Australian Genomics

Research Snapshot

June 2021

Genomics in the community

Australian Genomics in collaboration with Patient Support and Advocacy Groups identified and responded to a need for patients and the community to have access to reliable and evidenced-based resources on genomics and its implications.

Background

Australian Genomics is committed to preparing Australia for genomic medicine.

To implement this testing into the healthcare system in a responsible manner, both patients and the general community will need to feel they understand the outcomes, recognise the risks and benefits, and have reasonable expectations of the test.

As the general population becomes increasingly exposed to genomics through a number of channels, patient and community groups report that the general community has limited genomics knowledge and do not fully understand the limitations of this technology.

We recognise that a key element of successful implementation is the provision of reliable, relatable and clear information on the outcomes, risks and benefits of testing for patients and the general community.

Patient Support and Advocacy groups (PSAGs) play a significant role in disseminating information to the wider community. It is very important they receive reliable and current information to ensure the community is accurately informed of genomics and its impact.

This is why the Genomics in the Community initiative, a collaboration between Australian Genomics and Patient Advocacy Groups, was created.

Project aims

The Genomics in the Community project has the overarching aim of providing consistent, accurate and evidence-based messages to PSAGs and the community on the use of genomic technology and its benefits and limitations.

The project has three main outcomes:

1) A consistent and accurate message regarding genomics, promoted through PSAGs to the wider community

2) Clear and concise patient facing materials to be used to inform patients and the general community about genomics and its benefits and limitations

3) Robust relationship between Australian Genomics and PSAGs

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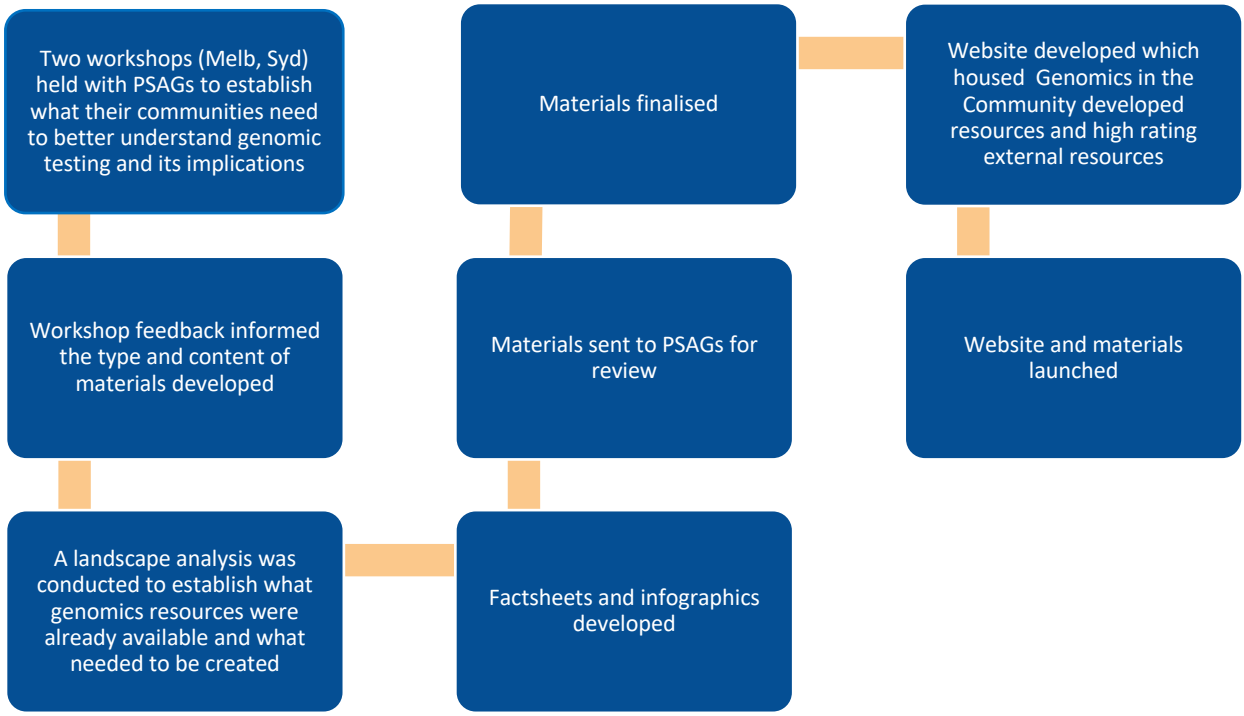
To deliver the outcomes outlined, the project followed the process below:



Key findings

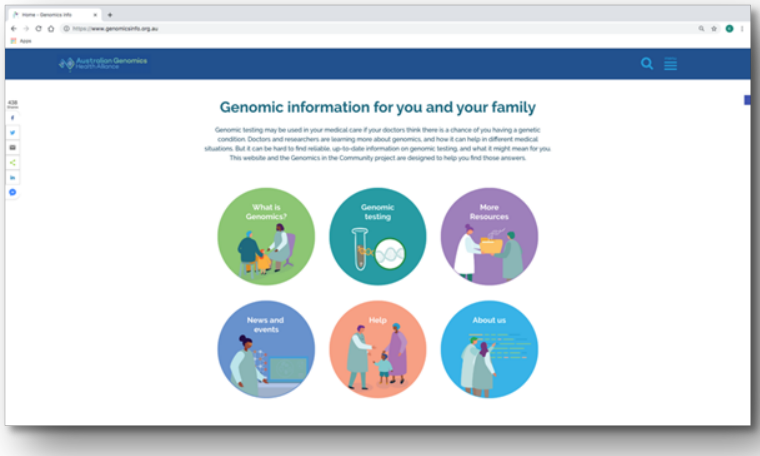
The Genomics in the Community initiative has developed four factsheets and two infographics on the topics of genomics, genomic testing, data sharing and insurance.

The products address key areas of concern established through the workshops.

We encourage everyone to access the site at **genomicsinfo.org.au**

The genomicsinfo.org.au website was launched in March 2019.

The website presents a whole range of easy-to-understand genomic materials, including the Genomics in the Community developed resources and others shared from research and medical organisations.



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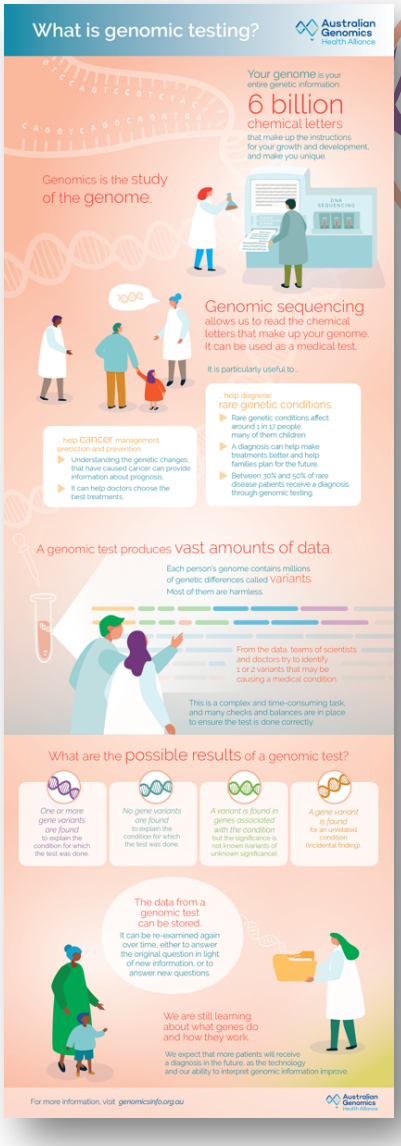
Potential impact

The **genomicsinfo.org.au** website has been met with very positive feedback from many different stakeholder groups.

Clinicians have been sharing the website with their patients and PSAGs. Even those not involved in the initiative have been sharing the website with their communities.

Already there has been interest from external organisations to adapt the resources developed through the initiative for other, more specific populations such as acute care and oncology.

Australian Genomics is eager to work collaboratively on the project and encourages individuals and organisations to make contact should they have an interest in this area.



Conclusion

Australian Genomics in collaboration with PSAGs identified and responded to a need for patients and the community to have access to reliable and evidenced-based resources on genomics and its implications.

The development of genomics materials and the subsequent website have been very well received by PSAGs and health professionals.

Future work by the initiative will centre on the development of resources for targeted groups.

These include people from a CALD (Culturally and Linguistically Diverse) background and children and adolescents. It will focus on the development of materials in other formats such as videos and animations to service a wider audience.

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