



Information Sheet for Inclusion Health staff

UCL Research Ethics Committee Approval ID Number: 6202/006

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study: Understanding access to palliative care support for people with advanced ill health, who have unsettled immigration status and are homeless

Department: Marie Curie Palliative Care Research Department, Division of Psychiatry, UCL

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You are being invited to assist in our research project. Before you decide it is important for you to understand why the research is being done and what participation involves. Please read the following information carefully and discuss it with others if you wish. One of our team will also go through this information with you and answer any questions. This should take about 10 minutes. Thank you.

What is the project's purpose?

People experiencing homelessness are a group whose health is often poor. The average age of death for someone experiencing homelessness is around 30 years younger than for people in stable housing. Previous research has shown that PEH are rarely able to access palliative care. In this research we want to explore what happens for people who are homeless, very unwell but **who are not able to access hostel accommodation** due to their immigration status.

To help us learn more about the challenges for this group we plan to do three things.

1. hold focus groups or individual interviews with health and social care professionals who support this group to hear what they see as the challenges and opportunities in accessing palliative support.
2. Speak with people with ill health who have unsettled immigration status and are experiencing homeless about their experiences of accessing health care (over the phone or online), participants in section 1 will assist in the recruitment of this group
3. Conduct a UK-wide online survey of hospice staff to learn of their experiences of supporting this group (if any) and their awareness of issues such as eligibility for NHS care.

Why have I been chosen?

You are someone who works with people with unsettled immigration status. We feel you have a lot you could contribute to this project.

Do I have to take part in the project?

Taking part in the project is entirely voluntary. If you do decide to take part you will be given this



information sheet to keep and will also be asked to provide recorded verbal consent at the start of the focus group or interview. Even if you do decide to take part you are free to withdraw from the project at any time and without giving a reason. If you withdraw from the project, this will have no consequences for you. If you do decide to participate, you can still withdraw all the information that you have shared with us up to two weeks after the date of the interview.

What do I have to do if I participate?

If you agree to participate in the project, you will be invited to take part in an online focus group or interview using MS teams. This will last for approximately an hour and will be attended by around 6 other inclusion health and social care professionals and staff from charitable organizations that support people with unsettled immigration status, homelessness or advanced ill health.

During the focus group or interview you will be asked to discuss your experiences of supporting people with advanced ill health who are homeless and who have unsettled immigration status, including any challenges in accessing palliative care support for this group and how care for this group could be improved in the future. In addition, we will also ask for your help in identifying people with advanced ill health who have unsettled immigration status and are experiencing homeless who you think may be interested in being interviewed about their experiences by the research team. We would ask you to seek permission from the individual to pass their contacts details to the research team. We would then contact them to answer any questions about the study, seek consent and arrange a time for interview if they are happy to proceed. We proposed offering supermarket vouchers or phone credit to individuals being interviewed as a thankyou for their time. You can participate only in the focus group or interview, only contact someone you think may be interested, or both, whichever you prefer.

Will I be recorded and how will the recorded media be used?

The audio from the focus group or interview will be recorded but no names or identifiable information will be included. The recordings will be transcribed by the UCL transcription service and the audio recordings will be deleted once transcription is complete. The recordings will be stored in a secure location on the UCL S drive.

What are the possible benefits of taking part?

You are already supporting clients with very challenging problems. We hope that the project will result in better care and support for people with unsettled immigration status, whose health is poor and who are experiencing homelessness by highlighting the challenges faced and advocating for change.

What if something goes wrong?



If you have a concern about any aspect of this project, in the first instance you should ask to speak to the research team (Briony Hudson, B.hudson@ucl.ac.uk) who will do their best to answer your questions. However you feel your complaint has not been handled to your satisfaction you can contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk. Should you feel distressed by the project, a health care professional with psychosocial expertise will be available for you to speak with you if required (caroline.shulman1@nhs.net)

Will my taking part in this project be kept confidential?

Any information that we collect about you during the course of the research will be kept strictly confidential. Data will be pseudo-anonymized with you and other participants being assigned a project ID number. Neither you nor any other participants will be identifiable in any ensuing reports or publications. Please be advised that although the researchers will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents the researchers from guaranteeing confidentiality.

Limits to confidentiality

Confidentiality will be respected subject to legal constraints and professional guidelines meaning there are compelling and legitimate reasons for this to be breached. If this were the case we would inform you of any decisions that might limit your confidentiality.

What will happen to the results of the research project?

All the information will be anonymised before we analyse the results. The anonymised results will be presented to people working in homeless health and social care. It will also be published in scientific journals and at academic meetings. Results will be fed back to you and a written copy of the final report will be available on the Marie Curie website once the research is complete.

Data Protection Privacy Notice

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data.

Please see the UCL website for more details regarding the data protection for research participants: <https://www.ucl.ac.uk/legal-services/privacy/ucl-general-research-participant-privacy-notice>. If you are concerned about how your personal data is being processed, please contact Dr Briony Hudson or Dr Caroline Shulman in the first instance. If still concerned please contact UCL at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>. The



lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible. The project team will keep your name and contact details confidential and will not pass this information to any other organisation. We will only use this information to contact you about the project and to link your interviews. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. All information that identifies you will be deleted before the data is analysed. Once your interview has been written up, we will delete the original recording. Once the project is complete, we will transfer the pseudo anonymised transcripts and other data from the project to the UCL Records Office for long-term storage within 6 months of completing the project. The data will then be stored for a minimum of 10 years. We do not intend to store any data from this project in a research repository. All information collected during the project will be combined, and no individual will be identified in any report or publication.

Who is organising and funding the project?

This is a collaborative project being led through the Marie Curie Palliative Care Research Department at UCL and supported by charities that are interested in helping to improve the lives of people who are homeless: Pathway, The Oak Foundation and Marie Curie.

Contact for further information

For further information please contact Dr Briony Hudson or Dr Caroline Shulman via email: B.hudson@ucl.ac.uk, caroline.shulman1@nhs.net

Thank you for reading this information sheet and for considering taking part in this research study. The information sheet is for you to keep.