Neurofibromatosis Health and Social Impact Assessment
Survey Participant Information Sheet

Neurofibromatosis Health and Social Impact Assessment

The Children's Tumour Foundation (CTF) is undertaking a health and social impact assessment of Neurofibromatosis (NF).

The purpose of the study is to understand the lived experience of Australians living with or impacted by NF, identifying gaps and priorities in healthcare, wellbeing, and social supports, while also providing an evidence base of lived experience. A survey and stakeholder consultations will inform the study.

To help determine the impacts of NF, the CTF has engaged PricewaterhouseCoopers (PwC) to conduct this study.

Survey

As part of the assessment, we are conducting a survey to understand the impact of NF on the NF community.

The survey will give you the opportunity to provide your feedback, experience, and perspective on living with NF and accessing medical care and support.

The survey results will seek to illustrate to government, policy makers and industry the impact of NF.

Completing the survey

The questions will take about 30 minutes to complete. If you are unable to complete the survey in one sitting, you can save your progress and return to the survey.

We are not collecting any personal identifying data. Your responses are anonymous.

Completion of this survey is entirely voluntary. You can choose to stop completing the survey at any time. You can choose to not respond to particular questions.

If you choose to participate in the survey, **please complete it by 11:45pm AEST Friday 19 April 2024.**

Eligibility

You need to be over 18 years of age to be eligible to complete the survey.

Consent

Your consent is required to complete the survey. You can provide your consent by clicking on the consent button in the survey link.

What are the benefits of participating?

The survey provides you with an opportunity to have your voice and experience heard and accounted for in future advocacy and policy. This study will hope to build an evidence base around NF and its impacts. It will seek to raise awareness of the condition and the need for greater system support.

What are the risks of participating?

The survey includes questions about your experience with NF, including questions on diagnosis, care and management of NF, and the mental health physical impacts you have experienced.

We acknowledge that filling out the survey may cause distress for some people. Your participation in the survey is voluntary. You are free to choose not to answer any of the questions. You can stop participating in the survey at any time.

If you experience any distress when answering these questions and wish to discuss any issues it may raise for you, please contact the Children's Tumour Foundation on (02) 9713 6111.

You can also ring or chat online with Lifeline at 13 11 14 or https://lifeline.org.au/.

Privacy

Throughout the entirety of this project all data will be housed on secure servers, where responses will be downloaded into an excel format without any identifying data. This data will only be accessible by the research team.

Your survey responses will be combined with those of other participants when being considered, and as such, will collectively inform the report.

You will not be identified in any way in the report.

Given the privacy protections and anonymity, no one will know if you have participated and what you answered.

A privacy statement approved by Bellberry Limited, a Human Research Ethic Committee, is included on the final page of this sheet.

Analysis

The data analysis of this research will seek to meet the study objectives through an assessment of four key impact categories:

- **Direct impacts:** what is the direct health system medical and non-healthcare costs due to NF diagnosis and management?
- **Indirect impacts:** how does NF impact the productivity of people with NF and their families and care givers?
- **Individual health and wellbeing impacts:** how does NF impact the daily function (including physical, social, emotional, and work impacts) of people with NF and their families and care givers?
- **Health system impacts:** what are the current state-based barriers to accessing medical care and treatment for NF? What needs to be improved to enable a better experience for people with NF and their families and caregivers?

Analysis of data across these four impact areas will be reported as key themes, across all survey and consultation responses.

Who can you contact if you want to ask any questions regarding the survey?

If you have any questions regarding this survey, please contact the Children's Tumour Foundation at: support@ctf.org.au or 02 9713 6111.

Thank you for your cooperation and we look forward to receiving your feedback.

The Bellberry Human Research Ethics Committee has reviewed and approved this study in accordance with the National Statement on Ethical Conduct in Human Research (2023).

This Statement has been developed to protect the interests of people who agree to participate in human research studies.

Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Director of HREC Operations, Bellberry Limited on 08 8361 3222

If, as a result of your participation in this study, you feel discomfort, immediately advise your clinician and seek medical help. Any question about compensation should be directed to the CTF who should advise their insurer of the matter.

It is the recommendation of the independent ethics committee responsible for the review of this study/investigation that you seek independent legal advice before taking any steps towards compensation for injury.

STANDARD PRIVACY STATEMENT BY BELLBERRY

The study will gather certain personal information about you. This information will be held by PwC and its authorised representatives and will be non-identifiable.

Your data will be stored on PwC servers for a period of seven years and will be accessed by only the PwC research team. At the end of this storage period your data will be deleted.

Your treating doctor/s will be notified of your participation in this study and the exchange of clinically relevant information noted by the trial doctor in the conduct of the trial will occur.

Unless required by law, only your doctor, the study team, the Sponsor and its authorised representatives, the Therapeutic Goods Administration (TGA), health authorities from other countries where the study drug may be considered for approval (or already approved) and the Bellberry Human Research Ethics Committee will have access to data which identifies you by name or from which your identity is otherwise apparent or can be reasonably ascertained.

The Children's Tumour Foundation of Australia is sponsoring this study.

All personal information will be used only for the purpose of administering your participation in this study and in accordance with the laws governing the protection and privacy of personal information under Australian privacy legislation.

Participants should note that, some data from your participation in this study will be sent overseas or shared with persons outside Australia. The regulatory regimes governing data access and use in other countries may not be the same as those that are in place in Australia.

In the case of data that identifies you, or from which your identity may be ascertained, a person or organisation subject to Australian privacy laws that has collected your information must take reasonable steps to ensure that an overseas recipient handles the information in accordance with any relevant Australian privacy principle (unless an exemption applies). If you have any questions about this, direct them to the Principal Investigator.

By providing your consent through the survey, you authorise the release of/or access to this confidential information to the relevant study personnel and regulatory authorities as noted above.

In most cases, you have the right to access personal information collected from you in connection with the study and request corrections of any such personal information that is incorrect.