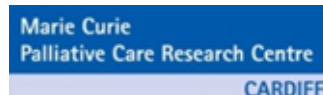


# Development of Guidelines for the communication of Research results to patients, members of the public, and other Stakeholder groups: The GIRASOL study



## Information sheet



You are being invited to take part in a research study. Before you decide, it is important for you to understand why this 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.

### What is the purpose of the study?

Publication of health research results is an important part of the research process. In the UK the agencies that fund health research require that researchers have a clear plan about how study findings are reported back to patients and members of the public. The aim of the study is to determine guidelines which will ensure that the way researchers communicate meets the other interested parties' expectations. These include patients, carers, other study participants and members of the public who might want to learn about health research findings. This project is funded by the Division of Population Medicine, Cardiff University, and it has received the ethical approval of the School of Medicine Research Ethics Committee, Cardiff University.

### Why have I been chosen?

This questionnaire has been sent to you because you are a member of the public who may be interested in finding out about the results of health research but has not previously taken part in a health research study. A similar questionnaire is being sent to researchers and people who have taken part in a health research study.

### Do I have to take part?

You do not have to take part in the survey if you do not wish to do so. If you decide to take part, you can still skip the questions you do not wish to answer.

If you decide not to take part, or to withdraw at any stage, you do not have to give a reason. If you decide to withdraw after having completed the survey, you may request for your answers to be removed from the study.

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

You are asked to fill in a questionnaire. The answers you provide will be combined with the answers from other members of the public and this will inform us as to how and when members of the public would prefer to find out about health research findings. This information will then be compared to the answers provided by study participants and researchers.

### What about confidentiality?

Any personal information collected in the survey will be kept strictly confidential. All survey responses will be fully anonymised so that they cannot be connected with any particular person. The data will be kept securely for 15 years after the study is completed in line with Cardiff University and Cardiff and Vale University Health Board policies and the General Data Protection

Regulation (GDPR; EU 2016/679). For more information on data protection, please follow the link <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32016R0679&from=EN>.

### **What do I have to do?**

The survey questionnaire is available online or in paper version and can be completed at your convenience. It will take approximately 10 minutes to complete. If you wish us to provide you with a paper version, please contact Mirella Longo (details given below). You can also contact Mirella to request a Welsh language version of this survey (online or paper).

If you do not want to take part in the study, then you do not need to do anything further. Thank you for taking the time to read this information.

### **Are there any risks?**

We do not anticipate that taking part in this study will cause you any harm. If you have a concern about any aspect of this study, please contact Mirella Longo who will do her best to answer your questions (Phone: 02920 687 476; email: [longom1@cardiff.ac.uk](mailto:longom1@cardiff.ac.uk)).

If you are unhappy and wish to make a complaint, you can contact Annmarie Nelson or Anthony Byrne on 02920 687 175 or alternatively email them on [mariecuriecentre@cardiff.ac.uk](mailto:mariecuriecentre@cardiff.ac.uk).

### **What will happen to the results of the research study?**

The results of this study will be presented at academic meetings and published in academic journals. Where possible, summary reports and publications will be made available on Cardiff University website and other relevant websites. At the end of the questionnaire we will ask if you would like to receive a copy of the summary of the study results. If you would like to receive a copy of these, please complete the question by providing your email or postal address.

### **Who is organising and funding the research?**

This study is funded by the Division of Population Medicine, Cardiff University.

### **Contact for Further Information**

If you have any questions about the study, please contact:

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## **PLEASE FOLLOW THE LINK BELOW TO ANSWER TO THE ONLINE SURVEY:**

[https://cardiff.onlinesurveys.ac.uk/girasol-survey\\_general-public](https://cardiff.onlinesurveys.ac.uk/girasol-survey_general-public)