

Youth Cystic Fibrosis Workshop

We would like to invite young people (aged 13-25) living with cystic fibrosis (CF) to participate in a research project being undertaken at the Telethon Kids Institute.

We want to know what health outcomes matter most to you as a young person living with CF. This is important to make sure we ask meaningful research questions in this upcoming CF study that we hope will improve outcomes for patients and their families.



9th April 2019



1630 AWST



Via dial-in teleconference

Dial-in details will be provided closer to the date



For more information or to register your interest, please
email: charlie.mcleod@health.wa.gov.au or contact
Charlie McLeod M: 0428 899 886

WHAT IS THIS STUDY ABOUT?



We would like to invite you to participate in a workshop where we will be discussing what matters to you as a young person living with CF. This information will be useful for doctors and health workers in determining the best research questions to ask and to work out how healthcare should be delivered.

HOW DO YOU THINK WE CAN IMPROVE YOUR MEDICAL CARE?

Your participation in this workshop will help us work out the best research questions to ask in an upcoming clinical CF trial. We hope this research will contribute to improving outcomes for patients living with CF and their families.

Participation in this workshop is voluntary and your identity will be protected if you choose to take part.

This research project is being conducted across multiple sites including Telethon Kids Institute, Perth Children's Hospital and Sir Charles Gairdner Hospital.



Dr Tom Snelling

(Infectious Diseases Physician and Scientific Lead at Telethon Kids Institute)



Dr Charlie McLeod

(Infectious Diseases Physician and PhD Candidate)



Dr Steve Webb

(ICU Physician and Researcher at St John of God Subiaco Hospital)



Mr Jamie Wood

(Senior Physiotherapist at Sir Charles Gairdner Hospital)



Ms Kate Spaapen

(Consumer advocate)



Mr Mitch Messer

(Consumer Advocate)



Dr André Schultz

(CF Respiratory Physician at Perth Children's Hospital)



Dr Richard Norman

(Health Economist at Curtin University)



Dr Siobhain Mulrennan

(CF Respiratory Physician at Sir Charles Gairdner Hospital)