

# Embracing diversity in engaging the community in clinical trials with **ConViCTioN**

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On behalf of Consumer Voices in Clinical Trials in NSW<sup>1</sup>

## BACKGROUND

Clinical trials provide essential evidence for effective and sometimes lifesaving therapies that improve healthcare. Generalisability of results from clinical trials is often qualified by the lack of diversity among trial participants. Achieving greater inclusivity in trials and other health research requires greater engagement with the people served by health services and research.

## OBJECTIVES

To engage with consumers to identify strategies and approaches that help raise clinical trial awareness and participation including under-represented communities such as Culturally and Linguistically Diverse (CALD) and First Nations peoples, and people with disabilities.

## METHOD

Following an open call for expressions of interest, 15 people were invited to join a consumer group. Members represented communities from metropolitan, regional, and rural NSW, and included people with CALD and Indigenous backgrounds, and different health conditions. Within the first 3 meetings, the group (supported by a project team) established: terms of reference; communication and reimbursement plans; election of co-chairs; and agreement on the name: Consumer Voices in Clinical Trials in NSW (ConViCTioN). Consumer members completed fact-finding exercises about clinical trials to identify gaps in consumer knowledge and proposed resources that could be developed given associated budget and time constraints.

## RESULTS

Conversations with ConViCTioN members' diverse networks found general understanding of clinical trials ranged from low to moderate. Online searches identified websites that explained clinical trial processes but finding trials to participate in was time-consuming and difficult. Existing registers were challenging to navigate, used language aimed at researchers, and did not account for cultural differences. ConViCTioN agreed to develop *three resources for consumers by consumers*: a video, an infographic poster, and a checklist for those interested in clinical trials. These were developed to be inclusive and improve health literacy: the video incorporated CALD, First Nations, and other community members in a yarning circle to discuss trials; the infographic and checklist allowed for those with visual impairments and used simple, easily translatable language.



## CONCLUSION

Engagement with diverse consumers has led to the development of resources about clinical trials that are accessible and appropriate for diverse communities. Genuine partnerships with consumers lead to real impact – *nothing about us without us*.



Access resources at:



[Clinicaltrials-consumervoices.com.au](https://Clinicaltrials-consumervoices.com.au)

Ask your doctor about clinical trials, and learn more at [clinicaltrials-consumervoices.com.au](https://clinicaltrials-consumervoices.com.au)



A collaborative, consumer-led project supported by:



With thanks to funding from the NSW Government's Office of Health and Medical Research