# Checking Out: Project Summary

The Checking Out project forms part of a three year fellowship, funded by the Wellcome Trust, exploring attitudes towards and experiences of death and dying in low-income communities in the UK. The research employs mixed qualitative methods in community settings to focus on the views and experiences of those living on a low-income in relation to end-of-life care and bereavement.

## Background

The UK adopted an End of Life Care Strategy in 2008 (Department of Health) and there is a growing recognition of the need to address palliative care as a public health issue, encouraging early intervention to ‘reduce harms related to ignorance, fear, social distancing and isolation, stigma and prejudice’ (Kellehear, 2013). At the same time research shows that people with a lower socio economic status are less likely to access palliative care services (Buck et al., 2018), and that inequalities in access are actually increasing (Sleeman et al., 2016).

Given the UK’s ageing population, the crisis in health and social care and the recognition that inequalities accumulate across the life course (Hudson, 2016), end-of-life care for people in lower socio-economic groups is a key issue. The population most likely to experience multi-morbidity, to have complex needs and to require management of advanced disease is also least likely to have the social and material resources to ‘augment the gaps between formal and informal care contexts’ (Lewis et al., 2014). Whilst some of the situational barriers to accessing to palliative care are known (Wahid et al., 2018) a fear of the dying process, lack of information and communication are also significant issues (Buck et al., 2018).

In 2016 the Care Quality Commission reported on the need to address inequalities in end of life care and recognised the importance of community engagement as part of a wider approach to changing the culture around death and promoting understanding of the role of the hospice (Care Quality Comission, 2016). However there is little discussion within palliative care literature about approaches to engaging low income communities (Lewis et al., 2014).

Whilst we have seen the emergence of a ‘death awareness’ movement in the UK and elsewhere in recent years, it has been argued that primacy has been given to middle class ‘death ways’ in current discourse about ‘a good death’ (Conway, 2012). Similarly, whilst there is an emerging literature calling for a public health approach to end-of-life care (Sallnow et al., 2016), with initiatives such as ‘Compassionate Communities’ arguing that dying should be an issue for the community rather than the individual (Horsfall et al., 2013; Kellehear, 2013), evidence of the impact of these approaches is limited (Sallnow et al., 2016), and little is understood about the effectiveness or relevance of these approaches to people who may be struggling to live well.

## Aims

The aims of the Checking Out project are therefore

* to explore the notion of ‘a good death’ within low-income communities, using an engaged research approach to examine and contextualise the ways that individuals talk about and view death and dying
* to understand the impact of poverty on experiences of end of life and bereavement
* to advance understanding of the ways in which fear, stigma and trust impact on communication, relations (between patients, carers, families, social networks, healthcare professionals and organisations) and access to end-of-life care

## Overall study design

The study uses an engaged research approach, employing mixed qualitative methods to explore people’s views and attitudes in community settings.

The original study design (beginning in Oct 2019 for one year) included 2 strands:

1. Community engagement and observation activities (e.g. visits to existing groups and community settings to have initial conversations about the research, and use of the ‘Departure Lounge’ pop up installation to initiate discussion in venues such as community centres and food projects)
2. Followed by focus groups and interviews with individuals.

After an initial period of engagement work the study was interrupted by the Covid pandemic in March 2020. After a period of reflection, and after discussion with the project advisory group and community groups and individuals who had already shown an interest, the study design was adapted in June 2020 to operate online and by telephone, as described in the methods section below.

This dataset includes interviews with bereaved individuals (n=14) and professionals involved in supporting people experiencing poverty at end of life or in bereavement (n = 15) and represents one strand of the Checking Out study. Once Covid-related research restrictions are lifted further community engagement work is planned from Jan – Dec 2022, conditions permitting.

## Methods

Interviews were conducted with 15 professionals whose roles and geographical area of work meant that they have extensive experience of supporting people living on a very low income either at end of life or in bereavement. Participants were recruited by the researcher using convenience sampling and snowballing methods, for example publicising the research through the National Bereavement Alliance and Association of Palliative Care Social Workers, and directly contacting relevant professionals who had expressed an interest in the research during the community engagement phase. Professionals had a variety of job roles (e.g. funeral directors, faith leaders, welfare advice workers employed by charities or hospices, social workers and a credit union employee), and were working in different areas across the UK including England, Wales and Scotland.

14 interviews were held with bereaved individuals who were also recruited using convenience sampling and snowballing methods; some were informed about the study and invited to take part by one of the professionals interviewed with whom they had an existing relationship, some expressed an interest in participating during the engagement work. Participants either chose to contact the researcher directly or gave the professional permission to pass on their contact details. Individuals were eligible to take part if they were 18 or older and had been bereaved within the last five years. Initial conversations took place between the researcher and the individual to explain that the focus of the research was on poverty at end of life, and individuals self-identified if they felt that their experience was relevant. Ethical permission for the study was obtained from the University of Exeter College of Humanities Ethics Committee.

The characteristics of the participants including age range, gender, ethnicity, and the job roles of professionals are described in the Overall Data List.

Due to the pandemic, the interviews were conducted either by telephone or video call (according to the participants choice), from July 2020 to March 2021. The researcher talked through the information sheet (which had previously been sent to participants) at the beginning of the call and gave the participant the opportunity to ask questions. Verbal consent was then sought, with the researcher reading out the consent form statements and checking comprehension.

The duration varied from 25 to 69 minutes for individuals, and 47 to 154 minutes for professionals. The semi-structured interviews were guided by a Topic Guide which is available in the data archive. All interviews were audio recorded and conducted by the researcher (LH) who is experienced in sensitive interviewing. Interviews were transcribed verbatim, and all participants were asked if they would like the anonymised transcripts to be returned to them for comment and/or correction. 17 said yes and two participants added an extra written comment via email in response; this was added to the transcripts.

Following the principles of thematic analysis (Braun & Clarke, 2006) interview data were coded and analysed using QSR International’s NVivo 11 Software. This involved iterative thematic coding, including constant- comparison and combining both a deductive approach informed by the topic guide and an inductive approach whereby codes were derived from the data; all codes were then integrated into a coding framework incorporating the emerging themes and sub-themes. Feedback on the formulation of themes was sought from the project advisory group who had access to the data.

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