

Supplementary files

Supplementary Appendix S1. Participant Information Sheet for the clinician interview series



NUFFIELD DEPARTMENT OF
PRIMARY CARE
HEALTH SCIENCES

Optimising the implementation of advance care planning in heart failure

Participant Information Sheet (Qualitative Clinician Interviews)
REC reference: **R44601/RE001**

We would like to invite you to take part in this research study. Before you decide whether or not you would like to take part it is important that you understand why the study is being done and what it would involve for you. Please take time to read the following information carefully. It explains why we are doing this study, what your involvement would be, and hopefully answers any questions you may have at this stage. Please feel free to contact us if there is anything you do not understand, or would like more information about.

What is the purpose of the study?

Many patients suffering from heart failure are not aware that the illness leads to inevitable decline and their clinicians find it difficult to tell them this. This can have an effect on the care patients receive. We know that clinicians find it difficult to initiate discussions about future end of life care. This is a process also known as advance care planning. Conversely, patients are willing to engage in advance care planning, but studies show that the emphasis needs to be on enabling conversations with skilled and trained clinicians rather than just focusing on the completion of a document. Difficulties for clinicians in implementing advance care planning can be due to a number of barriers like time constraints, a lack of confidence in communicating end of life issues or other competing clinical pressures. As a result, patient care suffers leading, for instance, to unnecessary hospital admissions or an excessive amount of investigations. This study wants to develop an intervention to support GPs and nurses to engage with their patients in a competent, timely and sensitive way on planning their future care.

We have been conducting three systematic literature reviews and meta-analyses. The findings of these reviews demonstrate significant effects of several intervention components to support clinicians in the implementation of advance care planning but also highlight a number of barriers in doing so. The main aim of the interview study is to identify in much greater detail what your experience is with advance care planning and how you think its implementation can be achieved given your pressurized clinical workload.

Why have I been invited to take part?

Our research team is designing and carrying out interviews with healthcare professionals, who have indicated an interest in participating in this study. Your name was chosen from a list of participants who have registered an interest as a response to an invitation in person or advertised through local and national organizations. Therefore, we are very interested in any contribution you may have to support clinicians in planning the future care of their patients suffering from heart failure. We will be contacting approximately a total of 50 participants about this research.

What would taking part in the study involve?

To help us to understand ways of supporting clinicians in delivering advance care planning for their patients, we want to run a number of qualitative interviews, each lasting maximal 30-45 minutes. Interviews are informed by research findings but predominantly give you the opportunity

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to express your views on advance care planning and how end of life care for patients suffering from heart failure might be improved. To help us get the most out of what you tell us, we would like to record some of your answers. Your answers will be anonymized (your name will not be included) and be treated in strict confidence. The researcher can discuss the study with you before the interview begins, and answer any questions you may have.

Where and when will answering the interviews take place?

The interviews can take place at your surgery or at the Nuffield Department of Primary Care in Oxford at a time of your choosing. If you elect to come to the Nuffield Department of Primary Care, we will send you directions once we agreed on the specific date and time.

Do I have to take part?

No. Taking part is entirely voluntary. If you decide to take part but later change your mind, you can withdraw from the study without penalty at any time and do not have to give a reason. No one will be upset if you do this.

What are the possible benefits of taking part?

Participating in the research will give you and us a greater understanding of what enables GPs and nurses to deliver advance care planning for patients suffering from heart failure. This will contribute to the development of an intervention. We believe this will ultimately result in improved clinician skills and improved patient care. What you tell us will probably benefit other healthcare professionals like cardiologists and heart failure specialist nurses as well since they talk to people who may approach the end of their life.

What are the possible disadvantages of taking part?

There are no specific risks associated with taking part in this study. Participating in the interviews is completely independent from any medical care you may deliver.

Will my taking part in this study be kept confidential?

Any information that you give us during the research will not be used or made available for any purpose other than for this research. Only authorized individuals at the research institution (if necessary for monitoring research quality) will have access to the study data. All authorized individuals will have a duty of confidentiality to you as a research participant. Any paper records of the study will be stored in a locked room, which is only accessible to the research team. They will be stored separately from any record of your identity. Any information stored on computers will be protected with passwords. If you choose to withdraw from the research, any information that has been collected about you will be destroyed. At the end of the research, the confidential records will be kept securely for 5 years and then destroyed.

What will happen to the results of the study?

The research results will be used to help develop an intervention for health professionals involved in care for patients suffering from heart failure. The findings will be submitted for publication in medical journals, and for presentation at relevant conferences. We will not present the findings in any way that could allow the identification of individual people. If you would like to receive a copy of the research findings we would be happy to arrange this for you. They will be available by post and accessible on a website.

What if I have concerns about this study, or there is a problem?

If you have any concerns about any aspect of this study, or the way it has been carried out, please speak to the lead researcher, Dr. Markus Schichtel. He can be contacted at the Nuffield Department of Primary Care Health Sciences, University of Oxford, Radcliffe Observatory Quarter, Woodstock Road, Oxford OX2 6GG. Telephone 01865 289 300, or by email:

markus.schichtel@phc.ox.ac.uk. He will do his best to answer your query. The researcher should acknowledge your concern within 10 working days and give you an indication of how he intends to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Research Ethics Committee at the University of Oxford (Chair, Medical Sciences Inter-Divisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford, OX1 2JD). The chair will seek to resolve the matter in a reasonably expeditious manner.

Who is funding and organizing the study?

The study is not funded by any funding body but by the lead researcher himself, and is being carried out by a collaborative research group from the University of Oxford.

Who has reviewed the study?

This study has been reviewed and given a favourable opinion by the Research Ethics Committee, reference number R44601/RE001.

What should I do next?

Whether you decide to take part or not, we would be grateful if you would complete the Study Reply Form accompanying this information leaflet, and return it to us in the FREEPOST envelope provided. If you have decided not to take part we will make no further contact with you. If you have indicated that you would like to take part in the study, we will contact you to arrange your participation in one of the interviews. Please feel free to get in touch with us if you have any questions about what you have read, or if you want to talk about the study. We ask that you keep this Information Sheet for future reference.

If you would like further information about this study please contact Dr. Markus Schichtel on 01865 289 300, email markus.schichtel@phc.ox.ac.uk, or write to him at the address below.

Thank you for taking the time to read this leaflet!

Nuffield Department of Primary Care Health Sciences, University of Oxford, Gibson Building,
Radcliffe Observatory Quarter, Woodstock Road, Oxford OX2 6GG.

Supplementary Appendix S2. Consent form for the clinician interviews



NUFFIELD DEPARTMENT OF
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Optimising the implementation of advance care planning in heart failure

The purpose of this study is to develop an intervention that optimises the implementation of advance care planning in heart failure.

INTERVIEW CONSENT FORM

REC reference: R44601/RE001

	Declarations	Please initial the box
1.	I confirm that I understand that this project has been reviewed, and received ethics clearance through, the university of Oxford Central University Research Ethics Committee.	
2.	I confirm that I understand who will have access to personal data provided, how the data will be stored, and what will happen to the data at the end of the project.	
3.	I confirm that I understand how to raise a concern and make a complaint.	
4.	I confirm that I have read and understood the participant information sheet for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
5.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without legal rights being affected.	
6.	I agree that the interview may be audio-recorded, and I agree that any words that I may say during the discussion can be used anonymously in the presentation of the research.	
7.	I understand that data collected during the study (including audio-recordings) will be kept for five years and then destroyed.	
8.	I agree to take part in the above study.	

Name of participant

Date

Signature

Dr Markus Schichtel

Name of interviewer

Date

Signature

1 Copy for Participant / 1 Copy for Researcher

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Contact details of researchers:

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Prof Rafael Perera	Director Medical Statistics, Supervisor: rafael.perera@phc.ox.ac.uk
Dr John MacArtney	Qualitative Researcher, Co-Supervisor: john.macartney@phc.ox.ac.uk

Nuffield Department of Primary Care Health Sciences, Gibson Building, 1st floor, Walton Street, Jericho,
OX2 6NW, Tel: 01865 289 300

Postal address: Radcliffe Observatory Quarter, Woodstock Road, OX2 6GG

Supplementary Appendix S3. Interview topic guide

Interview topic guide for qualitative interview series with GPs and nurses to optimise the implementation of Advance Care Planning in heart failure

Interview Topic Guide

The purpose of this study is about heart failure and about reducing stress for GPs and nurses to do advance care planning (ACP) for patients suffering from heart failure. Even if you don't have much experience with ACP, your perspective is much appreciated since you know your own clinical environment and the pressures of your daily routine best.

Interview Format

Part One – unstructured, narrative section

“Alternative” in the text below indicates alternative questions that I may use to see whether that version of the question is easier understood.

General Questions

The following are some general questions to start the interview with:

- “Please, tell me about your experience(s) with ACP.”
Alternative: Could you tell me about a time when you did ACP with one of your patients?
- What are your issues with implementing Advance Care Planning?
- What would make advance care planning easier for you?
Alternative: What might reduce the problems you have found with your stress levels in doing advance care planning?
- What are your issues with implementing ACP in heart failure?
Alternative: What would make advance care planning in heart failure easier for you?
Alternative: What might reduce the problems you have found when doing ACP for HF patients?

Part Two – semi-structured section

When the narrative is finished, a semi-structured interview guide will be used to explore any potentially relevant issues that had not already emerged such as barriers and facilitators of ACP. As follows are some examples of specific questions about barriers and facilitators to the implementation of ACP.

Specific Questions

Barriers to the implementation of ACP

- What are barriers for you to undertake ACP as a GP or nurse?
Alternative: What is the main factor that prevents you from doing ACP?

In the course of that conversation, I may explore how significant the following barriers are:

- Lack of time
Examples: “What are your main time constraints in undertaking ACP with patients suffering from heart failure?”

“Does the complexity of heart failure treatment affect you in having an ACP conversation with your patient?”

- Lack of knowledge about ACP
Example: What training have you received in ACP?
- Lack of EOL communication skills
Example: Please, could you tell me an occasion when you communicated with a patient about end-of-life issues?

In the context of communication skills, participants are asked some of the following questions: “What type of communication training would you find most helpful?” “What do you think about forum theatre role-play to practice communication skills?” Participants are given an explanation of what forum theatre role-play is and what the differences are compared to traditional role-play.

- Lack of confidence
Example: What promotes or erodes your confidence in communicating end-of-life issues?
- Unpredictable disease trajectory of heart failure
Example: Is there anything about heart failure that might promote or inhibit you having an ACP discussion?
What knowledge about ACP and heart failure do you find most useful?

Facilitators of implementing ACP

Question we asked to explore the usefulness of facilitators to implement ACP are:

- What are factors that would help you in undertaking ACP?
“Would you find it helpful if a patient asks you a question about ACP?”
 - What is the factor that would help you most in doing ACP in heart failure