

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR ONLINE SURVEYS/QUESTIONNAIRES

Notes for researchers (please delete these paragraphs before submitting your informed consent form to the HREC):

- *The structure/format of this information leaflet and consent form template is intended as a guideline only, for information that should be included in the information leaflet for potential participants in your online survey/questionnaire. Researchers may format, amend and/or shorten the form, provided that the required information is included in the letter to participants. Notes for researchers are included in italics below each heading and should be deleted once the relevant information has been inserted.*
- *If the online survey will be advertised by means of electronic communication (e.g. email), please submit the text to be included in the email that will be distributed to potential participants, together with this ethics application. It is advisable that the email contains an abbreviated version of the information included in this participant information leaflet and consent form.*
- *If the online survey will be advertised by means of electronic communication (e.g. email), it is the researcher's responsibility to ensure that individual participants do not have the option of replying to all, thereby revealing their identities and/or responses to the email group. It is strongly suggested that email addresses are included only in BC (blind copy) on email correspondence. Using Stellenbosch University's SURvey (<https://surveys.sun.ac.za/>) can facilitate such privacy and confidentiality safeguards.*
- *Please see Section 8 of our Health Research Ethics Committee (HREC) Standard Operating Procedures (SOPs) for more detailed information about requirements for Informed Consent (IC). You will find the SOPs here: <http://www.sun.ac.za/english/faculty/healthsciences/rdsd/Pages/Ethics/SOP.aspx>.*

TITLE OF RESEARCH PROJECT: *(Insert title of study here)*

We would like to invite you to take part in a research project which involves the completion of an online questionnaire. . [Kindly provide details: state who 'we' relates to, that is, whether you are a student registered at Stellenbosch University for a specific degree or part of a research team (names of the team members) and so forth.]

Your participation is **entirely voluntary** and you are free to decline to participate or to stop completing the questionnaire at any time, even if you have agreed to take part initially. However, once you have submitted your completed questionnaire online, you will no longer be able to withdraw your responses as there will be no way of linking your responses back to you.

This study aims to... / What is the study about?

- *Explain in participant-friendly language what your project aims to do and why you are doing it. Imagine having a conversation with one of your participants. Write in plain English and use the active form; avoid passives as far as possible. This applies to all text that you add to this form.*
- *Explain who the study is being conducted by.*
- *Explain how many participants you are expecting to recruit to participate in the survey, and all the sites they will be recruited from.*
- *Explain what sorts of questions participants will be asked in the survey/questionnaire.*

You are being asked to participate because.../ Why are you being asked to participate?

- *Explain this question clearly using the inclusion criteria outlined in your protocol.*

If you agree to participate you will be requested to.../ What will participating in the study entail?

- *Explain this question clearly – including the types of questions that participants will be asked and the approximate length of time it is expected to take them to complete.*

The potential benefits of this research are... / Will you benefit from taking part in this research?

- *Explain all benefits objectively. If there are no personal benefits then indicate that there are no direct benefits for participating and explain who would be likely to benefit from the findings of the research in the future, e.g. future patients.*
- *If there are rewards / incentives offered for completing the survey, explain this here. Also explain the implications for supplying their name / email and how this will be delinked from their survey responses.*

The potential risks involved in participating in this research are.../ Are there any risks involved in your taking part in this research?

- *Identify any risks objectively – particularly with respect to protecting participant confidentiality.*
- *Explain what will be done with their data and how this will be managed to protect participants' confidentiality (e.g. by anonymising or de-identifying the data), as well as any limits on confidentiality.*
- *Explain that participants should be aware that the online survey is not being run from a "secure" https server of the kind typically used to handle credit card transactions, so there is a small possibility that responses could be viewed by unauthorized third parties (e.g., computer hackers).*
- *Caution participants against revealing their identities by replying all on group email correspondence.*

Permission to have all anonymous data shared with journals:

When this study has been completed, the researcher(s) would like to publish results of the study in journals. Most journals require us to share your anonymous data with them before they publish the results. Therefore, we would like to obtain your permission to have your anonymous data shared with journals.

You can phone the Principal Investigator of this study, *[insert PI's name here]* at *[insert PI's telephone number and email address here]* if you have any questions about this study or encounter any problems.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University**. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that concerns you about how this study is being conducted, or if you have a complaint.

You will receive a copy of this information and consent form for you to keep safe.

- *There should be an option for participants to download the information leaflet and consent form. If it is not possible to provide a downloadable pdf document on the survey site, consider inserting a link to the document saved on Google drive, for example, or providing instructions for how to take a screen shot so that participants have the option of keeping a copy of the information provided on the survey front page.*

By clicking START SURVEY *(modify if the click to continue button is called something else, like NEXT)* you are confirming that you are:

- over 18 years old;
- have read and understood the above explanation about the study; and
- you agree to participate.

You also understand that your participation in this study is strictly voluntary.

- *PLEASE NOTE: If your study involves children, remove "are over years old and". This form is then only covering assent – the consent given by individuals under the age of 18 years. You will need to obtain written signed informed consent from a parent or legal guardian if your study participants are under the age of 18 years.*

Tick the Option you choose for anonymous data sharing with journals:

I agree to have my anonymous data shared with journals during publication of results of this study

☐

Signature_____

OR

I do not agree to have my anonymous data shared with journals during publication of results of this study

☐

Signature_____

Tick the Option you choose for storage and reuse of data for studies in the future:

I do not want information (data) to be stored for reuse for future studies

☐

Signature_____

OR

I hereby agree that my information (data) may be stored for future research in a field related to ...
[describe the field of your study, e.g., caregivers of persons with rare diseases etc.]

☐

Signature_____