

Participant Information Sheet for Delphi Survey

Chief Investigator: Dr Sara MacLennan

Name of Study: giving patients a mEaningful VOice in the design and deLiVery of carE (EVOLVE) Phase 3

You are being invited to take part in a research study. Before you decide to take part 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. Talk to others about the study if you wish. Please do not hesitate to contact us (see below) if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Clinical practice guidelines are recommendations based on the best available clinical evidence. These guidelines are a tool to support clinicians and patients to make informed health care decisions. Patient involvement within development of clinical practice guidelines has been shown to improve quality of care and is particularly important when considering “preference-sensitive” decisions, where preference is more important when considering pros and cons of treatment options. An example of a “preference-sensitive” decision is the choice of treatment for early (localised) prostate cancer, where patient characteristics such as age, education and socioeconomic status as well as views and experiences have been shown to indicate differences in patient treatment and outcome preferences. There is a need to develop a model of meaningful patient engagement to address which stakeholders to involve, how to involve them and at what stage of the guideline development process. This study aims to develop a model that will give patients a meaningful voice in the design and delivery of care and will investigate how wider stakeholders (e.g. patient organisations) can help to integrate the patient voice into clinical practice guidelines.

Why have I been chosen?

You have been chosen because of your expertise and experience in treating patients with urological cancers and your experience developing or using clinical practice guidelines.

Do I have to take part?

No. It is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep. If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your involvement in any medical association.

What will happen to me if I decide to take part?

If you decide to take part in this study you will be invited to participate in an online Delphi survey. A Delphi survey uses multiple rounds of questions to achieve group consensus whilst keeping all participants anonymous. There will be up to three rounds of surveys. The

surveys will be sent to you via email along with instructions and you will have up to two weeks to complete each survey in your own time. Each survey is predicted to take approximately 20 minutes to complete. For each survey you will be given a list of topic areas within urological cancer and asked to rate the importance of patient involvement for each topic area on a nine-point scale according to the following criteria: are patient preferences and values of high importance for the topic area?

If you do not complete a round of the study you will be considered withdrawn from the study. If you decide to withdraw from the study, anonymised data collected in previous survey rounds and up until the point of your withdrawal may still be used in analysis. Your identifiable contact information will be kept after the end of this study, if you consent to this, and your information will be held in accordance with the General Data Protection Regulation.

What is the main research question for this study?

This study aims to determine the priority topics to be considered for patient and public involvement (i.e. areas where patient preferences and values are particularly important) within clinical practice guideline development and implementation for prostate cancer, testicular cancer, bladder cancer and kidney cancer.

What are the possible disadvantages and risks of taking part?

There are no identified risks to taking part in this study.

What are the possible benefits of taking part?

By taking part in this study you may be contributing to the design of a meaningful model of patient involvement in the development and implementation of clinical practice guidelines. By ensuring patients are involved at the optimum stages of the guideline development process and patient preferences are routinely embedded into clinical practice guidelines this may result in improved quality of care for patients diagnosed with urological cancers in Europe. Clinicians may have better quality guidelines and may be better equipped to provide shared-decision making and patient-centred care and guideline developers may benefit from increased guideline adherence.

What if there is a problem?

At any time during the study, if you have a complaint or a concern you may contact the researcher or Chief Investigator via the contact details below. At any time during the study, if you have a complaint or a concern regarding the collection, analysis and storage of your data that you have been unable to resolve with the Chief Investigator, you may contact the Data Controller of the University (Tel: 01224 272596, email: dpa@abdn.ac.uk) or contact the University Research Governance Team at researchgovernance@abdn.ac.uk.

Who has reviewed this study?

This study has been reviewed by the Proportionate Review Sub-committee of the West Midlands - Solihull Research Ethics Committee.

Who is organising and funding the research?

The study is sponsored by the University of Aberdeen, run by Academic Urology Unit at the University of Aberdeen, and is funded by urological cancer charity UCAN via NHS Endowment.

Will my taking part in this study be kept confidential?

University of Aberdeen is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. University of Aberdeen will keep identifiable information about you for 12 months after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information here:

<http://www.abdn.ac.uk/privacy>

University of Aberdeen will use your name and contact details to contact you about the research study and to oversee the quality of the study. Individuals from University of Aberdeen and regulatory organisations may look at your research records to check the accuracy of the research study. The only people in University of Aberdeen who will have access to information that identifies you will be people who need to contact you to administer the Delphi survey for the EVOLVE (Phase 3) study or audit the data collection process.

What will happen to the results of the study?

We will only use anonymised data for publications and study participants will not be identifiable in publications. Study results will be available via the Academic Urology website by late 2020: <https://www.abdn.ac.uk/iahs/research/urology/>

CONTACTS FOR STUDY

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