

# An ounce of prevention: The impact of early community engagement on the Melbourne Genomics Health Alliance

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## Introduction

Genomic medicine is a powerful tool that can help patients by improving the diagnosis, treatment and prevention of disease. The Melbourne Genomics Health Alliance was established to address the challenge of introducing the processes and systems to support the appropriate use of genomic sequencing into clinical care in the state of Victoria, Australia. Seven founding members of the Alliance came together in 2013 with a shared interest in bringing genomics into healthcare to benefit patients. The Victorian Government supported extension of the project with an allocation of funding.

The members recognised that community advice and partnership/co-design were vital to this project and established a Community Advisory Group (CAG), within weeks of its founding, making it one of the world's first community-based groups to advise a major genomics' project. The CAG guided input from patients and the community in every aspect of the demonstration project work.

The Alliance is building a proof-of-concept system comprising the infrastructure, software, policies and procedures for genomic sequencing in clinical care, encompassing the full pathway from counselling and consent to return of results and the challenges of additional findings. The CAG continues in its role into the next 5-year phase of the project involving additional public hospitals.

## Objectives

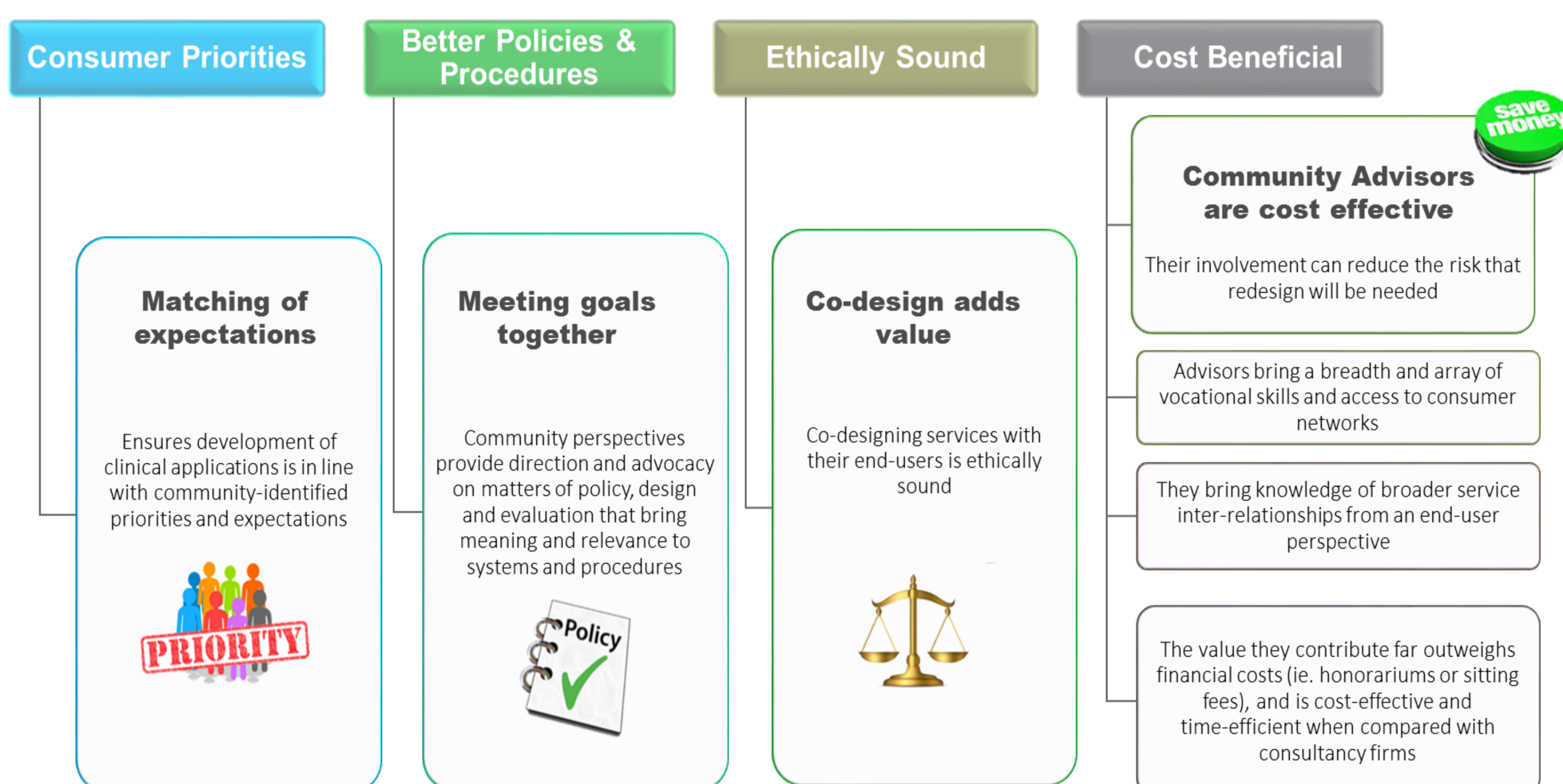
Alliance: to facilitate the integration of genomic sequencing into clinical practice in Victoria.

Community Advisory Group: to provide a platform for broad community input for use by the Alliance, and as a source of informed community members to participate in working groups, selection panels, discussions and events.

## Why seek community input?

When the Melbourne Genomics Health Alliance established a Community Advisory Committee, the CAG became the first to be established by a major genomics project.

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



## Example 1: Communication, visual identity and 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
  - Clarity and flow of information
  - Navigation

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

Project Manager  
Information Management & ICT  
Melbourne Genomics Health Alliance

## Methods

CAG members attend meetings, presentations and forums, respond to requests for experiential information through access to member networks, evaluate documents and public interfaces, and provide advice and assistance to the Project Team.

The CAG developed its own **Community Impact Register** to evaluate its value to the Alliance. The Community Impact Register is a live Google Document 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 name
- ✓ Advice given
- ✓ Action taken
- ✓ Benefits/impacts observed (by Project Team)
- ✓ Team member responsible for progressing item (not shown on sample)

## Example 2: 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."*

Chair, Phase 1 Steering Group  
Melbourne Genomics

## Outcome

Evaluations demonstrated that CAG members provided advice during Phase 1 which was sound and well-received, with many of the CAG's recommendations taken on board and actioned.

The report on the impact of early consumer participation during Phase 1 of the Alliance meant that member organisations of the Alliance gained a greater understanding of the benefits available through co-design, and were encouraged to pursue and support increased consumer participation within their own organisations.

Alliance members



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