



Consumers Health
Forum **OF** Australia

Research & Data: Special Interest Group

General purpose and operation of the group

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Consumers Health Forum of Australia (2019)
*General purpose and operation of the Research
and Data Special Interest Group.* Canberra,
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Background

Consumers Health Forum

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, support by accessible health information and systems.

CHF does this by:

1. advocating for appropriate and equitable healthcare
2. undertaking consumer-based research and developing a strong consumer knowledge base
3. identifying key issues in safety and quality of health services for consumers
4. raising the health literacy of consumers, health professionals and stakeholders
5. providing a strong national voice for health consumers and supporting consumer participation in health policy and program decision making.

CHF has previously had various special interest groups (SIGs) operating at different times. These are informal networks of consumers who have self-selected to work more intensively on policy issues. Each SIG is intended to be informal and therefore CHF believe a 'term of reference' document is not appropriate to outline the purpose and activities of these SIGs. As such, this document has been developed to outline the general purpose and operation of the Research and Data SIG.

CHF research agenda: consumer-led research, consumer-focused data

How and why consumers can be involved in research is a growing area of interest for CHF. We are conducting more research projects of our own which we would like to do with greater consumer involvement. We are interested in shaping the national policy discussion about how consumer involvement in research is resourced and where it is placed, improving the confidence and skills of the research community in patient and public participation, ensuring that data collected through research is beneficial to consumers and supporting consumers to become more involved in research.

While the CHF has only recently begun to be more proactive in the research space, we have led or been involved in a range of project including, but not limited to:

- **Australia's Health Panel (AHP)**
 - CHF has started the Australia's Health Panel program with the intention to proactively and regularly 'take the pulse' of consumer experiences and opinions on topical healthcare issues.
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- **Australia Clinical Trials Alliance (ACTA)**
 - CHF is a member of the *ACTA Reference Group E: Consumer Involvement*, intended to increase consumer awareness and involvement with clinical trial research in Australia.
- **Australian Alliance for Artificial Intelligence in Healthcare:**
 - CHF is a member of the *Consumer Flagship Working Group*, intended to ensure that consumer perspectives and requirements are considered when AI tools are considered for use in the Australian healthcare system.

- **Australian Bureau of Statistics Health Statistics Advisory Group (HSAG):**
 - CHF is a member of the ABS HSAG, which supports the ABS in maintaining the collection of official, timely, quality and relevant health data.
- **Consumer Sentiment Survey**
 - CHF partnered with the National Health and Medical Research Council's Health System Sustainability Partnership Centre to develop and pilot a survey to measure current consumer sentiments of, usage of and experiences with the Australian healthcare system. Having demonstrated proof of concept it is our intention that this become a survey we conduct at regular intervals.
- **Patient Activation Measure Survey**
 - CHF developed and ran a research survey investigating the levels of 'Patient Activation' in Australians with chronic illnesses.
- **Social Prescribing Survey**
 - A research survey run in partnership with the Royal Australian College of General Practitioners to gather consumer views and experiences on the merits and use of 'social prescribing' in Australia.
- **Mental Health Lived Experience Survey**
 - A research survey run in partnership with the National Rural Health Alliance to gather consumer ideas, perspectives and lived experiences to develop our submission to the Productivity Commission inquiry into mental health in Australia.
- **AIHW National Primary Healthcare Data Asset project and AIHW-led National Health Information Strategy**
 - CHF developed and ran focus group research to understand consumer views and opinions on the proposal for the AIHW to develop a 'Data Asset' of consumer national primary healthcare data.
 - CHF's CEO is a member of an Independent Expert Panel developing a National Health Information Strategy for the consideration of COAG Australian Health Ministers in late 2020. There will be a public consultation phase to which SIG input would be valuable.
- **Consumers in their Health Data Journey project**
 - CHF and NPS MedicineWise collaborated on a research project about consumers' attitudes to data. This included a literature review, exploratory interviews with consumers, a nationally representative survey of consumers and a leadership roundtable.

Purpose of the Research and Data SIG

To date the research projects, activities and policy of the CHF have been led and developed by CHF Staff and staff of organisations the CHF has partnered with. However, as the CHF is a strong supporter of consumers shaping health and having meaningful engagement in all areas of the healthcare system, we want to directly involve consumers in our research program.

With the group established, we hope to have consumers involved in both 'reactive' research and data projects that external groups bring to the CHF and 'proactive' research on CHF initiated topics as determined by both CHF and consumers that align with our priority areas and objectives.

Consumer participants in the Research and Data SIG will identify what in health research matters to consumers, where improvement can be made and contribute to the cultural changes needed among researchers, academics, analysts, policy makers and the wider research and data community that are needed for sustainable improvements in consumer involvement in research. Through this group, CHF hope to provide a space for those interested in healthcare research and data to share information, communicate perspectives and workshop ideas to enact change.

Other opportunities may arise that align with the areas of focus and will be promoted to the group when appropriate.

Operation of the Research and Data SIG

The Research and Data SIG has the capacity to influence CHF research activities, with final decisions remaining with the CHF Board and CHF staff. Resourcing and support for the group will be determined by the CEO.

What will be the focus of the group?

There will initially be three areas of focus;

- A) Australia's Health Panel (AHP):
 - o CHF has started the Australia's Health Panel program with the intention to proactively and regularly 'take the pulse' of consumer experiences and opinions on healthcare topics. The Research and Data SIG will be involved in identifying potential areas for the AHP to investigate and co-designing relevant survey tools for selected topics.
- B) CHF Research Program:
 - o CHF has in recent years begun to conduct in-depth research studies as a primary investigator, often in partnership with other organisations, to get quality healthcare research in the Australian context that can inform our policy position. The Research and Data SIG will, where possible, be involved in the design of these research studies to help ensure that data of importance and relevance to consumer interests are being obtained.
- C) External Research Activities:
 - o CHF is often asked by other healthcare organisations to provide input into research and data activities. The Research and Data SIG will, where possible, be

involved in the design of these research studies to help ensure that data of importance and relevance to consumer interests are being obtained.

In the more medium to longer-term CHF also has an interest in supporting skills development in the research community to enable them to identify and promote best practice, implement effective engagement strategies as well as in promoting research literacy among the consumer community. We are in early discussions with organisations such as the Australian Research Health Alliance which represents the national network of NHMRC Advanced Translation Centres and the Population Health Research Network on options for collaboration on such a capacity building agenda and the practical actions it could involve, and would be keen to seek SIG advice in this regard.

Co-Facilitators

The Research and Data SIG will be co-facilitated by a CHF staff member and a consumer. The consumer co-facilitator will be selected by the members of the Research and Data SIG. This process will be coordinated by the CHF co-facilitator.

What will their role involve?

The co-facilitators will work closely to:

- finalise the Agenda Items for each meeting;
- facilitate discussion during meetings;
- document outcomes of each meeting, including any actions arising;
- distribute meeting documents / Agenda papers and other relevant documents, to members in a timely manner; and
- keep SharePoint updated and monitor group discussions.

Members

This SIG is open to all consumers and consumer representatives with an interest in health research. The maximum number of people within the group at any time will be 25. This number includes the co-facilitators. This cap helps keep the group manageable while assuring diversity.

People can choose to leave the group if they no longer have the capacity. An email should be sent to the co-facilitators of the group to advise them of your withdrawal. This will not influence your relationship with CHF.

What contribution is expected from members?

Members of the Research and Data SIG are expected to participate actively in SIG teleconference meetings, which are initially expected to be held approximately bi-monthly (six per year) during business hours. This will include reading circulated papers before the meetings and sharing their relevant information, opinions or expertise to help prepare for meetings.

They may also be asked to assist in the design of research activities or provide feedback to proposed research activity protocols 'out of session' to then be discussed as required at the SIG meetings. This may require members to agree to confidentiality requirements stipulated by CHF's research and partner organisations.

An online forum, SharePoint, will be established for members to engage in friendly discussion, share information and ideas between meetings. Members are expected to treat each other with respect and listen to each other.

Reporting

- A draft agenda will be distributed to members two weeks prior to a meeting inviting suggestions for additional agenda topics.
- A copy of the final agenda and all papers to be discussed will be distributed to all members at least one week prior to a meeting.
- A draft document highlighting outcomes of meeting, including actions arising will be distributed to attendees of a meeting within one week of a meeting.
- Other documents or activities members may work on may have reporting requirements specific to those documents and activities.