



## Thinking Ahead: Exploring and Understanding Experiences and Decisions in End of Life Care

Welcome to the **Spring** edition of the **Thinking Ahead** newsletter.

We hope that you are all keeping safe and well and we hope that our news will be a welcome distraction during this challenging time. As always, we thank you for your support.

### Recruitment is now closed

Through your support we recruited 18 patients and have completed 93 interviews around these 18 'cases'. We also interviewed 19 bereaved family carers. So you have helped us achieve a grand total of 112 interviews.

**THANK YOU!**

### The project

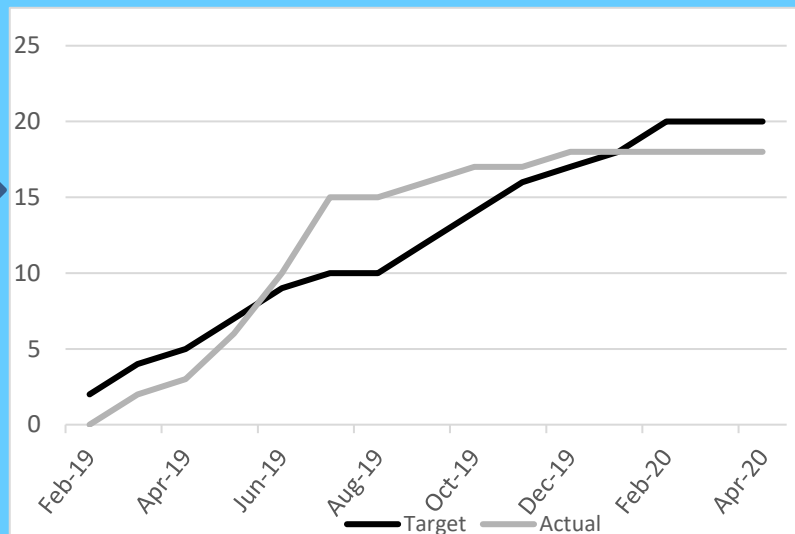
The first phase of this 30 month project involved patients and family care givers from Black, Asian and minority ethnic (BAME) communities and health care professionals who support them.

We are now looking for public and professional participants for workshops in the **next phase** of the project. Might you be interested?

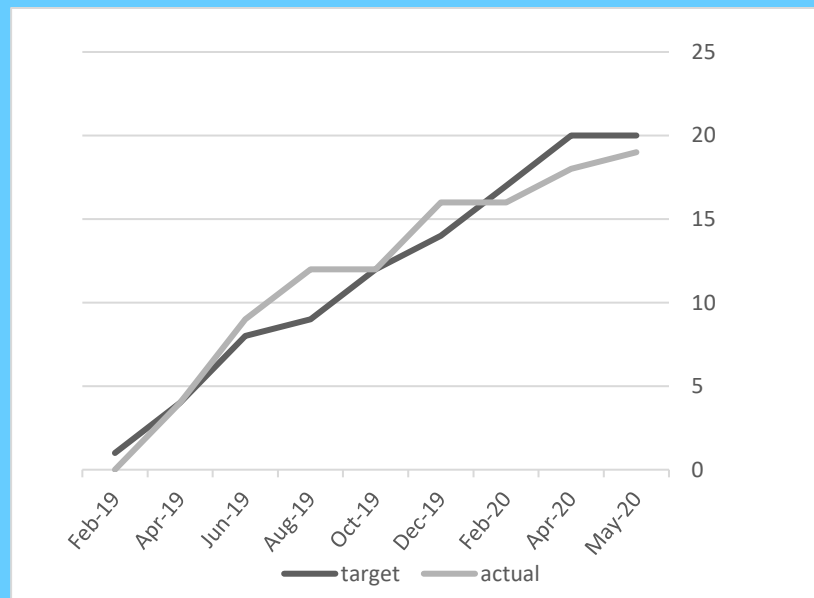
Find out more about the project at [loros.co.uk/thinkingahead](http://loros.co.uk/thinkingahead) or contact at us [research@loros.co.uk](mailto:research@loros.co.uk)

### Recruitment over the past 16 months

#### Patient Recruitment



#### Bereaved Carers Recruitment



## Impact of Covid-19 on the Project

As in many other areas of society and work, Covid-19 has had an impact on how we have worked in the latter part of data collection, and it will also impact the way we continue to work on Thinking Ahead. Despite the pandemic we have managed to complete most planned activities of the project.

In an attempt not to overload NHS staff at this time, we ceased requesting interviews with health care professionals and those assisting us with reviewing medical notes, so we have less of these than anticipated, and those we currently have are thus all the more valuable to us.

We extend **sincere thanks** to those who were able to help us with these aspects before the pandemic.

With **kind agreement** from remaining participants in the study, we were able to conduct telephone interviews rather than face-to-face interviews.

Data analysis is deep in progress and we are now planning the next phase of the project, which may need to look a little different due to Covid-19. Please see below for further information and a

**'CALL FOR PARTICIPANTS'**.

## Project News & Events

### January

- Our second video log (vlog) appeared <https://www.loros.co.uk/thinkingahead/>
- Prof. Christina Faull (Chief Investigator of Thinking Ahead Project) was interviewed about the project and palliative care for BAME communities by the *The Hospice Biographers*, a nationwide charity. The live monthly radio show transmits globally and covers topical palliative care issues <https://www.mixcloud.com/threadsradio/we-remember-lives-w-the-hospice-biographers-21-jan-20/>
- The Thinking Ahead project convened and hosted at LOROS, the new National Think Tank on education and training in palliative care. This gave the project a huge profile with a large number of key organizations involved in standards of care and practice including the GMC, NMC, HEE and CQC. It has had an immediate impact on the curriculum for foundation doctors and a steering group has formed to focus on how the workforce can be prepared for open and honest conversations. (Reconvening after Covid-19 crisis)

### February

- Dr Zobia Islam (Principal Investigator of Thinking Ahead Project) presented at the Leicester Research Live Conference on *"Emotional complexities of undertaking research exploring thinking ahead about medical treatments in advanced illness"*. This shared our study experiences and emergent findings from our analysis.

### May

- Prof. Christina Faull, together with LOROS CEO John Knight participated in a special broadcast on the Leicester based pop-up radio Ramadan FM during the 'Nourish 2 Flourish' slot hosted by co-applicant Irfan Mururajani. See <https://www.youtube.com/watch?v=LCvydTPL8F0> for interviews.

## CALL FOR PARTICIPANTS

Would you be willing to be a research participant to share your thoughts about the findings of our research with patients with advanced illness from minority ethnic communities and their families and the health professionals who support them? We would like to hear your thoughts on how these findings can be most usefully translated into training for doctors, nurses and allied health professionals.

We would like to hear from professionals and community and faith leaders who are interested in joining us for 'workshops'. We currently envisage these might take place via **electronic** means and the format and way these will happen will be communicated in due course. If you are interested in knowing more please contact [research@loros.co.uk](mailto:research@loros.co.uk)

*The views expressed in this newsletter are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.*