone's death with news often coming suddenly. Sharing their experiences with friends and people in the local community and within cultural and faith communities was important, nevertheless the mental health of the people who were bereaved was a major challenge and they described feeling very isolated, particularly as they could not see anyone in person.

I have no dependants and no close family living nearby, so at the time of my husband's death in the 'first wave' of the Covid pandemic, I found myself very isolated and relying solely on telephone conversations with my brother."

Friends are important, but during the pandemic, they could not come to the house."

In case of Mr Y (a Korean man who lived on his own), the council was contacted, and a lot of help was provided by them. He was killed by depression. We were only *allowed to take food to his door (because of Covid). He wasn't eating. Depression killed him."*

The local Korean senior community lost several members during the pandemic. One person lost his best friend suddenly; he died less than 10 days after he caught Covid-19. The respondent said he did not feel ready and no preparations had been made for his death.

Others commented that the loss of friends due to Covid-19 had compounded their sense of isolation, or that the loss of a partner to Covid-19 has affected their mental health significantly and they continued to suffer from anxiety.

The service provided by the specialist bereavement service was excellent. However, it took a further 5 months from my referral until the time I actually commenced counselling. Furthermore, all the sessions were inevitably held via 'Zoom' and I personally would have benefited more from something face-to-face, or better still, a Bereavement Support Group for local people who had lost loved ones to Covid-19."

Service providers' experiences:

We also asked those providing bereavement services to describe their experience of providing support during Covid-19. One member of a chaplaincy in a clinical setting said simply "torrid".

A palliative care clinician commented:

The rapid deterioration of patients and the isolation of lockdowns etc. appears to have amplified grief. There has been a lot of concerns about delays in accessing healthcare and 'what ifs' experienced by loved ones. Limited visiting and concerns about the spread of Covid has also meant that people have seen their loved ones less frequently and as a result their isolation has increased"

GP comments on providing bereavement support during the pandemic included that they had insufficient time and resources to provide effective support. New processes on registering deaths took time for smaller surgeries to get used to, and it was reported that there was a need for clarity on who would contact families if there were delays.

“Challenging - having to move to remote working and deliver services online rather than face to face. Our usual referral pathways were disrupted during the pandemic - GP appointments fell, and schools were closed for periods of time. We were still able to deliver a service - giving telephone support to parents and carers when schools were closed and for all services, online counselling was offered.”

Christian ministers’ comments on providing bereavement support during the pandemic included:

“The hardest thing has been less face-to-face contact during lockdowns. The need for support has been greater than ever as people have generally felt more isolated in their grieving, and so trying to make funeral arrangements and offer support over the phone has been very unsatisfactory, though at times the only option. [Over the phone it is] much harder to establish relationships and have meaningful conversation compared to face-to-face meetings.”

“Fragmented and at times distressing. Continual changes in regulations around funerals and meeting have been challenging. Many families have not been able to grieve properly because of restrictions.”

A range of other professionals (including social workers, counsellors and registrars) dealing with the impact of Covid-19 also responded to this research, and their qualitative feedback showed the emotional demands created by the pandemic:

“It has fluctuated over time. Initially, access to GP services was restricted so referrals dropped. Funding uncertainty led to a pause in our children’s service from July. More complex referrals unsuitable to our small organisation has increased. Staff redundancies and illness have also affected our service delivery. Qualified volunteer counsellors choosing to leave in order to focus on/start up their private practice because of the public demand has resulted in a reduction of our service delivery both in numbers and client complexity.”

It's been demanding in every way, professionally, emotionally, and physically. Not just the sheer volume of deaths but having to adapt to new ways of working, changes in the law, managing relationships with colleagues all the while dealing with the anxiety of knowing we're in the middle of a pandemic and seeing the evidence of it on the MCCDs (medical certificate of cause of death). Aware of all the deaths in care homes, aware of NHS staff dying and knowing that, at least in the early days of the pandemic, the dying were without family near them and the bereaved families couldn't be with their dying relative or even be at the funeral sometimes. It was heart breaking and exhausting, but we demand high standards of ourselves and remained professional and kept rising to the challenge, week after week. I personally have suffered more anxiety in the last year and a half than ever before and a few bouts of very low mood. But I was grateful to be able to come to work every day and make a contribution, it also gave me structure and taught me a lot about myself, which has helped me get through it all. I've had a lot of positive feedback from the bereaved when I speak to them, so it helps to know I am supporting them, even if it's just for 20 minutes on the phone.”

Registrars were affected since their work became “a continuous flow of death”.

It has been full on. You work nonstop and it isn't until you have a quiet period, after the 2nd lockdown, that you realise you are exhausted. You have assisted the bereaved through the registration and disseminated the documentation as quickly as you can. You work to help the bereaved to explain what is required of them, obviously some of the detail is retained by you and to have a continuous flow of death detail, without the births and marriages. I enjoy the job, helping people through it, but the sadness is overwhelming at times.”

It has been a very challenging time supporting people registering deaths during Covid-19. I have dealt with people who are experiencing a range of different emotions. I am lucky that I work in an excellent team who are very supportive.”

Organisations also reflected on how they would deliver their service in the future.

“We have been able to use digital tools to deliver our service but there is a gap in the level of digital literacy which needs to be addressed. Having said this many of our counsellors are keen to get back to face to face counselling but many have seen the benefits of a remote service, giving many greater flexibility. We have learnt that we can use a greater variety of tools to deliver our service, but that [the] traditional form of delivery is still very much needed.”

“Offer community-based training for volunteer counsellors to increase their ability to work with more complex issues. Consider paying counsellors to reduce the turnover time and costs of recruiting more volunteers. Drop in/long term therapy option for those who require longer term support.”

“Increasing funding to enable a sense of security so organisations can focus on service delivery without concerns for the future using our assets in the community to help absorb the pressures on the voluntary sector.”

“To ensure all bodies whether medical, undertakers, and the bereaved know what is expected of them. Collaborative teamwork is essential, to have empathy with the bereaved to make the process as smooth as possible for them whilst not being too professional i.e. empathy is important.”

In summary:

The impact of the Covid-19 pandemic played a major role in both the experience of bereavement, and the provision of bereavement service delivery, not least because of the various lockdowns and lack of access. The emotional fall out was immense and damaging for many respondents, and there is little doubt that the effects of those bereavements will continue to reverberate.

Suggestions made as a result of the pandemic are covered in all the sections in this report but in addition we need to consider better use of technology and increasing access to digital training, whilst recognising that an estimated 11 million UK citizens lack digital life skills (Digital Poverty Alliance 2022).

There is an obvious gap in providing services for people who lack internet access or who are reluctant to join online groups.”

7. Conclusion

Research reported recently in the BMJ (British Medical Journal) suggests that the implications of the pandemic for bereavement care practice and policy are:

- Improving resources for existing bereavement services to enable coordination between local, regional and national networks, and encourage a sustainable model of bereavement care
- Developing a proactive approach to supporting those bereaved during this period and making services accessible for all
- Enabling regular communication with families prior to a death and after to ensure families have opportunities to ask questions and receive reassurance
- Where possible, finding ways for families to be with dying relatives
- Integrating assessment of bereaved families’ needs to help identify and signpost those who might require further support
- Training in bereavement care to be integrated into medical, nursing and other healthcare professional training
- Acknowledging the challenges on staff and encouraging grief training for those who feel unequipped to manage the needs of grieving families

“Ultimately grief can be a really transformative experience. It can change who you are as a person. Grief is interesting, because it has a psychological dimension, but it’s something which is going to happen to all of us and it’s more of a social issue. Community initiatives can feel poorly signposted and knowledge about and access to community-based support feels variable.... Community-based initiatives feel less integrated than medical services, with no clear roadmap for accessing them and a lack of awareness of what is available. Despite this, some people had been signposted to support and others had proactively searched for and found local initiatives. For those with dementia, community initiatives can feel particularly hard to

access with little NHS signposting being reported and a limited knowledge of what is available.”

Dr Lucy Selman, Associate Professor in Palliative and End of Life Care at the University of Bristol, and founder of “The Good Grief” Festival

HWK, KVA and all the partners and respondents in this research project worked hard to proactively embrace a challenging and difficult topic, particularly since the Covid -19 pandemic and its subsequent fall out, and the findings have illustrated the deep rooted and distressing impact of bereavement, and the importance of ensuring that a comprehensive package of culturally appropriate services is developed which encompasses the broad range of challenges faced by those left behind.

The consultation and survey data showed us the importance of good emotional support, and although these needs were mainly described as being met by family, friends and communities, there were also the thorny challenges faced around legal and practical tasks which have to be done when people we care for and care about die. Those practical aspects can be extremely challenging with lack of access to relevant information on how to address them a recurring theme, especially for those who are alone, isolated or for whom English is not their first language. Some typical responses included the following:

“It helps to speak to others during bereavement.”

“Important to have clear signposting and links with the voluntary organisations.”

“There is benefit to a bereavement service that can support each other – peer support/lived experience.”

“Faith groups can work together and support each other.”

The research showed us that there is much to be done to improve our bereavement services across the board, and that improving access to relevant, helpful information is crucial. GPs and hospital services need to know what is available locally and have up to date information to support their communities.

The important role of community was highlighted regularly in the findings, with an emphasis on the support provided by churches, voluntary agencies and peer led organisations all of whom play a key role in times of bereavement. Given the current resource pressures across the whole system, and overwhelming demand for improved service delivery, active collaboration and pooled resources may be necessary to meet those needs. This will be particularly important as we face the “tsunami of grief” following Covid-19 and its devastating impact.
Listening carefully to our diverse communities and implementing the clear and collaborative recommendations will lead to a stronger foundation on which to build our bereavement service provision and meet the needs of those communities.

Following the Compassionate Communities approaches, expanded provision of informal community-based support and activities could help with isolation, whilst longer-term educational and societal initiatives are needed to improve how we communicate and support people experiencing death, dying and bereavement.

8. Thank you and next steps

The engagement exercise is complete with a large and rich data set captured to support the next phase of the work. The success of the approach is evidenced by the richness of the data and the diversity of the local community groups engaged in the surveys and focus groups.

So, what are we doing next?

- This will involve the co-design of future bereavement services and support over the coming months in Kingston.
- This project approach can now be replicated across the SWL ICS (formerly SWL CCG) at Place to help improve bereavement services and support more widely.
- A Bereavement Services and Support Quality Improvement Implementation Framework has been created which provides guidance and templates as used in this project.
- This work was undertaken in the context of the wider Compassionate Communities programme of work being delivered at SWL ICS level.
- All Places will be invited to review the recommendations of the Kingston report and to sense-check for their local population by using a scaled application of the engagement activities piloted in Kingston.

A huge thank you to all the participants in the research and the respondents who gave their time so generously on such an emotional and challenging issue facing us all. Your contribution has been invaluable to help us improve access and relevant, appropriate and essential support for the future of our bereavement services.

If you have any questions about this report, please contact:

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If you would like to find out more about bereavement community engagement across SWL please contact:

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9. Appendices

Appendix - 9.1 About Healthwatch Kingston

Healthwatch Kingston was set up by the Health and Social Care Act of 2012 to be the independent champion for local NHS and social care.

We seek the views of patients, service users, carers and the public to help services work better for the people who use them. We play an important role bringing communities and services together. Everything we say and do is informed by what local people tell us.

As well as encouraging those who run local services to act on what matters to people, we also share local views and experiences with Healthwatch England and the Care Quality Commission who make sure that the government put people at the heart of care nationally.

Tell us what you think about NHS and social care

Healthwatch Kingston upon Thames
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Appendix - 9.2 About Kingston Voluntary Action

Kingston Voluntary Action

Kingston Voluntary Action (KVA) is the infrastructure and umbrella organisation for voluntary and community organisations in the Borough of Kingston upon Thames. We are a registered charity, with Charitable Incorporated Organisation number 1160403 (formerly 257551).

KVA works to create, support and amplify community action in Kingston upon Thames. We offer a comprehensive wrap-around service to charities and community groups of advice, guidance, training, networking, representation and brokerage.

We work closely with Kingston stakeholders, ensuring that the work of the VCS sector is best utilised to benefit those who live, work or study in Kingston.

We want - and work towards - a Kingston where communities are active, strong and connected.

Kingston Voluntary Action includes the projects Superhighways, Connected Kingston, Kingston Eco-op.

Contact

☎ 020 8255 3335

✉ admin@kva.org.uk

@KingstonVA

@KingstonVoluntaryAction

Please visit the KVA team page to contact individual staff members.

🏠 Siddeley House, 50 Canbury Park Road, Kingston upon Thames, Surrey, KT2 6LX

KVA is based a 5 - 10 minute walk from Kingston Rail Station.