

# EXPLORING DEATH AND DYING IN THE UK

## PATIENT, FAMILY AND PUBLIC PERSPECTIVES (EDDUK)



### WELCOME TO THE EDDUK NEWSLETTER

In this edition, we will be giving you the latest information on

- What we have done so far
- Who has taken part in the study
- How Covid-19 has affected our work
- Future plans

In response to some requests for information from participants, we have also included a focus on advanced care planning – What is it? and How can I start making a plan? We hope you will find this useful. If you have any questions or comments on EDDUK, you are welcome to get in touch at:

[kristian.pollock@nottingham.ac.uk](mailto:kristian.pollock@nottingham.ac.uk)

## WORKING TOWARDS BETTER END OF LIFE CARE FOR ALL

The UK population is becoming older. Most people die in great old age, often after a period when they are affected by one or more chronic conditions, such as diabetes, cancer or heart failure. Current care for patients approaching the end of life has not caught up with this changing population profile. We know very little about what members of the public think about death and dying, their experience of giving and receiving care within their family, or how they themselves would wish to be cared for in future.

The EDDUK research study has been **funded by Marie Curie** to:

- explore public, patient and family perspectives and experiences of death and dying in different care settings in the UK, and
- establish participants' concerns and priorities for end of life care.

We hope that the knowledge gained from the study will help policy makers and healthcare professionals to develop end of life services which are better tailored to the needs of people from all sectors of society.



## WHAT ARE PEOPLE TELLING US?

We have been gathering information on experiences of death and dying in the UK from three sources

### Interviews with bereaved people

Interviews took place with 34 people who had been bereaved: 24 women and 10 men. Bereaved participants were aged 19-82, with just over half being in the age category 50-69. Most had lost a close family member, e.g. parent, partner, or grandparent. In almost half of the deaths, cancer was the main cause. Nearly a third of the deaths took place at home; others were in a care home, hospital, hospice or an assisted dying facility.



*So I suppose for me the most important thing is to die with dignity and respect, and being recognised for who I am. So the care setting for me wouldn't be the end of the world, as long as I was cared for in a way that was still allowing me to be me.*  
BP121

### Interviews with patients who are aware they have a terminal illness

Twelve patients took part in the study: seven women and five men. Patient age ranged from 58-88, with the majority being over 70 years old. Over half had a diagnosis of cancer, but heart failure, COPD and neurological illnesses were also reported. Eight of the twelve patients had some form of written plan in place to guide decisions about their future care.

### Discussion groups with members of the public

7 discussion groups met for 4 sessions, with 38 participants in total. In addition, 5 individual interviews were carried out with people who wanted to take part in a group but were not able to attend. The majority of participants were women; 9 were men. They ranged in age categories from 30 – 89. The topics for the four sessions were 'Talking about death and dying', 'The good death', 'Choice and Future Planning' and 'Compassionate Communities'.

*If I just drop dead with no warning whatsoever of a massive heart attack or a massive stroke ...that'd be fantastic, because I wouldn't know it was coming, it would just come out of the blue and that would be that. It'd be horrible for the family, but for me it'd be fantastic.*  
BP110

*And when five minutes later they came back he had died. So I think he had just slipped away... in a funny way I'm not sure that I do want a cluster of people around my bedside; I'd rather just slip away by myself.* BP119



## THE IMPACT OF COVID-19

Just like other forms of social contact, our research interviews and discussion groups were affected by Covid-19, with all activities having to move online. Some people may have been put off taking part because of a preference for face to face contact, or because they lacked the necessary technology. However, most people took this in their stride.

The online format of the discussion groups required some changes; the groups were smaller (4 – 5 participants) and lasted one hour instead of the two originally planned. The added flexibility and convenience meant that people were able to contribute to the study regardless of where they lived.

Patients interested in taking part in the study were willing to engage in online or telephone interviews and these worked well. However, recruitment to the patient interviews was delayed due to the lockdown and we were not able to recruit as many patients as originally hoped (up to 20). We were able to increase the number of bereaved people interviewed from up to 20 to 34.



## FUTURE PLANS

We are in the process of preparing some papers for inclusion in academic journals on the themes of:

- Talking about death and dying
- Place of death / the good death
- Rituals and accompaniment at the end of life

A further update with more detailed information about what we have found will be available later in the summer. The results of the study will contribute to the development of Marie Curie's policy in supporting end of life care in future.





## FOCUS ON ADVANCED CARE PLANNING (ACP)

Advanced care planning involves making decisions about the care and treatment you might want in the future. The idea is for these plans to be shared with family, friends or health and social care professionals so that if you become unable to make your decisions known, someone else can make sure your choices and preferences are taken into account and acted upon wherever possible. There are numerous organisations whose websites provide further information on advanced care planning, including tools you can use to help you think and plan ahead:

<https://www.mariecurie.org.uk/help/support/terminal-illness/planning-ahead/advance-care-planning>

<https://www.nhs.uk/conditions/end-of-life-care/?tabname=planning-ahead>

<https://compassionindying.org.uk/library/advance-decision-pack/>

<https://www.ageuk.org.uk/information-advice/money-legal/legal-issues/advance-decisions/>

## MEET THE TEAM

The EDDUK research study is being carried out by a team at the Nottingham Centre for the Advancement of Research into Supportive, Palliative and End-of-life Care (NCARE) at the University of Nottingham. Team members are:

**Kristian Pollock:** Principal Investigator

**Glenys Caswell:** Senior Research Fellow

**Elli Wilson:** Senior Research Fellow

Elli was recently awarded a prestigious Anne MacLaren Research Fellowship starting in October 2020. She remains involved in the research but has reduced her input.

**Nicola Turner** was able to join the study as a Research Fellow in November 2020.



EDDUK is funded by Marie Curie UK's leading end of life charity

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