Consumer and Community Involvement in Clinical Trials: Webinar 2: Consumers involved in clinical trial planning, development and design

24th May 2022, 11am-12.30pm (AEDT)

Post webinar notes

- Consumers* bring a different type of expertise, including lived experience of a health condition which compliments the expertise of scientific and clinical leaders
- One size does not fit all; important to try to make sure the "consumer" member/representative is able to contribute where they are able to provide the most appropriate feedback according to their skills and commitment
- A “consumer advocate” is different from someone who is a patient or trial participant. An advocate has often undergone advocacy training and aims to represent the broad views and experiences of a range of people affected by a common health condition
- Consumers add value to research in many ways; some consumers have benefited from media engagement; some have given presentations to researchers on their lived experience and what research means to them; describing their challenges can help researchers identify problems that need to be solved
- Importance of keeping a focus on increasing diversity, including regional and remote access to clinical trials to support Indigenous and other under-represented patient groups
- Importance of including consumers at all levels of a project or an organisation, have consumers involved from the very beginning to provide input into the design of a study
- Consumers and researchers can be engaged in all three stages of getting a medical innovation into the community: (1) Discovery, (2) Clinical trials, and (3) Clinical practice
- About 33-50 % of clinical trials are industry-sponsored; companies are increasingly developing trial protocols in consultation with consumers/patients and clinicians
- Many companies have public commitments to patients/consumers, publish factsheets/scorecards on these commitments (including improving diversity in clinical trials), and provide plain language clinical trial summaries
- Can be helpful to provide consumers with a key contact person or “buddy” from within the research team; this should be a ‘people person’ who has time to offer if needed
- Commitment of researchers and clinician leaders is vital
- Develop policies/practice that integrate consumer perspectives/priorities into the selection of research projects, give equal weight to the views of consumers
- Communicating in non-scientific language is beneficial for everyone (i.e., through lay summaries), develop the lay summary in the early stages of the project and place it at the front of the project/grant document
- Consumers need to be “looked after”/kept informed from start to finish
- Provide support and education for consumers, including face to face training, if possible
- Consumers with training in research are well positioned to contribute to discussions from a community perspective
- Some trials extend over a long period; need to sustain relationship with consumer; when a trial starts there may be a lot of initial then very little for extended periods
- Also consider that consumers with lived experience may find hospital environments difficult depending on their past experiences

- Include a consumer consultant role in the research project budget from the onset; move away from the idea that consumer roles are volunteer roles
- Consumers should not have to cover 'out-of-pocket' expenses when contributing to research, especially if the trial runs for a period of years and they have a distance to travel
- Wider family and community involvement can promote clinical trials to others and contribute to public donations, etc.

Link to the webinar recording: https://vimeo.com/713553594

* The term "Consumer" is somewhat contested; best to check with individuals; another option could be 'contributor'