

Research Participant Information Sheet

Defining meaningful scientific engagement and identifying areas of Health and Wellbeing with the greatest community interest: Survey

Project overview

The concept of engaging members of the public in science is commonly referred to as “Citizen Science” and has been utilised for many years in environmental studies, such as observing plants and wildlife. It has rarely been used in the Health and Wellbeing space. Execution of collaborative science projects can be applied to many different methodologies, ranging from simply answering a survey to working with scientists to analyse data or write scientific reports. This project aims to start the discussion with the community about what collaborative science could look like in the Health and Wellbeing space.

From this project we hope to understand your views on citizen science, factors that would incentivise and deter you from participating in this process, and which areas of health and wellbeing you believe should be prioritized.

What does participation involve?

Participation in this study will involve taking part in an online survey hosted on Qualtrics. The survey will cover the following topics:

1. Your understanding of citizen science and its terminology
2. Your motivators and barriers to volunteering in science
3. Your priorities relating to health and wellbeing research

We will also gather some demographic information about the people who participate in the study (e.g. gender, occupation). Your raw data will be retained by CSIRO until they are collated and analysed and then deleted. The final dataset will be stored at CSIRO on its servers for 5 years and then deleted.

Risks and benefits

Aside from giving up your time, there are no foreseeable risks associated with participating in this study. Whilst your participation in this project may not benefit you directly, your participation will increase our understanding of how to develop citizen science in the health and wellbeing space.

There will be some questions about topics in health and wellbeing that you are interested in learning more about. If you have experienced challenges in these areas recently, discussing these may cause upset. The purpose of this study is not to hear more about your specific experience, but what topics people could learn more about. If you feel this is a risk for you, it may not in your best interest to be involved.

Withdrawal from the research project

Participation in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at CSIRO. If any topic is you prefer not to answer, you can stop the survey by navigating away. Your data up to this point will not be able to be removed because there will be no way of linking it to you.

Confidentiality

All information provided by you will be treated confidentially. Any individual personal information will not be included in any publications resulting from the study. All data collected in this study will be reported in such a

way that responses will not be able to be linked to any individuals. De-identified, non-sensitive data collected by the project may be shared with other researchers for the purposes of verifying published results or advancing other research on this topic.

How will my information be used and how will my privacy be protected?

Your personal information is protected by the *Privacy Act 1988* (Cth) (Privacy Act) and CSIRO will handle your personal information in accordance with this Act. You are able to participate in this survey anonymously, which means that your personal information will not be collected (the survey contains some mandatory demographic information, which will aid high level analysis of the results. Given the sample size and virtual nature of this survey, CSIRO is confident no one will be able to identify an individual respondent).

Your personal information (in particular, your email address) will be collected if you wish to be considered in the prize draw which is open to survey respondents. These email addresses will not be connected in anyway with your survey response. You may complete the survey without providing your email address, but you will not be entered into the prize draw. You may use an email address that does not identify you by name.

Your email address will not be stored by CSIRO beyond the conclusion of the prize draw and will not be used for any purpose other than conducting the prize draw and contacting winners. CSIRO is providing other options to join a mailing list if you wish to remain informed about research and developments in this field.

Your email address will not be disclosed overseas or to any third party. CSIRO will be using Qualtrics to conduct this survey. Qualtrics will only use Australian-based servers and is contractually committed to complying with the Australian Privacy Principles.

It is anticipated that aggregated survey results will be published and/or presented in a variety of forums. This includes the production of a general report on community perspectives about citizen science as well as scientific journal publications and conference presentations. De-identified information collected through the surveys may also be shared with other researchers for the purposes of verifying published results or future research. Sharing of this information may include putting it in data repositories where anyone can easily access it. We will ensure this information cannot be linked to you before it is published or shared.

For further information on how CSIRO handles your personal information and our access, correction and complaints process, please read our [Privacy Policy](#) available on our website or by contacting us at privacy@csiro.au.

Ethics clearance and contacts

This study has been approved by CSIRO's Low Risk Human Research Ethics Committee in accordance with the National Statement on Ethical Conduct in Human Research 2007 (Updated 2018).

This study has been approved by the CSIRO Low Risk Review Panel. If you would like to speak with someone with respect to ethical matters or wish to register a formal complaint about the conduct of this research, please contact the Secretary of the Committee via email at chmhrec@csiro.au.

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Thank you for taking the time to help with this research project.

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and innovation catalyst, CSIRO is solving
the greatest challenges through
innovative science and technology.**

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