
An ounce of prevention

The impact of early community engagement on Phase 1 of the Melbourne Genomics Health Alliance

Melbourne Genomics Health Alliance Community Advisory Group - June 2016

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Alliance members



Supported by



Executive summary

In designing any healthcare system, policy, process or service, we need to consult with those whose health is to be cared for.

By doing this we have a greater opportunity of 'getting it right' the first time, preventing possible costly redesign work. If we understand what matters most to patients and their families, then we're better able to design care that is relevant, responsive to expectations and has the greatest chance of consumer uptake.

We believe this to be a first – bringing together a precinct-wide Community Advisory Group (CAG) on a project with significant public and personal health implications.

We applaud the Steering Group and Project Team for their foresight in appointing a CAG at the earliest stages of the Melbourne Genomics Health Alliance Project, ensuring that work to bring genomic medicine into the clinical setting is guided not only by scientific, research and clinical objectives, but by ethical considerations of community values, perspectives and priorities.

While we were guided by the Project's original priorities and time schedules, we were also able to bring new information to the table that sometimes altered these priorities and resulted in improved system designs and usability.

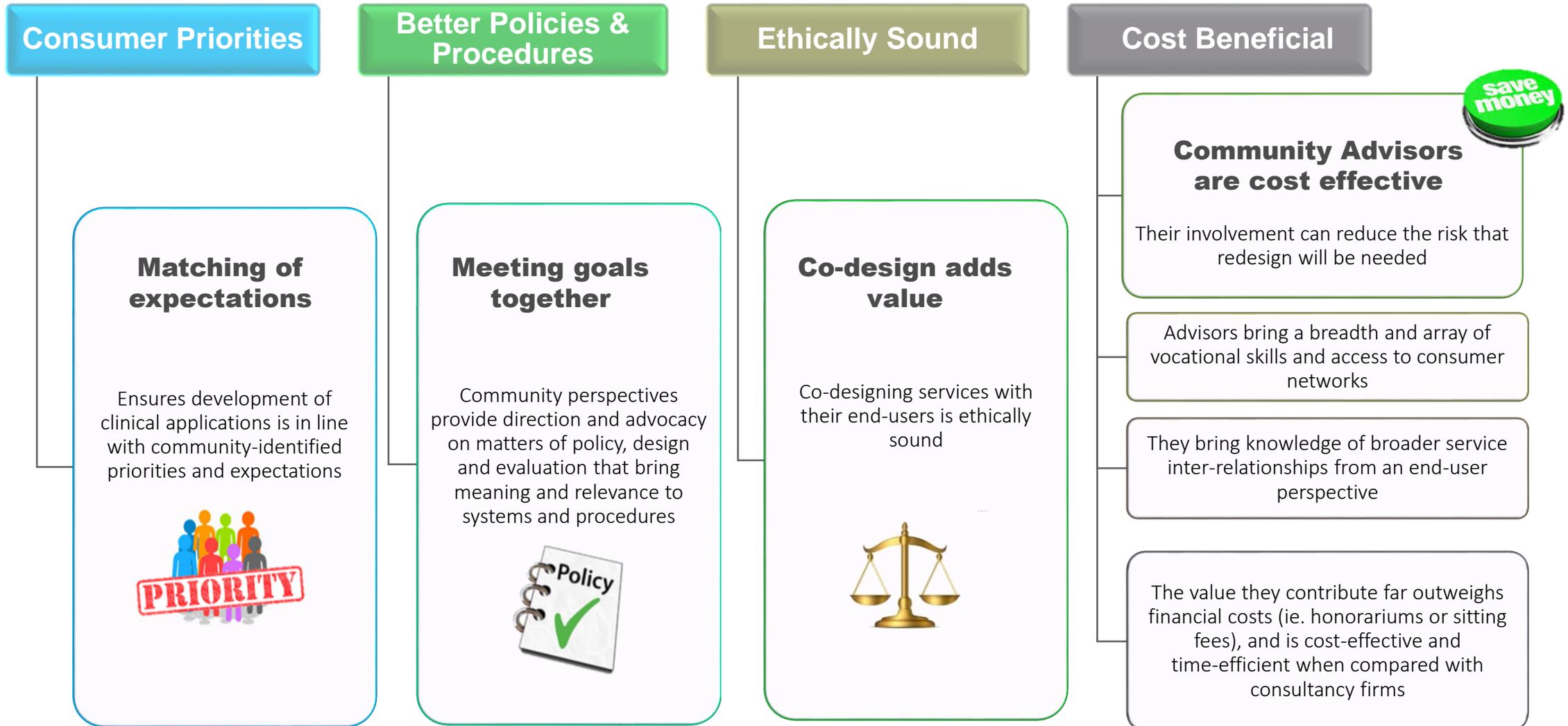
As a CAG, we have endeavoured to acquit ourselves to the best of our abilities according to individual skills, limitations around time, and availability – attending meetings, presentations and forums, responding to requests for experiential information through access to member networks, evaluating documents and public interfaces, and providing advice and assistance to the Project Team.

We believe the input and advice we provided during Phase 1 was sound and well-received, with many of the CAG's recommendations having been taken on board and actioned.

It is our hope that by providing this report on the impact of early consumer participation during Phase 1 of the Alliance, members will gain a greater understanding of the benefits available through co-design, and be encouraged to pursue and support increased consumer participation within their own organisations.



Why seek community input?



Evaluated Impacts

In order to evaluate the impact of community involvement in Phase 1, the CAG established a

COMMUNITY IMPACT REGISTER

The Register captured CAG-specific input and advice to the Alliance, along with any resulting benefits and impacts observed.

A number of key impact areas were subsequently identified by the Alliance Project Team [figure 1] and the following pages discuss these areas in more detail for the benefit of the Steering Group and Alliance members.

The Register continues to be maintained into Phase 2 of the Alliance.



Figure 1

"We have taken a very proactive approach in seeking out and acting upon community advice.

Possibly unique among genomics initiatives internationally, this ongoing community-based group determined when and how there should be consumer input into the program.

We have followed their advice and the outcomes have been greatly strengthened as a result."

A/Professor Clara Gaff
Executive Director
Melbourne Genomics

Communication, Visual Identity & Website

- **LAUNCH:** CAG provided the media with quotes regarding benefits of genomics in healthcare
- **REAL STORIES:** CAG used their media contacts and access to patient networks to provide real and compelling patient stories
- **PANEL SPEAKERS:** CAG spoke on community perspectives at events for professionals and general public
- **WEBSITE MODEL:** CAG provided examples of patient-friendly websites (including *LabTests Online* and *Inside Radiology*)
- **WEB CONTENT:** CAG reviewed words, visual content, priorities and structure to provided advice from a patient perspective
- **BRAND IDENTITY:** CAG provided feedback on identity development for the Alliance and for the integrated genome data platform

Impact

- Real patient stories and community perspectives appealed to media outlets and resulted in publicity
- Improvements to the website:
 - ❖ Wording, structure and content
 - ❖ Navigation
 - ❖ Clarity and flow of information

Financial & Strategic Planning

- **LOBBYING:** During the 2014 election campaign, CAG lobbied both major parties to commit funding to the Alliance
- **MEDIA:** CAG influenced the media to pressure both major parties to support the Alliance
- **COMMUNITY IMPACT REGISTER:** The need to track CAG's impact was recognised early on by members, resulting in development of the Register

Impact

- \$25m government funding gained
- Community Impact Register developed and template now available to all Alliance members

"CAG's support and input has been particularly important in helping convey the power of genomics to assist patients and their families. In this way, CAG has strengthened public communication of the Alliance's work and the case for government funding."

Professor James Angus
Chair, Phase 1 Steering Group
Melbourne Genomics

"The Community Advisory Group has been key in the development of patient-centred genomics information for the website."

Tim Bakker
Project Manager
Information Management & ICT
Melbourne Genomics Health Alliance



Information Management

- **SYSTEM PLANNING:** CAG involved in workshops and provided a list of priorities from the end-user perspective
- **TEST TRACKING:** By input to the Solution Architecture, CAG identified the importance of building test-tracking software into the patient-facing portal
- **PATIENT EXPERIENCE:** To optimise patient experience, recommendations were made around providing incremental levels of information during period where test results were pending



Impact

- A relevant and responsive foundation for the IM systems was developed
- Time was saved in identifying areas of the system which would be of most importance to patients, allowing the IM Team to factor them into foundational aspects of planning
- Suggestions around ease of access and improved utility will ensure the system-build is patient-centred and user-friendly



Clinical & Research Consent

- **RESEARCH CONSENT:** CAG assisted in developing community consultation process around research consent for clinical genomic data
- **CLINICAL CONSENT:** CAG provided in-depth analysis and recommendations into Melbourne Genomics Clinical Consent form, including suggestions around CALD-specific utility



Impact

- Forms provide a high level of clarity to patients around research and clinical consent

"The group's further input will be vital in developing the Information Management Governance Framework for sharing genomic information across the State of Victoria."

"This framework will consider patient and public expectations in relation to ethics, privacy and data security relating to the sharing of genomic information for clinical and secondary uses, such as for research."

Tim Bakker
Project Manager
Information Management & ICT
Melbourne Genomics Health Alliance

"The members of the CAG provided really practical and useful insights into so many aspects of Melbourne Genomics' work. Their involvement in media and educational activities, testing of a range of patient tools and surveys and contributions to the overall project plan were particularly valuable."

Ivan Macciocca
Clinical Project Manager
Melbourne Genomics Health Alliance

Evaluation & Patient Portal

- **PATIENT SURVEYS:** CAG highlighted the importance of patients' data, and also identified problems with survey return rates (including issues for CALD participants)
- **PORTAL CONTENT:** CAG advised on patient priorities for content during development of a mock patient portal
- **PORTAL STRUCTURE:** CAG developed particular areas of content and suggested changes to improve access and navigation
- **HEALTH LITERACY:** CAG provided advice on how such a portal could improve users' health literacy
- **PATIENT-FACING MATERIALS REVIEW:** CAG evaluated all Alliance patient-facing materials and information, including
 - ❖ Participation surveys
 - ❖ Workshop formats
 - ❖ Patient education materials & fact sheets
 - ❖ Invitation letter for patient focus groups

Impact

- Improved navigation within initial Portal mock-up
- Improvements to patient documentation in clarity, ease of use, relevance and language
- New website sections were also flagged for Phase 2:
 - ❖ A glossary of genomic terminology
 - ❖ 'Navigate your Results' section
 - ❖ Links to visual media content for education

"CAG member input has been instrumental in understanding the information needs of patients when they are undergoing genomic testing. The Group has also significantly assisted in the development of online surveys that enable the Alliance to understand patient preferences for providing additional health information to supplement a genomic test."

Tim Bakker
Senior Project Manager – Information Management & ICT
Melbourne Genomics Health Alliance

"In designing the Participant Survey, the CAG assisted in shaping the analysis of open-ended comments....[and] helped me better describe categories to more accurately reflect the wording used by participants regarding their hopes, expectations and concerns. CAG also suggested a flyer to advertise the CSIRO patient portal focus groups - rather than sending a very wordy letter - and identified some logistical issues for addressing around the attendance of adolescents."

Dr Melissa Martyn PhD
Evaluation Project Manager
Melbourne Genomics Health Alliance



Community Impact Register

Melbourne Genomics Health Alliance

COMMUNITY IMPACT REGISTER

The Community Impact Register is a live Google Doc that all CAG members are able to access. Items are flagged for inclusion at or between meetings, and the Register is administered by Alliance staff.

Demonstrating the achievements and impacts made by the CAG over the course of the project, the Register includes:

- Date of recommendation/advice
- Applicable project category
- Recommendation provided
- Action taken
- Benefits/impacts observed (by Project Team)
- Further item information
- Team member responsible for progressing item (not shown on sample)

| Date Raised | Category | Item | Actions | Benefits & Impacts observed | Details |
|-------------|--|---|---|--|--|
| 28/01/2014 | Laboratory workflow/process (scientific) | CAG should have input into the development of research result template, as this will guide what is said to patients | Janney Wale attended workshop, reinforcing use of regular practice and a fit for purpose report. | Robust and acceptable report | Input into the development of a research results template to be used when communicating to patients to ensure a clear and systematic laboratory workflows. This resulted in a strong convincing report. |
| 12/05/2014 | Online engagement /Communication | CAG should review the patient entered data tool for ease of usability/clarity | All CAG members provided comments, which were included. Issues raised covered: clarity and pitch of questions, logical flow of tool, produced a clearer introduction to the tool for participants. | greater usability by patients | Review and test patient portal prior to the tool being used by patients, to ensure greater usability for easy of access, clarity and understanding. We were able to determine improvements in the clarity of the questions asked, identify gaps in the process and easy of use for the end consumer. |
| 12/05/2014 | Evaluation/ Communication | Ask CAG to review the participant surveys for clarity and ease of use | All CAG members provided comments, via a modified delphi technique, which were included. Issues raised covered: use of appropriate language, clarity of questions & relevance of certain questions to answer research questions. | greater usability by patients | Review and evaluate the draft project participation surveys, with the emphasis on reviewing appropriate language, clarity and relevance of questions asked. This ensured the surveys were more user friendly for patients. |
| 12/05/2014 | Information management/ Education | CAG to provide input Melbourne Genomics information requirements | An initial list of requirements for patient access and use was developed and incorporated into the IM requirements, which will be used as the basis for the solution architecture | relevance and usability of future IM systems for patients | CAG members attended workshops to provide greater input into the project. By developing and providing an initial list of important requirements for patients to use and incorporating them into the IM requirements, we were able to ensure a relevant IM system was developed for patients ease of access and use. |
| 20/08/2014 | Communication/ Information Sharing | Seek input of CAG into the development of the Melbourne genomics website | Majority of CAG members provided comments, which were included. Issues raised included: use of appropriate language and explanations of genomics, suggestion to include patient stories, suggestions for logical flow of information from a consumer perspective and suggestions about website formatting | greater usability/relevance for patients | CAG input ensured website displayed relevant information for patients and was easy to navigate. Main improvements around use of appropriate language to ensure the website was understood by target audience, particularly around genomics and testing methods; Ensuring the logistics of the website flowed smoothly from the consumers aspect; Various formats were suggested to improve the usability of the website for end-users, including patient portals. A personal touch of including patient stories was also added as patients like to identify with others in similar situations. |
| 28/01/2014 | Communication/ Information Sharing | CAG members are available to support publicity and communication through media outlets | Liet H. provided a statement for the launch in the RCH press release Heather R. arranged for a SWAN family to be interviewed for Nov Herald Sun article Heather R. interviewed at the time of launch | Wide media coverage, election promise of \$25M | CAG networks utilised to gain publicity for project through press releases and newspaper articles. Also involved with lobbying politicians to ensure they committed money to genetic testing and research as part of the Victorian State Government election campaign. By attracting media attention and bipartisan agreement to commit funds we were able to continually pressure government to commit to their election promise and ensure funding was included in state budget. |
| 12/09/2014 | Workforce development/ Process (scientific) /Participation | Involve a CAG member in the Genomics in Medicine symposium | Liet H was a panel member for the ethical debate. Two CAG members attended the symposium | Enhanced understanding of clinical genomics: Professional attendees at the symposium were able to hear a community/personal perspective. | One of our CAG members participated in an ethical debate at the Genomics in Medicine Symposium. Two other CAG members attended and supported this symposium. The ideas was to enhance the understanding of clinical genomics by having medical professionals attend and hear personal and community perspectives of such delicate issues. |

Advice for the next phase

- Continue the integrated work of CAG into Phase 2.
- Request that in Phase 2 of the Project we seek to broaden community consultation through the appointment of additional CAG members or by further consultation to ensure the group represents the diversity of the community in terms of age, gender, ethnicity and disability.
- Develop and pursue initiatives to access input from CALD and Aboriginal communities to ensure the relevance of information resources and inform the consent process.
- Progress outstanding and pending recommendations on the Community Impact Register, including:
 - ❖ Lobbying work around increasing community access to, and availability of, Genetic Counsellors; and
 - ❖ Access to standardised consumer-friendly genomic test result reports to support best practice.
- Continue to resource and support the CAG to extend participation opportunities during Phase 2. Also develop succession planning protocols to ensure strength and viability of CAG into the future.
- Ensure CAG members have sufficient time to evaluate documents to allow for maximum input.



Melbourne Genomics
Health Alliance

Community
Advisory
Group

6 members

2 years

250
HOURS