

PARTICIPANT INFORMATION SHEET: “Human Rights in Care Homes: A Survey-Based Study”

This survey is part of a larger research project, “Protecting human rights in care homes”, which is in partnership with the National Mental Capacity Forum and funded by the Arts and Humanities Research Council (AHRC). Before you decide whether or not to take part in the survey, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

The survey is part of a larger research project, “Human Rights in Care Homes”, focusing on the impact of the pandemic on respect for human rights in care homes in England and Wales. Our goal is to help care professionals protect human rights in care homes going forward.

A first step is to conduct an online survey, in which we will ask participants some general questions about their experiences during the pandemic. By completing this survey, you will help us understand the situation on the ground and what support may be needed.

In a second step, we will conduct a series of focus groups, in which we will speak to selected care professionals to further discuss some important issues identified in the survey.

This information will be analysed and used to help both care professionals and policy makers protect human rights in care homes: we will develop a training programme aimed at frontline workers, and we will publish our findings in the form of podcasts, blog posts, webinars, research papers, and reports.

Why have I been invited to participate?

You are invited to partake in this survey because we are interested in the experiences of care sector professionals on the ground during the pandemic.

Do I have to take part?

Participation is entirely voluntary: it is up to you to decide whether or not you wish to take part in this survey. If you do decide to take part, you will be informed at the start of the survey that, by completing the survey, you are consenting to participate in this study. You are free to withdraw at any time, without giving a reason, by closing your browser.

What will happen to me if I take part?

You will then be asked a number of questions on four topics: restrictions on movement and visits, the usefulness of guidance, access to services, and the use of DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation) orders. The survey should take you between 10-25 minutes to complete.

What are the possible disadvantages and risks of taking part?

It may be difficult to reflect on some experiences. We would like to reassure you, therefore, that you do not have to answer every question in the survey (each question has a “Prefer not to say” option) and that you can withdraw at any time by simply closing your browser.

What information will be collected?

We will collect your responses to the online survey, which will be completely anonymous. This means we do not collect any information that could be used to directly establish your identity, such as your name, gender, or place of residence.

How will my information be stored?

Survey responses will be safely stored on a secure University of Essex shared drive. Access to the data will be restricted to researchers directly associated with the research project (you can find the names and contact details of the research team below). After the project is finished, information will be removed from the drive and deposited for ten years in the UK Data Archive. During this time, access will remain restricted to members of the research team and their successors in post, and to researchers who are registered with the UK Data Service. After this time, it will be deleted.

What is the legal basis for using the data and who is the Data Controller?

Our legal basis for using the data will be informed consent. The Data Controller is the University of Essex, and the contact is the Data Protection Officer (dpo@essex.ac.uk).

What will happen to the results of the research study?

The survey results will be analysed to identify key themes, which will be discussed in more depth during follow-up focus groups. Survey results will also be published on the Essex Autonomy Project [website](#).

Results from both the survey and the focus groups will be analysed and used to help both care professionals and policy makers protect human rights in care homes: we will develop a training programme aimed at frontline workers, and we will publish our findings in the form of podcasts, blog posts, webinars, research papers, and reports. These outputs will be published on the Essex Autonomy Project [website](#), and research articles will be made Open Access, meaning anyone can read them free of charge.

Who is funding the research?

This study is funded by the Arts and Humanities Research Council (AHRC).

Who has reviewed the study?

This study has been reviewed and approved by the Humanities Sub-Committee at the University of Essex.

Concerns and Complaints

If you have any concerns about any aspect of the study or you have a complaint, in the first instance please contact the principal investigator of the project, prof. Wayne Martin, using the contact details below. If are still concerned, you think your complaint has not been addressed to your satisfaction or you feel that you cannot approach the principal investigator, please contact the departmental Director of Research in the department responsible for this project, Daniel Watts (email dpwatts@essex.ac.uk). If you are still not satisfied, please contact the University's Research Governance and Planning Manager, Sarah Manning-Press (e-mail sarahm@essex.ac.uk). Please include the ERAMS reference which can be found at the foot of this page.

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