

Participant Information Sheet.

V1.0, 17th September 2021

Identifying Patient priorities for reseArch in global surgery through a qualitative exploratiON of patients' cAre experiences in low- and middle-income countries (PANDA)

Introduction

This Participant Information Sheet tells you about the PANDA research project. It explains the research and what taking part in the study will mean. Knowing what is involved will help you decide if you want to take part in the study.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Participation in this research is voluntary and it is your choice to agree to be a part of the study or not. If you do not wish to take part, you do not have to. If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent (agree) to take part in the research project
- Consent to the research that is described

You will be given a copy of this Participant Information and Consent Form to keep.

Background and purpose of this study

You are invited to take part in this research project because you have recently had surgery. Surgery is an important part of healthcare and worldwide, approximately 40% of illnesses, which can't be spread from person to person, require surgery. Over the past 10 years, there has been an increase in the research into how to make surgery safe, affordable, and effective.

Research is a very important part of surgery and the healthcare system, and it includes a varied group of people, not just healthcare workers like doctors and nurses. These people include policy-makers (all people involved in making decisions on how healthcare is provided to patients), governments, transport providers, businesses and, most importantly of all, patients like you.

One challenge has been making sure that patients voices are heard at the heart of research. Patients like you are the reason that health workers do research, to try and improve care and help you recover from your condition.

The PANDA study addresses this challenge. Through talking about patients' experiences and what is important to them at each stage of their surgical journey from diagnosis of their condition to recovery after surgery, we hope to understand what common priorities patients have for future research.

Larger studies can then be focussed on these common priorities and used to help to improve for other patients like you by changing the way healthcare is provided. This important information can then be compared between countries like South Africa (low- and middle-income country) and England (high-income country). By comparing the results, we can hope to design research to improve patients' surgical care wherever they are in the world.

In addition, taking part in this study could be important in helping to make the patients and the community more involved in healthcare and the surgical journey, for the benefits of the community in the future.

What would taking part involve?

After your surgery, one of the researchers will explain the study process to you and if you agree, to sign a consent form. You will then be asked a set of questions which will be audio-recorded and transcribed (copied word-by-word). The interview will either be done while you are still in hospital in the ward, in the out-patient clinic, or over the telephone. You will either be asked to answer a set of questions in a conversation with a member of the research team, or asked to complete a questionnaire on paper.

The questions you will be asked will include the whole time around when you had your surgery. This will be from the time you were told you needed surgery, your admission to the hospital, your time before and after your surgery and your recovery. The questions will be focused on what you considered to be both positive and negative about this time, and to give us reasons for your answers. You can decide in which language you would like to have the interview and we will provide a translator if needed.

Time commitment

The time commitment for you is low and only involves the interview to complete the questionnaire. We will also ask you if you are interested in the research process, and if we can contact you in the future to possibly be involved in the community. This is entirely voluntary.

Information to be collected, and stored confidentially

Only simple information about you, your operation, and how it affects you will be collected. This will include your name and contact telephone numbers, but you will only ever be viewed by your hospital 'patient number'. All information about you will be kept confidentially and securely at your local hospital. Information that is needed for the research will also be sent to the University of Birmingham (in England) which is coordinating this study first with the team in South Africa but is also looking to work with other countries in the future. This information will be stored securely for 5 years after the end of the study and will then be deleted.

Who is organising and funding the research?

The PANDA study is being coordinated by the University of Birmingham (England), which is also the sponsor/organiser for the study, the University of the Witwatersrand, Johannesburg (South Africa) and Groote Schuur Hospital/University of Cape Town, Cape Town (South Africa). PANDA is funded by the National Institute for Health Research (NIHR), which is also based in England.

Will I get paid to take part in this study?

If you agree to take part in the study and sign the consent form, you will be reimbursed for your time taken to complete the questionnaire. This will be costed at R100 per participant for their involvement in the study.

Can I be involved in future research?

We are looking for patients that would be interested in helping us as researchers to improve the way that we do research to ensure that all patients benefit. If you would like to be part of our 'patient involvement' group, you will have the opportunity to volunteer for this at the end of your interview/questionnaire. This would not involve you being the 'subject' of research (i.e., nothing being changed about your care) but helping us to improve the way that we perform research for other patients. We would be very grateful for your support.

Consent

It is up to you to whether you decide to join the study. If you agree to take part, we will ask you to sign (or fingerprint) a consent form. You are free to leave the study at any time, without giving a reason. Whether or not you take part in the study, if you wish to complain, or have any concerns

about any aspect of the way you have been treated during this study, you should ask to speak to your local lead researchers who will do their best to answer your questions (contact details are at the bottom of this form).

The UCT's Faculty of Health Sciences Human Research Ethics Committee can be contacted on 021 406 6338 in case you have any ethical concerns or questions about your rights or welfare as a participant in this research study.

Contact details

For any further information you may require, please contact:

1. Professor Bruce Biccard (021 4045004)
2. Mr Simphiwe Gumede (021 4045035)
3. Dr Margot Flint (021 4045144)
4. Dr Lina Hahnle (021 4045001)