

Deaths at home during Covid-19 and implications for patients and services: project stakeholder group terms of reference

Version 1.1, 21 January 2022.

Objective

To act as a stakeholder group for the project, by bringing expertise from different perspectives to inform and support the delivery of the project, and dissemination of results.

Project aims

This project will use the [OpenSAFELY](#) platform to understand the service impact of the shift in place of death during the Covid-19 pandemic.

The objectives of the project are to:

- 1) Pilot the onboarding process for OpenSAFELY
- 2) Understand what services were provided to patients who died over the course of the pandemic, compared with pre-pandemic, and how did service use vary between sub-groups of patients?
- 3) Establish the quality of data relevant to assessing the quality of end of life care for patients who died at home within OpenSAFELY, in order to inform future research on the shift in place in death and its impact on patients and services
- 4) Develop questions for future research

The project commences in December 2021, and will run until at least June 2022. A review of progress and outputs will be undertaken during June 2022.

Terms of reference for stakeholder group

- To ensure the project builds on existing knowledge and expertise, specifically relating to end of life care and use of the OpenSAFELY platform.
- To sense check the interpretation of emerging findings, from the perspective of national policy and service delivery, and be informed by input from the patient and public panel which will be established.
- To facilitate communication about the project, through members networks, and feedback on relevant other work which may impact on the project.
- To review and comment on draft findings and reports, where appropriate.

Way of working

- It is expected that the Group will meet at appropriate times over the course of the project. Likely timescales for meetings are December (initial meeting), February (to discuss emerging findings following the initial analysis phase) and every six weeks from then.

- Meetings will be held via Zoom or MS Teams.
- Members may be asked to comment on papers and share their views between meetings, on an ad hoc basis.
- The group will be supported by the project team at the Nuffield Trust.
- Communication will be via email.
- The group is advisory. Professor Bee Wee is also the NHSEI sponsor for the project.
- For further information please contact: Dr Sarah Scobie, sarah.scobie@nuffieldtrust.org.uk, 07780 475568

Membership (proposed)

<i>Name</i>	<i>Role</i>	<i>Organisation</i>
Professor Bee Wee (Chair)	National Clinical Director for End of Life Care	NHS England/Improvement
Neil Bannister	Assistant Deputy Director Health Analysis	Office for National Statistics
Professor Katherine Sleeman	Chair of Palliative Care	Cicely Saunders Institute, King's College London
Brian McKenna	Honorary Research Fellow	EBM Datalab, OpenSAFELY
Dr Helen Curtis	Researcher	EBM Datalab, OpenSAFELY
Dr Sarah Mitchell	GP and CCG/Regional clinical lead for palliative care	Sheffield CCG and North East and Yorkshire SCN
Professor Julia Verne	Clinical Lead - National End of Life Care Intelligence Network	Office for Health Improvement and Disparities
Dr Sarah Scobie	Deputy Director of Research	Nuffield Trust
Theo Georghiou	Senior Fellow	Nuffield Trust
Eilís Keeble	Fellow	Nuffield Trust

Review of terms of reference

The role of the group and terms of reference will be reviewed in June 2022.