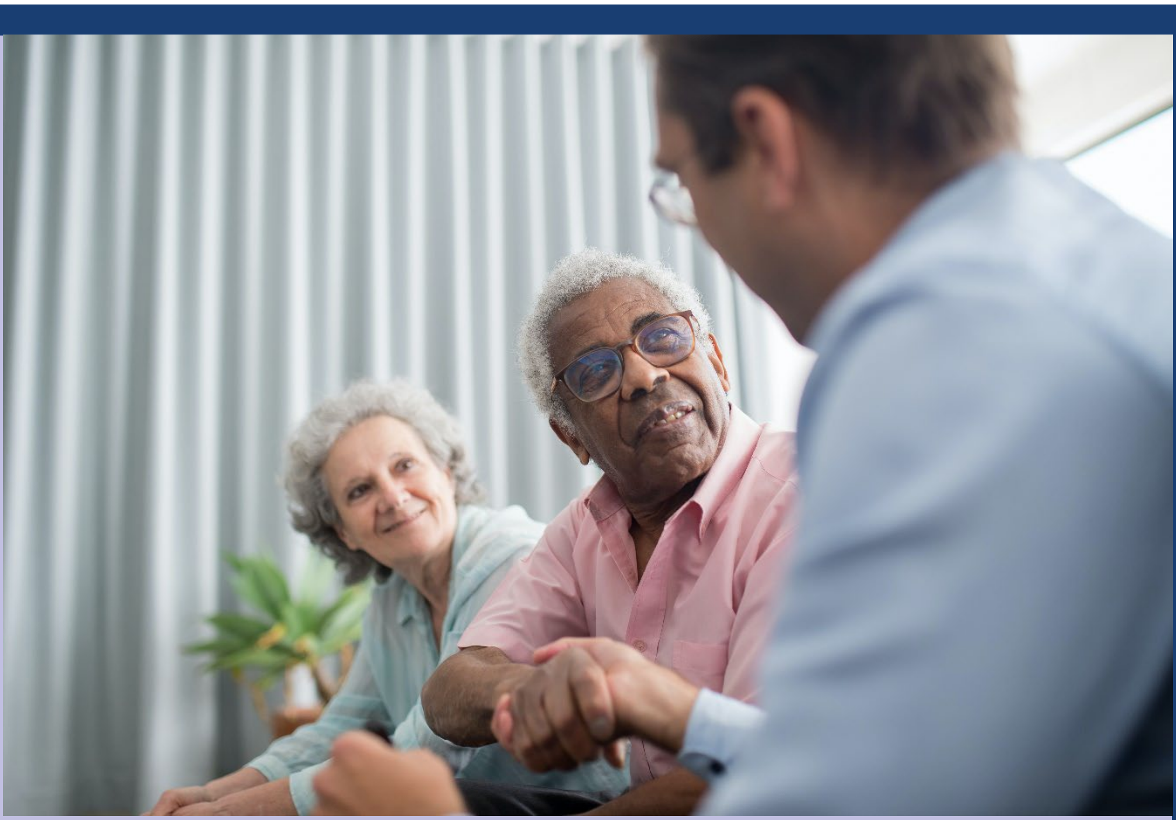
NIHR | Policy Research Unit
Older People and Frailty



Improving discussions about resuscitation in COVID-19

Louise Tomkow, Felicity Dewhurst,
Michaela Hubmann, Efioanwan Andah,
Barbara Hanratty, Chris Todd

Full Report

October 2022

Improving discussions about resuscitation in COVID-19

Full Report

Louise Tomkow, Felicity Dewhurst, Michaela Hubmann,
Efioanwan Andah, Barbara Hanratty, Chris Todd

NIHR Older People and Frailty Policy Research Unit

This report is independent research commissioned and funded by the National Institute for Health and Care Research (NIHR) Policy Research Programme (Ref: NIHR202690 - PRP-000651) in collaboration with the NIHR Older People and Frailty Policy Research Unit (Ref: NIHR PR PRU 1217-21502 . The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR, the Department of Health and Social Care, or its partners.

Please note that this report has not been peer-reviewed.

Table of Contents

Executive Summary

This research explored the experiences of people who discussed Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) with a health care professional on behalf of a relative during the 2020-2022 COVID-19 pandemic.

Background

A decision not to attempt resuscitation (DNACPR) can prevent futile medical intervention at the end-of-life. Clinicians are the decision-makers, but they are expected to engage patients and families in the process. More DNACPR decisions were made in 2020 than in any previous year.[1,] COVID-19 presented particular challenges. Many patients underwent rapid deterioration and social restrictions limited face-to-face interactions between clinicians, patients, and relatives. The aim of this study was to explore relatives' experiences and perceptions of DNACPR discussion during the coronavirus pandemic.

Methods

Thirty-nine people participated in semi-structured interviews via video conferencing software or telephone. Data were evaluated using Framework Analysis.

Results

Findings are presented around three main themes. Restrictions to hospital visiting were important across all three themes, as this caused barriers to communication and distress for patients and relatives.

Theme 1: Knowledge and understanding about DNACPR. Participants' knowledge of DNACPR varied. People with better understanding reflected on their experiences more positively. Some viewed DNACPR discussions as an opportunity to better understand their relative's medical condition, treatment, and illness trajectory. Most felt that more information about DNACPR would have improved their experiences.

Theme 2: Communication around DNACPR discussions. Communication skills were critical. When clinicians had adequate time, participants reported that resuscitation and the rationale for DNACPR decisions were explained, relatives were allowed to raise concerns and their questions were answered. However, many relatives felt that discussions about DNACPR were 'rushed' with few opportunities to ask questions. Communication within families was also important, as DNACPR conversations were less burdensome for participants when they understood their relatives' wishes. Communication of DNACPR decision-making across care settings was poor, and resulted in repeated discussions about DNACPR, which some found distressing.

Theme 3: Impact of DNACPR discussions. Discussions with healthcare professionals about DNACPR were viewed as significant events by our interviewees. Relatives often misunderstood their role, believing that they were being asked to make a decision about DNACPR. Relatives who perceived that they were responsible for DNACPR decision-making felt burdened and had a persisting sense of guilt.

Conclusion

During the COVID-19 pandemic, discussion of DNACPR has been a source of enduring distress for many relatives. Coordinated action at individual, family, care system and population levels has the potential to enhance relatives' experiences of DNACPR discussions. Better public understanding of DNACPR, early discussion in families, more time and communication skills training for clinicians, may all be helpful. This research also suggests that scrutiny of how the current legal framework impacts on clinical practice is merited.

Summary Briefing

Background

Outcomes following cardiopulmonary resuscitation (CPR) are often poor, and most frail older people who undergo in-hospital CPR do not survive to go home.[3] A decision not to attempt resuscitation (DNACPR) can prevent futile and undignified medical interventions. Following a Court of Appeal decision in 2014, clinicians must inform patients or their relatives (if a patient lacks capacity) if a DNACPR decision is made.[2] DNACPR decisions were a source of criticism and complaints before the coronavirus pandemic. However, COVID-19 presented multiple challenges to best practice, including the speed at which patients deteriorated and restrictions on face-to-face interactions between clinicians, patients and relatives. Numerous reports from regulatory bodies, including the Care Quality Commission (CQC), detail poor practice around DNACPR decision-making and communication during the 2020-2022 COVID-19 pandemic, whilst academic literature shows that more DNACPR decisions were made in 2020 during the pandemic than in previous years.[1,2]

Aims and methods

This qualitative research aimed to understand the experiences of people who discussed DNACPR with a clinician on behalf of their relative during the pandemic. Thirty-nine relatives took part in semi-structured interviews using telephone or video conferencing software. A patient and public involvement and engagement group (PPIE) was commissioned to refine the research scope; develop the interview topic guide, and guide analysis. Data were analysed using Framework Analysis.

Results

Three main themes were identified from the data: (i) Knowledge and understanding about DNACPR; (ii) Communication around DNACPR discussions; and (iii) Impact of DNACPR discussions. The issue of visiting restrictions was important across all three themes. Being separated from relatives at the end-of-life was highly distressing for those interviewed and impacted on the quality of communication with clinicians.

Theme 1: Knowledge and understanding about DNACPR

We interviewed people with a range of knowledge and understanding about DNACPR. Those with better understanding reflected on their experiences more positively. A frequent misunderstanding was the relative's role in DNACPR decision making. Although DNACPR is a decision made by the medical team (when CPR is felt to be futile – which represents the majority of DNACPR decisions made), relatives often felt they were being asked to make the decision. Some reported being asked to give permission for a DNACPR to be in place.

> *'[the doctor] said, 'well, it's likely that he's got COVID and it's unlikely that he would survive this, if it is COVID. So, what would you like to do?' And I then spoke to my husband… we made the decision that he probably wouldn't be…he shouldn't be for CPR given how far advanced his Parkinson's was, his own quality of life and the fact that none of us were going to be able to come and see him.'* Participant 11

Participants described frustration when they were asked to be involved in decision-making about DNACPR, and then their wishes were overruled. Those with a limited understanding confused DNACPR with other types of medical treatment. Some believed that DNACPR was a mechanism for rationing care in an overwhelmed health service. Participants felt that having more information about DNACPR would have improved their experiences. Some recommended that public education about DNACPR should be improved.

Theme 2: Communication around DNACPR discussions

The ability of clinicians to lead DNACPR discussions was critical to all participants. Many described discussions about DNACPR as rushed, and felt they were not given the opportunity to ask questions. Some felt they were being coerced into agreeing with a DNACPR. Others described how, as general communication about their relatives' condition was so poor, they felt the discussion about DNACPR came without adequate warning.

> *'The ICU consultant brushed all my concerns aside … He tried to convince me absolutely, he didn't say, oh, there is an option … He had made up his mind that my husband would not be resuscitated and that's what he tried to convey. That my input was very minimal, there was no opening to ask any questions.'* Participant 2

However, participants also reported more positive experiences. Here, clinicians had adequate time to spend on the discussion about DNACPR. The process and rationale were explained well, and relatives were given the opportunity to raise concerns and have questions answered. Participants also reported that communication within families was important. DNACPR conversations were easier when participants clearly understood their relatives' wishes. Some participants reflected that normalising conversations about DNACPR in everyday life would be helpful.

Communication of DNACPR decision-making across care settings was felt to be poor. Repeated discussions about DNACPR caused distress and gave the impression that recording of discussions was poor.

Theme 3: Impact of DNACPR discussions

Discussions with healthcare professionals about DNACPR were considered to be significant events, even pivotal moments, for our interviewees. Participants often described feeling a burden of responsibility from being involved in decision-making and expressed the guilt associated with this. This was particularly significant for those who felt clinicians had asked them to decide on DNACPR. However, people who were simply informed of the medical decision not to offer CPR were often left feeling overlooked.

> *'It was probably one of the hardest things I've ever done in my life, you know, giving permission for your mum not to be resuscitated and basically saying that if this happens, she's going to die, know what I mean, that's as hard a decision as you will ever have to make.'* Participant 24

DNACPR discussions were also viewed as an important opportunity by some participants. Involvement in conversations around DNACPR left people feeling that the clinicians had listened to them, and allowed them to better understand their relatives' condition, treatment, and illness trajectory. This was also an opportunity to explore other aspects of advance care planning, such as the preferred place of care and death. Many described a sense of relief when DNACPR was discussed, and plans made for what would happen when their relative deteriorated. A key feature of these positive experiences appears to be that the relative understood the patient's wishes, the patient's wishes were respected, and the discussion between relative and clinician incorporated the wider aspects of advance care planning and allowed time for explanation and questions.

Research implications

Participants recommended ways in which discussions about DNACPR may be improved. These were in the following key areas:

- **Education about CPR and DNACPR**: Many recommended that efforts be made to increase public understanding of DNACPR. Our data suggest that this should include clarity around the role of relatives in DNACPR decision-making.
- **Public understanding and discussion about death and dying**: Many participants described a need to 'normalise' conversations about dying. Participants valued having a clear understanding of their relatives' wishes around DNACPR, suggesting that communication within families and communities is essential.
- **Improving communication of DNACPR across care settings**: This is expected to negate the need for repeated discussions about DNACPR. This also implies that these discussions and decisions should be properly recorded onto systems.

- **Improving clinicians’ communication around DNACPR**: Clinicians need sufficient time to speak to relatives about DNACPR decisions, respond to questions and consider advance care planning. Clarifying the role of the relative in the decision-making process is an important issue that may not be appreciated by clinicians.

Highlighting the personal impact of relatives’ involvement in DNACPR discussions during the pandemic, draws attention to tensions between current clinical guidance and the legal framework. Best practice dictates that DNACPR should be discussed by a medical professional well known to the patient as part of advance care planning. However, during the pandemic, the majority of DNACPR discussions occurred during an acute admission and were led by hospital doctors who are obliged to discuss DNACPR at the earliest opportunity. Furthermore, the legal framework requires clinicians to inform patients and relatives about resuscitation regardless of the patient’s wishes, even when resuscitation would be futile and unlikely to be offered on clinical grounds.

Conclusions

During the COVID-19 pandemic, discussion of DNACPR has been a source of enduring distress for many relatives. This research raises questions about the current approach to DNACPR decision-making, including how the legal framework impacts on clinical practice. Co-ordinated action at individual, family, care system and population levels has the potential to enhance relatives’ experiences of DNACPR discussions. Better public understanding of DNACPR, early discussion in families, more time and communication skills training for clinicians, may all be helpful.

Full Report

1.0 Background

Cardio-pulmonary resuscitation (CPR) and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions: History and legal framework

Cardiopulmonary resuscitation (CPR) is a medical intervention that is used when a person's heart has stopped. CPR involves chest compressions and support for breathing (mouth to mouth or via a tube inserted in the airway. Depending on the type of cardiac arrest, Direct Current (DC) defibrillation, (or electric shocks) may be administered via pads attached to the chest wall. CPR does not treat underlying illnesses, such as infections, cancer, or heart and lung disease. In the UK, only 18.4% of people who have a cardiac arrest in hospital survive to be discharged and CPR increases the chances of needing long-term care. A recent review of in-hospital cardiac arrests showed that no frail patients who received CPR survived to hospital discharge.[5]

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions were first used in the 1970s. DNACPR aims to reduce harm by preventing people from being given CPR inappropriately: when it is judged that CPR would not be effective; when the risks outweigh the potential benefits; or when the patient declines to be given CPR. DNACPR is also sometimes referred to as DNAR or DNR. In this report, we use DNACPR.

In 2014 there was an important change in case law around DNACPR decision making, with a Court of Appeal decision in the case of Tracey versus Cambridge University Hospitals NHS Foundation Trust. Here the Court held that a failure to consult with a patient before placing a DNACPR on their medical record amounted to a breach of their right to respect their private life under Article 8 of the European Convention on Human Rights.[6] Lord Dyson stated that:

> *'A DNACPR decision is one which will potentially deprive the patient of life-saving treatment, there should be a presumption in favour of patient involvement. There needs to be convincing reasons not to involve the patient.'* [6]

The only convincing reason suggested was the causation of psychological harm. Still, Lord Dyson added that '*doctors should be wary of being too ready to exclude patients from the process on the grounds that their involvement is likely to distress them'*, as discussions about end-of-life are likely to bring distress regardless. Where a patient cannot participate in a consultation, they have a right under Article 8 for their family members to be consulted where it is practical and appropriate.[2,7] This puts discussions around DNARCPR in a unique position, as healthcare providers are not legally required to discuss other medical treatments or interventions they judge inappropriate or futile.

Alongside two similar cases, the 'Tracey judgement' led to a change in clinical guidance around DNACPR decision making. The British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing issued a joint statement, which included a comprehensive overview of how DNACPR decisions and discussions should be approached.[8] The decision-making framework is presented in Appendix 1, and salient points from the guidance are summarised in Box 1.

Box 1: Main messages from 'decisions relating to cardiopulmonary resuscitation' from British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing'

- When involving those close to the patient in discussions about CPR, it is important to ensure that they understand that they are not the final decision makers, but they have an important role in helping the healthcare team make a decision that is in the patient's best interests.
- It is not necessary to obtain the consent of a patient or those close to a patient to decide not to attempt CPR with no realistic prospect of success.
- The patient and those close to the patient do not have a right to demand treatment that is clinically inappropriate, and healthcare professionals have no obligation to offer or deliver such treatment.
- Where a patient or those close to a patient disagree with a DNACPR decision, a second opinion should be offered. Endorsement of a DNACPR decision by all members of a multidisciplinary team may avoid the need to provide a further opinion.

1.2 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions before the COVID-19 pandemic: synthesis of evidence

Communication around DNACPR decision-making was the focus of much academic literature following the 2014 Court of Appeal decision and before the COVID-19 pandemic.[9] Patients, relatives, and healthcare professionals can find talking about death and dying difficult.[10] Literature has drawn attention to the inadequate discussions about DNACPR between health care professionals, patients, and their families, as well as health care professionals' inadequate communication with each other about a patient's DNACPR status across health and social care settings. Reviews have identified variation and suboptimal practice in DNACPR communication and decision-making across UK health and social care settings, and there have been calls for a national standardised approach.[11] Simultaneously, patients and the public can have unrealistic expectations about the outcomes after CPR,[9] at least in part derived from medical soaps and other TV dramas.

Hall et al.[12] provide the most comprehensive overview of available literature on pre-pandemic DNACPR communication and decision-making in the UK. They reviewed 20 studies and found:

- Patients prefer discussions to be initiated by a healthcare provider known to and trusted by them.
- Families wishes for their involvement vary.
- Decisions about resuscitation should be part of a broader discussion about future care.[13]
- There is variance around the most appropriate time to discuss DNACPR orders. Some patients prefer community planning well in advance of illness, and others prefer the discussion to be closer to the end-of-life. However, there is consensus that discussions should not be conducted during an acute admission to the hospital or at the same time as a new diagnosis.
- Adequate communication skills training is important.

There is less research focussing on the perspectives of relatives. Although the involvement of relatives in these discussions is largely viewed as positive by patients, this is not always the case, with some patients finding family involvement burdensome.[14,15,16] Not all relatives want to be involved either: Gorton et al.'s survey[15] found that 21% of respondents would not be comfortable discussing their relatives' resuscitation status. Nevertheless, there is some evidence that relatives' knowledge of the presence of a DNACPR order can be associated with improved bereavement adjustment in relatives.[16,17]

Only three studies evaluate relatives' experiences discussing resuscitation before the pandemic. In Higginson et al.'s[18] ethnographic study, relatives reportedly did not want to make decisions about resuscitation because they felt ill-prepared. Preferences for the level of involvement varied, but generally, relatives wanted information to allow them to understand the process. The relatives of patients, who had had a recent stroke, in Cowey et al.'s[19] study, expressed most dissatisfaction when they were excluded from making decisions, but at the same time felt responsible for making the 'right' choice. Livingston et al.[20] explored the decision-making of relatives of patients living with dementia. Relatives found end-of-life decisions particularly difficult but were helped by knowledge of the person living with dementia's previous views, clear prognostic information, and family support.

1.3 DNACPR decision-making during the COVID-19 pandemic: Insights from 'grey literature' reports and press releases

During the 2020-2022 COVID-19 pandemic, there was concern regarding DNACPR decision making. We undertook a review of the available grey literature in February 2022. The search strategy, inclusion and exclusion criteria, and results can be found in Appendix 2. Below, we summarise the three most robust reports from three key organisations:

- The Care Quality Commission (CQC)[1] published the most extensive report on DNACPRs during the pandemic, consulting 50 external stakeholders; 2048 adult social care providers and 613 patients with a DNACPR and/or their families. They also reviewed 166 DNACPR records.
- Compassion in Dying[21] commissioned a YouGov survey in September 2020 with a total sample of 2026 adults.
- The British Institute of Human Rights (BIHR)[22] surveyed 230 individuals with support needs and/or their families, friends and carers, advocates and community support groups, and staff working in care and support services.

All reports stressed the importance of transparent, consistent, and regular communication. Compassion in Dying[21] reported that *'when people were distressed, usually it was not because of the decision to withhold CPR, but how this decision was communicated.'* (p16) BIHR[24] similarly stated that *'less than a third of people (29%) who were involved in DNAR decision-making felt fully listened to.'* (p2) Some felt pressured to agree with DNACPRs and *'may have been rushed into making DNACPR decisions…[and] relatives often felt these conversations came out of the blue…and was made worse due to the lack of available accessible information.'*(p17,41) The CQC[1] report highlights how digital technology was not provided equitably, introducing further barriers to adequate and appropriate communication during the pandemic.

All three reports also emphasised that DNACPR decisions had been made on behalf of people without their knowledge or consultation with relatives. The BIHR[22] found that 21% of people were unaware that they or their relative had a DNACPR (p2). Instead, paperwork was discovered once a patient was discharged from the hospital or after they died.[21, 22] This *'caused significant upset among families,'*. [24(p17)] Both the CQC and BIHR articulate this as a breach of human rights:

> *'individuals' human rights – to be involved in DNACPR decisions about themselves or their families - were potentially* being *breached in more than 500 cases across the adult social care services.'* [1 (p20)]

The CQC[1] described how this negatively impacted trust in health and social care providers, particularly for the relatives of older people, where 51% expressed a decline in trust. (p55) In addition, inadequate communication of DNACPR decisions across healthcare settings 'led to repeated DNACPR conversations.' which patients and relatives found inappropriate and distressing (p27)

The reports also describe the use of blanket DNACPR decisions – where DNACPR decisions were applied to groups of people with specific characteristics, such as learning disabilities or care home residents. This practice was particularly prevalent at the beginning of the pandemic. Again, the BIHR[22] and CQC[1] detail the implications of this for Human Rights:

> *'if these decisions are made in ways that do not protect people's rights to life, it is possible that this may be a breach of Article 2…. Not consulting with the person or their representatives when making a DNACPR decision also risks breaching Article 8 of the European Convention on Human Rights, which protects their right to respect their private and family life.'* [1 (p11-12)]

The CQC[1] state that national guidance on DNACPR lacked clarity during the pandemic and changed rapidly, leading to confusion among providers and *'risk[ed] undermining public trust and confidence in the health and care system and demonstrate[ed] the need for better oversight of DNACPR decisions'* (p23). This was echoed by the House of Commons[23] inquiry concerning lessons learned from the pandemic.

The three reports provided similar recommendations, including (i) the need for improved public-health education concerning what DNACPR entails and the DNACPR process and improved training for healthcare staff leading DNACPR discussions; (ii) a consistent national approach to DNACPR decision-making and documentation across care settings; (iii) improved oversight and assurance of DNACPR decisions from health service providers and regulators.

1.4 DNACPR decision-making during the COVID-19 pandemic: Insights from peer-reviewed academic literature

We undertook a review of the available academic research literature in February 2022. This literature points to three main findings. The search strategy, inclusion and exclusion criteria, and results can be found in Appendix 3.

First, as set out in the grey literature, there is evidence that communication of DNACPR decisions was poor during the pandemic. Aker et al.[24] explored the challenges faced by family carers of people living with dementia during the first wave of the COVID-19 pandemic in England, as reported by charity telephone support line staff. They reported that conversations about DNACPR were not always conducted sensitively, resulting in a lack of trust in healthcare providers. However, the study was small (n=8), and conclusions were based on second-hand accounts from charity workers.

Second, studies suggest more DNACPR decisions were made during the pandemic than had been documented. Connellan et al.[25] compared rates of DNACPR documentation in older hospitalised patients before and during the COVID-19 pandemic. They showed that practice during the pandemic and COVID-19 had prompted more widespread and earlier decision-making regarding resuscitation status. Patients above the age of 65 with COVID-19 were significantly more likely to have a DNACPR in place (60.3%) than those without COVID-19 (25.4%) and during a comparable time period pre-pandemic (15.4%). Fifty per cent of DNACPR orders were recorded within 24 hours of a positive swab result for SARS-CoV-2. 70.2% of older COVID-19-positive patients survived. Similarly, Bows and Herring[2] examine the use of DNACPRs across 23 Trusts in England. They found overall increases in the number of patients with a DNACPR decision during the two primary Covid 'waves' (23 March 2020 – 31 January 2021) compared with the previous year. Overall, approximately one in five patients were not informed of the DNACPR decision. However despite this being a shocking statistic, more patients were appropriately informed during the first wave than before the pandemic.

Thirdly, despite more DNACPR decisions being made, there were more in-hospital cardiac arrests during the pandemic, and outcomes were poor. Those with a DNACPR were less likely to survive to 30 days. Contrary to some public discourse that DNACPR was used as a proxy measure to withhold active treatment, this study shows that those with a DNACPR in place did receive active and invasive treatment[26]. Sutton et al.[27] undertook a secondary analysis of 13,977 adults admitted to the hospital with suspected COVID-19 and categorised patients as early DNACPR (before or on the day of admission) or late/no DNACPR (no DNACPR or occurring after the day of admission). They found that early DNACPR decisions were associated with recognised predictors of adverse outcomes (death or organ support) of up to 30 days. Patients with early DNACPR decisions were more likely to be older, have active malignancy, chronic lung disease, limited performance status, and abnormal physiological variables. Patients with early DNACPR had higher mortality (40.7% v 13.1%) and lower use of any organ support (11.6% v 15.7%). Still, they received a range of organ support interventions, with some being used at rates comparable to those with late or no DNACPR (e.g. non-invasive ventilation 4.4% v 3.5%). This data suggests that the presence of DNACPR does not preclude active treatment and that many DNACPR decisions were being made based on sound clinical reasoning.

1.5 Gaps in the literature

COVID-19 has presented several challenges in the discussion of resuscitation with relatives. Rapid, untimely clinical deterioration limits the opportunity for conversations with usual medical practitioners. Instead of being undertaken during discussions about advance care planning, almost half of DNACPR decisions are made during emergency hospital admissions at the time of diagnosis.[1,28] Social restriction measures limited face-to-face hospital visits; instead, discussions with relatives occurred over the telephone.[29,2] Studies describing the quality of communication of DNACPR decisions during the pandemic are limited. Therefore, there remains a pressing need to understand relatives' experiences of resuscitation discussions better. This research project will address this gap in the literature.

2.0 Research aims

This research aimed to understand relatives' experiences of discussions about DNACPR during the pandemic. Insights into what did and did not work, will inform improvements in policy and practice relating to DNACPR.

3.0 Methods

3.1 Study design

This research project used qualitative methods. Semi-structured interviews were undertaken with relatives who had a discussion with a healthcare professional about DNACPR on behalf of a relative during the pandemic.

Inclusion Criteria	Exclusion Criteria
Over 18 years of age. Experience discussing DNACPR with a healthcare professional on behalf of a relative during the pandemic in a hospital or community setting	Under 18 years Lacking the capacity to consent to be involved in research

3.2 Recruitment

We used a combination of purposive and snowball sampling to maximise recruitment. Local and national health, social care, voluntary, charitable and educational organisations were approached via email. (Appendix 4 lists the organisations contacted). We also used 'word of mouth' recruitment by asking participants and PPI members to promote our study through their personal networks. Lastly, we disseminated information about the research via email, social media, and WhatsApp.

We sought bereaved relatives who had discussed DNACPR with a health professional during the coronavirus pandemic. Initially, we only included relatives of people who died in hospital. However, a decision was made in November 2021 to broaden the inclusion criteria to include relatives who discussed DNACPR with a healthcare professional in a hospital **or** community setting. This removed the restriction for the patient to have died, and the need for the conversation to have taken place in a hospital setting. This was driven by a recognition that as the pandemic progressed, many people with a DNACPR decision survived COVID-19 and the percentage of deaths (and therefore DNACPR discussions) occurring in the community increased.

3.3 Data collection

A topic guide was developed in collaboration with a patient and public involvement and engagement group (PPIE). Interviews explored when and where discussions about resuscitation took place, who led those discussions, and how healthcare professionals communicated DNACPR decisions. We also investigated possible (mis)understandings of what CPR/DNACPR entails and the psychological and emotional impacts of the discussion on relatives. Interviews were conducted via the videoconferencing platform Zoom or telephone and lasted between 45 minutes and 2 hours. Participants taking part in interviews were not offered payment.

3.4 Analysis

Data were analysed using framework analysis[30]. This approach enabled us to situate our findings in a policy and practice context and produce structured outputs of summarised data.[(ibid)] A coding frame was developed, adapted, and applied to the data. The research team met regularly to discuss, develop and refine themes. PPIE partners were involved in the analysis, providing their insights and reflections on suggested themes and anonymised data extracts. NVIVO software was used to manage the data. The project was approved by the University of Manchester Research Ethics Committee (2021-11386-19227).

3.5 Patient and public involvement and engagement (PPIE)

Our PPIE partner group comprised of seven people. They were diverse in self-reported gender, geographical location, and occupation. Some had experience of bereavement, some were academics, and others worked voluntarily in health-related services. The group met online using secure video conferencing software. This ensured the reliability of the meetings, given current social restrictions. To reduce the potential for digital exclusion, we drew on NIHR guidance on 'holding a PPI meeting using online tools'. Three meetings were held, each of two hours duration.

PPIE partners influenced the research in several key areas:

- ***The scope of the research question***: Partners felt that questions should address the broader context of the DNACPR conversations, the conflict these discussions might have generated, and the care process.
- ***The importance of a qualitative approach***: Semi-structured interviews were perceived as an effective way of exploring individual narratives and providing a good understanding of lived experience. All partners stressed the inclusion of open-ended positive questions.
- ***Recruitment:*** Some PPIE partners and stakeholders suggested broadening our research focus to include patients' experiences. This was outwith the scope of the funded research, but we acknowledged it as an important area for future research.
- ***Ethical concerns about interviewing people with potentially traumatic experiences***: Contributors supported the view in the literature that discussion may be therapeutic, but stressed the importance of sensitive/appropriate questioning and offering bereavement support.
- ***Developing recruitment materials and interview topic guide***: The group co-designed the interview topic guides and public and participant-facing material to ensure they were sensitive and comprehensive.
- ***Analysis***: PPI partners offered their views on anonymised transcripts and helped identify themes.

4.0 Research findings

Thirty-nine people were interviewed. Nine were male, and 30 were female. Of these 39 participants, two couples participated in joint interviews (n=4). Further demographic details can be found in Appendix 5. Results are organised around three main themes: (i) knowledge and (mis)understanding about DNACPR; (ii) communication around DNACPR discussions; and (iii) the impact of DNACPR discussions. Participants had a wide range of experiences when discussing DNACPR with clinicians. The findings section which follows provides an overview of the most common themes that emerged from the data analysis.

The impact of COVID-19 associated restrictions on hospital visiting is relevant across all themes. A lack of hospital visits was significant for three reasons. First, separating relatives during a significant illness caused considerable distress to many of the participants. Some had cared for their relatives before their admission to hospital, and separation was particularly difficult for these people. Although media and news reports at the time suggested otherwise, the technology to support video calls was not widely available:

> *'I'd gone from seeing him four times a day to not speaking to him at all … We were not provided with the facility to do a video call. My father didn't have a smartphone, so couldn't video call us, but, although we were informed that there were tablets provided to the hospital for that, when I did enquire about it, they weren't available'*
> Participant 3

Second, the lack of visits meant that some people received no updates on their relative's overall clinical condition. This introduced barriers to good-quality information provision:

> *'Normally if anyone was in hospital you can visit and you can see how they are yourself. You are able to look and say, oh, you're looking a bit better today, or, you know, that kind of thing. With my husband, I didn't have that … that's why I found the fact that they phoned me to say he was terminally ill so difficult to consolidate because I couldn't see him.'* Participant 10
>
> *'if we could have been there in person, we would have had longer discussions. They should have been more open about how bad it was.'* Participant 4

Third, visiting restrictions mean that communication of DNACPR decision-making was done by telephone, particularly at the beginning of the pandemic. As visiting restrictions eased, some participants had face-to-face discussions about DNACPR with healthcare staff.

4.1 Theme 1: Knowledge and (mis)understanding about DNACPR

4.1.1 Inequalities in understanding

We spoke to people with a wide range of knowledge about CPR and DNACPR. Some had personal or professional experience of DNACPR, and those with a good understanding tended to reflect more positively on their experiences discussing DNACPR on behalf of their relative during the pandemic. Other participants were less well informed, and reported learning about the subject from televised medical dramas:

> *'I know a little bit … I've watched Holby City, I've watched Casualty … CPR, keeping them alive, doing everything they need to do to bring them back, so that they continue with treatment. Or, that's my understanding of it anyway.'* Participant 38

The way in which some DNACPR discussions were undertaken during the pandemic did not provide relatives with opportunities to ask questions or better understand DNACPR:

> *‘People used the acronym, DNR, as if you knew what they were talking about.’* Participant 23

> *‘We were left in the dark … we didn't know anything, nobody told us anything until they said, we're putting him in a side room and the consultant or surgeon or whoever spoke to us said, “oh well, we've spoken to your husband and he's agreed to a DNR.” And that was about as much information as I got.’* Participant 39

Many of the participants acknowledged the gaps in their knowledge about DNACPR. Some suggested a reluctance to talk about death and dying prevented better understanding. A number of relatives suggested that there should be efforts made to increase public understanding about what CPR and DNACPR is:

> *‘I think we all need to be educated a bit better into what DNAR is all about, how it is dealt with, what your legal or personal standing is in it.’* Participant 4

> *‘I think the information should be easily accessible. To have leaflets in the doctor’s surgery that people could pick up to read more about DNAR … I mean, even in COVID, there have been so many deaths, there’s a larger public awareness about death, but people still aren’t willing to have those conversations. So it almost needs a culture shift really to get people as comfortable talking about death as they are talking about birth.’* Participant 35

4.1.2 Relatives being asked to make DNACPR decisions

The role of the relatives in DNACPR decision-making was a frequent source of misunderstanding. Despite DNACPR being a medical decision, we heard from people who felt they were asked to ‘*give permission’* for DNACPR to be in place, or to make the decision about DNACPR themselves on behalf of their relative.

> *‘I was somewhat taken aback when the SHO in A&E, said ‘does he have a DNR’. I said ‘no, that’s not a conversation we’ve ever had’. And he said ‘well, it’s likely that he’s got COVID and it’s unlikely that he would survive this, if it is COVID. So, what would you like to do?’ And I then spoke to my husband while I was on the phone with this SHO and we made the decision that he probably wouldn’t be…he shouldn’t be for CPR given how far advanced his Parkinson’s was, his own quality of life and the fact that none of us were going to be able to come and see him.’* Participant 11

> *‘All that power was down to me, it was my decision, as I’m the oldest son, but I obviously did it with…in conjunction with my brother. If he hadn’t agreed with me, we’d have then…I would have had to have discussed it at length, but he pretty much agreed with me, and we decided, yeah, that’s what we want to do.’* Participant 24

Even those who felt they had a good understanding of DNACPR described this as difficult:

> *‘I think that's a very difficult situation to be in, isn't it? To say don't bring them back.’* Participant 22

Some participants with a clinical background described how they felt an additional, inappropriate responsibility during DNACPR discussions:

> *'It impacted on me … I didn't want to be a nurse in this situation, I wanted to be a relative ... I want other people to take charge, for two reasons, partly because I want to be allowed to be a relative, and my second reason is my professional reason as well, I don't want to make end-of-life care plans. I don't want to be in charge of medications. I don't want to do verification of expected death and I don't want resuscitation discussions for my own family because they are…my son calls it church and state, I don't want those boundaries blurred.…I want to be a daughter…I don't want to be a nurse.'* Participant 30

Participants described the negative impact of this burden of responsibility, which we explore in more detail in section 4.3.

Participants were often frustrated when they perceived they were asked to be involved in decision-making about DNACPR, and their wishes were overruled.

> *'I explained that I couldn't overrule my mother's wishes, and the doctor said … 'we can … it's a*
>
> *clinical decision really'. And I thought, oh, okay … we did think well why have we had all these phone calls? Why are we here today talking…why are you talking to us about it if it's a clinical decision?'* Participant 36

4.1.3 DNACPR and other medical treatment

Some participants described feeling that having a DNACPR in place impacted other types of medical care. There was a particular perception that DNACPR prevented their relative from receiving other forms of medical treatment, such as that available in critical care:

> *'what I found quite upsetting was that the intensive care treatment and that once I had agreed to the do not resuscitate decision, he was denied a chance to even be treated in the ICU…that's what it says in the letter and that's what the consultant'*
> Participant 2

Some participants who opposed DNACPR, confused it with other forms of palliative care, or decisions not to offer medical treatment:

> *'I said I know exactly what [DNACPR] means: it means you're going to come out with your syringe drivers and your midazolam and you're going to stop treating my mum. No, no, we're not going to do that; we're going to continue treating your mum. And I said, okay, well we do not want her to not be resuscitated. We want her resuscitating.'*
> Participant *34*

Others spoke about DNACPR in the context of the health service being overwhelmed, and the consequent need to ration care:

> *'I think they thought, well, he's got cancer, if he's got COVID … we're not taking up a bed in intensive care, let's just sign this [DNACPR]. That's my feeling … I mean, I can't prove that, but that's my feeling … There aren't enough ventilators, they're having to make these decisions and have these discussions, brutally on the phone, in order to ensure that the treatment goes to those that are most likely to survive.'* Participant 10

Others, who opposed DNACPR, felt that it represented the hospital not wanting to care for their relative or their relative being ‘*written off*’:

> *‘I think because of my father’s pre-existing conditions, and the DNR being in place, it was easy for them to kind of be like, yeah, we don’t need to offer him a ventilator, we’re just going to put him on End-of-life . That’s what I feel like, and I might be completely wrong, I’m not medically trained at all. But I think it’s left a very bitter taste in my mouth.’* Participant 3

> *‘My husband was suffering from Lewy body dementia with Parkinsonism. Basically, I felt that they had written him off as soon as he went in because obviously they had this, for want of a better phrase, a tick chart from the government as to who would and who wouldn't get more treatment.’* Participant 4

4.2 Theme 2: Communication around DNACPR decisions

4.2.1 Clinicians' communication skills

Most participants spoke about the importance of the communication skills of the clinician leading the DNACPR discussion. Participants in this study had a range of experiences. Although we identified some features of good practice, many felt that clinicians’ communication could have been better. When participants interpreted DNACPR discussions negatively, they frequently described the conversations as rushed. Some associated this with the pressure clinicians were experiencing, due to the pandemic:

> *‘the conversation was really rushed, you know … But equally, I fully understand the pressures that A&E services continue to be under and can’t imagine what that must have been like two weeks into the pandemic when patients were coming in, in their droves, you know, of…and we were running out of ventilator beds, you know?’* Participant 11

Some spoke about how they were not given a chance to ask questions or raise concerns about the DNACPR decision, and felt they were not involved in decision-making in a meaningful way:

> *‘The ICU consultant brushed all my concerns aside … He tried to convince me absolutely, he didn’t say, oh, there is an option, you know, we could do this or do that or the other. He had made up his mind that my husband would not be resuscitated and that’s what he tried to convey. That my input was very minimal, there was no opening to ask any questions.’* Participant 2

Participants described how the content of communication was inadequate and that DNACPR was not explained clearly (see also 4.1.1). In some cases, DNACPR decisions were not communicated to participants at all. Here, DNACPR paperwork was only discovered after the discharge or death of their relative.

> *‘My father had a DNR put against him, but we knew nothing about it. We didn’t have a discussion around it at all. It was put in place without our knowledge … they hadn’t actually phoned me about the decision to put it in place, it was only by chance that he mentioned that there was a red form in my father’s file….’* Participant 3

Some described how they felt overlooked by healthcare professionals, despite having expertise in the care and needs of their relatives. This impact is explored in more detail in Theme 3 (4.3).

Many of the participants who had positive experiences reported how clinicians spent sufficient time with them explaining DNACPR and listening to concerns. This appeared to be a significant feature of good communication:

> *'Yeah, they were really good, yes. It was a young female doctor explained it really, really well, just in layman's terms. Obviously, we'd had that conversation anyway but she was really good and explained to my mum. Very compassionate, lots of empathy. She was really kind. And I just felt that she started the conversation and obviously reacted to us and how open we were to it. I thought she managed it very, very well. She made an uncomfortable situation very comfortable.'* Participant 28
>
> *'It wasn't a hurried conversation at all … she gave me as much time as I needed. And we soon built up a rapport, you know, but I've got to say, when she wasn't there, and it was another member of staff, I thought they were equally receptive to what I was saying.'* Participant 1

Clear communication was also critical to participants. Participants were more positive about DNACPR discussions when the clinician was clear about the roles of the family member and clinician in decision-making and the rationale for the decision.

> *'The … consultant said to me we're asking you for your thoughts and considerations. We would like the family to support this. But ultimately it does sit with the doctor. But said in the nicest of way. I didn't feel as if it was well, my decision anyway. It was said in the nicest… And it was explained … Because it's the patient that we're looking after.'* Participant 12
>
> *'I could see that they had their reasons, they weren't just deciding: oh no, we're going to give up on this person. I could see that… And I think she had said that they'd discussed it as a team and they'd made that decision, which made me feel a little bit happier with that decision, which it wasn't just down to one person. I could see that there was a logical path to that decision, even though I didn't quite medically understand why.'* Participant 19
>
> *'The doctor … took me into a room off the emergency ward and explained everything that was happening with my mum, and the fact that she was very frail, she was old. And if they tried to resuscitate her, it could probably do more damage than it was worth doing. He was very kind, he was very understanding, he spoke clearly, he spoke with passion. He kept us informed about everything that was wrong with her. He was absolutely superb, to be fair…I remember his voice, and I remember his voice being ever so calm and collected and straight to the point and compassionate.'* Participant 24

In addition, the provision of regular updates about the general medical condition also appeared to contribute to a positive experience for participants experienced in discussing DNACPR. This could be achieved either over the phone or face to face, as visiting restrictions eased.

> *'Doctors and nurses kept us fully up to date all the way through … the day before my dad caught COVID … the doctor came in to speak to myself and my mum … They did share some information about my dad having an acute kidney injury and, you know, obviously they thought that it would be quite difficult to resuscitate him. And discussed the DNAR with him at that time.'* Participant 28

> *‘Looking back, I feel that they did it as compassionately as they could and I feel that they didn’t rush me. They made me feel that they had time for me and made sure that I had all my questions answered and that kind of thing….I came across members of staff who were really lovely and I felt that they were doing everything they possibly could to help him and to help me and make me feel like they had all the time in the world, even though I know that they clearly didn’t.’* Participant 19

Participants frequently described the importance of care provision and decision-making that was felt to be sensitive to the needs of the individual:

> *‘the thing that stood out with that clinician is the focus of his decision-making was my granddad’s wishes and feelings. And taking my granddad, not just from a medical perspective but actually as the whole person, the impact of his dementia’* Participant 14

This data suggests that clinicians should set aside adequate time for speaking to relatives about DNACPR decisions and allowing time for clear explanations and questions. Relatives should be given the opportunity to ask questions about DNCPR. One participant summarised:

> *I feel that perhaps there should be far more explanation and far more consideration for both the patient and the next of kin when dealing with it.* Participant 4

4.2.2 Communication between relatives and patients

Communication between the relatives and patients about the patient’s wishes for DNACPR appeared to be important. When relatives understood the patient’s wishes about CPR in advance of their illness, it tended to make later discussions about DNACPR with healthcare professionals easier.

> *“She never wavered in do-not-resuscitate. She had looked after my dad when he got senile dementia and she was very clear about that for him when he died. He had some sort of heart attack and he was in hospital and she called for the nurses, and they came in and they were going to get the defibrillator out and everything, and she asked them not to, and then she got the priest to give him the last rites. I knew how she had handled that, and that she was very clear, she was a ward sister and she had been a matron and she seemed to have a very clear idea about how things should be done.”* Participant 8

Participants described how a lack of understanding of their relative’s wishes made discussing DNACPR more difficult:

> *‘I’m wondering “what would he want” and just trying to guess and trying to make the right decision. If we’d had that conversation before, it might have made that a bit easier.’* Participant 19

4.2.3 Communication between healthcare providers across care settings

Participants reported having multiple discussions about DNACPR with different clinicians due to a lack of communication between healthcare providers and across healthcare settings. Some found revisiting DNACPR decisions frustrating and distressing.

> *‘if that information has been discussed once you shouldn’t need to have that conversation again and again and again.’* Participant 7

> *‘[DNACPR] is a horrible thing to have to say about your father … we know we had collectively said yes, do not resuscitate … it’s a horrible decision to have to revisit…. Like who wants to do that?’* Participant 29

4.2.4 Timing of discussion about DNACPR in patients’ illness

Many participants spoke about the timing of the discussion in their relative’s illness, but our data does not point to a consensus on the best time to discuss DNACPR. Most felt that decision-making about DNACPR should be done well in advance of acute illness and deterioration, whilst a minority felt that DNACPR should only be initiated towards the end-of-life.

> *‘He had only been in hospital maybe an hour and a half and in my mind, I am thinking, “well hang on a minute, give it a few days, let's see. You are asking for this [DNACPR] to be put in place already and we don't know how the situation is going to pan out”. So to me it was definitely at the wrong time, very rushed.’* Participant 4

> *‘[DNACPR] should be prepared when the patient has got all the faculties in place and they are capable of making decision, that discussion should take place then.’* Participant 7

4.3 Theme 3: The impact of DNACPR discussions

Discussions with healthcare professionals about DNACPR were considered significant events for the people interviewed. Often DNACPR discussions were the most important or memorable aspect of communication about care.

> *‘He explained everything that I thought I needed to know at the time. Whether he explained the care process, not sure … I had the focus obviously on the DNR bit and my mum, right, if she does go…her heart does go into arrest, they’re not going to resuscitate her. Everything else sort of seemed unimportant.’* Participant 24

For some, the discussion about DNACPR was seen as a pivotal moment in their relative’s illness trajectory. This gave some participants insight into the severity of their relative’s illness and the likelihood of recovery:

> *‘I think it certainly helped in terms of understanding just how serious what we were dealing with … to be having a conversation about do not resuscitate round about the time that we ought to have been getting ready for Christmas was just very, very hard but I think it did help with the reality of the situation.’* Participant 23

4.3.1 Negative impact of DNACPR conversations

As described in section 4.1.2, many of the participants we spoke to described feeling responsible for making decisions about DNACPR for their relatives. Some described the guilt and burden associated with this:

> *'It was probably one of the hardest things I've ever done in my life, you know, giving permission for your mum not to be resuscitated and basically saying that if this happens, she's going to die, know what I mean, that's as hard a decision as you will ever have to make.'* Participant 24

> *'DNACPR was probably the right thing for my husband, because by that time he was quite weak, so I appreciate… trying to resuscitate would have been cruel, but by the same token I had this guilt thinking that I had just let him die … I thought, as I didn't say anything about that [DNACPR] document, that I had let him die'* Participant 10

Even those who understood that DNACPR is a medical decision described the guilt that involvement in decision-making caused:

> *'So you're left feeling guilty for things that you had no control over. It's really difficult, it's had a huge impact on…sorry …on my life.'* Participant 3

> *'As much as I've got a background in it, I know the legalities of it, I understand what resuscitation is, the responsibility on my shoulders of having to…I suppose contribute significantly to that decision is really difficult'.* Participant 14

> *'It was mainly that kind of… I suppose it's guilt, in have I done enough, have I fought enough, have I questioned or argued this as much as I should have done? Have I just accepted this when maybe I could have done a bit more?'* Participant 19

These excerpts show the significant personal toll that DNACPR discussions can have on individuals who feel responsible for taking the decision. This raises questions about the harm caused by DNACPR discussions where relatives are made to feel that they are decision-makers. However, our data suggest that a careful balance needs to be struck, as those who were informed of the medical decision not to offer CPR without considering the wider aspects of care, were often left feeling overlooked:

> *'It was an annoyance and a further affirmation that they were in control and I wasn't, so it was more that they were definitely in control and I was not. …when you've generally been in control it's not a place you'd like to be. This has all been taken away, your father's there now and we're taking over, even those major life decisions we're taking them over.'* Participant 20

Some described the impact of not feeling adequately involved in decision-making had on grieving:

> *'It was more like a [DNACPR] decision that they had made already and that they were just telling us what was going on, but that they were trying to find out whether or not we had agreed with that decision. That's how it felt…. I'm still angry. And the anger, yes, is part of the grief process and it's trying to point a finger at somebody.'*
> Participant 34

> *'It's made the grieving process harder because I don't understand a lot of things still, and I'm an educated woman, but I still can't put the bits together. You're dealing with grief as it is, you don't need guilt on top of that grief, and if people can have those open and frank conversations, and I will appreciate that would have been an upsetting conversation for me to hear, but I would have known. I would have known what to expect. I would have known how to plan.'* Participant 10

Relatives who described the negative impacts of the DNACPR conversations suggested that better explanations about the decision-making and rationale from clinicians might have helped:

> *'And just that feeling that it's been put in place because your relative isn't valid enough to resuscitate, and not understanding the reasons behind it … It's that lack of feeling of value, for us I think it's just…if we understood more, if we'd had more information about it, then maybe we wouldn't be left feeling like that, it's just the undervalue of my father's life, I think.'* Participant 3

4.3.2 Conflict around DNACPR

Where disagreements between health care professionals and relatives about DNACPR occurred, this caused conflict:

> *'I spoke to [the doctor] and said to him, 'so now you've heard it from her. She wants to be resuscitated, so kindly do whatever you do with that form or whatever it is that you've got: take it off your system, tear the form up. You've heard it from Mum.' And he turned round and said to me, again, it wasn't my decision. So I said no, but you heard Mum's decision. She wants to be resuscitated. So he was very angry and when we left, he came to pay her a visit to say that his word stood and he was keeping her Do Not Resuscitate form active.'* Participant 34
>
> *'So the home knew he didn't have a DNAR registered because we told them he didn't, we hadn't given consent. But they still put it on him, they still told the ambulance service that he had one on him.'* Participant 37

These excerpts show how this conflict often was rooted in a misunderstanding about how DNACPR decisions are made. In this case, Participant 34 believed that patients could choose to receive treatment that clinicians feel would be futile, and Participant 37 believed that relatives needed to consent for DNACPR to be in place. For some, this resulted in a lack of trust in hospitals and healthcare:

> *'Of course it [the DNACPR] affected my trust because it demonstrated to me, they had no empathy towards my mother, and all, from that point on, I wanted to do was to get her out that hospital as soon as possible'* Participant 7

> *‘My relationship and trust in the hospital which was at a very low point before is now absolutely non-existing. I quite definitely should anything happen to me, I would rather die I think than be moved to that hospital.’* Participant 2

> *‘when you look at the way in which the DNACPR was handled, that to me is indicative of the ethos in the ward that he was in, that it was very much closed off, nobody’s going to find anything out, we’re in COVID times, nobody’s going to challenge me, and that’s it, you know?’* Participant 17

We spoke to people who had made complaints and taken legal action as a result of DNACPR decision-making, often with the help of support groups.

4.3.3 Positive impact on individuals

Some participants described the positive impacts of being involved in discussions about DNACPR, including the feeling of being listened to, and having a chance to ask questions:

> *‘But this doctor was very, very good. He sat and…well, he took his time and he let me ask questions. And there were very few questions that I needed to ask because I was just relieved. You know, I had discussed it with my daughters before … we ought to be asking her if she wants a DNACPR put on her notes. But it’s very difficult to bring that up, especially over the phone and I hadn’t seen her since just before lockdown. So, I hadn’t wanted to bring that up with her on the phone, so I was very grateful that he brought it up.’* Participant 21

People also described how discussing DNACPR left them feeling that their relatives' wishes were respected. Participant 21 continued:

> *‘So because I knew her wishes were do not resuscitate, I feel that that doctor who rang me up and who had that conversation with her, took a great burden off my shoulders in this last few weeks really because I know that she doesn’t want to prolong things if she is nearing the end of her life.’* Participant 21

> *‘And I remember coming home from the GP with the documentation and my mum was just really relieved and she did explicitly say that, thank you to me, and I’m so relieved we have that in place now. It really gave her peace of mind.’* Participant 35

Many described this feeling of being ‘relieved’ that DNACPR was discussed and a plan made:

> *‘I felt relief. I mean … I was worried about her. The phone went and it was…I knew it was the hospital … so as soon as I realised that she was alright, she had rallied, and that this DNR was now in place, then I felt relief more than anything else.*
> Participant 21

> *‘my mum had said a number of times ‘if something happens, don’t resuscitate me, I’ve had a good life.’ So I was focused on that being her wish and getting it organised quite pragmatically, just getting the paperwork … I was just glad to have it in place.’*
> Participant 34

A key feature of these positive experiences appears to be that the relative understood the wishes of the person and that those wishes were in line with the medical decision for a DNACPR (see 4.1.3).

> *‘the fact that he had capacity took a lot of stress away from me, because if, for example, the dementia had progressed, and he hadn’t been able to make that confirmation, I think it would have been more challenging. But I’ve got to say, it can be a very lonely place for the former carer, the next of kin, it can be a very lonely place to be in, to make decisions around resuscitation when you haven’t got a partner or a sister or a brother to discuss it with, you know? I just felt I was very alone with this.’* Participant 1

Making advanced plans and having access to professional support was important for some, to reduce the burden of being responsible for difficult decisions.

Others described how the DNACPR discussion provided a better understanding of their relative’s medical condition and treatment:

> *‘It was a good discussion. I felt at the end of it that I wasn’t be fobbed off. Everything had been told that I needed to know, and from what I remember, he said to me at the end, have you got any questions, which I think is important. And I thought to myself, no, you’ve covered it all I need to know, and so yeah, I’m quite happy with that situation as it stands. [The conversation] helps you….[it] does help you prepare, it sort of…it helps you focus your mind, right, this is likely to happen, rather than a complete shock, you know. It helps you put things in perspective and think about things clearer. Your mind’s still in an emotional high turmoil. You still…you know that that’s there and you’ve been told in a clear and precise manner that this is what’s happening’* Participant 24

Our data suggest that when DNACPR decisions are taken as part of broader discussion around advance care planning and end-of-life decision-making, this can increase understanding and acceptance:

> *‘So it wasn’t just about DNR it was about whether he was sent in an ambulance into A&E on his own in the middle of the night, unable to communicate, I think they wanted us to understand that trajectory and to have thought about it. We weren’t being asked to make any decisions about it. We were just asked to think about how we would feel and what our reactions would be.’* Participant 23

For a small number of people interviewed, the role of religion and faith and a more accepting attitude to death and dying also emerged as an important factor in whether DNACPR decisions were considered acceptable or appropriate by relatives:

> *‘She was a very religious person, went to church all her life while she could and was perfectly comfortable with the prospect of death. And so I had no hesitation in agreeing to the DNR.’* Participant 6

> *‘She always said when I go, I'd just rather go in my sleep like my father did or your dad did. I knew that those were her underlying wishes ... My mum's a Christian and I'm a Catholic and so is the solicitor.’* Participant 8

5.0 Discussion

This section presents an overview of the main findings in relation to existing research, an outline of some of the strengths and limitations, and a discussion of the implications of the work for policy and practice.

5.1 Summary of main findings in relation to existing research

Since the beginning of the pandemic, the way in which DNACPR decisions have been made has received much critical attention (see section 1.0). However, this is the first piece of commissioned research to explore relatives' experiences of discussing DNACPR in an objective way.

Participants' knowledge and understanding about DNACPR had a significant impact on their experiences and interpretation of DNACPR discussions. People with a better understanding of DNACPR reflected more positively on their experiences, whatever the source of their knowledge. There is a paucity of research on relatives' knowledge and understanding in DNACPR decision-making. However, more generally, poor health literacy - associated with lower socioeconomic status and older age – has been shown to contribute to ineffective communication with healthcare professionals and, therefore, is known to impact healthcare decision-making and health outcomes.[31]

The role of the relative in the DNACPR decision-making process was a frequent source of misunderstanding. DNACPR is unique in that, unlike other medical interventions, clinicians are expected to inform patients and/or their relatives that CPR will not be offered, even when CPR is deemed futile. Where CPR may be successful, clinicians should involve patients in a joint decision. Where the patient lacks capacity then clinicians make a best interests decision after consulting relatives or a legal proxy.–Previous research has pointed to the need for a delicate balance when informing and involving relatives in DNACPR discussions.[20] Like Cowey and colleagues,[19] we found that relatives felt dissatisfied at being excluded from decision-making, whilst simultaneously feeling responsible for making the 'right' choice. Our findings emphasise the potential for involvement in DNACPR decision-making to have a significant emotional impact, particularly when the roles and responsibilities of clinicians and relatives are unclear. The implications of this are discussed in more detail in section 5.3.

Previous research has stressed the importance of families talking about care wishes before the onset of illness.[32] In our study, DNACPR conversations were easier for those who clearly understood their relative's wishes. Distress associated with repeated discussions about DNACPR leads us to echo calls for improved communication of DNACPR decisions across care settings.[33] Although these insights are not new, our data shows that despite previous attention to this over the past decade, improvements have been slow to be implemented

We also identified aspects of good practice and spoke to people who reflected on the discussion about DNACPR positively. On these occasions, relatives told of how clinicians spent adequate time on the discussion; they felt involved in the process yet were clear it was a medical decision and were given the opportunity to ask questions. Involvement in conversations around DNACPR can allow people to better understand their relative's medical condition, treatment, and illness trajectory and provide reassurance that clinical teams will respect their relative's wishes.

Restrictions to hospital visiting were important across all three themes. This has been well described as causing distress, particularly for those with relatives who died during the pandemic.[34,35] Restrictions also introduced barriers to adequate communication between relatives, patients and the clinical team. However, our data also highlights how, despite these barriers, clinicians can discuss DNACPR with relatives in a way that is sensitive and appropriate. Our data suggests that time spent on the conversation is more important than whether it was undertaken face to face or over the telephone.

5.2 Strengths and limitations

This is the first qualitative study to focus solely on relatives' experiences of DNACPR discussions during the COVID-19 pandemic. We undertook in-depth, open-ended semi-structured interviews, which allowed the researcher time and flexibility to foreground the priorities of the participant. We were able to capture a diverse range of experiences from a group with varying levels of knowledge and understanding of health care. The research team was multidisciplinary, contributing to the analysis and discussions from distinct and contrasting positions.

This was a qualitative study, and we do not claim to have recruited a sample that was representative of the general population. People who found the experience of discussing DNACPR memorable are more likely to have volunteered to participate in research. This may have led to some overstatement of the significance and importance of DNACPR discussions. Use of predominantly online recruitment and zoom and telephone interviews ensured the study could be completed during the pandemic. However, this approach may also have excluded some potential participants who are uncomfortable with or did not have access to the requisite technology.

5.3 Implications for policy and practice

Participants made recommendations for how discussions about DNACPR might be improved in several key areas.

- Public education around DNACPR. Many recommended that there should be an effort to increase public understanding of CPR and DNACPR. Our data shows that this should include clarity around the role of relatives and the responsibility of clinicians in DNACPR decision making, as confusion around this was common.
- ‘Normalise’ conversations about death and dying. There is increasing public discourse around end-of-life issues and wishes for end-of-life care. Normalising communication with health care professionals and within families and communities was felt to be important - our data shows that DNACPR conversations were easier when participants clearly understood their relative’s wishes.
- The timing of DNACPR decision-making and associated conversations should be individualised. However, most expressed a wish to be provided with information and the opportunity to discuss DNACPR early in the illness trajectory.
- Improving communication of DNACPR across care settings to avoid the need for repeated discussions about DNACPR, which some found distressing.
- Improving clinicians’ communication skills around DNACPR. Clinicians must have adequate time for speaking to relatives about DNACPR decisions, allowing such discussions to be performed in the wider context of advance care planning and ensuring time for clear explanations and questions. The role of the relative in the decision-making process should be made clear. Participants believed that having more information about DNACPR would have improved their experiences.

Analysis has highlighted several tensions between the current guidance and statutory framework around DNACPR discussions. We also draw attention to the tensions raised by the change in practice brought around by the 2014 Court of Appeal decision.

This analysis, which highlights the personal impact of relatives’ involvement in DNACPR discussions during the pandemic, draws attention to some of the idiosyncrasies of current clinical guidance and legal framework. This may warrant further consideration by policymakers.

First, the principles of best practice around DNAR discussions with patients and relatives appear to be at odds with how DNACPR guidance was enacted during the pandemic. Best practice denotes that DNACPR should be discussed by a medical professional well known to the patient as part of advance care planning. However, during the pandemic, the majority of DNACPR discussions occurred during an acute admission, led by hospital doctors who are legally obliged to discuss DNACPR at the earliest opportunity. This data draws attention to the consequences of this. For many relatives, the conversation was rushed, with little opportunity to ask questions, and was felt to be at the wrong time in their relative's illness. Not only is this a missed opportunity to provide information about DNACPR and wider advance care planning, it can also cause dissatisfaction and even mistrust, in the healthcare system. The rushed conversations with patients' relatives during the pandemic may also suggest that this guidance presents a challenge for professionals working in an already stretched health service. The perspectives and experiences of professionals in undertaking DNACPR discussions is an area in need of future research.

Second, is the peculiarity of the legal requirement for clinicians to inform patients and relatives about futile treatments, which, based on clinical reasoning, would not be offered regardless of the patient's wishes. This is particularly problematic when relatives object to DNACPR decisions. In this research, this was made evident by the accounts of relatives who were left frustrated by being nominally involved in decision-making yet having their wishes overlooked by clinicians. This impacted some participants' trust in healthcare services. Even when relatives understood the rationale for DNACPR and agreed with the decision, being involved in that decision-making process can be burdensome and may result in enduring feelings of guilt.

In the 2014 Court of Appeal judgement, Lord Dyson stated that the only convincing reason for not discussing DNACPR was the causation of psychological harm, but distress is always a risk when discussing issues about end-of-life.[2] This research raises questions about the current approach to DNACPR decision-making by highlighting how current practice can have difficult to anticipate and lasting negative impacts on relatives.

6.0 Conclusion

In conclusion, this qualitative research explores the experiences of 39 people who discussed DNACPR with a clinician on behalf of their relative during the pandemic. Using framework analysis, results have been presented around three main themes.

Knowledge and understanding were important factors in participants' experiences of DNACPR discussions. Those with better understanding of DNACPR described their experience more positively. DNACPR discussions were an opportunity to better understand their relative's medical condition and ensure wishes were respected. Participants made suggestions around increasing public understanding of DNACPR, as well as normalising discussions around death and dying.

Despite clear and readily available guidance for clinicians from the about undertaking DNACPR discussions (see Box 1), many participants recounted how they felt they were asked to make the decision about DNACPR or give permission for a DNACPR to be in place. These accounts point to a need to better understand clinicians' perspectives, identify knowledge gaps, and improve awareness of the available guidance.

There has been extensive academic work on the importance of good communication around end-of-life care issues. Yet, this data shows that clinicians' communication skills fell short during the pandemic. It is conceivable that the exceptional strain on NHS resources compounded shortfalls during 2020. Nevertheless, clinical pressures have remained high for NHS staff in the pandemic recovery, so continued effort is needed in this area. Further research might consider the impact of the pandemic around shared decision-making at end-of-life care, work to which this data could contribute.

Perhaps the most salient and notable finding of this project has been the impact that DNACPR discussions can have on relatives. The accounts of burden and guilt bring to the fore the risks of these highly sensitive discussions. Research shows that patients prefer conversations about DNACPR with a medical professional known to them, often their GP, and as part of broader advance care planning. Yet during the pandemic, DNACPR decisions were often made in the setting of acute illness by hospital doctors, who are now legally obliged to discuss this with patients and their relatives at the earliest opportunity. Our research highlights this tension and, in doing so, raises questions about the current legislative framework and clinical guidance.

7.0 References

1. Care Quality Commission (CQC). Protect, Respect, Connect—Decisions about Living and Dying well during Covid-19. [Internet]. 2021 [cited 2022 June 13]. London: CWC. Available from: https://www.cqc.org.uk/sites/default/files/20210318_dnacpr_printer-version.pdf.
2. Bows H, Herring J. DNACPR decisions during Covid-19: An empirical and analytical study. Med. Law Rev. [Internet]. 2022 Jan 14 [cited 2022 Feb 10];30(1):60–80. Available from: https://pubmed.ncbi.nlm.nih.gov/35029676/. doi: 10.1093/medlaw/fwab047
3. Ibitoye SE, Rawlinson S, Cavanagh A, Phillips V, Shipway DJ. Frailty status predicts futility of cardiopulmonary resuscitation in older adults. Age and Ageing [Internet]. 2021 Jan [cited 2022 March 12];50(1):147–152. Available from: https://pubmed.ncbi.nlm.nih.gov/32500916/. doi: 10.1093/ageing/afaa104
4. Timmermans S. Closed-chest cardiac massage: The emergence of a discovery trajectory. Science, Tech. & Human Val. [Internet]. 1999 Apr [cited 2022 Feb 10];24(2):213-40. Available from: https://www.jstor.org/stable/690255#metadata_info_tab_contents. doi: 92.40.182.160
5. Nolan JP. High-quality cardiopulmonary resuscitation. Current opinion in critical care [Internet]. 2014 Jun [cited 2022 Feb 10];1;20(3):227-33. Available at: https://pubmed.ncbi.nlm.nih.gov/27054627/. doi: 0.1097/MCC.0000000000000296
6. (Tracey) v Cambridge University Hospitals NHS Foundation Trust & Ors. 2014; EWCA Civ 822.
7. Samanta J. Tracey and Respect for Autonomy: Will the Promise Be Delivered? Med Law Rev [Internet]. 2015 Summer [cited 2021 Dec 8];23(3):467-76. Available at: https://pubmed.ncbi.nlm.nih.gov/25717149/. doi: 10.1093/medlaw/fwv003
8. British Medical Association, Resuscitation Council (UK) and Royal College of Nursing. 3rd edition. Decisions Relating to Cardiopulmonary Resuscitation Council [Internet]. 2016 [cited 2022 June 13]. Available at: https://www.resus.org.uk/sites/default/files/2020-05/20160123%20Decisions%20Relating%20to%20CPR%20-%202016.pdf
9. Loertscher L, Reed DA, Bannon MP, Mueller PS. Cardiopulmonary resuscitation and do-not-resuscitate orders: a guide for clinicians [Internet]. Am J Med. 2010 Jan [cited 2022 Feb 10];123(1):4-9. Available from: https://pubmed.ncbi.nlm.nih.gov/20102982/. doi: 10.1016/j.amjmed.2009.05.029
10. MacKenzie AR, Lasota M. Bringing Life to death: the need for honest, compassionate, and effective end-of-life conversations [Internet]. Am Soc Clin Oncol Educ Book. 2020 Mar [cited 2022 Feb 10];40:1-9. Available from: https://pubmed.ncbi.nlm.nih.gov/32207670/. doi: 10.1200/EDBK_279767
11. Callus T. One day I will find the right words, and they will be simple - Rethinking DNACPR at a national level [Internet]. J of Pub Health. 2018 Jun 1 [cited 2022 Feb 12];40(2):404-8. Available from: https://pubmed.ncbi.nlm.nih.gov/28472516/. doi: 10.1093/pubmed/fdx047
12. Hall A, Rowland C, Grande G. How should end-of-life advance care planning discussions be implemented according to patients and informal carers? A qualitative review of reviews [Internet]. J Pain Symptom Manage. 2019 Apr 18 [cited 2022 Feb 08];58(2):311-335. Available from: https://www.sciencedirect.com/science/article/pii/S0885392419301812. Doi: 10.1016/j.jpainsymman.2019.04.013
13. Hall CC, Lugton J, Spiller, JA, Carduff, E. CPR decision making conversations in the UK: an integrative review [Internet]. BMJ sup. & pal. care. 2019 [cited 2022 Feb 08]; 9(1): pp.1-11. Available from: https://spcare.bmj.com/content/9/1/1. doi: 10.1136/bmjspcare-2018-001526

14. Ackroyd R, Russon L, Newell R. Views of oncology patients, their relatives and oncologists on cardiopulmonary resuscitation (CPR): questionnaire-based study [Internet]. Pal. Med. 2007 Mar [cited 2022 Feb 10];21(2):139-44. Available from: https://journals.sagepub.com/doi/10.1177/0269216306074629. doi: 10.1177/0269216306074629
15. Gorton AJ, Jayanthi NV, Lepping P, Scriven MW. Patients' attitudes towards "do not attempt resuscitation" status [Internet]. J of Med. Ethics. 2008 [cited 2022 Feb 05];34(8):624–626. Available from: https://jme.bmj.com/content/34/8/624.full. doi: 10.1136/jme.2007.022772
16. Vandrevala T, Hampson S, Chrysanthaki T. Breaking the death taboo — Older people's perspectives on end-of-life decisions [Internet]. Qual Ageing Older Adults. 2002 Sept [cited 2022 Feb 05];3:36–48. Available from: https://www.emerald.com/insight/content/doi/10.1108/14717794200200020/full/html. Doi: 10.1108/14717794200200020
17. Garrido MM, Prigerson HG. The end-of-life experience: Modifiable predictors of caregivers' bereavement adjustment [Internet]. Cancer. 2014 Mar 15 [cited 2022 Feb 10];120(6):918-25. Available from: https://acsjournals.onlinelibrary.wiley.com/doi/10.1002/cncr.28495 doi: 10.1002/cncr.28495
18. Higginson IJ, Rumble C, Shipman C, Koffman J, Sleeman KE, Morgan M, et al. The value of uncertainty in critical illness? An ethnographic study of patterns and conflicts in care and decision making trajectories [Internet]. BMC Anesthesiol. 2016 [cited 2022 Feb 10];16:11. Available from: https://bmcanesthesiol.biomedcentral.com/articles/10.1186/s12871-016-0177-2. doi: 10.1186/s12871-016-0177-2
19. Cowey E, Smith LN, Stott DJ, McAlpine CH, Mead GE, Barber M, Walters M. Impact of a clinical pathway on end-of-life care following stroke: a mixed methods study [Internet]. Pal. Med. 2015 Mar [cited 2022 Feb 05];29(3):249-5. Available from: https://journals.sagepub.com/doi/10.1177/0269216314551378?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed. doi: 10.1177/0269216314551378
20. Livingston G, Leavey G, Manela M, Livingston D, Rait G, Sampson E, et al. Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK [Internet]. BMJ. 2010 Aug [cited 2022 Feb 05];341:c4184. Available from: https://www.bmj.com/content/341/bmj.c4184. doi: 10.1136/bmj.c4184
21. Compassion in Dying. Better Understanding, Better Outcomes: What We've Learned about DNACPR Decisions before and during the Coronavirus Pandemic [Internet]. England and Wales: Compassion in Dying. 2021 Mar [cited 2022 June 13]. Available from: https://compassionindying.org.uk/wp-content/uploads/2021/03/Better-Understanding-Better-Outcomes-DNACPR-decisions-before-and-during-the-pandemic.pdf.
22. Hosali S, Miller C. *Scared, Angry, Discriminatory, Out of My Control: DNAR Decision Making in 2020.* British Institute of Human Rights [Internet]. *2020 Dec* [cited 2022 June 13]. *Available from:* https://www.bihr.org.uk/Handlers/Download.ashx?IDMF=25da164a-f598-4963-b99c-c554bf59bab2.
23. House of Commons Health and Social Care, and Science and Technology Committees. Coronavirus: lessons learned to date. Sixth report of the Health and Social Care Committee and third report of the Science and Technology Committee of session 2021-22 [Internet]. 2021 Sept [cited 2022 June 13]. Report No: HC 92 Available from: https://committees.parliament.uk/publications/7496/documents/78687/default/.

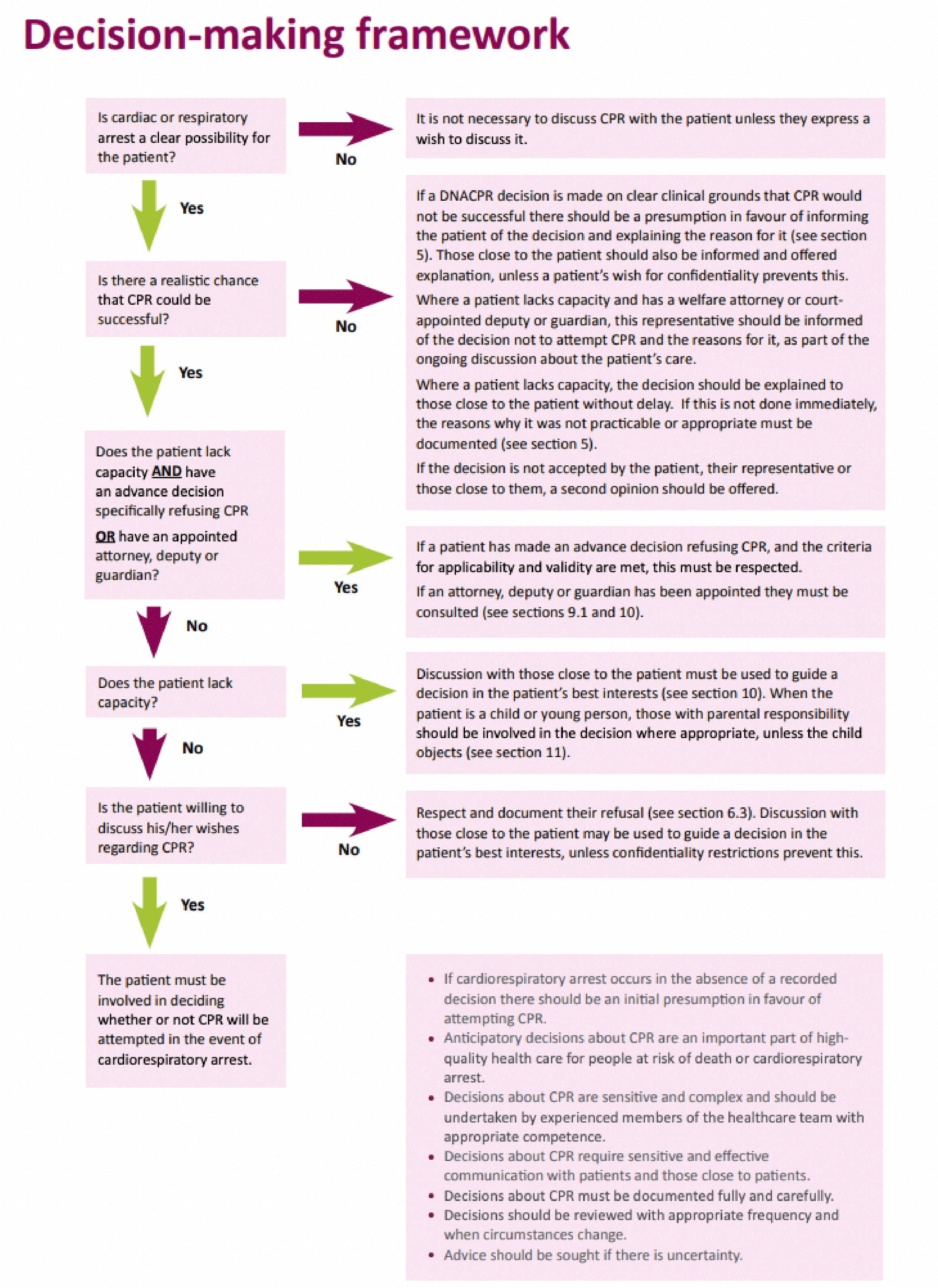
24. Aker N, West E, Davies N, Moore KJ, Sampson EL, Nair P, Kupeli N. Challenges faced during the COVID-19 pandemic by family carers of people living with dementia towards the end of life [Internet]. BMC Health Serv Res. 2021 [cited 2022 Feb 05];21(996):1-10. Available from: https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-021-07019-6. doi: 10.1186/s12913-021-07019-6
25. Connellan D, Diffley K, McCabe J, Cotter A, McGinty T, Sheehan G, et al. Documentation of Do-Not-Attempt-Cardiopulmonary-Resuscitation orders amid the COVID-19 pandemic [Internet]. Age and Ageing. 2021 [cited 2022 Feb 05] 50(4):1048-1051. Available from: https://academic.oup.com/ageing/article/50/4/1048/6255991?login=false. doi: 10.1093/ageing/afab075
26. Edwards JM, Nolan JP, Soar J, Smith GB, Reynolds E, Carnall J, et al. Impact of the COVID-19 pandemic on in-hospital cardiac arrests in the UK [Internet]. Resuscitation. 2022 Apr [cited 2022 Feb 08];173:4-11. Available from: https://www.resuscitationjournal.com/article/S0300-9572(22)00042-9/fulltext. doi: 10.1016/j.resuscitation.2022.02.007
27. Sutton L, Goodacre S, Thomas B, Connelly S. Do not attempt cardiopulmonary resuscitation (DNACPR) decisions in people admitted with suspected COVID-19: Secondary analysis of the PRIEST observational cohort study. Resuscitation. 2021 Jul;164:130-138. doi: 10.1016/j.resuscitation.2021.04.028.
28. NICE. COVID-19 rapid guideline: Managing COVID-19 [Internet]. Report No: 26.0. 2020 June 15 [cited 2022 June 13]. Available at: https://www.nice.org.uk/guidance/ng191/resources/covid19-rapid-guideline-managing-covid19-pdf-51035553326
29. Selman LE, Chao D, Sowden R, Marshall S, Chamberlain C, Koffman J. Bereavement Support on the Frontline of COVID-19: Recommendations for Hospital Clinicians [Internet]. J Pain Symptom Manage. 2020 Aug [cited 2022 Feb 05];60(2): 81–86. Available from: https://linkinghub.elsevier.com/retrieve/pii/S0885-3924(20)30244-X. doi: 0.1016/j.jpainsymman.2020.04.024
30. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research [Internet]. BMC Med. Research Method. 2013 Sept 18 [cited 2022 Feb 05]; 13(117):1-8. Available from: https://bmcmedresmethodol.biomedcentral.com/articles/10.1186/1471-2288-13-117. Doi: 10.1186/1471-2288-13-117
31. Koay K, Schofield P, Jefford M. Importance of health literacy in oncology [Internet]. Asia-Pacific J of Clin. Onc. 2012 Mar [cited 2022 June 10];8(1):14-23. Available from: https://onlinelibrary.wiley.com/doi/10.1111/j.1743-7563.2012.01522.x. doi: 10.1111/j.1743-7563.2012.01522.x
32. Chan HY, Pang SM. Let me talk–an advance care planning programme for frail nursing home residents [Internet]. J of Clin. Nurs. 2010 Nov [cited 2022 Feb 10];19(21-22):3073-84. Available from: https://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2010.03353.x. doi: 10.1111/j.1365-2702.2010.03353.x
33. Hawkes CA, Fritz Z, Deas G, Ahmedzai SH, Richardson A, Pitcher D, Spiller J, Perkins GD. Development of the recommended summary plan for eEmergency care and treatment (respect) [Internet]. Resuscitation. 2020 Mar 1 [cited 2022 Feb 12];148:98-107. Available from: https://www.resuscitationjournal.com/article/S0300-9572(20)30019-8/fulltext. doi: 0.1016/j.resuscitation.2020.01.003
34. Wallace CL, Wladkowski SP, Gibson A, White P. Grief during the COVID-19 pandemic: considerations for palliative care providers [Internet]. J Pain and Symptom Manage. 2020 Jul 1 [cited 2022 Feb 05];60(1):e70-6. Available from:

https://www.jpsmjournal.com/article/S0885-3924(20)30207-4/fulltext. doi: 10.1016/j.jpainsymman.2020.04.012

35. Andrist E, Clarke RG, Harding M. Paved with good intentions: hospital visitation restrictions in the age of coronavirus disease 2019 [Internet]. Ped. Critic. Care Med. 2020 Oct [cited 2022 Feb 10];21(10):e924. Available from: https://journals.lww.com/pccmjournal/Fulltext/2020/10000/Paved_With_Good_Intentions__Hospital_Visitation.37.aspx. doi: 10.1097/PCC.0000000000002506

Appendix 1: Decision-making framework for DNACPR discussion

Reproduced from British Medical Association, Resuscitation Council (UK) and Royal College of Nursing. 3rd edition. Decisions Relating to Cardiopulmonary Resuscitation Council. 2016



Decision-making framework

Is cardiac or respiratory arrest a clear possibility for the patient?

No

It is not necessary to discuss CPR with the patient unless they express a wish to discuss it.

Yes

Is there a realistic chance that CPR could be successful?

No

If a DNACPR decision is made on clear clinical grounds that CPR would not be successful there should be a presumption in favour of informing the patient of the decision and explaining the reason for it (see section 5). Those close to the patient should also be informed and offered explanation, unless a patient's wish for confidentiality prevents this.

Where a patient lacks capacity and has a welfare attorney or court-appointed deputy or guardian, this representative should be informed of the decision not to attempt CPR and the reasons for it, as part of the ongoing discussion about the patient's care.

Where a patient lacks capacity, the decision should be explained to those close to the patient without delay. If this is not done immediately, the reasons why it was not practicable or appropriate must be documented (see section 5).

If the decision is not accepted by the patient, their representative or those close to them, a second opinion should be offered.

Yes

Does the patient lack capacity **AND** have an advance decision specifically refusing CPR

OR have an appointed attorney, deputy or guardian?

Yes

If a patient has made an advance decision refusing CPR, and the criteria for applicability and validity are met, this must be respected.

If an attorney, deputy or guardian has been appointed they must be consulted (see sections 9.1 and 10).

No

Does the patient lack capacity?

Yes

Discussion with those close to the patient must be used to guide a decision in the patient's best interests (see section 10). When the patient is a child or young person, those with parental responsibility should be involved in the decision where appropriate, unless the child objects (see section 11).

No

Is the patient willing to discuss his/her wishes regarding CPR?

No

Respect and document their refusal (see section 6.3). Discussion with those close to the patient may be used to guide a decision in the patient's best interests, unless confidentiality restrictions prevent this.

Yes

The patient must be involved in deciding whether or not CPR will be attempted in the event of cardiorespiratory arrest.

- If cardiorespiratory arrest occurs in the absence of a recorded decision there should be an initial presumption in favour of attempting CPR.
- Anticipatory decisions about CPR are an important part of high-quality health care for people at risk of death or cardiorespiratory arrest.
- Decisions about CPR are sensitive and complex and should be undertaken by experienced members of the healthcare team with appropriate competence.
- Decisions about CPR require sensitive and effective communication with patients and those close to patients.
- Decisions about CPR must be documented fully and carefully.
- Decisions should be reviewed with appropriate frequency and when circumstances change.
- Advice should be sought if there is uncertainty.

Appendix 2: Review of reports and press releases

In February 2022 we reviewed the three most widely published reports about DNACPR decision-makingin the pandemic: CQC, Compassion in Dying and British Institute for Human Rights. We then performed a secondary search through their reference list, identifying reports that met the inclusion criteria below.

Inclusion criteria

- Primary research
- UK based study
- Reports focusing on older people (55+)
- Reports focusing on patients and relatives experiences of 'DNAR' or 'DNACPR' or 'Resuscitation' during the COVID-19 pandemic

Exclusion criteria:

- Secondary research
- Not UK based
- Reports focusing on younger people (<55)
- Reports focusing on health care workers experiences of 'DNAR' or 'DNACPR' or 'Resuscitation' during the COVID-19 pandemic

This yielded a result of 16 reports and 4 press releases

Reports:

Alzheimer’s Society. Worst hit: dementia during coronavirus. 2020 Sept 2. Available at: https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf

Alzheimer’s Society. The impact of Covid-19 on people affected by dementia. 2020 July. Available at: https://www.alzheimers.org.uk/sites/default/files/2020-08/The_Impact_of_COVID-19_on_People_Affected_By_Dementia.pdf

Care Quality Commission. Review of Do Not Attempt Cardiopulmonary Resuscitation decisions during the COVID-19 pandemic: Interim Report. 2020 Nov.

Carers UK. Supporting working carers in COVID-19. Recovery and return: Employer survey report. Carers UK: London. 2021 Nov. Publication code UK4094_1121. Available at: https://www.carersuk.org/images/News_and_campaigns/Supporting_working_carers_in_COVID-19.pdf

Carers UK. Unseen and undervalued: The value of unpaid care provided to date during the COVID-19 pandemic. Carers UK: London. 2020 Nov. Publication code UK4090_1120

Available at:
https://www.carersuk.org/images/News_and_campaigns/Unseen_and_undervalued.pdf

Carers UK. Caring behind closed doors: six months on. Carers UK: London. 2020 Oct. Publication code UK4089_1020. Available at: https://www.carersuk.org/for-professionals/policy/policy-library/caring-behind-closed-doors-six-months-on#:~:text=The%20report%20found%3A,in%20the%20last%20six%20months .

Department of Health and Social Care, Care Quality Commission, Public Health England, and NHS England. Coronavirus (COVID-19): admission and care of people in care homes. [Online] 2020. https://www.gov.uk/government/publications/coronavirus-covid-19-admission-and-care-of-people-incare-homes

Institute for Government. Coronavirus lockdown rules in each part of the UK. [Online] 2020. https://www.instituteforgovernment.org.uk/explainers/coronavirus-lockdown-rules-four-nations-uk

Thomas C. Institute for Public Policy Research. The state of end-of-life care: building back better after COVID-19. 2021 Apr. Available at:
https://www.ippr.org/research/publications/the-state-of-end-of-life-care

Queen’s Nursing Institute. The Experience of Care home Staff During COVID-19: A Survey Report by the QNI’s International Community Nursing Observatory. 2020. Available at: https://www.qni.org.uk/news-and-events/news/major-new-survey-of-care-home-leaders-confirmssevere-impact-of-covid-19/

Marie Curie. Better end-of-life : Dying, death and bereavement during Covid-19. Research Report. 2021 Apr. Available at:
https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2021/better-end-of-life-research-report.pdf

Mencap. My health, my life: Barriers to healthcare for people with a learning disability during COVID-19. 2020. Available at: https://www.mencap.org.uk/sites/default/files/2020-12/MyHealthMyLife_COVID%20report.pdf

Office for National Statistics. Impact of coronavirus in care homes in England: 26 May to 19 June 2020. [Online] 2020.
https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/ articles/impactofcoronavirusincarehomesinenglandvivaldi/26mayto19june2020 41

Office for National Statistics. Analysis of death registrations not involving coronavirus (COVID-19), England and Wales: 28 December 2019 to 1 May 2020. [Online] 2020. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/analysisofdeathregistrationsnotinvolvingcoronaviruscovid19englandandwales28december2019to1may2020/technicalannex

Press releases:

Jackson M. Marie Curie. Marie Curie response: The House of Lords Select Committee on Public Services: lessons from coronavirus. No date. Available at: https://www.mariecurie.org.uk/policy/publications/briefings-and-consultations

Marie Curie. Families struggle to know what’s best for older relatives with dementia during COVID-19. 2020 May 7. Available at: https://www.mariecurie.org.uk/media/press-releases/dementia-and-covid19-new-research/274788

Marie Curie. New support for carers when making difficult decisions for people with dementia and COVID-19. 2020 Sept 2. Available at: https://www.mariecurie.org.uk/media/press-releases/new-support-for-carers-when-making-difficult-decisions-for-people-with-dementia-and-covid-19/280132

The Health Foundation. COVID-19 chart series: Care homes have seen the biggest increase in deaths since the start of the outbreak. 2020. Available at: https://www.health.org.uk/news-and-comment/charts-and-infographics/deaths-from-any-cause-incare-homes-have-increased

Appendix 3: Academic literature review - methodology

Date of searches: February 2022

Search 1
Search terms: 'CPR' or 'DNAR' or 'DNACPR' or 'Resuscitation' and 'pandemic' or 'covid'

Date parameters: Since 2020

This yielded 56 results, which can be found at:
https://scholar.google.co.uk/scholar?q=%27CPR%27+or+%27DNAR%27+or+%27DNACPR%27+or+%27Resuscitation%27+and+%27pandemic%27+or+%27covid%27+&hl=en&as_sdt=0%2C5&as_ylo=2020&as_yhi=

Search 2
Search terms: **'CPR' or 'DNAR' or 'DNACPR' or 'Resuscitation' and 'pandemic' or 'covid' and 'decision'**

Date parameters: Since 2020

This yielded 54 results, which can be found at:

https://scholar.google.co.uk/scholar?q=%27CPR%27+or+%27DNAR%27+or+%27DNACPR%27+or+%27Resuscitation%27+and+%27pandemic%27+or+%27covid%27+and+%27decision%27&hl=en&as_sdt=0%2C5&as_ylo=2020&as_yhi=

Abstracts were then reviewed by LT and tested against the following inclusion and exclusion criteria:

Inclusion criteria
- Peer reviewed
- Primary data collection
- UK based study
- Concerning DNACPR decision-makingduring the pandemic

Exclusion criteria
- Not UK based
- Not peer reviewed

Appendix 4: Organisations, charities, advocacy groups, self-help groups, churches and online forums contacted for recruitment

Name of Organisation	Method of contact	Date contacted
Voice global	Application form	27.08.2021
Join dementia research	Application form	02.09.2021
Resuscitation Council UK	Email	02.09.2021
Age Scotland	Email	02.09.2021
Age UK	Email	02.09.2021
Scottish Partnership for palliative care	Email	03.09.2021
Advanced Care Research Centre /University of Edinburgh	Email	03.09.2021
BBC Inside Health	Email	03.09.2021
Cruse Bereavement Care	Email	06.09.2021
The Jolly Dollies	Email	06.09.2021
Greater Manchester Combined Authority Ageing Hub	Email	06.09.2021
Grasnet	Email	06.09.2021
GM Ageing Hub for weekly bulletin	Email	06.09.2021
GM Older People’s Network for bulletin	Email	06.09.2021
MCC Ageing Team for monthly bulletin	Email	06.09.2021
The Good Grief Trust	Email	09.09.2021
The Loss Foundation	Email	09.09.2021
GriefChat	Email	09.09.2021
The Silverline	Email	09.09.2021
Sudden	Email	09.09.2021
WAY Widowed & Young	Email	09.09.2021
Bereavment.co.uk	Email	09.09.2021
Friends together bereavement support network	Email	09.09.2021
Death Café	Email	13.09.2021
Leads Bereavement forum & Online Death Café Leeds	Email	13.09.2021
Alzheimers.org	Email	14.09.2021
National Bereavement Alliance	Email	14.09.2021
Healthwatch Manchester	Email	14.09.2021
Healthwatch Darlington Ltd	Email	14.09.2021
Healthwatch Newcastle	Email	14.09.2021
Healthwatch Birmingham	Email	14.09.2021
Healthwatch Brent	Email	14.09.2021
Healthwatch Croydon	Email	14.09.2021
Healthwatch Southwark	Email	14.09.2021
Healthwatch Wandsworth	Email	14.09.2021
Dementia UK (Head of Research & Publications)	Email	15.09.2021
Rights for residents	Online form	16.09.2021
Dying Matters Leeds	Email	16.09.2021
Dying Matters.org	Online form	16.09.2021
hospice UK	Online form	17.09.2021
Full Circle Funerals	Online form	17.09.2021
Maggies Cancer Support	Online form	17.09.2021
Soul Midwives	Email	20.09.2021
Age UK North Tynside	Email	20.09.2021

Edinburgh Old Town Community Council	Phone/email	20.09.2021
Morningside Community Council	Phone/email	20.09.2021
Celebration Church Maidstone	Phone/email	20.09.2021
Covid Families for Justice	Email	21.09.2021
Carers Leeds	Phone/email	21.09.2021
The Carers Trust Scotland	Phone/email	21.09.2021
The Carers Trust Wales	Phone/email	21.09.2021
The Carers Trust HQ	Phone/email	21.09.2021
Caring together	Phone/email	21.09.2021
Cross Gates & District Good Neighbours' Scheme CIO	Phone/email	21.09.2021
Farsley Bereavement Support Group	Phone/email	21.09.2021
Let's Talk About Loss	Phone/email	21.09.2021
Methodist Homes	Phone/email	21.09.2021
Middleton Elderly Aid	Phone/email	21.09.2021
St Vincent's Centre	Phone/email	21.09.2021
Sue Ryder Online Bereavement Community	Phone/email	21.09.2021
Edinburgh South Bridge Resource and Education Centre	Flyer	21.09.2021
Grassmarket Community Project	Flyer/email	22.09.2021
University of Edinburgh Chaplaincy	Flyer/email	22.09.2021
St Peter's House, University of Manchester Chaplaincy	Email	22.09.2021
Compassion in Dying	Email	23.09.2021
Faith in Older People	Email	05.10.2021
Scottish Partnership for Palliative Care	Phone/email	05.10.2021
The Eric Liddell Centre	Email	05.10.2021
Carers UK	Email	14.10.2021
Carers Wales	Email	14.10.2021
Carers Scotland	Email	14.10.2021
Carers NI	Email	14.10.2021
Carers Network	Email	14.10.2021
Coalition of carers in Scotland	Email	14.10.2021
Community Care	Email	14.10.2021
Care for the carers East Sussex	Email	14.10.2021
Association for Carers	Email	14.10.2021
Health and Social Care Alliance Scotland	Email	14.10.2021
Carers World Live	Email	14.10.2021
At a Loss	Email	21.10.2021
Independent Age	Email	21.10.2021
Sudden Arrhythmic Death UK	Email	21.10.2021
National Bereavement Service	Email	21.10.2021
The Compassionate Friends	Email	21.10.2021
Amanda Jones Life Coach 55+	Email	21.10.2021
Connected Voice Advocacy	Email	21.10.2021
Advocacy Focus	Email	21.10.2021
Health Advocacy UK	Email	21.10.2021
POhWER	Email	09.11.2021
Health Advocacy Services Bury	Email	09.11.2021
N/compass – Bury Advocacy Hub	Email	09.11.2021
Jackon's Row Synagogue	Email	09.11.2021
Bury Voluntary Community & Faith Alliance	Email	10.01.2022
Bury Involvement Group	Email	10.01.2022
Age UK Bury	Email	10.01.2022
Rethink Mental Illness Manchester Group	Email	10.01.2022

Carers direct	Email	10.01.2022
The Fed	Phoned/Email	10.03.2022
Carers Manchester	Phoned/Email	10.03.2022
Bury Local Care Organisation	Phoned/Email	10.03.2022
Health Watch Bury	Phoned/Email	10.03.2022
Newcastle Carers	Phoned/Email	10.03.2022
Birmingham Carers Hub	Phoned/Email	10.03.2022
Carers Support Centre Bristol & South Gloucestershire	Phoned/Email	10.03.2022
Carers Leeds	Phoned/Email	10.03.2022
Glasgow North East Carers Centre	Phoned/Email	10.03.2022
Quarriers Scotland	Phoned/Email	10.03.2022
VOCAL Carer Centre Edinburgh & Midlothian	Phoned/Email	10.03.2022
Carers in Southampton	Phoned/Email	10.03.2022
Portsmouth Carer Centre	Phoned/Email	10.03.2022
Local Solutions – carer support	Phoned/Email	10.03.2022
Belfast Health and Social Care Trust	Phoned/Email	10.03.2022
Carers Centre for Brighton and Hove	Phoned/Email	10.03.2022
Carers Hub for Brighton and Hove	Phoned/Email	10.03.2022
Support for Carers – Leicestershire County Council	Phoned/Email	10.03.2022
The Carers Centre – Leicestershire & Rutland	Phoned/Email	10.03.2022
Claremont Resource Centre	Phoned/Email	10.03.2022
Connect and Support, Manchester	Phoned/Email	10.03.2022
Gaddum Advocacy, Manchester	Phoned/Email	10.03.2022
Indian Senior Citizens Centre, Manchester	Email	10.03.2022
Stroke Association	Email	10.03.2022
Together Dementia Support	Email	10.03.2022
Bury Cancer Support	Phoned/Email	21.03.2022
Staying Well Team Bury council	Phoned/Email	21.03.2022

Adult Care Service Bury council	Phoned/Email	21.03.2022
One Community, one Bury	Phoned/Email	21.03.2022
Phoenix Community and Youth Centre, Prestwich	Phoned/Email	21.03.2022
Growing Together, Bury	Phoned/Email	04.04.2022
The British Institute of Human Rights	Email	04.04.2022
Inclusion North (Stop People Dying Too Young programme)	Email	04.04.2022
Mencap	Email	04.04.2022
Grasnet	Post in forum	04.04.2022

Appendix 5: Demographic details of participants

Gender	F = 30, M = 9
Self-defined ethnicity	White British = 29 White Welsh = 1 White Scottish = 2 White Irish = 4 British Indian = 2 Indian African = 1
Area of residence	Scotland = 2 Wales = 3 Ireland = 1 North West = 9 North East = 7 Midlands = 6 South East = 8 London = 2 Northern Ireland = 1
Relationship to relative	Daughter/Son = 28 Spouse/partner = 6 Niece/Nephew = 3 Granddaughter/Grandson = 1 Sibling = 1
Self-reported occupation	**Retired** (Head Teacher; Teacher Trainer; Senior Teacher; Technology Analyst; Office Worker; Lifeguard; Clinical Psychologist; Primary School Teacher) = 8 **Unemployed** = 2 **Civil Servant** (Local Government Officer; Attendance and Welfare Officer; Welfare Rights Officer; Civil Service Director; Manager Department of social care) = 5 **Academic** (Research Fellow; Professor; Lecturer) = 4 **Teacher / TA / Child Carer:** (Teacher; Classroom Assistant; Carer in school) = 3

	Medical Professional: (Physiotherapist; GP; Nurse/Social Worker; Palliative Care Nurse) = 4 **Social Worker/Support Worker:** (Support Worker; Social Worker) = 2 **Self-employed:** (Self-employed small business owner; Self-employed NOS) = 2 **Full time Carer** = 1 **White-collar:** (IT Project Manager; Manager; Solicitor; Data Manager; Police; Architect) = 6 **Blue-collar:** Garment Maker = 1 **Volunteer**: Hospital Governor = 1
Age of relative (n22)	40 – 50 = 1 60 – 70 = 1 70 – 80 = 4 80 – 90 = 8 90+ = 8

NIHR | Policy Research Unit Older People and Frailty

This document is available in large print.

Please contact the NIHR Older People and Frailty PRU for assistance.

Email: pru-manager@manchester.ac.uk

Telephone: 0161 306 7797

Front Cover Image

Photo by Kampus Production from Pexels

MANCHESTER 1824
The University of Manchester

Newcastle University

CPEC
CARE POLICY AND EVALUATION CENTRE
Research at LSE