A picture containing graphical user interface

Description automatically generated

**Participant information sheet**

The lived experience of people affected by cancer: A global cross-sectional survey

**Introduction**

We would like to invite you to participate in a research study to better understand the lived experience of people affected by cancer around the world.

**What is the purpose of this research?**

This study will help us learn about the emotional, social, and financial experiences of people affected by cancer around the world. This information is important to define ways that Governments and professionals can better support people affected by cancer.

**Who can participate?**

* Anyone who is 18 years old or older and has/had cancer as a child or as an adult

OR

* Anyone who is a family member of a person who has/has had cancer (including if you have lost a family member to cancer)

**What does it involve?**

* Completion of an anonymous, voluntary online survey (no personal identifiers such as your name or address will be collected)
* The survey should take approximately 30 minutes to complete

**What is the survey about?**

The survey will ask questions about your quality of life, your physical and mental health, your current access to health care, the social supports around you, your financial well-being, and the impact that cancer has had on your life. You can skip any question you are uncomfortable answering, or do not prefer to answer.

**Are there any risks?**

We do not foresee any significant risks. If any questions cause you distress, please reach out to a local organization in your country that can support you, or to our research team at [whocancer@unsw.edu.au](mailto:whocancer@unsw.edu.au).

**Are there any benefits?**

You will not receive any compensation or remuneration for participating in this study. You may not experience direct benefits from participating in this survey. However, we are hoping this study will benefit people affected by cancer worldwide by improving policies and healthcare practices.

**How will the results be shared?**

The information collected through this survey is anonymous and cannot be linked to you. The information will be securely stored through the World Health Organization's DataForm platform, which will only be accessed by the WHO project team. We will share the results of this study through the WHO website and through a webinar that will be announced through the WHO website and local organizations involved in cancer care and survivorship. De-identified research results will also be shared through publications and conferences.

This research study has been reviewed by the WHO Research Ethics Committee, which is a committee whose task is to ensure that research participants are protected from harm.

If you have any questions about this survey, please contact our team at [whocancer@unsw.edu.au](mailto:whocancer@unsw.edu.au).

A qr code with a white background

Description automatically generated