



## King's Research Portal

DOI:

[10.18742/pub01-034](https://doi.org/10.18742/pub01-034)

*Document Version*

Publisher's PDF, also known as Version of record

[Link to publication record in King's Research Portal](#)

*Citation for published version (APA):*

Johnson, H., Brighton, L. J., Clark, J., Roberts, H., Pocock, L., Ogden, M., ... Evans, C. (2020, Jun). Experiences, concerns, and priorities for palliative care research during the COVID-19 pandemic: A rapid virtual stakeholder consultation with people affected by serious illness in England. *London: King's College London*. <https://doi.org/10.18742/pub01-034>

### **Citing this paper**

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

### **General rights**

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

### **Take down policy**

If you believe that this document breaches copyright please contact [librarypure@kcl.ac.uk](mailto:librarypure@kcl.ac.uk) providing details, and we will remove access to the work immediately and investigate your claim.

# Experiences, concerns, and priorities for palliative care research during the COVID-19 pandemic

**A rapid virtual stakeholder consultation with people affected by  
serious illness in England**

Halle Johnson, Lisa Jane Brighton, Joseph Clark, Helen Roberts, Lucy Pocock,  
Margaret Ogden, Rashmi Kumar, Clare Gardiner, Irene J Higginson,  
Catherine J Evans

**June 2020**

## Executive Summary

The palliative care research community has responded quickly to COVID-19. However, the experiences, concerns and research priorities of people affected by serious illness and their families remain unknown. We conducted a rapid public consultation from March 16th to April 15th, 2020 to understand the emerging experiences, concerns and research priorities of people affected by serious illness, in relation to palliative care, during the COVID-19 pandemic.

Using virtual methods (online forum, email, telephone) we consulted members of patient and public involvement networks across four palliative care research groups in England. These networks include individuals living with serious illness, and their family members and/or informal carers. Responses were synthesised into categories by a team including people with clinical, academic and lived experience relevant to palliative care.

We received responses from 44 patient and public involvement contributors. Their concerns and research priorities centred around four key areas: reduced professional support; strains on informal care networks; risk of reduced quality of care; and increased loss, grief and bereavement. Responses described anxieties around disrupted services, and concerns for how existing health inequalities may be exacerbated. Issues around increasing informal care responsibilities, as well as losing informal support due to isolation measures, were also raised. Contributors had questions around how individualised and holistic care would be maintained, and how care may be rationed with rising demand for healthcare. Many also felt that bereavement support should be prioritised.

Research priorities to innovate access to palliative care during a pandemic and beyond should address: ensuring timely professional support with increasing service demand; sustaining informal care networks under increasing strain; ways of monitoring and detecting compromised outcomes of care; and bereavement support responsive to increasing loss and grief. It is essential that, going forward, people affected by serious illness can continue to contribute to the palliative care response to COVID-19.

## Introduction

Increased morbidity from COVID-19 is placing huge strain on health and social care services<sup>4</sup>. Significant reorganisation of services, postponement of non-urgent care, and use of additional personal protective equipment (PPE) has been required<sup>6</sup>. In parallel, social distancing measures have been implemented by governments to limit further transmissions<sup>7</sup>. National research bodies are continuing to emphasise the importance of public involvement in shaping health research responding to COVID-19<sup>8</sup>. However, the involvement of the public in research in the UK has decreased substantially during this time<sup>9</sup>.

People living with serious illness (defined as health-related illness and suffering associated with the need for palliative care<sup>10, 11</sup>), are most at risk of adverse outcomes as a result of COVID-19<sup>12</sup>. Many are following guidance on increased levels of isolation ('shielding') to limit their chances of contracting the disease. These individuals often have complex needs<sup>13</sup>, and high service use<sup>14, 15</sup>. Current strains on services and recommended isolation measures may disrupt supportive networks, including informal support from family and friends<sup>16</sup>. It is therefore essential that the voices of people with serious illness and their informal carers are included in the palliative care response to COVID-19.

An important aim of public involvement is ensuring research addresses what is relevant and important to the general public. Several consultations have sought to understand palliative care research priorities from the perspectives of patients, families and professionals<sup>17</sup>. In 2014, out-of-hours care, geographical access, advance care planning, supporting informal carers, and staff training were raised as priorities for palliative care research in the UK<sup>18</sup>. However, the unprecedented impact of COVID-19 on services and communities may have resulted in new concerns and different priorities in the context of a global pandemic. We therefore aimed to understand the emerging experiences, concerns and research priorities of people affected by serious illness, in relation to palliative care during the COVID-19 pandemic.

## Consultation Process

We undertook a rapid exploratory stakeholder consultation, using virtual methods, from March 16<sup>th</sup> to April 15<sup>th</sup>, 2020.

### Inviting people to take part

We invited members of existing patient, family and public involvement (henceforth public involvement) groups associated with palliative care research to contribute to this consultation. These groups include people with serious illness and their informal carers (including those living with frailty and/or multimorbidity), with historic and/or current experiences relevant to palliative care, who have registered an interest in contributing to palliative care research. We aimed to be inclusive of people with experience of palliative care, and those who are rapidly developing palliative care needs due to the COVID-19 pandemic (including those directly affected by COVID-19 symptoms, and those indirectly affected by COVID-19 through impacts on services and communities).

We began by inviting public members at one Institute based in London to contribute. Researchers at this Institute introduced the consultation to public members within their existing network by creating a discussion thread on an online forum for palliative care research<sup>2</sup>, and by publicising the consultation more widely via email and twitter. The consultation then expanded to include palliative care researchers at University of Sheffield, University of Hull, and University of Bristol. Researchers from these teams shared the invitation to contribute to the consultation via email within their own public involvement contacts and relevant local networks (e.g. regional healthcare charities, Biomedical Research Council public involvement groups).

### What we asked, and how

Initially, through the London and Sheffield networks, we invited patient and public involvement members to respond to a single broad open question asking individuals to

share their experiences and concerns relevant to palliative care in light of COVID-19, and areas which they considered most important for palliative care research to address (example in Appendix A, Box A1). As the consultation and collaborations developed, initial responses to this open question were used to create a more structured prompt sheet, used by the teams at Hull and Bristol when consulting members of their public involvement networks. This prompt sheet included the original open question, and listed broad potentially relevant issues raised so far, such as symptom management, use of technology for care delivery. These prompts were used to explore emerging areas of concern and enable identification of further areas (see Appendix A, Box A2). To facilitate rapid responses and to avoid deterring people, we did not collect information about personal characteristics.

Responses were received via the online forum, email, and phone. On the online forum, some responded directly to the original post, while others responded to each other. In some cases, people responded more than once as the discussion continued. Members of the collaborative team moderated these responses, and periodically contributed prompts inviting further response on topics such as advance care planning and to gather the views of informal carers in addition to those with serious illness. People responding by email sent free text responses, some reflecting on the prompt sheet detailed above. For responses by phone, a researcher took notes and responses were read back to the contributor to enhance accuracy.

### **Collation and synthesis of responses**

Our multidisciplinary team of researchers, clinicians, public involvement coordinators, and public involvement representatives collated and then synthesised the contributions. To do this, we drew on processes used in thematic analysis<sup>19</sup>. This intended to ensure the collation and synthesis of responses was undertaken in a planned, rigorous and transparent way. As there are known tensions and debates around the boundaries of qualitative research and public involvement<sup>20</sup>, this distinction is important.

All team members independently read through the consultation responses multiple times. HJ, LJB, and JC began synthesising responses by attaching short descriptive labels to sections of text to identify topics raised. During a virtual team meeting, related topics were grouped together under larger categories, and each category was given a broad descriptive label. Categories and descriptions continued to be refined with input from all team members via email and subsequent virtual meetings, until the team agreed that they adequately represented contributor responses. We shared a preliminary summary of results on the online forum to ensure key issues were not missed and/or misinterpreted, and to provide opportunity for further input. The final synthesis was organised into a narrative, incorporating illustrative quotes.

### **Ethical considerations**

We referred to the Health Research Authority decision tool<sup>21</sup> to guide our approach to ethics. As this was a consultation exercise rather than primary research, ethical approval was not required. However, we took steps to ensure an ethical approach.

We provided information about the purpose of the consultation with invited patient and public representatives before they shared their views. To minimise distress, we responded to all contributions and signposted to relevant support and resources if needed. We anonymised all contributions and stored this information securely in Excel with restricted access. Where it was felt that anonymised quotations would best illustrate contributions, we contacted individuals to obtain their permission to include these. This enabled people with direct experience of palliative care to contribute to the ongoing debate around the response to COVID-19.

### **Patient and Public involvement**

We worked together with two patient and public involvement representatives (MO, RK) throughout the consultation. For further detail about their involvement, please see the Guidance for Reporting Involvement of Patients and Public (GRIPP) short-form checklist<sup>22</sup> in Appendix B.

## Findings

Forty-four people responded to the consultation. Twenty-nine responses were received via email, 8 on the online forum and 7 by telephone. Five respondents provided multiple contributions as they responded to the online forum discussion thread.

Experiences, concerns and priorities relevant to palliative care centred around four areas (Figure 1):

- reduced professional support;
- strains on informal care networks;
- risk of compromised care; and
- increased loss, grief and bereavement

Broader experiences and issues relating to the impact of the pandemic on daily life and healthcare services, beyond the scope of this consultation, were also highlighted and are detailed in Appendix C.

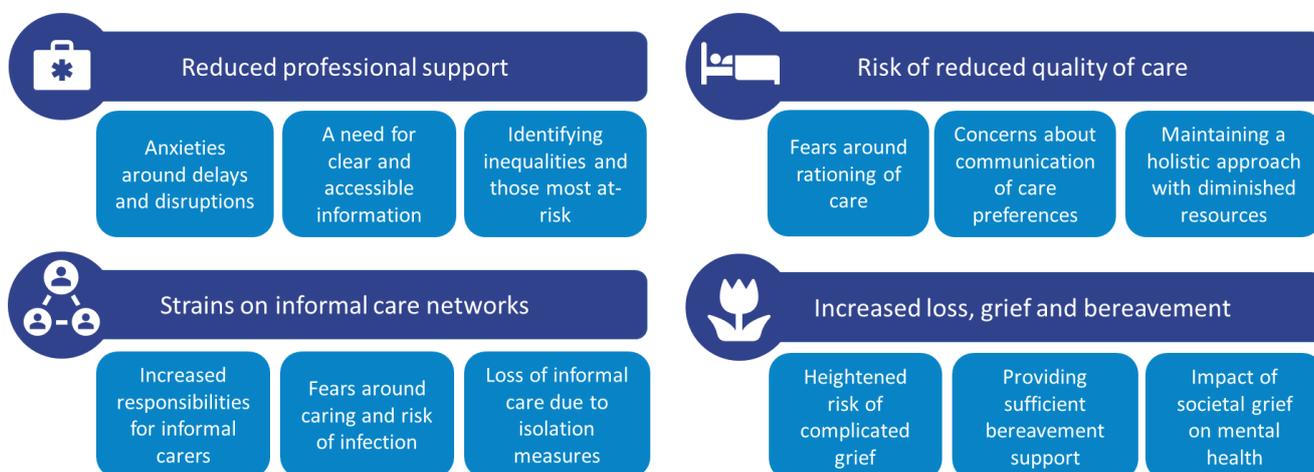


Figure 1: Concerns for people with serious illness and their families during the COVID-19 pandemic

## Reduced professional support

### Anxieties around delays and disruptions

Responses highlighted the importance of continued usual care for those living with serious illness. Typical formal care networks had often fragmented due to increased strain on care systems, social distancing measures and staff illness. Contributors were experiencing increased anxiety, unsure if they would get the support they needed if their health declined or if facing an emergency (e.g. a fall). Many had already experienced disruptions to services, including support groups, GP appointments, medical advice, and out of hours support, plus issues accessing usual medications and equipment (e.g. incontinence pads, portable oxygen).

*“I tried to ring the GP surgery for 2-3 days [following a reaction to a new medication], but the line would go dead as soon as I rang. At the same time no one could enter the surgery without an appointment, so I had no way of communicating!” (Contributor 28)*

Delays and cancellations of important tests and treatments also heightened anxieties for contributors who were uncertain of when, or if, planned treatments would re-commence. For example, delays to follow-up tests following surgery for cancer increased distress due to the uncertainty of not knowing if still “living with cancer”. Contributors noted the risk of premature deterioration linked to the disruption of treatments needed to maintain their own or their relative’s health. The risk of poor outcomes was also raised for people who were now unable to undertake their usual self-management strategies, such as exercising at the gym to help manage their breathlessness.

Alongside increased risks, others highlighted positive impacts of changes including learning and using virtual technology (e.g. Zoom, WhatsApp, Skype) to access support (e.g. exercise groups, singing-for-breathing groups). Research into how services have reorganised, and the consequences of this, was suggested.

## **A need for clear and accessible information**

Contributors reported significant information needs in the context of rapidly evolving health guidance and high quantities of information available from different sources. Some noted that clear communication from the government and healthcare services about being part of the 'extremely vulnerable' group, and outlining available support, was helpful and reassuring.

*"I have received communication from the team that supports me and advice to follow in case of particular issues that might arise in relation to my condition. This has been helpful in reducing my anxiety and although I do have concerns about what would happen should I need routine procedures during this time I feel some reassurance that I know who to contact for support." (Contributor 39)*

However, other contributors with complex care needs who self-identified as 'extremely vulnerable' reported not receiving any information and were unsure of available support.

## **Identifying inequalities and those most at-risk**

Contributors were particularly concerned about how social distancing, isolation and service changes might exacerbate existing inequalities for some groups (e.g. people living alone, those without technology, people with disabilities, care home residents). They emphasised the importance of identifying and prioritising support for these individuals.

## Strains on informal care networks

### Increased responsibilities for informal carers

For many, caring responsibilities have rapidly shifted towards informal networks. This resulted in increased anxieties about the need to provide care, symptom management, maintain adequate sanitation, monitor health, and ensure comfort of their family and/or friends, without the necessary knowledge, skills and support.

*“My mother had a professional carer who visited three times a day, every day, and now, due to the pandemic, they are only able to come two times a week. I am now responsible for all aspects of her care, including correctly dosing and administering my mother’s medication, something I fear I am inadequately managing as I do not have the required skills.” (Contributor 8)*

Research into how symptom management and palliative care can be supported by virtual means in the community was seen as important.

### Fears around caring and risk of infection

Carer contributors also voiced fears around catching the virus and infecting the person they care for, who would be at an increased risk of poor outcomes due to existing illness. They were also anxious about not being able to provide informal care if they also became unwell:

*“I feel very tired & not too well but I dare not admit this as the care worker who came today will then stop coming...I am doing my best to keep my mother, [my husband] & me in separate rooms, not easy when my mother hallucinates at night...I am praying that I will soon recover as my very vulnerable family need me, and that I’ll manage not to spread to them whatever it is that I have.” (Contributor 28)*

## Loss of informal care due to self-isolation measures

Contributors who did not live with the person they care for and/or those caring for multiple people were concerned that, if required to self-isolate, they would be unable to fulfil usual caring duties. Many feared that those who they care for would have unmet needs, or that care would fall to already strained professional services.

*“I am involved with two family members and one long term friend now in a care home... If the government insists on everyone over 70 "self-isolating" this could cause chaos... I am over 80. Fairly physically fit. Apart from the effect on family and friends, the cover I provide would have to be picked up possibly by overstretched Health and Social services!” (Contributor 3)*

Those who had lost support, however, were grateful for assistance received from the local community and volunteer groups who helped with important tasks, such as grocery shopping and collecting prescriptions.

*“All the neighbours have joined a WhatsApp group and their teenage children are offering to do all manner of jobs, shopping, posting letters and such. I think kindness for our fellow humans could be a big winner as a result of coronavirus.” (Contributor 9)*

## **Risk of reduced quality of care**

### **Fears around rationing of care**

Many patient contributors shared increased anxieties around resource prioritisation, and how this could influence the care they might receive if they became ill. Reflecting on media reports, many feared that they would not receive the same quality of care as those who were younger, or without comorbidities:

*“If I were a clinician, I'd chose to help the patients who had the best chance of surviving. That means sacrificing the older patients. As an over 70 with leukaemia it would on paper be a waste of valuable resources to keep me alive” (Contributor 9)*

Anxieties and frustration shared towards the concept of rationing were amplified by a lack of clarity around how decisions were being made. Some contributors felt that age was often misused in UK Government decision-making and stressed that this was an arbitrary way of assessing health.

### **Concerns about communication of care preferences**

With many COVID-19 patients experiencing sudden deterioration in health, contributors highlighted the importance of sharing preferences for future care, for example through advance care planning. Priorities were for advance care planning conversations to be undertaken sensitively, and for conversations to be documented and accessible to health and social care professionals across care settings, to ensure wishes could be carried out. Ways for individuals to record and share preferences, such as virtual resources, that didn't require facilitation by a healthcare professional were deemed important during this time.

Alongside this, contributors questioned how health professionals would use advance care decisions, such as do not attempt cardiopulmonary resuscitation (DNACPR) orders, at this time:

*“My mother has a DNACPR and I am not sure how it will be used. Will a ventilator be seen as resuscitation or will they use it as an excuse not to give her one?” (Contributor 35)*

*“I have long since registered this asking for NO RESUSCITATION - but am anxious that, should I fetch up in hospital currently with or without Covid 19 I might be treated aggressively against my will. Living alone, I'm not sure what alternative arrangements there could be?” (Contributor 24)*

Another contributor raised the challenge of discussing care planning over the phone rather than face-to-face, and feeling that staff were trying to sway preferences away from going to hospital. Understanding how to ensure preferences are still considered in the context of rapid deterioration and minimal family presence in hospital was considered an important area for research.

Despite these concerns, some contributors were encouraged by the possibility of greater societal awareness and open discussion of death following the pandemic.

*“Hopefully, one of the many things that will change due to this, will be a greater awareness of facing up to the end of our lives, as part of the natural process of being a human being.” (Contributor 20)*

### **Maintaining a holistic approach with diminished resources**

Contributors expressed fears that higher demand and fewer staff may reduce holistic and personalised care. They were concerned that end-of-life experiences may be worsened by infection-control procedures, which may stop family from visiting and stop health professionals providing hands on care and reassurance, for example by hand holding.

*“I haven't wanted to think much about 'end-of-life care' but the Virus has forced me to think about this because I am one of the vulnerable, (over seventy with underlying health condition) ... I haven't made a*

*will...I have no family nearby (I have a few GOOD friends) ...if I get it [the virus], it means I die alone. The last thing I want to do..."*  
(Contributor 36)

Contributors felt more could be done to appraise the risks versus benefits of physical contact towards the end of life. One contributor suggested, if immunity could be demonstrated, that the use of volunteers to provide some face-to-face contact for those at the end of life could be beneficial.

## **Increased loss, grief and bereavement**

### **Heightened risk of complicated grief**

Contributors acknowledged the complexity of the grief that bereaved people might experience, resulting from a lack of contact with dying loved ones, sudden and unexpected deaths, and the inability to attend funerals in the usual manner. One contributor highlighted how grief may be multiplied, and the bereavement process significantly altered:

*"My grief over losing my Mum was much less because I was there to comfort her at the end... I then had the normal sequence of a burial and all that goes with it as part of our cultural norm to help me move to the next stage... We need to think about how to help people move on after this epidemic." (Contributor 6)*

### **Providing sufficient bereavement support**

Supporting those who are grieving was raised as a priority. Contributors suggested that memorial ceremonies could be facilitated in the short-term through adapted funerals (e.g. via technology) or through other remembrance activities (e.g. planting trees). In the long term, ensuring funerals take place, and offering bereavement counselling for affected individuals, were raised as very important to overcome grief.

## **Impact of societal grief on mental health**

A concern for many was the large number of bereaved people resulting from COVID-19 and the associated grief at societal level. Daily exposure to increasing deaths was highlighted as a potential threat to the mental health of the general population. Some suggested research into how to help people 'move on after the pandemic', especially as some may have to adapt to a new normal.

*“Currently there is insufficient support for people to obtain bereavement counselling or support after losing a loved one. It is currently not valued as a necessary part of health care. This will be multiplied after we get through this period. That underlying trauma needs to be assessed, supported and managed for the sake of the whole nation's mental health.” (Contributor 20)*

## Discussion

### Changes to priorities of people affected by serious illness during COVID-19

Understanding optimal models of palliative care have previously been raised as a priority for palliative care research<sup>17, 18</sup>. However, changes in context resulting from COVID-19 have dramatically shifted the priorities for optimal palliative care provision during and beyond the pandemic. A priority for people affected by serious illness was research to ensure changes in community and acute care in response to the pandemic mitigate against the emergence of new, and the extension of existing, health inequalities<sup>23, 24</sup>. Researchers and policy makers need to understand how services have been reorganised, what works for different patients (or not), and how new models can be adapted across settings.

Reduced professional support resulting from service reorganisation in response to COVID-19 has increased the reliance on informal carers, family and friends to provide care and support for those with serious illness. Support for informal carers is an established priority in palliative care research<sup>17, 18</sup>, and the compounding impacts of COVID-19 have underscored its importance. Research is urgently needed on sustaining and supporting carers under increasing demand, equipping them with the knowledge, skills and resources to provide adequate care in the community for those close to them. Access to timely skilled professional support is crucial to manage increasing care needs as disease progresses and when nearing the end of life<sup>25</sup>.

Prominent concerns were raised around risk of compromised access to critical care for individuals who may benefit, and quality of care at the end of life with rising demand on services. Key areas of future research are developing and evaluating holistic and individualised approaches to care amid increasing demand and service pressures. Consideration of care preferences at the end of life was emphasised during COVID-19, reiterating an existing research priority<sup>17, 18</sup>. Contributors raised concerns about how their preferences could be communicated and considered in the context of rapid deterioration, with infection control measures reducing family members' ability to advocate for loved

ones, and potentially rushed conversations with staff conducted by telephone. Research on communicating decisions about care and treatment to patients and family, to ensure a dignified death under increasing service demands, is required.

For many, the pandemic had raised new concerns around dying and bereavement. Lack of physical contact with loved ones who were dying was a frequent concern for contributors, with many viewing this as a crucial aspect of person-centred care. Contributors emphasised the need for research evaluating alternative ways of connecting with loved ones, for example patient-family communication via virtual means<sup>26</sup>. Contributors identified the escalating complexities of multiple deaths and widespread grief during the pandemic and the impact at individual and societal levels. Research priorities focused on identifying and implementing effective models of bereavement support. Such models should consider recognising and caring for individuals at risk of complicated grief in routine care and acknowledging and preventing the impact of grief on mental health at a societal level.

## **Conclusions**

Palliative care research in response to the COVID-19 pandemic should address the concerns and priorities reported by people affected by serious illness around reduced professional support, strains on informal care networks; risk of compromised care; and increased loss, grief and bereavement. It is essential that people affected by serious illness can contribute to the palliative care response to COVID-19 and impact on research and care during and after the pandemic.

## **Reflections on the strengths and limitations of the consultation**

Using multiple consultation methods and working across several public involvement networks enabled a rapid consultation that involved a range of individuals. However, our reach was limited to those with access to email or the online forum. The stories shared illustrated diversity in terms of circumstances, health status and caring responsibilities. Most comments appeared rooted in current experience, although some reflected on past experiences and how the current circumstances would have made a difference (e.g. noting the benefit of being physically present when a relative was dying). Not requesting information about personal characteristics may have facilitated willingness to respond, but this also meant we were unable to check for potential gaps in the breadth of representation.

Our consultation included people who were members of public involvement networks, whose characteristics, concerns and priorities may differ from people with serious illness outside of these networks. For example, people in patient and public involvement networks may have greater understanding of health systems and services. We captured views from one country (England) during the first month of national public health restrictions to contain the pandemic. With international differences in health systems and government responses, and ongoing changes to public health measures over time, ongoing context-relevant public involvement will be required. Reflections on our experience of conducting a collaborative, virtual consultation are shown in Box 1.

### **Box 1. Reflections on collaborative, virtual consultation**

Our virtual and collaborative consultation approach allowed us to rapidly consult a range of people across England with relevant lived experience to inform research during an international emergency. This was the first time our public involvement groups have worked as a collaborative network across organisations to inform palliative care research and showed the potential benefit of sharing expertise and resources. By offering diverse and flexible opportunities to respond (online forum, e-mail, phone) we could also facilitate involvement in a way that suited different individuals, while usual face-to-face approaches were not possible.

Our experiences resonate with previous recommendations for more joined up and collaborative approaches to public involvement in research<sup>1</sup>, and the potential importance of flexible and virtual involvement opportunities<sup>2, 3</sup>. Already, the findings of this consultation have been fed back to our local researchers and informed the development of COVID-19 research<sup>5</sup>. As such, expanding and developing the role of collaborative and virtual approaches to go beyond this type of emergent situation and facilitate public contributions throughout the research cycle may be an important next step.

## **Acknowledgements:**

Thank you to all the people who kindly contributed their experiences and thoughts to this consultation during this difficult time. We are grateful to Yorkshire Cancer Research, South East London Consumer Research Panel for Cancer, and the NIHR Applied Research Collaboration South London for distributing information about our project with their patient and carer support groups. We also thank those who reviewed previous versions of this work for their valuable comments that helped to greatly improve the clarity of this report.

## **Funding & Declarations:**

This consultation, the online forum, HJ, RK, MO and IJH are supported as part of the National Institute for Health Research (NIHR) Applied Research Collaboration South London (NIHR ARC South London) at King's College Hospital NHS Foundation Trust, with additional funding from Cicely Saunders International. LJB is supported through a NIHR Career Development Fellowship (CDF-2017-10-009). CJE is funded by HEE/NIHR Senior Clinical Lectureship (ICA-SCL-2015-01-001). IJH is an NIHR Senior Investigator (Emeritus). JC and HR are funded by Yorkshire Cancer Research. LP is funded by a NIHR School for Primary Care Research GP Career Progression Fellowship. The views expressed are those of the author(s) and not necessarily those of the NIHR, the Department of Health and Social Care, Cicely Saunders International or Yorkshire Cancer Research.

## **Our team & institutions**

Halle Johnson, Lisa Jane Brighton, Irene J Higginson, Catherine J Evans  
*Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College  
London, London, UK*

Margaret Ogden, Rashmi Kumar  
*Cicely Saunders Institute Patient & Public Involvement Group, King's College London,  
London, UK*

Joseph Clark  
*Wolfson Palliative Care Research Centre, University of Hull, Hull, UK*

Helen Roberts  
*Institute for Clinical and Applied Health Research, University of Hull, Hull, UK*

Lucy Pocock  
*Centre for Academic Primary Care, University of Bristol, Bristol, UK*

Clare Gardiner  
*Division of Nursing & Midwifery, Health Sciences School, The University of Sheffield,  
Sheffield, UK*

## References

1. Chambers E, Gardiner C, Thompson J and Seymour J. Patient and carer involvement in palliative care research: An integrative qualitative evidence synthesis review. *Palliative medicine*. 2019; 33: 969-84.
2. Brighton LJ, Pask S, Benalia H, et al. Taking patient and public involvement online: qualitative evaluation of an online forum for palliative care and rehabilitation research. *Research Involvement and Engagement*. 2018; 4: 14.
3. Daveson BA, de Wolf-Linder S, Witt J, et al. Results of a transparent expert consultation on patient and public involvement in palliative care research. *Palliative medicine*. 2015; 29: 939-49.
4. Public Health England. Number of coronavirus (COVID-19) cases and risk in the UK. <https://www.gov.uk/guidance/coronavirus-covid-19-information-for-the-public>. 2020.
5. Higginson IJ MF, Preston N, Sleeman K, Maddocks M, Bajwah S, Fraser L, Hocaoglu M, Oluyase A, Walshe C on behalf of the CovPall Team, . CovPall Study. Cicely Saunders Institute, , 2020.
6. Stevens SS. Next Steps on NHS Response to COVID-19. In: Chief executives of NHS trusts and Foundation trusts CAO, GP practices and Primary Care Networks, Providers of community health services, (ed.). 2020, p. 17.
7. Public Health England. Guidance on social distancing for everyone in the UK. 2020.
8. National Institute for Health Research. Shared NIHR commitments to public involvement, participation and engagement during the COVID-19 pandemic. 2020.
9. Hanley B TM. Involving the public in COVID-19 research: a guest blog by Bec Hanley and Maryrose Tarpey. NHS Health Research Authority, , 2020.

10. Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: the Lancet Commission report. *Lancet (London, England)*. 2018; 391: 1391-454.
11. Sleeman KE, de Brito M, Etkind S, et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *The Lancet Global health*. 2019; 7: e883-e92.
12. NHS England. Advice for people at higher risk. <https://www.nhs.uk/conditions/coronavirus-covid-19/advice-for-people-at-high-risk/>. 2020.
13. Stafford M. SA, Thorlby R., Fisher R., Turton C., Deeny S. Understanding the health care needs of people with multiple health conditions. The Health Foundation, 2018.
14. Bone AE, Evans CJ, Henson LA, Gao W, Higginson IJ and study B. Patterns of emergency department attendance among older people in the last three months of life and factors associated with frequent attendance: a mortality follow-back survey. *Age and Ageing*. 2019; 48: 680-7.
15. Wagner E, Patrick DL, Khandelwal N, et al. The Influence of Multimorbidity on Health Care Utilization at the End of Life for Patients with Chronic Conditions. *Journal of Palliative Medicine*. 2019; 22: 1260-5.
16. Leong IY, Lee AO, Ng TW, et al. The challenge of providing holistic care in a viral epidemic: opportunities for palliative care. *Palliative medicine*. 2004; 18: 12-8.
17. Hasson F, Nicholson E, Muldrew D, Bamidele O, Payne S and McIlfratrick S. International palliative care research priorities: A systematic review. *BMC Palliative Care*. 2020; 19: 16.
18. James Lind Alliance. Palliative and end of life care Top 10. 2015.

19. Payne S. *Qualitative methods of data collection and analysis*. Oxford: Oxford University Press 2007, p.139-61.
20. Locock L and Boaz A. Drawing straight lines along blurred boundaries: qualitative research, patient and public involvement in medical research, co-production and co-design. *Evidence & Policy: A Journal of Research, Debate and Practice*. 2019; 15: 409-21.
21. NHS Health Research Authority MRC. NHS HRA Decision Tool 2017.
22. Staniszewska S, Brett J, Simera I, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. 2017; 358: j3453.
23. Davies JM, Sleeman KE, Leniz J, et al. Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. *PLOS Medicine*. 2019; 16: e1002782.
24. Gardiner C, Brereton L, Frey R, Wilkinson-Meyers L and Gott M. Exploring the financial impact of caring for family members receiving palliative and end-of-life care: a systematic review of the literature. *Palliative medicine*. 2014; 28: 375-90.
25. Bowers B, Pollock K and Barclay S. Administration of end-of-life drugs by family caregivers during covid-19 pandemic. *BMJ*. 2020; 369: m1615.
26. Selman LE, Chao D, Sowden R, Marshall S, Chamberlain C and Koffman J. Bereavement support on the frontline of COVID-19: Recommendations for hospital clinicians. *Journal of pain and symptom management*.

## Appendix A

### Examples of consultation text

#### Box A1: Example of text sent to public members via email / the online forum

##### **Your experiences and research ideas relating to palliative care, rehabilitation and COVID-19**

As you will be aware the global spread of COVID-19 brings many challenges for patients, family, carers, members of the public, alongside the health care system and health professionals. We now know that those who are elderly, frail, and/or those with underlying chronic illness - populations which are at the core of palliative care, are most at risk from the novel coronavirus.

At this challenging time, we believe, as palliative care and rehabilitation researchers, we have a responsibility to use our expertise in support of the international response to the COVID-19 outbreak. This is not limited to finding treatments, but also concerns for instance, guidance on symptom management, impact on mental health and broader social and economic impacts.

I am aware that the ongoing situation is likely to be impacting many of you and your family and friends. At this time, it is imperative that any research and action is aligned to the needs of the population. Together with some of our researcher and public member colleagues, we believe it would be helpful to conduct a rapid consultation to collate your key concerns and ideas and share these more widely with other palliative care researchers and others undertaking COVID-19 research.

The aim of this consultation will be to highlight and promote the patient, family and public voice in this rapid and fast-changing environment. This is particularly important given the isolating nature of the current situation, and that the experiences and ideas of people managing their health in the community and at home might otherwise be missed.

I therefore wanted to provide you with an opportunity to share your thoughts on the current and developing situation. We would be interested to learn of any concerns that you currently have, or have had, and areas which you think are important for research to address at this time. You may wish to refer to the attached prompt sheet to guide your thinking.

We would welcome responses via email or phone, and we will be collating responses up until the 15<sup>th</sup> April 2020.

## **Box A2: Prompt sheet sent to some public involvement members**

### **Priorities for palliative care research in the context of COVID-19**

We are interested in any thoughts you may wish to share regarding priority issues for palliative care in the current emergency. In the context of the ongoing pandemic, some topics you may want to think about are:

- How symptom management and palliative care should be provided
- Preferences for where care should be provided in the context of 'lockdown'
- Opportunities for technology to aid care delivery
- Risks and benefits of face-to-face care in the context of social distancing
- How clinicians can find out patient preferences in terms of treatment options
- How to maintain standards of care
- How family carers can best be supported, particularly in the community
- Any other comments or concerns that are not being addressed?
- What people have found helpful or reassuring at this time.

Please share any thoughts you wish to share regarding research priority issues for palliative care in the context of Covid-19 in the space provided (box will expand if necessary):

## Appendix B

### Guidance for Reporting Involvement of Patients and Public – short form checklist<sup>22</sup>

Section and topic	Item
<b>1: Aim of Patient and Public Involvement</b>	<p>The aims of patient and public involvement throughout this consultation were as follows:</p> <p>(1) To ensure that our conduct and processes were acceptable and appropriate to patients/carers who were participating</p> <p>(2) To ensure a fair synthesis of findings that represented the responses received</p> <p>(3) To improve clarity and reach of dissemination.</p>
<b>2: Patient and Public Involvement methods</b>	<p>We used flexible remote methods (via videoconference and email).</p>
<b>3: Involvement throughout project</b>	<p>Two public members were part of the consultation team throughout the project. Contributions to specific components to date are as follows:</p> <p><i>Project development and management:</i></p> <ul style="list-style-type: none"> <li>• Helping to ensure an acceptable and ethical approach to consulting people affected by serious illness during a potentially stressful time</li> </ul> <p><i>Data Collection</i></p> <ul style="list-style-type: none"> <li>• Advising on the language used in the consultation invitation</li> <li>• Helping guide responses to people who contributed, including recommending supportive resources the research team were not aware of</li> </ul> <p><i>Consultation synthesis and interpretation</i></p> <ul style="list-style-type: none"> <li>• Reading through and familiarising themselves with all the responses</li> <li>• Contributing to videoconference meetings to develop and refine the synthesis of responses, including the final narrative. This helped ensure responses were not missed and/or misrepresented</li> </ul> <p><i>Dissemination:</i></p> <ul style="list-style-type: none"> <li>• Co-authoring the report, including intellectual contribution to main messages of the report, review of report drafts</li> </ul> <p>Going forward, we also plan to work with our public members to further disseminate the findings of the consultation and share our experiences of working together as a collaborative network for this project.</p>
<b>4: Outcomes of Patient and Public Involvement</b>	<p>There have been multiple positive outcomes from patient and public involvement in our study, in line with our aims:</p> <p><i>(1) ensure that our conduct and processes were acceptable and appropriate to patients/carers who were participating:</i></p>

Section and topic	Item
	<p>Involvement of our public members within this project was critical to ensure that our processes would be sensitive and appropriate to the patient, carer and public representatives we invited to be involved. Conducting this consultation during the COVID-19 pandemic we were particularly conscious that those we were inviting to be involved in the consultation may be experiencing highly stressful situations, which required additional sensitivity. Public members were helpful in both suggesting the language which should be used for inviting patients, carers and public to take part, and critically, in helping to advise on resources/organizations which would be helpful to signpost to, if respondents were experiencing distress or facing issues.</p> <p><i>(2) To ensure a fair synthesis of findings that represented the responses received</i></p> <p>Involving public members in the synthesis of the consultation responses ensured that topics were not missed and/or misinterpreted as a result of only including people on the team with clinical and research perspectives. This influenced how related topics were grouped together and ensured that how these responses were then described in the narrative were a fair reflection of the original responses.</p> <p><i>(3) To improve clarity and reach of dissemination:</i></p> <p>Involving our public members as co-authors has also increased the clarity of the results narrative and the overall paper. Our public members reminded the researcher authors that while the paper may have a predominately academic audience, it is also likely that this paper will be of interest to patients and the public. They therefore helped pick up on academic language that could instead be phrased in more plain-English terms, helped ensure readability and clarity, and ensured that the emphasis of the paper remained in line with what was raised by contributors.</p>
<p><b>5: Reflections on Patient and Public Involvement</b></p>	<p>We feel that this project, particularly the data synthesis and interpretation component, benefited greatly from including two public members as core members of the project team.</p> <p>It was helpful that the two public members involved had a pre-existing relationship with the project leads, so each were familiar with the others preferred ways of working. As the project was extremely relevant to those involved, public members often were contributing without prompt drawing on their own current experiences and were keen to be involved in-depth throughout the project.</p> <p>Our public members have commented that they felt valued as part of the team and while they had not been involved in a cross-institution collaboration before they felt this had worked extremely well, and led to a more rewarding and satisfying involvement, as well as widening their personal development in patient and public involvement.</p>

## **Appendix C**

### **Supplementary findings**

In addition to concerns and challenges specific to palliative and end of life care, people living with serious illness and families raised more general concerns relating to the broader social and economic impacts of the COVID-19 pandemic and suggested important areas for future research. These are detailed briefly below:

#### **Impacts of social distancing and isolation measures**

Contributors raised concerns regarding the possible psychological impact of social distancing and isolation measures, highlighting that those who live alone, in rural areas, and do not have access to technology may be particularly prone to poor mental health outcomes. Some contributors spoke of their frustrations towards having to isolate, particularly not being able to spend time with friends and family. Others highlighted the importance of maintaining a routine at this time, with one contributor sharing how he and his wife would still get dressed up for dinner once a week, as if they were going out on a 'date night'. Research into the impact of lockdown on mental health, including how people adapt during this time, and the benefits of peer support were suggested.

#### **Fears for healthcare staff having inadequate personal protective equipment (PPE)**

The safety of health care professionals was also a concern for many. Comments advocated for greater effort to obtain sufficient testing and PPE for those working across health care settings, with many concerned an increased strain on health care services as a result of staff illness or isolation. One contributor suggested research to understand deaths of frontline staff (e.g. was this related to lack of PPE, or the virus acting in unknown ways).

#### **Financial concerns**

Contributors also highlighted how the pandemic may have financial benefits for some, but serious negative consequences for others. Those with a stable source of income, reported how they would save money during social distancing as there was less opportunity to spend money on leisure activities. However, one self-employed contributor reported that she had largely had to give up work due to her caring role and others raised concerns for the financial wellbeing of others unable to work due to the pandemic.

A further issue related to access to money and banking services. Whilst internet banking was considered a valuable resource, concerns were raised that those unable to use this technology may struggle to access physical money. Distance to banks to access money and vulnerable people who may lack the social connections to trust people with access to banking details were highlighted as particular challenges.

### **Fear and reluctance to attend health care services**

Comments also revealed a fear and reluctance, by some, to attend health care services, particularly hospitals, both due to fear of the risk of infection and hesitancy to present due to not wanting to overburden the healthcare system.

### **Impact of the media**

Misinformation, information overload and sensationalised media coverage of the pandemic were also highlighted as a concern. Some contributors felt confused by 'mixed messages' from politicians and diverse sources available on the internet. Others were concerned about the impact on mental health of "constant updates about increasing numbers of deaths".

### **Uncertainties about the virus**

Contributors raised concerns around the spread and lethality of the virus. They suggested research to further understand how and why it differs from the usual flu, and whether we can be sure of immunity after having the virus.

### **Learning from the pandemic**

Overall, contributors emphasised the need to ensure that learnings from the pandemic are captured and are used to inform future health care planning and policy, in the hope that such dramatic impacts would not be required if a similar outbreak was to happen again in the future. Comments also suggested that many hoped that new behaviours such as use of technology, and greater community spirit would continue following the pandemic. Contributors suggested it would be important for research to capture, how things are done differently because of the pandemic, and what learning we can take forward.

## Contact us:

If you have found this report helpful and/or it has informed your work, please let us know – this sort of feedback is really helpful for our public contributors.

Cicely Saunders Institute, King's College London, Bessemer Road, London, SE5 9PJ  
[csi.ppi@kcl.ac.uk](mailto:csi.ppi@kcl.ac.uk)

## Suggested citation:

Johnson HJ, Brighton LJ, Clark J, Roberts H, Pocock L, Ogden M, Kumar R, Gardiner C, Higginson IJ, Evans CJ (2020). *Experiences, concerns, and priorities for palliative care research during the COVID-19 pandemic: A rapid virtual stakeholder consultation with people affected by serious illness in England*. Cicely Saunders Institute, King's College London. <https://doi.org/10.18742/pub01-034>



This is an open access work published under a [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/).