

Establishing a reliable and sustainable blood donation and blood quality system to support the nationalization of manufacturing of plasma fractionation in the Kingdom of Saudi Arabia



You are being invited to take part in a Cardiff University research study. Before you decide 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 and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

Introduction

This study aims to explore knowledge, attitudes and practice (KAP) regarding blood donation among the general public and professionals in Saudi Arabia and Wales to identify the main barriers to voluntary blood donation. The government of the Kingdom of Saudi Arabia (KSA) has an ambition to establish a national plasma fractionation programme, but a secure donor base is a pre-requisite for any such programme. It is therefore important to understand the factors that encourage as well as discourage volunteer blood donation.

This study will compare the findings in the KSA system with that in Wales, a constituent Home Country of the United Kingdom with over 70 years' experience of a national voluntary non-remunerated blood donor base to determine any key factors that might explain the differences in the blood donation systems. This study is part of PhD project undertaken at Cardiff University School of Medicine and which will be conducted over 3 years.

Information will be gathered via several surveys using validated questionnaires which will be distributed randomly to health care professionals including blood bankers as well as professionals who frequently use blood products, such as surgeons and haematologists. The interview process with key personnel will provide opportunity for deeper understanding regarding blood transfusion practice. In addition to heads of hospital blood transfusion laboratories, the opinions of key personnel in the Welsh Blood Service, QA leads and consultants in charge, given that they are people who directly influence practice, will also be sought and will provide valuable insight into the likelihood of achieving compliance with industry standards.

Third parties may be enlisted to support the dissemination of the questionnaire through its contact list. These may include Healthwise Wales, Welsh blood services, and scientific societies.

Why am I being asked to take part?

You are being asked to take part because you are either a professional working in blood transfusion laboratory or blood transfusion service or are a key user of blood components and products. We need to know your views on blood donation since this will help us to understand why some people choose to become blood donors and why others do not.

What would taking part involve?

If you choose to take part in the study, you will be asked to answer either a multiple-choice questionnaire (clinician who prescribes blood components and scientists working in the blood transfusion field) or validated questions in a structured interview (leaders in blood transfusion, whether hospital or transfusion service based). It is

anticipated that it will take 15-20 minutes to complete the questionnaire and about 30-45 minutes for the interview. If you answer electronically your answers will be automatically uploaded. If you prefer using a paper questionnaire, either return in the Free Post envelope supplied or hand it back to the researcher. The interview may be recorded (with permission) to facilitate accuracy of transcription for study purposes only and will conform with the principles of confidentiality and anonymity within the study.

Do I have to take part?

No. Participation in the study is totally voluntary. You are not obliged to take part. If you do decide to take part then you would need to indicate your consent on the consent form which is part of the questionnaire and pre-interview preparation documents. You are free to withdraw your consent at any time, even if you have already signed the consent form. No identifiable data will be collected, and no personal data will be used when analysing the results of the study.

What are the benefits of taking part?

While there will be no direct benefit to you, it is hoped that information gathered from this study will inform the process of realising the goal of the Kingdom of Saudi Arabia in establishing a national plasma fractionation programme. It is possible that the results may also help other Gulf Cooperation Council (GCC) states by identifying ways to increase national voluntary blood donation and potentially to also improve the quality of their blood donation programmes. The Embassy of Saudi Arabia will fund this project for education purposes, and it will directly pay tuition fees and other related costs to Cardiff University to organize the project under supervision of academic staff.

What are the disadvantages and risks of taking part?

Aside from taking up some of your time (we anticipate that it should take 15-20 minutes to complete the questionnaire and 30-45 minutes for the interview), there are no risks associated with taking part in this study.

What if something goes wrong?

If you have a concern about any aspect of the study, please contact the student or their supervisors in the first instance (contact details can be found at the end of this Information Sheet). If you remain unhappy or wish to speak to someone independent of the study, then please contact Dr Amanda Tonks, director of postgraduate research, school of medicine (TonksAJ@cardiff.ac.uk)

What will happen if I don't want to continue with the study?

You can withdraw from the study at any time without giving a reason and can stop completing the questionnaire if you wish. However, any responses provided up until the point you chose to leave the study, will be kept for use in the final study analysis.

How will my information be kept confidential?

We will not collect any information that will identify you personally. We may use initials age and gender data to better understand differences (if any) between different age and gender groups.

How will Cardiff University use information about you?

This information we collect will include your:

- Age / Gender
- Ethnic group
- Country / region
- Education level

People supervising and assessing the research study will use the information collected to make sure that the research is being done properly and that the conclusions drawn are valid.

OPTION where applicable: People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

Participant Information Sheets [Professional]

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We will keep all information about you safely and securely. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. All collected data will be stored for 5 years.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.
- **OPTION if data will be used for future research:** If you agree to take part in this study, your answers and personal demographics (for example age and gender) may be used for future research without contacting you again. If you do not want your data to be used for future research, please indicate this in the relevant section of the consent form.

Where can I find out more about how my information is used?

You can find out more about how we use your information.

- by asking one of the research team
- by viewing the Cardiff University Data Protection Policy: <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>
- by sending an email or writing to the University's Data Protection Officer- inforequest@cardiff.ac.uk? Assurance Services, Cardiff University, Friary House, Greyfriars Road, Cardiff CF10

What will happen to the results of the study?

The results from the study will be written up as part of Amr Maqnas' PhD thesis. It is hoped that the study will also be published as academic papers in international scientific and medical journals and presented at conferences. The results may also be shared with the study funders and relevant parties in the Kingdom of Saudi Arabia. Only anonymised results will be shared, published and presented. No one will be able to identify you in the results.

Who has reviewed and funded this study?

Amr Maqnas, a student researcher, designed this study as part of his PhD research. Then it was reviewed by his supervisory team from Cardiff University's School of Social Sciences and School of Medicine, as well as an external supervisor from King Abdul-Aziz University in Saudi Arabia. Dr. Keith Wilson, a clinical senior lecturer at Cardiff University's School of Medicine, leads the team as the main supervisor and the chief investigator.

This study is funded by the Cultural Bureau of Saudi Arabia.

Study Team contacts

For further information please contact the researcher Amr Maqnas on (email: maqnasay@cardiff.ac.uk), or his supervisor Dr. Keith Wilson on (wilsonkm@cardiff.ac.uk)