

# Developing a Knowledge Hub for Consumer and Community Involvement.

A national Knowledge Hub for Consumer and Community  
Involvement in research and healthcare improvement  
November 2021



## Project Leads

### **About AHRA**

The [Australian Health Research Alliance](#) (AHRA) is the voice of seven Advanced Health Research and Translation Centres and three Centres for Innovation in Regional Health – all accredited by the National Health and Medical Research Council.

Each Centre is a partnership of multiple health services, connected to research centres and universities. Collectively AHRA's members encompass more than 90% of researchers and 80% of acute healthcare services across Australia.

AHRA is uniquely positioned to address unmet needs in healthcare by helping researchers work with healthcare providers and consumers to deliver evidence-based care that offers better outcomes, best value and equity of provision.

### **Acknowledgement of Country**

The Australian Health Research Alliance (AHRA), together with its member Centres, acknowledges the Aboriginal and Torres State Islander nations of Australia as the traditional owners of our country. We pay respect to ancestors and Elders past, present and emerging.

### **Citation**

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**Corresponding Author:** Dr Angela Jones – [Angela.a.jones@monash.edu](mailto:Angela.a.jones@monash.edu)

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# Executive Summary

Strengthening consumer and community involvement (CCI) in health and medical research and healthcare improvement is a priority for the Australian Health Research Alliance (AHRA), encompassing the ten NHMRC-accredited Advanced Health Research Translation Centres and Centres for Innovation in Regional Health.

In 2018, a set of recommended priority actions to strengthen consumer and community involvement was established through a multi-step process, including: an environmental scan of relevant literature and the work of leading international and national agencies; an Australia-wide survey to capture the extent and nature of consumer and community involvement across AHRA member organisations; a national workshop to review the findings from the environmental scan and survey and develop a program of work.

A priority action identified through this process was that AHRA facilitates sharing of existing resources and expertise to support consumer and community involvement in translational research, with consideration given to utilising existing websites and similar clearing houses to avoid duplication. During further discussion and consultation, the term Knowledge Hub emerged to describe an accessible online place where CCI resources and expertise could be hosted. The recommendation is the basis for the body of work described in this report.

The aim of the National Knowledge Hub for Consumer and Community Involvement project was to explore the needs of consumers, clinicians, researchers and health service managers regarding CCI training and resources and access to these, and to use this information to develop a model for a national platform to meet these needs.

This work was led by Monash Partners Academic Health Science Centre (Monash Partners) and Maridula Budyari Gumal – Sydney Health Partnership for Health, Education and Research (SPHERE) and included the participation of 341 researchers, health professionals, managers and consumers across surveys, workshops and meetings.

A dedicated Project Team – Dr Darshini Ayton, Monash Partners Fellow; Sarah Carmody, Project Manager and Dr Angela Jones, Monash Partners Chief Operating Officer led the design, planning and implementation of the project.

The project was supported by Ms Ainslie Cahill, Leader, Consumer and Community Involvement and Engagement, Maridulu Budyari Gumal.

The project consisted of four phases:

- A rapid review of the academic literature to identify articles describing consumer and community involvement knowledge hubs and knowledge hub websites.
- A national online survey to identify and prioritise resources and features to include in the knowledge hub.
- A series of co-design workshop activities to explore and refine the information and priorities from the survey.
- Consultation workshops to obtain stakeholder feedback on proposed knowledge hub features and functions synthesised from co-design workshops.

The co-design process revealed that researchers, health professionals and consumers want CCI resources translated into everyday practice and to learn from each other. Stakeholders stated that the CCI hub needed to be practical, engaging and easy to access, and to link and connect people. The hub should facilitate access to high quality information, resources and training. To reflect the practical and translation focused priority arising from the workshops, it is recommended the hub be called a CCI 'Knowledge and Practice Hub'.

The Hub's priority features include an engaging, easy to use and time-efficient design, clear benchmarks for the resources and training included in the Hub, and a leadership and governance group to drive it.



This project found that researchers, health professionals and consumers are looking for CCI resources, translated into everyday practice, and also for opportunities to connect and learn from each other.





# Background and Overview



The Australian Health Research Alliance (AHRA) facilitates the integration of healthcare, health and medical research, and health professional education to deliver better health outcomes for all Australians.

As a national alliance of ten NHMRC-accredited Advanced Health Research Translation Centres and Centres for Innovation in Regional Health, AHRA brings acute health services, community health services, primary care, research institutes, universities and government together to translate research into best practice to improve patient care and health outcomes for the community.

The AHRA member centres are:

- Brisbane Diamantina Health Partners
- Central Australia Academic Health Science Network
- Health Translation SA
- Maridula Budyari Gumal – Sydney Health Partnership for Health, Education and Research (SPHERE)
- NSW Regional Health Partners
- Melbourne Academic Centre for Health
- Monash Partners Academic Health Science Centre
- Sydney Health Partners
- Tropical Australian Academic Health Centre
- Western Australian Health Translation Network.

The Centres are working on a wide range of projects locally as well as working together nationally to improve key areas of the health system and to develop Australia-wide research networks. These activities are funded by the Australian Government's

Medical Research Future Fund (MRFF) and align with national and government priorities.

Strengthening consumer and community involvement (CCI) in health and medical research is a priority for AHRA and the Research Translation Centres. Involvement of communities, consumers, patients, families and carers, ensures solutions are based on knowledge and understanding of the specific challenges they face. CCI is about researchers working in partnership with consumers and community members throughout the research cycle. This ensures that community members are actively involved in developing potential research questions as well as advising on research priorities, practices and policies (National Health and Medical Research Council, 2016).

Research by AHRA in 2018 demonstrated the need for quality CCI training and increased access to relevant information associated with Consumer and Community Involvement practice in healthcare research (Australian Health Research Alliance, 2018).

Results from the 2018 AHRA Audit of CCI in health and medical research (Australian Health Research Alliance, 2018) showed numerous models, frameworks, tools and resources exist within Australia and internationally to support CCI in research; however, facilitating access and evidence of efficacy is needed. The Audit also demonstrated the need for quality CCI training and increased access to relevant information associated with CCI practice in health and medical research.

The findings recommended that AHRA facilitate the sharing of existing resources and expertise to support CCI in translational research with consideration given to utilising existing websites and similar clearinghouses to avoid duplication. During further discussion and consultation, the term Knowledge Hub emerged to describe an accessible online place where CCI resources and expertise could be hosted.

### Project Aim

The aim of the National Knowledge Hub for Consumer and Community Involvement project is to explore the needs of

consumers, clinicians, researchers and health service managers regarding CCI training and resources and access to these, and to use this information to develop a national platform to meet these needs.

### Objectives

1. Scope current CCI activity across the AHRA Research Translation Centres and their members
2. Identify gaps, needs and priorities for CCI in Australian health and medical research
3. Inform on enablers, barriers and optimal processes for a national CCI Knowledge Hub.

## Project methodology

The project consisted of four phases as outlined in Figure 1. Each phase was informed by the previous phase in an iterative process. The chosen methods provided multiple opportunities for stakeholders to have input and to co-design a national AHRA Knowledge Hub for Consumer and Community Involvement. The methods aimed to reach AHRA members across Australia with web-based surveys and workshops.



Figure 1: Project Phases

### Phase 1: Rapid Review

The first phase of the project included a rapid review of the academic literature and web search to identify examples of knowledge hubs.

**Objective:** To identify articles describing consumer and community involvement knowledge hubs and knowledge hub websites informing the co-design and feedback workshops.

Rapid review of the academic literature using OVID Medline and PubMed databases.

- Initial search for articles specific to knowledge hubs including the terms 'health' or 'consumer and community involvement' - few relevant results.
- Search expanded to focus on examples of knowledge hubs more broadly.
- Terms searched: virtual, online, web, internet, community of practice, capacity building, knowledge hub, and information sharing.

- Five articles relevant to online knowledge hubs were identified.

Web search identifying examples of existing online knowledge hubs for health professionals, researchers and consumers:

- Aim: identify the features and processes of existing online knowledge hubs.
- Search: included health related and non-health related hubs.
- Search via Google Chrome: terms included knowledge, hub, resource, evidence, health, research, community of practice.
- Range of health and non-health knowledge hubs identified, 22 knowledge hubs and related websites were reviewed as examples.
- Seven knowledge hub websites selected as examples to review in co-design and feedback workshops.

These particular examples were included for their 1) design and layout, 2) presentation of evidence and practice-based resources and information, and 3) inclusion of features relevant to the AHRA knowledge hub.

# Project methodology *Cont'd*

## Phase 2: Online Survey

Building on the results from the previous AHRA CCI survey in 2018 and the rapid review, an exploratory survey was developed.

**Objective:** To identify and prioritise resources and features to include in the knowledge hub.

**Data collection:** Online Qualtrics survey (see Appendix 1), questions included:

- About you: current position, state, relevant employer/volunteer organisation.
- Your consumer and community involvement activity: CCI work, training and support for CCI accessed and/or provided, important CCI resources and information to include in the knowledge hub.
- Examples of online knowledge hubs to review.

**Recruitment:** Via email invitation with survey link, circulated in May 2020 to AHRA Consumer and Community Involvement coordinating committee and operational leads of AHRA Centres.

**Participants:** Academics, clinicians, consumers and managers working or connected with AHRA Research Translation Centres and their member organisations.

## Phase 3: Co-design workshops

Based on the survey results, the co-design workshop activities were developed. Six workshops were conducted (2 NSW; WA; 2 VIC; SA).

**Objectives:** 1) Explore and refine the information and priorities from the survey; 2) Identify ways to meet the CCI needs identified without duplicating existing resources.

**Recruitment:** Via email invitation from AHRA Centres to their stakeholders (July 2020); direct email invitation to survey participants who expressed interest in co-design workshops and provided contact details.

**Participants:** Academics, clinicians, consumers and managers working or connected with AHRA Centres and their member organisations.

**Workshop outline:**

- Introduction
- What is a knowledge hub and project background
- Example knowledge hubs
- Survey results and discussion about results

- Activity 1: Knowledge hub priorities – allocating priorities/ideas as important or not important
- Activity 2: Barriers and enablers to the knowledge hub.

**Data collection:**

- Workshops recorded, online platform MURAL used for activity 1 and 2 (see Figure 8).
- Participants could provide their perspectives and ideas verbally, in the Zoom chat function or via sticky notes in MURAL.
- The audio recording, Zoom chat and MURAL template with the sticky notes were all saved on a secure server at Monash University.

**Analysis:** Qualitative content analysis across all workshop data sources was conducted using the NVivo software package.

## Phase 4: Feedback workshops

Following the co-design workshops, we synthesised the results and created examples of knowledge hub features and functions. Three workshops were conducted.

**Objective:** To obtain stakeholder feedback on proposed knowledge hub features and functions synthesised from co-design workshops.

**Recruitment:** Via email invitation from AHRA Centres to their stakeholders (Oct-Nov '20); direct email invitation to Phase 3 workshop participants who expressed interest in feedback workshops.

**Participants:** Academics, clinicians, consumers and managers working or connected with AHRA Centres and their member organisations.

**Workshop outline:**

- Introduction and project overview
- Co-design workshop results followed by voting and ranking of proposed features and functions using the online platform Poll Everywhere and example websites.
  - Landing page
  - Main page
  - Directory of organisations/networks/groups
  - Maps
  - Case studies
  - CCI stories
  - CCI registry

*Cont'd*





- Event page
- Glossary
- Feedback processes
- Prioritisation of hub elements
- Brainstorming a name for the knowledge hub

#### Data collection:

- Workshops recorded, Poll Everywhere activities saved

- Participants were able to provide their perspectives and ideas verbally, in Zoom chat and/or via Poll Everywhere
- Audio recording, Zoom chat and Poll Everywhere slides were all saved on a secure server at Monash University.

**Analysis:** Qualitative content analysis across all workshop data sources was conducted using NVivo.

## Results

### Phase 1: Rapid Review



Figure 2: Project Results - Rapid Review

Relevant knowledge hub definitions, terminology, processes and findings were reviewed across the academic publications and knowledge hub website examples. Levac et al. (2015) defined knowledge hubs as:

“E-learning products that translate evidence-based knowledge to disseminate information that increases awareness, informs clinical practice and stimulates practice change.”

Early exploration of the knowledge hub concept occurred in the context of stroke with Kornet-Kitensky et al. (2008) describing the development and pilot testing of a StrokEngine Knowledge Hub, including a usability and navigability evaluation.

In recognition of the time constraints of clinicians, the hub was developed as a consolidated and readily accessible source of stroke information. Hardwick, Sinard and Silva (2011) describe a Pathology Knowledge Hub, created to provide authenticated and validated knowledge for the United States and Canadian Academy of Pathology. The Hub provides pathologists with freely available and real-time access to rapidly iterated clinical concepts.

Mostafavi et al. (2014) published about the World Health Organization (WHO) co-led regional HIV knowledge hubs initiatives to gather and provide up-to-date guidance on program development and implementation. These regional hubs aimed to foster exchanges of best-practice and build capacity. Common features of these regional knowledge hubs include a comprehensive website, along with a collaborative network structure, as presented in Fig 3 (Bozicevic et al. 2009) on the following page.

*Cont'd.*

# Results *Cont'd*

## Phase 1: Rapid Review

*Cont'd*

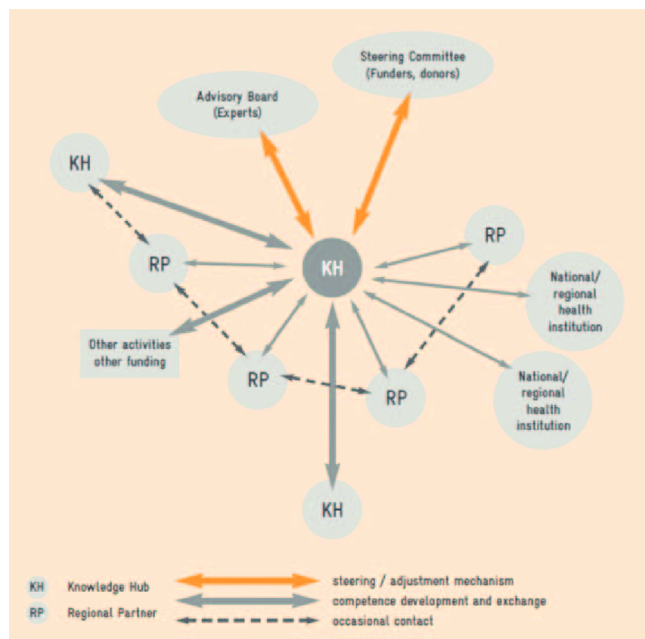


Fig. 3: Structure of regional knowledge hubs Bozicevic et al., 2009

Cross et al. (2018) reported on the co-development and pilot evaluation of a web-based knowledge hub for families and researchers in the disability sector. The evaluation focused on Hub usability and utility. Mehrotra, Grover and Chandra (2018) reported on another type of WHO Knowledge Hub,

focusing on Smokeless Tobacco, with a purpose to analyse, synthesise and disseminate knowledge and information. Part of the mandate included sharing expertise, facilitating communication and providing training.

Common knowledge hub features identified in the five studies highlighted here, include time-efficient access to consolidated and translated resources. Knowledge hubs can serve as go-to places for validated evidence and best-practice examples and bring groups of people together. Some knowledge hubs incorporated pilot-testing and usability and navigability evaluation.

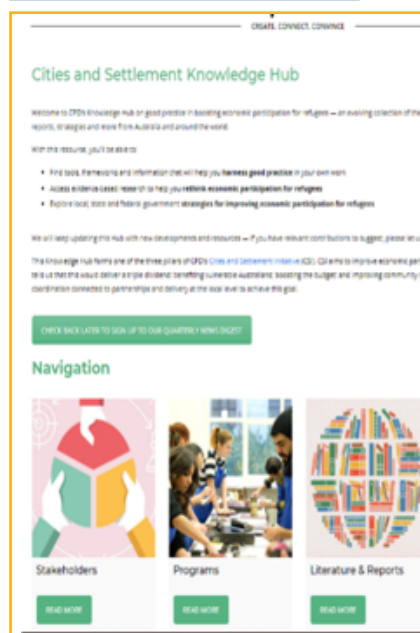
### Knowledge Hubs for detailed review

Three knowledge hubs were selected for detailed review and their common features were presented and discussed in the feedback workshops, namely:

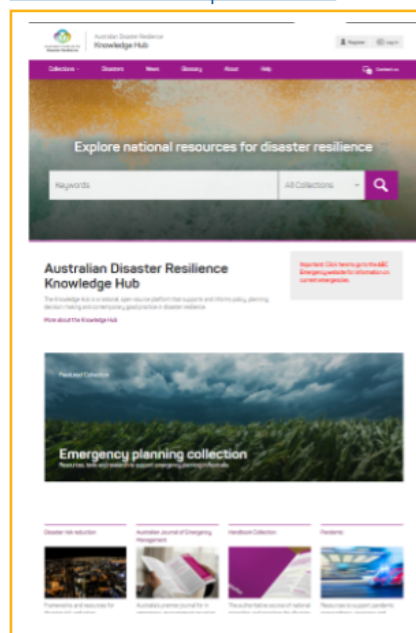
1. Clear and engaging design
2. Presentation of 'collections' of resources and information
3. Inclusion of features such as a search box, glossary and directory.

While the three knowledge hubs have similar purposes in providing resources and evidence of good practice, they are structured in slightly different ways, providing an excellent opportunity to explore different features and seek feedback on stakeholder preferences.

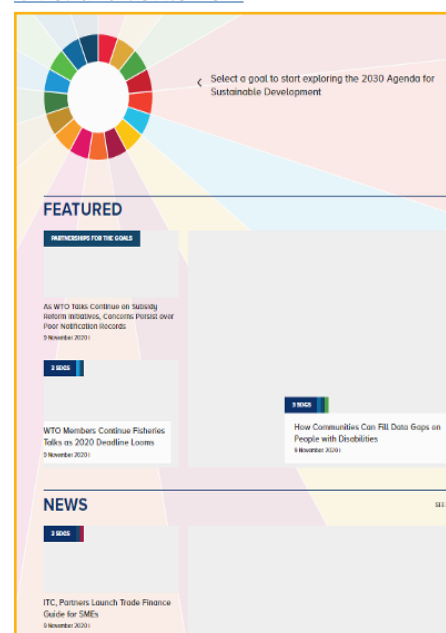
### The Australian Disaster Resilience



### Sustainable Development Goal



### Cities and Settlement



<u>The Australian Disaster Resilience (ADR) Knowledge Hub</u>	<u>Sustainable Development Goal Knowledge Hub</u>	<u>Cities and Settlement Knowledge Hub</u>
<ul style="list-style-type: none"> <li>Prominent search box at the top of the main page</li> </ul>	<ul style="list-style-type: none"> <li>A large, colourful, interactive wheel on the main page, representing the organisation's goals</li> </ul>	<ul style="list-style-type: none"> <li>Statement of hub's purpose at top of the main page, button to sign up for newsletter</li> </ul>
<ul style="list-style-type: none"> <li>Easy, one-click access to a range of resource collections presented in image tiles (pictures)</li> </ul>	<ul style="list-style-type: none"> <li>Popup information on each goal, accessed by clicking on the wheel</li> </ul>	<ul style="list-style-type: none"> <li>Navigation section, comprising image tiles (pictures) with headings to move into more detailed sections</li> </ul>
<ul style="list-style-type: none"> <li>A resource collection feature at the top of all resource collection tiles</li> </ul>	<ul style="list-style-type: none"> <li>The use of colour to indicate the alignment of initiatives with related sustainable development goals</li> </ul>	<ul style="list-style-type: none"> <li>Clicking on a tile (picture) takes the user to a webpage specifically for that topic, and additional resources</li> </ul>
<ul style="list-style-type: none"> <li>Easy navigation, including a navigation toolbar that sits up the top of each page</li> </ul>	<ul style="list-style-type: none"> <li>Tiles of resource collections on the main page (similar to the ADR Knowledge Hub)</li> </ul>	<ul style="list-style-type: none"> <li>Includes many examples of programs throughout Australia.</li> </ul>
<ul style="list-style-type: none"> <li>Interactive Australian map presenting location-based information.</li> </ul>	<ul style="list-style-type: none"> <li>Easy click through to more detailed information, news, the latest articles and policy briefs.</li> </ul>	

Table 1: Features of the Knowledge Hub.

## Phase 2: Online Survey



Fig. 4: Project Results 2— Online Survey

The purpose of the survey was to identify priorities for information and resources to include in the knowledge hub. For the majority of the survey responses, more than one option could be selected and hence percentages reported below do not add up to 100%.

### About the survey participants

The survey was completed by 201 people from across Australia. NSW had the highest number of participants (41%), followed by Victoria (23%) and Western Australia (17%). The remaining participants were from South Australia (7%); Queensland (7%); Tasmania (3%) and the Australian Capital Territory (0.5%). No participants were from the Northern Territory. The majority of the survey participants were academics (41%), followed by consumers (31%) and clinicians (16%). The remaining participants were executives or senior managers, program managers and a head of department or director. Participants could indicate more than one role. Most of the participants worked at a hospital (39%), university (38%) or research institute (30%). Primary and/or community

health, Advanced Health Research Translation Centre/Centre for Innovation in Regional Health and consumer organisations were the remaining organisations represented.

### Consumer and community involvement activities

Sixty-two (31%) participants were consumers and indicated the types of CCI activities in which they were involved. The majority of consumers were involved as representatives or committee members and in the design, development or prioritisation of projects. Consumers were less involved in delivering healthcare projects or research.

- 79% Consumer advisory committee or representative
- 50% Designing healthcare projects, tools and resources
- 45% Sharing or promoting research findings
- 44% Developing research or project publications and reports
- 42% Prioritising healthcare research and/or projects
- 18% Delivering healthcare research and/or projects.

Cont'd

# Results *Cont'd*

Other activities included advocacy, chairing a network, being a government advisor, being involved in ethics or funding applications, mentoring and supporting researchers or as an abstract reviewer for conferences.

The majority of healthcare professionals, researchers and managers (n=111) had involved consumers as representatives on a committee or as a member of a consumer advisory committee followed by designing projects and data collection tools and promoting and sharing research findings. Most of the responses below were from the academic participants, with fewer responses from clinicians and managers.

- 75% Consumer and community advisory committee or representative
- 71% Designing healthcare projects, tools and resources
- 62% Sharing or promoting research findings
- 53% Delivering healthcare research and/or projects
- 48% Developing research or project publications and reports
- 41% Prioritising healthcare research and/or projects.

## Training

The most commonly accessed training for CCI was attendance at a seminar (53%) followed by a workshop (44%). The majority of participants indicated they would like a practical training course (51%) and a CCI research project support service (51%) followed by mentoring (51%) and attendance at conferences (45%). Academics indicated preferences for training via CCI research support service (50%), practical training courses (49%) and workshops (48%). Clinicians were less likely to have accessed any CCI training and indicated equal preferences for seminars, practical training courses and CCI research project support service (78%). Consumers tended to access workshops (62%) and seminars (60%) and conferences (55%) and indicated they would also like to access a practical training course (36%).

## Consumer and community involvement resources – current knowledge and access

The most commonly known resource was the Australian Clinical Trials Alliance Consumer and Community Involvement toolkit (44%) and the National Health and Medical Research Council Statement on Consumer and Community Involvement (37%). The NHMRC statement was the most commonly used resource followed by Cancer Australia and Cancer Voices Australia - National Framework for Consumer Involvement in Cancer Control (22%) and



Consumers Health Forum of Australia (22%). Overall the knowledge and use of resources were low, supporting the need for a knowledge hub. The majority of participants reporting knowledge and use of resources were academics. The National Institute for Health Research UK – Involve Patients resource had the highest recognition (28%) and use from participants (17%), although this was still low.

## Information to include on the knowledge hub

Participants were asked to rate on a 5-point Likert scale the importance (i.e. not important to extremely important) of different types of information that could be included in the knowledge hub.

The information rated as extremely important to include was upcoming face-to-face training and workshops, funding opportunities that include CCI or co-design and CCI networks across Australia. Below we report on the proportion reporting that the following information is important to include on the knowledge hub after *collapsing the categories of important, very important and extremely important*.

- 93% Upcoming face-to-face training and workshops
- 92% Health and medical research funding opportunities that include a consumer involvement and/ or co-design focus
- 91% CCI networks across Australia
- 87% State-based advocates, mentors and ambassadors
- 81% A networking platform and opportunities
- 76% Recent news and updates on CCI across Australia
- 72% Newsletter or social media updates.



## Resources to include on the knowledge hub

Participants were asked to rate on a 5-point Likert scale the importance (i.e. not important to extremely important) of different resources that could be included in the knowledge hub. The resources rated as extremely important to include were handbooks, guides and tip sheets, online training and learning opportunities and Australian priorities and policies for CCI. Below we report on the proportion reporting that the following resource is important to include on the knowledge hub after collapsing the categories of important, very important and extremely important.

- 94% Australian priorities and policies for CCI
- 94% Contacts and networks for CCI
- 93% Online training and learning opportunities
- 92% Australian and international CCI websites
- 91% CCI handbooks, guides and tipsheets
- 91% Resources for evaluation
- 88% Templates
- 87% Evaluation/project reports
- 84% Case studies
- 77% Videos
- 75% Academic publications.



Fig. 5: Project Results Phase 3 - Co-Design Workshops

## Phase 3: Co-design workshops

Six online co-design workshops, held throughout New South Wales, Victoria, Western Australia and South Australia, were attended by 85 researchers, health professionals and consumers. Additional consultation was held with Queensland and Northern Territory. Co-design workshops refined the stakeholder survey's priorities and identified barriers and enablers for the CCI Knowledge Hub in a series of workshop activities.

### Key Themes:

The key themes from the co-design workshops are outlined in Table 2 and described further below.



Fig. 6: Co-design Zoom workshop.

Please see Appendix 2 for further details about the Themes

Theme	Sub-themes
<ul style="list-style-type: none"> <li>• The knowledge hub will have a practical focus, linking and connecting people</li> </ul>	<ul style="list-style-type: none"> <li>• A large, colourful, interactive wheel on the main page, representing the organisation's goals</li> </ul>
<ul style="list-style-type: none"> <li>• Facilitating access to information, resources and training</li> </ul>	<ul style="list-style-type: none"> <li>• Popup information on each goal, accessed by clicking on the wheel</li> </ul>
<ul style="list-style-type: none"> <li>• Prioritise accessibility and engagement</li> </ul>	<ul style="list-style-type: none"> <li>• The use of colour to indicate the alignment of initiatives with related sustainable development goals</li> </ul>

Table 2: Overview of key themes and subthemes from the co-design workshops.

### Theme 1: The knowledge hub will have a practical focus, linking and connecting people

Key outcomes from the co-design workshops include:

- Widespread support and enthusiasm for AHRA as a leader

in connecting people to high-quality CCI resources.

- The primary role of the Hub is to make it easier and more time-efficient to access evidence, tools, and training.
- Broad consensus across the six workshops, that the Hub should have a 'practical focus' with emphasis on translating CCI resources for supporting everyday practice.

Cont'd

# Results *Cont'd*

- The concept of a 'Hub and Spoke model' with the Hub a central place for people to find out what's happening and to be directed to quality resources, information and training.
- Strong desire for the Knowledge Hub to link and connect with others in Australian healthcare and health research who are doing CCI work.
- The creation of a shared space where researchers, health professionals and consumers can learn from each other.
- Clarity around the purpose of the Hub is important, an acknowledgement that the Hub 'can't be everything to everyone.'
- Concern that if the Hub tries to do too many things and meet too many people's needs, its purpose will become unclear and it will lose its effectiveness.

Workshop participants were also asked to identify the things the Hub shouldn't do, as a way of further refining priorities. Key messages:

- Overwhelmingly, participants said the Hub should not try to do too much, 'don't make it too complex.'
- Don't include every CCI resource.
- Focus on a curated selection of high quality, recommended resources.
- Make better use of existing tools and resources, rather than create something new.
- Avoid having too much 'static' information and being a social network.

## Linking and connecting information, organisations and people

Linking and connecting was a central theme across co-design workshops. Participants expressed a desire to:

- Connect with each other, and more broadly, to organisations and networks in the CCI space.
- Know who else is working in CCI.
- Come together and network informally and formally.
- Form special interest groups around priority populations and topics.

**"A supported environment and people can find what they need easily"**

**"Integrated knowledge translation as core"**

**"Something to pass through on the way to the destination"**

- Connect to information, national events and training opportunities via the Hub.
- Share experiences of everyday practice

There was extensive discussion about the opportunity to establish a Community of Practice through networking forums, chat groups and blogs.

However, concern was expressed about the workload this approach would generate – i.e. online forums requiring ongoing moderation and facilitation. There was also some concern about how much people would engage in online forums, compared to the investment of time and resources. With these concerns in mind, this is an area that would benefit from further investigation before proceeding. Across the workshops, there was a lot of support for the Hub creating networking opportunities and conversations for CCI practice. People discussed the Hub, including a facilitated networking space where people can ask questions, share experiences and learn from each other. There were many different ideas about connecting and learning from each other, including an organisational directory, live chat groups, blog-style question and answer forums, special interest groups, seminars, stories and case studies.

## **"Overarching community of practice but then have subgroups"**

Workshop participants discussed the value of a directory of national and local contacts for Australian CCI practice. A directory would help to 'map the landscape' and build the awareness of the people, organisations and groups working in this space. People across the workshops also wanted to see the Hub have strong and visible links with crucial groups leading Australian CCI practice, including the National Health and Medical Research Council (NHMRC), Australian Clinical Trials Alliance (ACTA) and the Consumers Health Forum of Australia (CHF).



Fig 7: Co-design Zoom workshop.

**“Practical information – the nitty-gritty of how to”**  
**“Focus on the practical. Take the research and make it practical”**

The workshops discussed many opportunities for the Hub to support consumers in their roles. A priority for consumers was the inclusion of a registry for consumers to sign-up for involvement opportunities; or a list of consumer involvement opportunities. In the workshops, consumers described the value in a directory of organisations and groups doing CCI work. They would also like consumer options for online forums and networking.

### **Learning from each other**

Another central theme across workshops was the Hub creating opportunities for people to learn from each other, and share the good work already happening, through:

- Examples of ‘good practice’ in CCI
- Case studies and stories to increase awareness of work throughout Australia and share examples of effective practice
- Discussing topics, sharing tools and resources used, as well as successes, challenges and learning
- Inviting people to submit examples of their practice, targeting a variety of CCI practices as a way of encouraging people and organisations to contribute
- Developing a consistent template to assist this process.

**“Local examples of CCI. Stories from the field”**  
**“Stories highlighting impact. Researcher stories about how consumers helped their project”**

### **Theme 2: Facilitating access to information, resources and training**

Many workshop participants described the Knowledge Hub as a place to find out what’s happening in CCI, with the Hub a central point highlighting relevant information, events, and training, linking people to the external websites and contacts they need. Types of information people want to access include funding and grants relevant to CCI; events, training, and updates about new resources. Other options discussed included a calendar of events and a process for people to upload their events and activities.

### **Resources need to be high quality and endorsed by AHRA**

Workshop participants expressed strong and consistent support for the Knowledge Hub being a place to access high-quality CCI resources and training. AHRA was identified as being ideally positioned to play a leadership role in reviewing and recommending resources. Participants described the notion of ‘AHRA endorsed’ resources and training sitting in the Hub, suggesting the need for a process to ensure resource and training quality.

**“Benchmarks for CCI evidence and training”**

**“Simple, high-quality resources. AHRA endorsed... Not too many... Up to date”**

When including resources in the Knowledge Hub, participants emphasised the need to keep it simple and not include everything. The priority is to offer a concise range of reviewed and recommended resources. Workshops discussed the need for AHRA to develop a process and criteria for including and updating resources for the Hub. People felt that if the Hub could achieve this, it would be a place to access quality resources in an easy, time-efficient way.

**“Training section – have it accredited – good way to get health professionals engaged”**

**“Hub creates its own accreditation and endorsement framework for training linked to practice”**

**“Training for consumers and researchers endorsed by funding bodies”**

### **Promoting available consumer and community involvement training**

Workshops participants were keen to access CCI training. They discussed the Hub as an ideal place to bring together existing training options throughout Australia. People suggested that the Hub doesn’t need to develop new training but support and work with current providers. Like resources, many people wanted to see the Hub offer quality training options and discuss a need to create a process for including training. Workshops also saw an opportunity for the Hub to progress the development of endorsed or accredited training. Many people suggested that endorsed or accredited training should be supported by funding bodies.

*Cont’d*

## Engagement and advice for priority populations and topics

The workshops emphasised the need to cater to different CCI groups and stakeholders through strategies such as creating collections or groups of special interest populations and topics.

### Priority population groups

Children; young people; culturally and linguistically diverse communities; Aboriginal and Torres Strait Islander communities; rural and remote communities; older adults; people with disabilities.

### Priority topics

Engaging diverse groups; evaluation designs and indicators; consumer-led research; researcher, health professional and consumer co-led research; ethics committees; measuring partnerships; remuneration - national guidance and standards; reporting back to consumers; consumer involvement in health service planning; partnering and connecting with state and national groups; working with GPs.

## Theme 3: Prioritise accessibility and engagement

One of the biggest priorities is making sure the Knowledge Hub is engaging and easy to navigate. Many participants suggested that if the Hub was not a quick, easy and visually appealing place to visit, people would soon lose interest. Across the workshops, participants also discussed the need for a Hub to be a facilitated space, giving a sense of interactivity and engagement. People suggested that a lead or host would help create a sense of interactivity and engagement, and provide an opportunity for people to ask questions. A Hub host or lead would also be a way to keep the site updated.

**“Create a tailored pathway through the hub”**

## Time-efficient searching features

A top priority for the Hub is time efficiency. Across workshops, participants consistently described a need for the Hub to be quick and easy to use, which could be achieved with careful planning. Many suggested that tailored pathways are needed by identifying the different types of Hub stakeholders and mapping their potential journeys

**1 Team Members**  
Who is on the team?  
Each team member list 2 of their strengths and 2 of their weaknesses to help better understand each other.

David Chin: Strengths: Professional, Hard-Worker; Weaknesses: Noisy, Tidy  
Jeanette Mergerado: Strengths: Communicative, Planning; Weaknesses: Visual Design, Time Management  
Kaj Zeng: Strengths: Project, Organizing; Weaknesses: Communication, Being Out  
Daniel Quon: Strengths: Project, Planning; Weaknesses: Visual Design, Technical Training  
Jennifer Connolly: Strengths: Project, Planning, Attention to Detail; Weaknesses: Attention, Time

**2 Core Values**  
What do you care about?  
Discuss which shared values can help guide how you approach your work and how you collaborate with each other.

1. Brainstorm: Use sticky notes to show your thoughts.  
2. Consolidate: Choose your team's top 6-8 values.  
3. Refine: Turn your notes into concise sentences.

Core Values:  
- Offer unashamed honesty to each other  
- Everyone has an equal stake in group decisions  
- Contribute to an enjoyable work environment  
- Push each other to succeed and bring out the best  
- Consider efficiency in the work process  
- Trust each other's constructive criticism

**3 Group Norms**  
How will you work?  
Establish a framework of ideals that you can expect each other to abide by.

1. Brainstorm: Use sticky notes to show your thoughts.  
2. Consolidate: Choose your team's top 6-8 norms.  
3. Refine: Turn your notes into concise sentences.

Group Norms:  
- Maximize our unique skill sets  
- Use our tools situationally. Reuse depending on the  
- Be able to step up and step back when necessary  
- Always address concerns, don't be afraid to speak up  
- Maintain a high level of camaraderie  
- Do your diligence outside of group work

**4 Roles**  
What roles are necessary?  
Determine the types of roles that will keep the team focused and drive productivity.

1. Brainstorm: Use sticky notes to show your thoughts.  
2. Consolidate: Choose your team's necessary roles.  
3. Refine: Turn your notes into concise sentences.

Roles:  
- Logistics Manager: note taking, agenda making, time k  
- Internal/External Email Lead  
- Visual Designer  
- Final Copy Editor  
- Use skill sets where they are relevant

**5 Metrics of Success**  
What does success look like to you?  
Consider how success can be measured beyond a letter grade or score.

1. Brainstorm: Use sticky notes to show your thoughts.  
2. Consolidate: Choose your team's top 6-8 metrics.  
3. Refine: Turn your notes into concise sentences.

Metrics of Success:  
- Achieving desired goals and accomplishments  
- Maintaining a high level of camaraderie  
- Validation from outside sources  
- Maintaining efficiency in our process  
- Individual and group learning and growth  
- Creativity and innovation in our work

Fig 8: An example of MURAL workshop feedback.



through the Hub. Some people discussed including navigator or filtering technology to help Hub stakeholders find resources and information. Many highlighted the need for an effective search function; however, gave feedback that search functions are best used as a support tool and should not be the primary way for stakeholders to navigate the Hub.

**“User-friendly website is critical”**

**“Searchable. Good search tool, visually appealing and easy to navigate”**

**“Continually updated as new resources and information are available”**

### Accessible language and formatting

Researchers, health professionals and consumers alike, raised concerns about the Hub's accessibility and identified a need to address online participation barriers. Workshops discussed clear Hub navigation as not only enhancing time-efficiency but also increasing access across different stakeholder groups. Further accessibility considerations raised include the wording, style of language and use of acronyms, which can be barriers or discouragements for participating in the Hub. Many people suggested including a glossary to identify CCI terminology. The choice of colour, text size and images was also described as essential to increase the Hub's engagement and consider the needs of people with visual impairments.

### Ongoing engagement

A consistent priority across workshops was for the Hub to plan for ongoing engagement. People described regular updates and new content as the key to maintaining participation in the Hub. Many suggested that the Hub provide notifications when new content is added and for the Hub to work with communication professionals to develop ongoing engagement strategies.

### Embed consumers into the governance structure to ensure acceptability and accessibility

Participants highlighted the importance of Hub leadership for ongoing management, engagement and sustainability. Hub leadership was described as a leading organisation or governance group to oversee the Hub and keep it up to date. Many workshop participants also emphasised the importance of consumers being involved in the Hub's governance structures. Priorities for consumer involvement in the Hub included consumer representatives on a governance committee or a separate consumer advisory group.

**“Knowledge Hub needs a host/someone to lead”**



Figure 9: Project Phase 4 – Consultation Workshops

### Phase 4: Consultation Workshops

Three feedback workshops were conducted in late November 2020. The Zoom workshops were attended by 45 Researchers, health professionals and consumers throughout Australia. Many participants had joined previous co-design workshops. A further feedback workshop was held with Queensland stakeholders, presenting a combination of the co-design and feedback workshop topics. Participants across the workshops continued to show support and enthusiasm for the CCI Knowledge Hub and AHRA's leadership role in this work. Feedback workshops aimed to explore specific Hub website

features and functionality. Continued messages with the co-design workshops included creating a simple design, being easy to read and navigate. Participants were keen to see the Hub website avoid the use of jargon and acronyms, acknowledging that while there is much technical language in the sector, it is important to create a resource that is inclusive of as many people as possible, no matter their prior experience with the topic. Workshop groups also wanted the Hub to focus on quality, starting with a couple of main priorities, doing them well and adding over time.

*Cont'd*

The key aspects from the workshop reported below are:

- Hub main page
- Website main page features
- Landing page
- Hub resources and topics
  - Directory
  - Case studies and stories
  - Maps
  - Hub name
- Ranking hub priorities.

## Hub main page

Workshop participants consistently described the importance of the Hub website's main page, ensuring it is engaging, clear and easy to use. Feedback workshops presented three examples of Hub website main pages, each with different features and benefits. Two of the three feedback workshops preferred the Australian Disaster Resilience Knowledge Hub's main webpage <https://knowledge.aidr.org.au/>. People described preferring the use of strong colour, but not too much, and use of tiles and headings.

**“Simple is best”**

**“Take it slow at first – make it great to start with and then build it**

The CPD website <https://cpd.org.au/knowledge-hub/> was the second preference. Workshop groups consistently liked the Hub introduction on the CPD webpage, discussing the importance of a highly visible purpose and introduction statement. However, people described the colours as dull and the layout less interesting. Some participants raised issues with the lighter colours in this website also not being suitable for people with visual impairments. A third Hub website, Sustainable Development Goals <https://sdg.iisd.org/> was described as ‘too busy’ and complex to navigate.

## Website main page features

Co-design and feedback workshop groups want to see the inclusion of a clear and easy to use search box, like the ADR Knowledge Hub. However many participants didn't want the search box as the first thing you see like with ADR, preferring a CCI Knowledge Hub to prioritise a good layout and tiles/ topics on the main page directing people where they need to go. Consensus was the search box was a secondary support feature of the Hub. Co-design

and feedback workshop groups wanted to see the CCI Knowledge Hub avoid the ‘long scroll’ by including too much content on the first page. However, some participants described not having ‘too many clicks’ to find the topics or information they are looking for; with the Hub needing for find a balance between the two priorities.

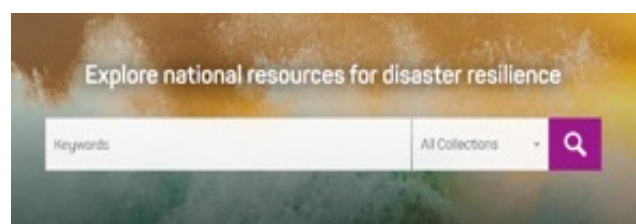


Image: Australian Disaster Resilience search box <https://knowledge.aidr.org.au/>

## Landing page

Navigation was a priority across co-design and feedback workshops, with participants wanting a clear and easy process guiding them through the Hub. Feedback workshops asked about landing page options and if participants would prefer to be directed through the Hub via their role e.g. researcher, health professional or consumer; or to navigate via the topic they are looking for, or both. All workshops consistently wanted both navigation options.

**“I think the main takeaway is that people want something that displays all the key areas immediately, beautifully and clearly”**

**“This one is easier to read - not so busy”**

**“Tiles are good for literacy [in ADR website] but not sure who chooses the pictures”**

**“CPD webpage for me is not very visually appealing, though the concepts of what is on the page is about right”**

## Hub resources and topics

The feedback workshops explored the importance and design of CCI directory, case studies and stories and CCI registry maps. The feedback workshops didn't delve into detailed aspects of resources and evidence to include in the Hub. However, many participants asked questions about how resources would be presented in the Hub and remains a top priority.

**“I think there's a tension between trying to streamline the content for users so it's easy to get to where you want to go and having content that is accessible to all such that people from all roles feel comfortable accessing any of the content”**

## CCI directory

Co-design and feedback workshop groups consistently highlighted the importance of 'mapping the landscape' through a directory of Australian CCI organisations and networks. The inclusion of a directory was not a high priority in the stakeholder survey, with the survey showing CCI resources and training as the top priority. However, the workshops' practical nature and well-established priorities for CCI resources and training allowed groups to consider additional Hub features, including preferences networking, information sharing, and mapping organisations.

**"A directory would be useful, but not too much information required"**

**"I'd prefer to see a quick summary of who and what the organisation is and does, together with a link if you want to find out more"**

**"What would be the criteria for being listed?"**

## Case studies and stories

Case studies and stories were discussed as a way to share Australian CCI examples. Feedback workshops presented examples of case study and stories and discussed important features. Groups liked the option for a case study and story template, suggesting they would provide consistency and save time. Most people indicated they would find case studies and stories useful and would read or watch them, however not as many would develop case studies or stories. Some participants commented that it would be useful to have targeted invitations to complete case studies and stories, along with providing support.

**"I think the main focus should be the resources, you could then attach a case study as a way to implement that resource"**

**"I would if the template was easy to use"**

**"One or two [stories] but not too many? Can you match them to case studies?"**

## CCI registry

A CCI registry, similar to clinical trials registries, was proposed as a way to search and keep track of CCI activities. However, in the feedback workshop, the time and resources to maintain a registry were considered too high. Additionally, people believed that the case studies and stories would serve a similar process.

## Maps

Previous co-design workshops suggested options for presenting information on the Hub using maps. However, further exploring this in feedback workshops showed that most people felt maps aren't necessary and would create extra work. People suggested that today's increased online focus means the location of CCI work is less important. Feedback workshops concluded that if maps are included, to use them sparingly.

## Name of the hub

Feedback groups didn't report strong feelings about the name of the hub. However, the most commonly suggested words to include in the name were: research, health, hub, knowledge, portal, directory, engagement, consumer, community, resource. Feedback from the group throughout the workshops was that the Hub's purpose needs to be clear.

## Ranking hub priorities

Workshop participants ranked their top priorities for the Hub, recognising that it is unlikely the Hub will provide all resources and features at once. Resources were not included as a ranking option in the feedback workshops. Yet all groups identified their importance, so was added as a top priority.



*Cont'd*

# Knowledge and Practice Hub Model

## Ranking hub priorities

cont'd

The ranking activity showed that a top priority for the Hub was including training and events, aligning with the stakeholder survey results. Feedback workshop groups described the directory and glossary as a priority; however, they want to see these aspects as streamlined as possible, concerned about potential high cost and time requirements.

Case studies and stories had good support to share success stories and learn about the practical aspects of planning and delivering CCI practice. However, case studies and stories need to be carefully planned and well-supported to ensure effectiveness. Networking was also raised as a continuing priority.



Fig. 10: Polleverywhere ranking exercise from two of the feedback workshops

**“Where are the resources on this list?  
Resources should be number one”**

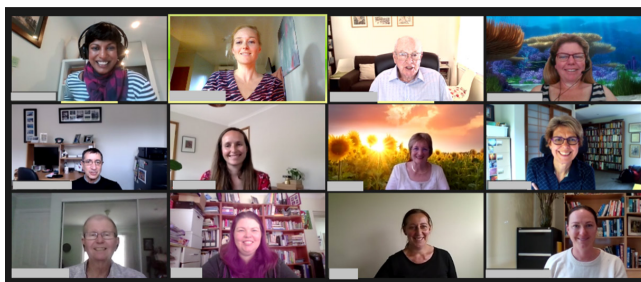


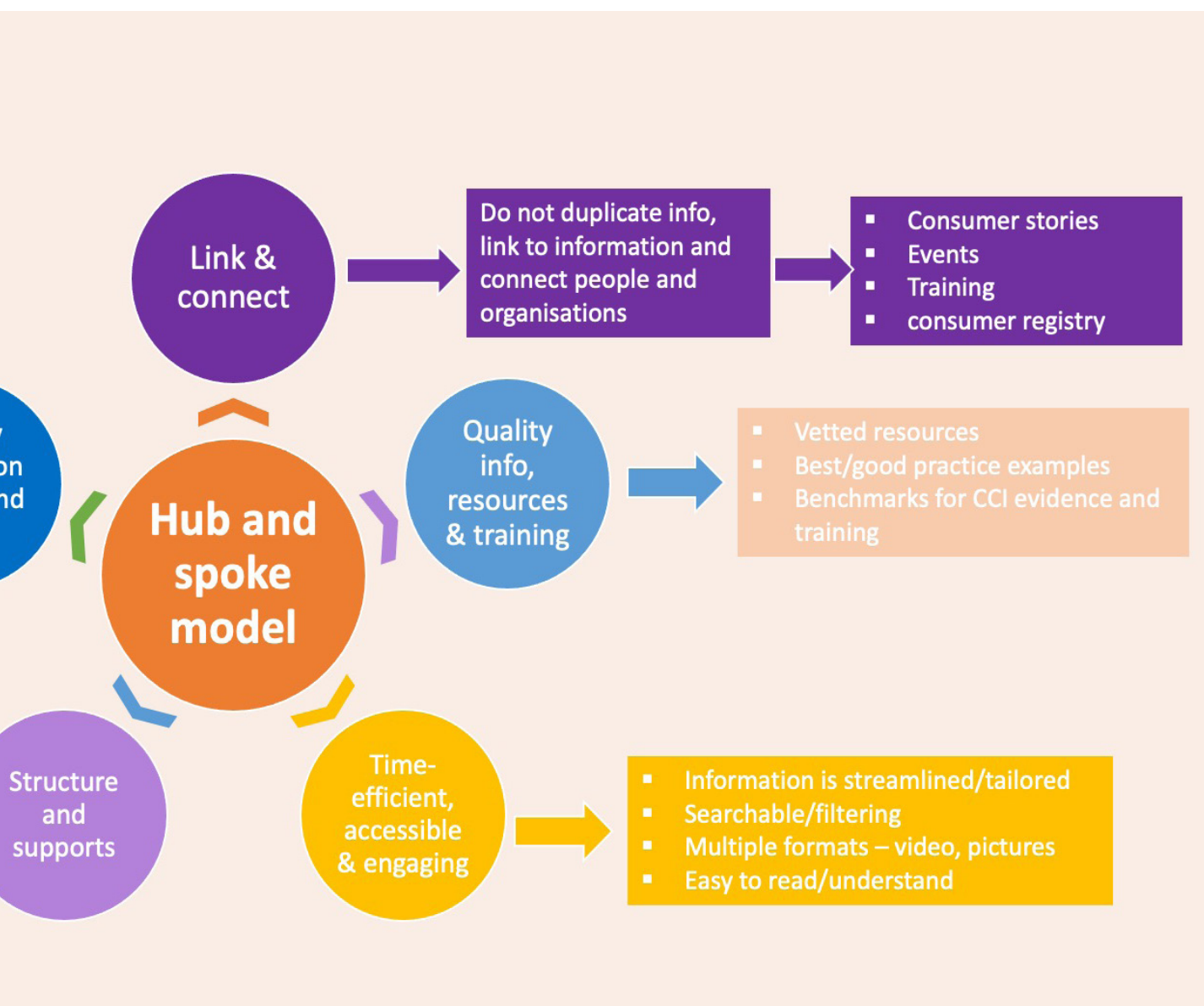
Fig. 11: Feedback Zoom workshop.

- Children and young people
- Aboriginal and Torres Strait Islander
- Culturally and Linguistically Diverse
- Rural and remote

Priority population groups and topics

- Governance group
- Consumer advisory group
- Employed navigator





# Conclusion

This project aimed to engage key stakeholders – consumers, researchers, clinicians, health services managers to explore their recommendations for a national knowledge hub for CCI.

The co-design process showed that researchers, health professionals and consumers want CCI resources translated into everyday practice and to learn from each other. Stakeholders stated that the CCI hub needed to be practical, engaging and easy to access. They also see AHRA as well-placed to lead these opportunities. To reflect the practical and translation focused priority arising from the workshops, it is recommended the hub be called a CCI 'Knowledge and Practice Hub'.

The Hub's priority features include an engaging, easy to use and time-efficient design, clear benchmarks for the resources and training included in the Hub, and a leadership and governance group to drive it. The themes from the survey, co-design workshops and feedback workshop are depicted in the Knowledge and Practice Hub Model on the following page.

The model was developed as a visual representation of the researcher, health professional and consumer contribution in co-designing the Hub. It is recommended that the model is included in the Hub website to recognise the co-design process but also as a potential navigational tool. An example of how the model could be applied is presented on pages 20 and 21.

The appendices include three mock-up web pages reflecting the priorities from the feedback workshops. These are the main page, case study template and example webpage for included resources. The table, Appendix 2, details the key themes, practice principles, operationalisation and further work required for the knowledge hub.

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## Appendices

### Appendix 1



CONSUMER AND COMMUNITY  
INVOLVEMENT HUB

Resources ▾
Training / Events
Directory
Case Studies
Glossary
Contact us

## About the consumer and community involvement hub

*Background image corresponding to main page specific image/ art/ logo on tile*

Outline the purpose of the hub here....

*Welcome message from AHRA Director – Gary.*

For enquiries about the AHRA consumer and community involvement hub please contact:

Website main page mock-up

# Appendices

Cont'd

THEMES	PRACTICE PRINCIPLES
<b>Link and connect</b> <ul style="list-style-type: none"> <li>• Build on relationships and partnerships forming the Hub.</li> <li>• The Hub is about how people use resources and practice CCI.</li> <li>• Sharing experience and creating opportunities for people to learn from each other.</li> </ul>	<ul style="list-style-type: none"> <li>» A practical space for researchers, health professionals and consumers to come together.</li> <li>» A platform to share learnings and processes for CCI.</li> <li>» A central place to find out about the latest information, events and training for CCI in Australia.</li> </ul>
<b>Information, resources and training</b> <ul style="list-style-type: none"> <li>• The Hub is about better use of existing resources, not developing new resources.</li> <li>• Need for a synthesised collection of quality resources, complemented with relevant information, events and training.</li> <li>• People described AHRA as being in an excellent position to bring existing resources and information together.</li> </ul>	<ul style="list-style-type: none"> <li>» Includes a small selection of high-quality and peer-assessed CCI resources.</li> <li>» Information and resources are regularly maintained and up-to-date.</li> <li>» Information, training and resources included in the Hub are reviewed by a Content Advisory Group comprising researchers, health professionals and consumers throughout Australia.</li> </ul>
<b>Time-efficient, accessible and engaging</b> <ul style="list-style-type: none"> <li>• Ensuring the Hub is concise, visually appealing and easy to use is essential for its effectiveness and longevity.</li> <li>• Stakeholders consistently described the priority for the Hub to be user-friendly and developed with diverse stakeholder groups in mind.</li> </ul>	<ul style="list-style-type: none"> <li>» The design and functionality are crucial for its effectiveness.</li> <li>» The website must use clear language, avoid jargon and acronyms.</li> <li>» Lead by example and include consumers in the governance, design, development and evaluation.</li> </ul>
<b>About the hub -Structure and supports</b> <ul style="list-style-type: none"> <li>• Hub leadership and governance are vital components for effectiveness and sustainability.</li> <li>• The Hub is more than a static website, participants want a person to contact with questions and help link them to relevant information.</li> <li>• The Hub needs a leader to bring all the priorities together.</li> </ul>	<ul style="list-style-type: none"> <li>» Led by a Governance Group to provide strategic oversight, with membership across the AHRA Centres.</li> <li>» A go-to person, who people can go to for assistance and tasked with keeping everything on track.</li> <li>» Has a Consumer Advisory Committee.</li> </ul>
<b>Population groups and topics</b> <ul style="list-style-type: none"> <li>• Researchers, health professionals and consumers consistently reported the need for resources and examples supporting CCI across a range of diverse population groups and settings.</li> <li>• They discussed the Hub bringing stakeholders together on shared topics of interest.</li> </ul>	<ul style="list-style-type: none"> <li>» Includes resources, information and training to support the practice of CCI with diverse and underrepresented communities.</li> <li>» Highlight CCI work across diverse and underrepresented communities. Share examples of practice, including tools and advice to help others get started.</li> <li>» Create opportunities for bringing researchers, health professionals and consumers together to discuss CCI practice across a range of population groups and topics.</li> </ul>



## Appendix 2

OPERATIONALISATION	FURTHER WORK
<ul style="list-style-type: none"> <li>» Establish partnerships with key Australian CCI organisations &amp; groups. Convey these partnerships in the Hub.</li> <li>» Design a simple directory &amp; process for listing CCI stakeholders, networks and groups.</li> <li>» Develop a process for including case studies and stories, including developing templates and supported process for their development.</li> <li>» This should likely occur once the initial inclusion of CCI resources, training and information has occurred.</li> </ul>	<ul style="list-style-type: none"> <li>» Establish a plan/ process for presenting and prioritising resources that support CCI practice across a range of population groups and topics. This could include establishing resource categories or collections across population groups and topics.</li> <li>» Support the development of case studies and stories highlighting CCI work with diverse and underrepresented communities.</li> </ul>
<ul style="list-style-type: none"> <li>» The Hub Governance Group develop criteria for including resources, training and information in the Hub.</li> <li>» Establish a Content Advisory Group and Terms of Reference. The Content Advisory Group meets at regular intervals (e.g. quarterly) to review and recommend resources, training, and information in the Hub.</li> <li>» The membership of this group to change every 1-2 years to provide opportunities for many researchers, health professionals and consumers to contribute to this work.</li> <li>» Develop a webpage template for displaying resources in the Hub (an example is provided on the following page).</li> <li>» The page should provide details about why the resource has been included on the Hub (i.e. the features of the resource or criteria for inclusion).</li> </ul>	<ul style="list-style-type: none"> <li>» Ensure the Hub is connected with the AHRA CCI handbook and evaluation projects.</li> </ul>
<ul style="list-style-type: none"> <li>» Establish/ confirm criteria for accessibility.</li> <li>» Consult web designers/ information technology researchers experienced in designing accessible and engaging online spaces.</li> <li>» Develop and get feedback on the accessibility, efficiency and engagement of the design of the Hub website.</li> </ul>	<ul style="list-style-type: none"> <li>» Develop routine monitoring and evaluation measures and methods for the Hub, as well as impact measures. It is also important to conduct an external evaluation of the Hub impact, reporting on the extent the Hub has supported CCI practice. The evaluation results are also essential for redeveloping aspects of the Hub where needed.</li> </ul>
<ul style="list-style-type: none"> <li>» Establish/ confirm criteria for accessibility.</li> <li>» Consult web designers/ information technology researchers experienced in designing accessible and engaging online spaces.</li> <li>» Develop and get feedback on the accessibility, efficiency and engagement of the design of the Hub website.</li> </ul>	<ul style="list-style-type: none"> <li>» We anticipate that a Project Manager will be needed full time to develop a 1-year Hub development plan in consultation with the governance group and consumer advisory committee. The Project Manager will then review and redevelop Hub structure and groups after the end of the plan based on evaluation and feedback.</li> </ul>
<ul style="list-style-type: none"> <li>» Establish a plan/ process for presenting and prioritising resources that support CCI practice across a range of population groups and topics. This could include establishing resource categories or collections across population groups and topics.</li> <li>» Support the development of case studies and stories highlighting CCI work with diverse and underrepresented communities.</li> </ul>	<ul style="list-style-type: none"> <li>» Explore the potential for developing networks and groups on various populations and topics, in areas of shared high interest e.g. online discussion groups, forums or virtual meetings, events.</li> </ul>

# Appendices

Cont'd

## SURVEY – What resources, information, and support do you need for consumer and community involvement in healthcare and health and medical research?

### ABOUT YOU

What is your current position? Please select the option(s) most appropriate

- ☐ Academic/researcher ☐ Clinician
- ☐ Consumer ☐ Executive/Senior Management
- ☐ Head/Director of Department
- ☐ Program Manager

### CONSUMER AND COMMUNITY INVOLVEMENT WORK

As a healthcare professional/researcher/manager tell us about the activities you have involved consumers in.

Have you involved consumers in any of these activities?

As a healthcare professional/researcher/manager tell us about the activities you have involved consumers in.			
	Yes	No	Not applicable
a) Consumer and community advisory committee or representative	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) Prioritising healthcare research/ projects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) Designing healthcare projects, tools and resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) Delivering healthcare research/ projects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e) Developing research/ project publications and reports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f) Sharing/promoting research findings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g) Other (describe)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="text"/>			

### TRAINING AND SUPPORT FOR CONSUMER AND COMMUNITY INVOLVEMENT

Tell us about the training or support you have received for consumer and community involvement work.

Please indicate if you have received any of the training and support options below:

Tell us about the training or support you have received for consumer and community involvement work.				
	Yes, I have	No, I haven't but I would like to	Not applicable	No, I haven't but I don't need to
a) Seminar or webinar	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) Workshop	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) Practical training courses	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) Mentoring – formal or informal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e) Consumer and community involvement research/community project support service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## CONSUMER AND COMMUNITY INVOLVEMENT RESOURCES

Tell us about the consumer and community involvement resources you have accessed.

Please indicate the websites and resources you have heard of:

Please indicate the websites and resources you have heard of	No - I have not heard of this website/ resource	Yes - I have heard of this website/ resource	Yes - I have heard of this website/ resource AND have used it
a) NHMRC - Statement on consumer and community involvement in health and medical research <a href="https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research">https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research</a>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) Health Issues Centre <a href="https://hic.org.au/">https://hic.org.au/</a>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) Cancer Australia and Cancer Voices Australia - National Framework for Consumer Involvement in Cancer Control <a href="https://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/national-framework-consumer-involvement-cancer-control">https://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/national-framework-consumer-involvement-cancer-control</a>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) Australian Clinical Trials Alliance - Consumer involvement and engagement toolkit <a href="https://clinicaltrialsalliance.org.au/resources/consumer-involvement-toolkit/">https://clinicaltrialsalliance.org.au/resources/consumer-involvement-toolkit/</a>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e) Consumer Health Forum of Australia <a href="https://chf.org.au/">https://chf.org.au/</a>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f) Consumer and Community Health Research Network - Western Australia <a href="https://www.involvingpeopleinresearch.org.au/">https://www.involvingpeopleinresearch.org.au/</a>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g) Victorian Comprehensive Cancer Centre Consumer - Consumer Engagement <a href="https://www.viccompccancerctr.org/about-vcco/consumer-engagement/">https://www.viccompccancerctr.org/about-vcco/consumer-engagement/</a>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h) Health Consumers Alliance of South Australia <a href="https://www.hcasa.asn.au/">https://www.hcasa.asn.au/</a>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## INFORMATION TO INCLUDE IN THE AHRA CONSUMER AND COMMUNITY INVOLVEMENT KNOWLEDGE HUB

Tell us about the different types of information and resources you would like included in the knowledge hub

Please rate the importance to include each of type of information. You can also provide (OPTIONAL) comments about including this type of information:

Please rate the importance to include each of type of resource. You can also provide (OPTIONAL) comments or feedback about including each type of resource	Not important	Somewhat important	Very important	Extremely important
a) Academic publications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) Australian and international consumer and community websites	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) Australian priorities and policies for consumer and community involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) Case studies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e) Consumer and community involvement handbooks, guides and tip sheets	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f) Contacts and networks for Consumer and community involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g) Evaluation/project reports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h) Online training and learning opportunities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i) Resources for evaluation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j) Templates	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k) Videos	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l) Other (describe)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="text"/>				

## Appendix 3

### EXAMPLES OF OTHER ONLINE KNOWLEDGE HUBS

We are looking for examples of other knowledge hubs that you find useful. Examples can be general websites, web resources and information. Examples can be from health, research, community or other.

Exploring the features of these examples will help inform the design of the AHRA consumer and community involvement knowledge hub.

Tell us about any examples of knowledge hubs that you find useful:

Tell us about any examples of knowledge hubs that you find useful

☐ No, I don't have any examples

☐ Yes, I have examples (please provide details below)

ORGANISATION NAME

WEB ADDRESS

WHAT MAKES THIS SITE USEFUL?  
(e.g. easy to navigate, format, relevant information)

ORGANISATION NAME

WEB ADDRESS

WHAT MAKES THIS SITE USEFUL?  
(e.g. easy to navigate, format, relevant information)

ORGANISATION NAME

WEB ADDRESS

WHAT MAKES THIS SITE USEFUL?  
(e.g. easy to navigate, format, relevant information)

### NEXT STAGE IN DEVELOPING THE AHRA KNOWLEDGE HUB FOR CONSUMER AND COMMUNITY INVOLVEMENT

Stage 2 in this project is to conduct online co-design workshops to further develop the scope and design for the knowledge hub.

Would you like to be involved in a co-design workshop to help create the AHRA knowledge hub for consumer and community involvement?

Would you like to be involved in a co-design workshop to help create the AHRA knowledge hub for consumer and community involvement?

☐ Yes, definitely

☐ Unsure, but please keep me updated

☐ No, not right now

Please provide your contact details below and we will inform you about the upcoming (web-based) co-design workshops.

Name

Organisation

Position

Email

Thank you for your interest in the AHRA knowledge hub for consumer and community involvement.



For more information:  
Email: [info@ahra.org.au](mailto:info@ahra.org.au)

**[ahra.org.au](http://ahra.org.au)**