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'A good death' during the Covid-19 pandemic in the UK: a report on key findings and recommendations

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'A Good Death' During the Covid-19 Pandemic in the UK
A Report of Key Findings and Recommendations

LSE Anthropology

Contents

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Introduction

There will be significant challenges during the next three months in terms of dealing with death and bereavement in the context of the Covid-19 Pandemic. The current situation does not allow a process of death in which families and communities can be involved in a way they would normally hope or expect to be. In addition, mortality rates will adversely affect vulnerable households. The government has identified the following communities as being at increased risk: single parent households, multi-generational Black and Minority Ethnic groups, men without degrees in lone households and/or in precarious work, small family business owners in their 50s and elderly households. Our report has focused on these groups.

This report presents a summary of findings and key recommendations by a team of anthropologists from the London School of Economics. A public survey and 58 cross-community interviews were conducted between 3-9th April 2020. It explores ways to prepare these communities and households for the impending deaths with communications and policy support. More information on the research methodology, data protection and ethical procedures is available in appendix 1. A summary of relevant existing research can be found in appendix 2. A list of key contacts across communities for consultation is available on request.

Research was focused on "what a good death looks like" for people across all faiths and for vulnerable groups. It examined how communities were already adapting to processes of dying, burial, funerals and bereavement during the pandemic, and responding to new government regulations. It specifically focused on five moments in the process of death, and what consultation processes, policies and communications strategies could be mobilised to support communities through these specific phases.

1. **Pre-Admission**
   How communities prepare for death.

2. **Hospital Admission**
   How communities were responding to hospital admission, and the inability to be present with their relatives through the dying process.

3. **Disposal and Release of the Body**
   How communities were responding to changing government restrictions surrounding the delayed release of the body to funeral directors.
   Community opinion on cremation and public health burials.

4. **Funerals**
   How communities were responding to the inability to congregate at funerals.
   How communities were adapting funeral rites and rituals given social distancing guidelines.

5. **Bereavement**
   How communities are managing bereavement while isolated.

Summary of Key Findings and Recommendations

Across communities, our interviews evidenced the following central issues for 1) policy, 2) consultation and 3) communications:

1) Policy Recommendations

*Dealing with National Loss***:**
UK citizens are experiencing a traumatic moment of collective loss. This is equivalent to that in the context of civil strife, terrorist events and large-scale accidents. To ameliorate this experience and create cohesion there could be several measures taken:

- **Compassionate** government communication at the national level that honours the loss of life. This could include non-religious ceremonies such as a minutes' silence, memorial programmes led by key, respected non-political charity figures and interfaith services.

- **Direct help** to those experiencing loss from COVID-19 deaths. This could include financial help with the process of death (such as free funerals, free livestreaming services from crematoriums, providing access to technology to disadvantaged families so they can experience funerals at a distance).

- Setting up a COVID-19 **national phone-in service** staffed by counsellors headed by a prominent professional psychologist. This is for help during the process of hospital admission and/or bereavement.

- **Specific, fast welfare support** could be given to disadvantaged families who have lost providers due to COVID-19.

- **Grants** for existing community and charitable organisations that counsel bereaved families.

Dealing with Community and Individual Loss:
UK Citizens expressed a strong desire to have the dignity of death preserved during the COVID-19 epidemic. This can be achieved through regulations, communications and policy around death that take into account the following issues:

- **Preparation for hospital admission and possible death** could be achieved by trusted local and national figures advising people to have conversations in their households about how they would like the process of death and commemoration to unfold. Advice and models could be taken from palliative care experts along the lines of Coordinate My Care Schemes. More generally people could be encouraged to prepare wills and write letters to their families conveying their wishes. Although a balance needs to be achieved between preparation and increasing anxiety.

- **Honouring the deceased** needs to be achieved by **flexible, general government regulations** that enable various cultural, religious and class communities to carry out their core practices. All citizens emphasised that these regulations did not need to include room for all their ritual practices, only those that are essential.

- **Uniform application** of government regulations across faith and non-faith groups to avoid resentment of minority groups or feelings of cultural exclusion.

- **Collaboration** should be encouraged across faith and non-faith leaders, palliative care specialists and funeral directors to formulate and implement these flexible regulations. A committee of prominent figures in these groups could be set up to support this.

- **Consistency** needs to be maintained across local authorities, mortuaries and funeral parlours on what ritual processes are permitted. At present there is inconsistency and if this becomes public knowledge in the media it may increase a sense of unfairness undermining cohesion.

- **Banning funerals** entirely should be avoided. Communities and individuals are likely to experience long-term emotional trauma if this is implemented

- **Enforced cremation**, especially mass cremation, and **delayed release of the body** after death should be avoided. There is significant and high level anxiety across communities about these possibilities. Any action by the government that removes choice from the process of dying is understood as a lack of respect and infringement of liberties.

- **Accessible to all technology** is important for facilitating communication during the process of death. This could be supported for disadvantaged groups by the government and/or tech companies/mutual aid groups collecting and re-circulating old technology to NHS Trusts.

2) Consultation Processes

UK citizens emphasised that they would experience the government as compassionate and enabling a dignified process of death if it carried out active consultations. These should occur along the following lines:

- Special effort should be made to consult and include **marginal communities,** especially communities affected by poverty, Black and Minority Ethnic (BAME) and Muslim communities; and **non-religious communities** such as Humanists, in building, adapting and communicating policy guidelines to create collective cohesion.

- Much can be learned from **historical precedent,** and consultation is advisable with those who have managed excess death and trauma in the past, seeking help from professionals involved with the Manchester Arena Bombing, Grenfell Tower Disaster, and the Northern Irish Troubles.

- **Consultation** needs to be with national level organisations, but also with **local level** organisations linked to local authority services, mutual aid groups and local resilience forums

3) Communications

UK citizens explained that they are adaptable if they are given **clear and consistent information** regarding regulations by trusted community leaders and/or media outlets at all stages of dying and memorialisation. To support this we advise the following:

- A **central support service** (helpline, text service) could be provided to support families through the hospital admission, release of body, funeral and bereavement process.

- Information and guidelines should be communicated in **multiple languages** to empower the families of deceased, funeral service providers, key faith-based institutional stakeholders, and grassroots organisations.

- The government can take a lead in **recognising and supporting** local expressions of positive work between ethnic and faith communities and avoid using stigmatising language that might inflame tensions.

- **National conversations** about preparedness for death, sensitively expressed, could be critical as the epidemic peaks, delivered using non-medicalised language at daily press conferences.

- **National commemoration** for those who have passed during this period is suggested.

Findings and Recommendations Across the Dying Process

Findings are first summarised across communities, spanning from pre-admission to hospital, through to bereavement.

Pre-Hospital Admission

Communities should be encouraged to prepare for loss.

- Community leaders are encouraging their communities to show love and care for those close to them in preparation for bereavements in their community.
- In some, particularly BAME, communities, there is slight stigma and shame surrounding contracting Covid-19, causing individuals and families to avoid sharing their symptoms or diagnosis.
- Many people do not have their affairs in order before they are admitted to hospital, causing significant distress for them and their family members.
- Pre-hospital admission time can be made more distressing when patients face additional stressors such as accessing welfare support, unemployment and caring responsibilities.

Recommendations:
- Paramedics could be trained to manage separation when patients are admitted to an ambulance.
- Community leaders could be mobilised to provide telephonic advice, death preparedness and information services for families whose loved ones are unwell. Lessons can be learned from those settings where multiple deaths have already been experienced, such as that of North Kensington following the Grenfell Tower fire.
- Information should be spread through communities via large institutions and leaders, but also through smaller grassroots organisations and figures.
- Digital or telephonic technology can also be used to facilitate the witnessing of wills and other legal processes.
- The government could support and encourage people at national level to prepare for hospital admission as the peak approaches. Precedent could be taken from the 'Coordinate my Care' palliative care schemes.

Hospital Admission

Patients and families feel confused and distressed about the hospitalisation process.

- Fear of not being able to visit family members in hospital is preventing some families from admitting their ill relatives to hospital.
- There is a lack of information on the process of hospitalisation and restrictions around visiting by family and religious leaders, leading to confusion and an inability to adapt procedures.
- Bedside ministry is crucial for some faith communities, and religious leaders are currently continuing this work while provided with PPE.
- Many non-Christian patients don't understand hospital chaplaincy services, and have particular anxieties about cost and personal preferences.
- NHS workers are facing the extra burden of providing companionship and spiritual support to the dying, yet there is a stunning sense of generosity across and between faith officiants and NHS staff.
- Prognosis for non-Covid-19 patients in hospitals has shortened in the past few days, shocking loved ones.

Recommendations:

- Patients could be asked to fill in a 'dying wishes' form (similar to an organ donation form), detailing their preferences should they have to go into ICU.
- Live-streamed prayer services, religious music, recorded prayers, religious items or iconography could be offered to patients when they are admitted, facilitated by hospitals; however PPE needs to be a consideration.
- Hospitals should maintain Chaplaincy and palliative care services where possible, allowing a select number of clergy from different faith communities to conduct bedside ministry, with adequate PPE.
- The language of 'dying alone' should be avoided; 'dying without family and friends close' could be a substitute.
- Telephone or video calls from the bedside should be considered where it is the wish of the patient and their loved ones, again with consideration of PPE.

Disposal and Release of the Body

There is a lack of information and support for families immediately after death.

- Cremation is unacceptable to certain Christian and the majority ofMuslim and Jewish communities. Even people of no faith may have strong personal reasons for preferring burial.
- The enforcement of cremation may well lead to social disturbances.
- Delayed release of the body is unacceptable for Sikh, Hindu, Muslim and Jewish communities, but more desirable than cremation for some Christian communities.

Recommendations:
- Uniform and clear information must be circulated on the following: receipt of a green certificate, release of body, passage to funeral parlour, and burial or cremation of body to families, funeral directors and religious leaders.
- Information should be communicated in multiple language using written and video media.
- Differentiating the death of those suffering Covid-19 from those who have died of other causes could be important.
- If the government hope to encourage the uptake of cremation, it may be productive to reframe the ritual as 'dry burials' or 'burial of ashes'

Funerals

Banning funerals would be unacceptable to most communities.

- Funeral directors and crematoria are the pinch-points currently determining whether a deceased person gets any officiant or attendees at a funeral, or nothing at all.
- While many communities have traditions of hosting large funerals, smaller funerals conducted down the lockdown can be experienced positively as more 'intimate' and 'personal' occasions.
- Small funerals do cause rifts in some families surrounding the question of who is able to attend.
- At present, there is inconsistency by different funeral parlours and local authorities in numbers of allowed congregants, and restrictions on permitting family to view, wash and carry the body. This is distressing for the bereaved particularly when neighbouring local authorities are carrying out different practices. Families nevertheless accept that the pandemic is unfolding in different ways in different regions and are prepared to accept restrictions that they see as proportionate.
- Funeral attendees are finding themselves torn between adherence to social distancing measures and their desires to physically comfort each other.

- The cost of funerals is a significant source of anxiety for some communities, where existing government grants are not sufficient to cover funeral costs leaving people reliant on credit or forced to opt for a 'pauper's funeral' which does not allow a dignified burial process.
- Live-streaming or recording funerals and mourning ceremonies, and private prayer meetings facilitated by technology, are current adaptations being implemented across communities.

Recommendations:
- Developing a dialogue between undertakers, funeral directors and crematoria would be critical to keeping mourners safe and maintaining uniform regulations.
- It is important to iron out local inconsistencies particularly those within regions in the number of people and ritual activity permitted at a funeral, during burial and cremation, and provide clear communication on these regulations.
- Provision could be made for a small number of chief mourners to see the deceased before the funeral.
- Governments should consider providing financial assistance for communities who will experience excess death to cover the cost of funerals and lost income.
- It is important to promote formal means of bringing mourners together after death through technology, particularly for those unable to attend funerals.

Bereavement

It is of utmost importance that families feel able to honour their dead to avoid 'complex grieving'.

- Normal practices of visiting, cooking and caring for the bereaved are unable to occur due to social distancing guidelines, leaving mourners isolated.
- This is particularly acute for those who are unfamiliar with, unable to use, or cannot afford internet and telephone. It is also particularly acute for those who are not used to openly articulating their feelings, or whose fluency in English is insufficient to take advantage of remote counselling.
- There is significant guilt experienced by families who feel they are unable to honour their dead sufficiently or with the correct ritual procedures, leading to poor mental health outcomes.
- Communities will interpret their experiences through cultural and historical lenses, and as such excess death and the denial of a funeral can trigger associations from traumatic events of the past; for instance WWII in the Jewish Community, and slavery in the Caribbean community.

Recommendations:
- Provision should be made to allow people from the community to express solidarity with the bereaved family remotely through means such as online books of condolences.
- Processes of memorialisation should be encouraged after social distancing guidelines are lifted.
- Such memorialisation could be promoted at a national level, where painful deaths are reframed as honourable deaths, and mourned through the likes of a moment of silence.
- A telephonic or text-based support line could be provided for the bereaved.
- Support should be provided for overburdened community leaders, funeral workers and care providers who bear the brunt of excess death, and may suffer burnout or traumatisation.
- HMRC deadlines could be extended, and processes of administration expedited for the bereaved during this period as they attempt to administrate the estate of the deceased.

Findings from Historical Precedent

Interviews were conducted with community leaders who had managed the process of dying through historical events in the UK including particularly the Omagh Bombing in Northern Ireland (1998) and the Grenfell Tower Disaster in North Kensington, London. Such interlocutors highlighted suggestions to manage the immediate response and management of trauma in the long-term.

Findings suggest:
- Improvisation of **new rituals around dying, death, and the funeral** is manageable and will be generally accepted, but the crucial point is that rituals must be seen as 'authentic', and based on already-existing rituals where possible.
- Short-term interventions need to be part of a **long-term plan for managing grief in the population**. Therapeutic services should be offered responsively rather than preemptively.
- A key ritual element of this plan would be to hold **communal memorials** at later date e.g. a community-wide memorial service or a national day of mourning. This allows for public recognition of the traumatic context of these deaths (and generates a sense of belonging) which is crucial for long-term mental health management.
- An element of personalisation is important in memorials, such as the 72 seconds of silence for the 72 victims of the Grenfell Tower Disaster.
- There must also be a plan for the management of impact on **'involved staff'** - medical staff, paramedics, funeral directors, ministers - some of who will likely experience PTSD.
- **Not allowing for individual burial** would be extremely distressing. This would be best managed by being part of local escalation plans, whereby it would only be triggered at a certain point of crisis.

Findings from Faith Communities

Christian

Interviews were conducted with representatives of Church of England, Church of Scotland, Catholic, Baptist, Pentecostal and Afro-Caribbean Christian denominations in London, Birmingham, East Anglia, South-East England, North-East Scotland, Northern Ireland and the Republic of Ireland. Across Christian denominations, a 'good death' was framed as one that "*brings the community together to accompany the dead on their spiritual journey*", primarily through physical togetherness. For most, a bad death is a death in pain, unsedated and alone. Christian religious leaders are adapting to the social distancing guidelines through the use of technology to bring their congregations and the bereaved together.

Performing last rites, or attendance of the dying by a priest is important to Christians and cannot be subsisted by anyone else such as a medical professional. With adequate PPE, ministers are willing to attend the dying in the hospital, and where possible and permitted, they are doing so already. Touch is important to this process, but voice can be substituted acceptable in these circumstances. However, at present how much PPE is available varies across contexts, and can be disruptive to the ritual process, and in donning and doffing. As hospital chaplains fall ill themselves, they expect a shortage of clergy and to draw on local parish priests. Interlocutors also indicated that the news of death should be given to family by religious leaders as opposed to the hospital.

The funeral is one of the most important rites for Christians, providing loved ones the opportunity to say goodbye and for grief to be held by the priest or other officiant. Often the officiant will visit the household prior to the funeral, and people congregate to comfort the bereaved and respect the dead. Washing and viewing the body is important for some African, Filipino, Irish and Catholic communities. The process of supporting bereavement perhaps is even more critical, through memorial services at later days cannot do the crucial work of funerals.

Church of England clergy have prepared adapted liturgy especially of committal (entrusting the deceased to God) including short-form and remote form. They are working on ecumenical shared forms which could be used across faiths if necessary e.g. for collective funerals.

Interlocutors suggested that they would be able to adapt to regulations surrounding small funerals, in particular movements to graveside services. Many indicated that they would prefer to delay the release of the body and conduct a physically proximate funeral after social distancing guidelines had been lifted. Cremation would not be preferable for many Christian communities and is already causing significant distress, some of whom believe that the soul may return to haunt the bereaved if cremated. Communities highlighted that the loss of the social event, a wake or 'tea' after the funeral, was a significant source of distress.

Northern Ireland

Funerals in Northern Ireland differ considerably from Great Britain. Certain communities have complex relationships with the state and policing of funerals has led to contestation, violence and death in recent history (e.g. the Milltown Cemetery attack in 1988, corporals killings in 1988, and more recently, arrests at dissident republican Michael Barr's funeral in 2016). Therefore, any decisions taken regarding funerals in Northern Ireland should be taken in consultation with local communities and respecting local funerary norms.

Funerals in Ireland generally take place within 2-4 days of death. Typically, the body is embalmed, dressed and prepared by the funeral director immediately after death for one or two nights of public viewing, advertised online (www.rip.ie) and held either in the deceased's home or a funeral home (the latter is more common). Large numbers of people come to viewings – anything between 100-1,000 people mourners is common. There is usually a Catholic funeral mass immediately before the disposal

of the remains. Burials are the most common method of disposal (79%) but cremations are becoming increasingly popular.

Funeral gatherings are limited to 10, which is being adhered to, though there is variation in what kinds of funerals are allowed to take place. As a large proportion of clergy are over 70 and unable to leave their homes, few priests are available to celebrate funeral masses and committal prayers in some parishes. Elderly funeral directors were taking more precautions and favouring direct burial/cremation out of concerns for their own health. There is a lack of refrigerated storage facilities for bodies.

Mourners are overcoming physical distancing through creative means such as forming a guard of honour as the hearse drives from the church to the cemetery. Many people send messages to the family on online condolence pages. Most people plan on holding a memorial mass and gathering once social distancing is lifted.

Muslim

Interviews were conducted with representatives of both Shia (Ismaili) and Sunni Islam, encompassing both 'traditional' and 'modernist' schools, and with connections to South Asian, Middle Eastern and East African Muslim communities across the UK. A good death in the Muslim community is one where "*you are surrounded by family members, by those who love you, those who are reciting for you, encouraging you to recite, let those be your final words.*"

There was a significant sense that existing feelings of alienation experienced by British Muslims were exacerbated by the pandemic. Inclusion of diverse Muslim communities in policy formation and messaging is critical to alleviating such feelings. There are significant feelings of mistrust for hospital staff and authority figures, manifest in fears that Muslim Covid-19 patients were "having cures tested on them" without their knowledge.

Many Muslim scholars and leaders have already set out detailed guidelines on how to adapt ritual while adhering to Sharia regulations during the pandemic. Successful change has been facilitated maintaining the essence of the rituals, where prayers are recited, the symbolic act of the practices is acknowledged, adjustments to rules and regulations are carried out with sensitivity. Such adaptation is specifically related to the care and washing of the body. There were some precedents following the Grenfell Tower disaster where intensive communications led Muslims to accept that they would not be able to wash the body. Shia and Sunni religious leaders are both working hard to support families at each step starting from hospital, to mortuary, to funeral parlour, to cemetery and burial, yet their inability to visit the family has caused distress. It is suggested that Muslim NHS staff might be able to play a role in supporting Muslim patients through death.

Respondents were uncomfortable with any scenario in which British citizens (even non-Muslims) were forcibly cremated. They felt that their own exemption from cremation should not be made on the grounds of being Muslim, but on the grounds that individuals' bodies should be honoured in the way they choose after death. This reflected their religious worldview, but would also allow better interfaith relations than if they were seen to be receiving 'special treatment'. Burial rites should not be delayed. Prayers for the deceased are being organised privately via technology platforms. Those who die from Covid-19 are being honoured as martyrs (*shahid*) in the eyes of Allah.

Information about regulations surrounding social distancing, hospital admission and funerals should be communicated in multiple languages. Information should not only come through Imams, who in some communities are disconnected from needs, but also through grassroots organisations.

Jewish

Interviews were conducted with Rabbis who work with the orthodox, non-orthodox and ultra-orthodox communities in London. In the Jewish community, a 'good death' is one where the dying person is accompanied by people who are able to say psalms and prayers, then followed by fairly rapid burials, within 24 hours of death.

The orthodox and non-orthodox communities have accepted government changes to burial practices, and acknowledge that there will be a number of memorials when regulations are lifted. A delay in post mortem body release is not desirable, as people are considered to be in limbo until the funeral has taken place, making it impossible for the family to move on with their lives. The current solution of allowing up to 10 people to a funeral is the preferred option given the current circumstances. However, the ultra-orthodox community in London, New York and Israel have not accepted such adaptations.

At present, Rabbis welcome the ability to go to the hospital and be with dying Covid-19 patients, if only to take the pressure off medical staff (nurses and doctors) who are currently being asked to take on the emotional burden of supporting dying patients. Rabbis are supportive of the use of technology to support family members who have been hospitalised, but issues of access need to be acknowledged, particularly for the ultra-orthodox community who eschew the use of modern technology in some cases.

Cremations, and mass cremations or burials, are to be avoided at all costs for the Jewish community, from both a religious point of view, and because they revive traumatic memories of the Holocaust. Measures such as the use of masks and social isolation have already been triggering such associations for some of the population, being reminiscent of the gas masks and restriction measure put on Jews during Nazi Germany.

Sikh
Interviews were conducted with Sikh community representatives from London and the Midlands. A "good death" in the Sikh community is one in which relatives are able to conduct prayers and cremate the body soon after death. The Sikh community is responding to government guidelines and coping well with social distancing, though there is some shame and stigma surrounding contracting the virus.

Treatment of the body after hospital admission may involve specific stipulations depending on the form of Sikhism the patient follows. Amritdhari or initiated Sikhs are required keep the '5 K's' on their person even after death, including the turban if the person wears one. The Sikh Council is developing guidelines surrounding the care of Sikh patients in hospital.

The lack of clarity in government guidelines concerning the treatment of the body is causing problems in this community. In Sikh practice, the family will wash the body and prepare it before it is cremated. With the current guidance, people are advised not to do this but are not actually prevented from it. In the Midlands, funeral directors are allowing families to do prepare the body, whereas in London they are not. This means that some vulnerable families are paying extortionate amounts for this service as a result of feeling guilty about doing 'the right thing.'

In the situation of mass cremations, it would be critical that a representative in the form of a Granthi (religious leader) perform the necessary Sikhs rites, including the prayers of Kirtan Sohila and the Ardas. It is understood that memorial services that bring the community together will be conducted after social distancing guidelines are lifted. It is important that guidance for the Sikh community is given on its own terms, and Sikhs are not counted as a sect of Hinduism.

Hindu
Interviews were conducted with nine members of the Hindu community, three of whom are British Hindus living abroad with family in the UK. A "good Hindu death" at minimum would have a cremation, religious songs at the deathbed, sacred water from the river Ganges to be given before death, and sacred chanting at the deathbed.

People agreed that Hindu rituals and rites are flexible and have become even more so due to Covid-19 but through small acts, some comfort can be drawn and a 'limited good Hindu death' can be achieved. Many religious communities and Hindu identity groups are already organising online religious

activities and prayers to keep older people and the vulnerable connected. Hindu leaders need to be approached to dispel myths circulating in their community.

Hospitalisation is a source of anxiety as there is a lack of information about being hospitalised, what happens once people are there and what restrictions are in place, apart from those in ICU. Rather than be involved in decisions, they feel they do not know what is not allowed so therefore cannot make any religious adaptations to prepare for a hospital stay, for themselves or loved ones. Chaplaincy services could be explained better for non-Christians who are unsure of what these are and how they can be used. Some are concerned about paying for prayers (as priests in Hinduism do charge for certain religious rituals) so people do not ask for Hindu bedside prayers in hospitals. Currently, people have suggested that religious music or verses be played for those in intensive care so that God is the final thoughts on peoples' minds.

In Hinduism, bodies are cremated on the same day as death. Rituals can also be carried out without the body, and with the ashes at the later date so this, though not ideal, is not an issue in the current climate. E-funerals are already being carried out through the crematoriums and local councils, again, there is a lack of information on how many people are allowed, and what rituals can be carried out. A suggestion would be to create Hindu rites pamphlets in conjunction with religious communities as there is a lack of information available as to how adaptable rites can be and what government guidelines can be followed.

Non-Faith (Humanist, Agnostic, Atheist)
Interviews were conducted with a Humanist celebrant, a representative of Humanists UK, and funeral directors. Most Humanists will be cremated (85%), though a small portion will be buried in natural sites or local authority cemeteries (15%), as per individual choice. The values of science, liberty and empathy are central to the Humanist approach to death and ritual. Humanists stress that criteria for action should be led by science, not faith. Other non-religious respondents echoed this, but also stressed the importance of local traditions and personal memories in shaping what counts as a good death (for example, being buried in a cherished place, or next to a loved one).

Humanists and other non-religious people are concerned that they will be left out of discussions and consultations as policy guidelines are developed. This was a particular concern for respondents in working class rural communities, who already felt a sense of exclusion from mainstream policy-making and also believed that their local situations (in terms of availability of burial plots, population density, etc) could accommodate funeral practices that might not be so practical in urban areas'

Humanists UK have had to take quick steps to retrain their celebrants to the new forms of online provision and funerals/burials. The work of supporting the bereaved, called in this community the beloved or loved ones, and not just including the family, is critical and has been managed through online and telephonic means.

Generally for Humanists UK, it would be unacceptable for the government to ban all funerals during the epidemic peak. This is because the association has always emphasised the individual's right to choice. However, whatever guidance is issued should also be in line with the latest scientific evidence.

At the Humanist funerals, there have been changes in the practices of crematoria, which are quite inconsistent. Celebrants have seen a great diversity of practices within crematoria in interpreting government guidelines. Humanists are willing to livestream or record funerals. Humanists are willing to delay funerals or memorial practices until after the peak of the pandemic.

Buddhist
We were unable to secure any interviews with representatives of the Buddhist community.

Findings from Vulnerable Groups

Interviews were conducted across vulnerable groups, however findings presented here are most notable from BAME and Single Parent households.

<u>Black and Minority Ethnic Households</u>

Interviews were conducted across the South Asian Hindu and Muslim communities, and the Christian and Muslim African and Afro-Caribbean Communities. It is critical to include BAME communities in the development of policy guidelines surrounding social distancing, hospitalisation and funerary rites. Illiteracy, technology illiteracy, low uptake of existing health/social welfare services and existing mental health issues were all factors mentioned during interviews experienced by some BAME households; these exacerbate the impact of social isolation, and prevent communities from adhering to social distancing guidelines. There is significant mistrust of the government in BAME communities, causing myths to circulate. The best way of correcting myths and promoting correct information is by empowering community and religious leaders through multi-lingual training, and by drawing on those community leaders that have already proved themselves trustworthy, as is the case in North Kensington following the fire in Grenfell Tower.

African Communities

A 'good death' in African communities is one where "*friends and family rally around a person, befitting of their religious faith. It is one where there is no family tension and all can say goodbye*". It was emphasised that African funerals are often celebratory events, where hundreds attend, a practice prevented by social distancing guidelines. The inability to visit and care for the bereaved is a significant loss in the African community, where technology illiteracy and lack of access means that in some cases telephone calls and ZOOM meetings are not a solution. The community are very concerned about potential cremation and mass public health burials. Congregation after death is important to many African communities, and is a significant loss at present. The community is willing to adapt to new regulations if they are given adequate knowledge and sensitisation. This would be best done through own community leaders.

Afro-Caribbean Communities

Funerals are extremely important, and are large affairs involving the entire community. A large and elaborate funeral is a sign of respect for the deceased, where rituals such as washing and preparing the body will continue for nine days after death. Rituals draw historical significance from experiences of slavery. A policy of mass cremation should be avoided at all costs, particularly for the Windrush generation. The delayed release of the body would be preferable to this. A failure to honour the deceased would exacerbate existing feelings of alienation and resentment.

<u>Single Parents</u>

Interviews were conducted with single mothers, mental health and domestic violence service providers. Single parents are particularly vulnerable during social distancing, as their existing isolation is exacerbated – "*a single parent, in good times, is in a precarious situation; now with her children at home she can't work and will likely lose her job, and cannot even leave them to go shopping*." Low income, loss of employment, delays in universal credit payments, and the collapse of Child Maintenance payments exacerbate existing financial and food insecurity. Many are heavily reliant on extended networks of kin, currently cut off due to social distancing. Anxieties about the cost of funerals, and increased financial insecurity or loss of housing following the death of kin, should not be underestimated in this group.

Women who have left their partner due to domestic violence face a number of significant threats. Perpetrators are using the social distancing guidelines as a reason to get back in touch with their victims and exploit their vulnerability. The release of perpetrators from prisons without notice puts victims at risk. The collapse of referral services mean the only option women have is to go to the police, who are already overburdened. Public messaging on identifying and accessing support for domestic violence is critical, as is funding for domestic violence services when regulations are lifted.

Concluding Remarks

Across communities, a 'good death' in these challenging circumstances means allowing the deceased to die with company (ideally that of loved ones, or someone who can provide spiritual support), ensuring their body undergoes appropriate ritual procedures (even if the ritual has been modified for the pandemic), and respecting their wishes regarding burial or cremation. In many communities it is important that the funeral take place without undue delay. These factors outweigh congregation when it comes to ensuring that the deceased has a *good enough death*.

Fears of a loved one dying alone are especially amplified amongst diaspora populations who worry that elderly loved ones, who may not speak fluent English, will not even be able to communicate with hospital staff. Fears of a 'bad death' are also amplified in communities that have historically experienced traumatic forms of death and burial, or if the deceased is young.

A major stressor is the fear of one's loved ones 'dying alone' in a hospital. If appropriate PPE can be provided, allowing a religious figure, volunteer companion, or a loved one to attend the bedside of the dying (especially if dying of a condition other than Covid-19) promises to significantly alleviate many of the anxieties currently surrounding this prospect.

Families are generally accepting of funeral restrictions, provided they feel that the decision for restriction is taken in consultation with their community members, and is sufficiently able to accommodate the kinds of choices that allow the deceased to be honoured. Restrictions must be seen to be proportionate to the effects of the pandemic in the local area, and consistent with restrictions in neighbouring local authorities. Forced cremation is likely to meet with resistance. Banning funerals outright may also meet with resistance.

Honouring those who have died during this pandemic should be prioritised as a matter of national and community importance.

Appendix 1: Research Methodology

The research team conducted 58 interviews lasting between 30 and 100 minutes between Friday April 3rd and Thursday April 9th.

Research participants were selected through the existing networks of the research team, and particularly through deep existing engagements with communities. Participants were contacted via telephone, WhatsApp or ZOOM. Research participants were asked for consent to be part of this study and assured that data would be anonymised and would not be shared beyond the research team. Interviews followed agreed themes set collectively by the research team, and directed by Laura Bear. In some cases, interviews were recorded. Interviews were transcribed and summarised. A survey was compiled by one researcher, Megan Laws, published on Google Forms and advertised publicly.

One researcher, Nikita Simpson, collated and thematically analysed the findings to produce this report. Recommendations were drawn from interview data, and suggested by a small team of researchers including Laura Bear, Deborah James, Nicholas Long, Insa Koch and Nikita Simpson. The select bibliography was compiled by Rebecca Bowers.

This study is guided by the ethics guidelines of the Association of Social Anthropologists in the UK. http://www.theasa.org/ethics.shtml Data collection processes were compliant with GDPR regulations.

Appendix 2: Select Bibliography of Existing Research

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