Genomic Health Care for Victoria - A discussion paper

Public feedback on the ***Genomic Health Care for Victoria – A Discussion Paper*** will be used to shape a new genetic/genomic healthcare strategy. Once the strategic framework is finalised, a statewide genetic and genomic design, service and infrastructure plan will be developed.

Please provide your feedback to the ***Genomic Health Care for Victoria – A Discussion Paper*** using this document and submit it via email to genetics@dhs.vic.gov.au or post it to:

Genetics and Health Technology Unit
Department of Health and Human Services
GPO Box 4057
MELBOURNE VIC 3001

Question 1. Key factors

The discussion paper lists six groups of issues:

- Literacy – public, health workforce
- Personalised (precision) medicine including personalised prevention
- Co-productive healthcare
- Ethical, legal and social issues associated with genetic and genomic information
- Ease and equity of access to medical consultation, testing and management/Models of care and service systems capacity and capability
- Value for money

Are these correct? Are there other factors or issues likely to impact genetic and genomic health care that should be included in the strategy rather than in a statewide service and infrastructure plan? If so, what are they?

Syndromes Without A Name (SWAN) Australia recognises the six issues mentioned above as being key factors that will impact genetic and genomic health care in the future. There are two key issues we would like to see included as key factors; the first is around the impact of **health research**, which needs to be funded on an ongoing basis for genomic health to be able to grow and be supported. The second issue is around **data management and the infrastructure needed to support it;** the process of how data is collected, how it will be used and how will it be stored in a secure manner to give consumer confidence when using genomic health in the future.

Question 2. A new strategy for Victoria

The discussion paper proposes:

Vision:

Optimising the health of all Victorians through appropriate integration of genomics into public health care.

Mission:

1. To optimise the detection and management of heritable disorders and infectious diseases and risk management of heritable predispositions.
2. To predict and optimise the management of the complications of disease.
3. To prevent the predictable complications of treatment.

Objectives:

1. To facilitate access for all Victorians to genomic knowledge to advance their health and wellbeing.
2. To contribute to Victorian health system sustainability through judicious use of genomic knowledge.
3. To leverage existing research and development in Victoria, and more broadly, to benefit all Victorians.

Principles

1. Patients as partners.
2. Equity of access - equal response for equal need.
3. The future is uncertain; the health system needs to promote responsiveness and sustainability.
4. All decisions and actions need to be ethically defensible and acceptable to the community.

Are the proposed Mission, Objectives and Principles appropriate to guide genetic and genomic health care developments into the future? If not, what should be changed?

Vision and Mission

SWAN supports the vision and mission outlined above.

Objectives

SWAN would like to see careful planning around access for all Victorians to genomic knowledge to advance their health and wellbeing. Access to genomic testing should not be determined by postcode, income, cultural background, level of intelligence or knowledge around genomic health. Careful consideration needs to be given around genomic information and explanations, as the terminology used by health professionals is not always easy to grasp for "every day" consumers.

Clear communication guidelines and protocols will need to be established around what is genomic health and how it will benefit consumers to ensure the key objectives are met. Currently there are a lot of misconceptions about the cost and accessibility of genome sequencing amongst SWAN families, many of who see advances in genetic testing as the key to gaining a diagnosis for their child. In order for consumers to have access to genomics, they first need to understand what it is, to take advantage of it.

Existing research should be used to advance genomic medicine but the Government needs to commit to fund ongoing research in this area too. Many SWAN families have benefited from the Governments contribution to the Melbourne Genomic Health Alliance and it is essential that the Government continues to invest, to ensure a smooth transition for all Victorians who want to benefit from genomic health.

Principles

SWAN supports the principals and would like to see that they are followed in practice and not just on paper in the new genetic/genomic healthcare strategy. Particularly the principle around the patient being a partner. Genomic health is about personalised medicine after all, and needs to be delivered through a person centred approach.

Question 3. Action areas

The discussion paper identifies five priority areas for action:

- Engaging all stakeholders and building awareness;
- Strengthening the evidence base;
- Clarifying the ethical and legal framework;
- Strengthening the service system; and
- Driving innovation.

Are the proposed five priority areas the right ones to achieve the vision or are there other areas of higher priority that should be considered?

SWAN agrees with the five priority areas but believes 2 other areas should also be a priority. The first is around **data management,** which we addressed also as a key factor in question one. The second area is around **workforce development and support.**

It is often a maternal health nurse or the family GP who first identify that something is wrong with a SWAN child. These key professions which support so many SWAN families at the grass routes level, will need to be included as stake holders when building awareness.

SWAN families have identified that not having access to genetic counsellors in the past when receiving genetic test results, has been one of the biggest disappointments and been detrimental to their families mental health. For SWAN families who have had access to genetic counselling, they have had a much more positive approach to receiving genetic information, as they have identified the experience with feeling supported.

The other main issue around workforce development is that SWAN families often don't feel their child is cared for by a multi disciplinary team. SWAN families often have to repeat their story and have the impression that their doctors don't communicate with one another. Different professionals need to relate and communicate with each other if genomic health is to work across every level to achieve personalised medicine.

Question 4. Engaging and building awareness

The discussion paper proposes the following actions:

Action 1: Work with consumer advocacy groups and other stakeholders to develop a robust communications and engagement strategy to raise public awareness of genomic health care and implement a genomics literacy program for the Victorian community.

Action 2: Scope a 'Family History' project to raise awareness of the genetic basis of disease and assist in developing personal and community responsibility for health and wellbeing.

Action 3: Establish a trusted and accessible portal of information for the general public through the department's Better Health Channel.

Action 4: Liaise with relevant clinical stakeholders, and their training bodies, to ensure that genetics and genomics are incorporated into undergraduate and post-graduate training and continuing professional development.

Are the proposed actions the right areas to achieve the vision or are there other actions of higher priority that should be considered?

As SWAN is a consumer advocacy group, we couldn't agree more with the need to include consumer advocacy groups who are often in touch with consumers at a grass roots level. SWAN would be willing to assist Government to increase public awareness of genomic health care. Genome sequencing will lead to more answers for families of undiagnosed children. Building consumer confidence around issues such as, personal information will be an ongoing task. Clear guidelines will be need to be developed around how personal information is recorded and stored and how DNA samples are collected, stored, de-identified and remain safe.

Consumer education needs to be addressed as important action around family health care. Education through existing platforms such as the well-respected "Better Health Channel" will be a pivotal tool in doing so. The use of patient consumer health groups, website and social media tools could also be used if the information was streamlined. It is important consumer groups involved deliver the same messages and accurate and up to date information.

Current information about genomic health needs to be accessible to everyone, not just the medical profession. Community health centres and GP's will often be the first point of entry for consumers for genomic health, so it is imperative that they are well trained and educated in this area. Genomic health information incorporated into health professional training as you stated in Action 4 will address this. However as SWAN is a voice for families of undiagnosed genetic diseases, we cannot stress to the Government enough the crucial role geneticist play with diagnosing previously undiagnosed genetic conditions after genetic testing. The relay of genetic information should require the specialist support of genetic counsellors who play a vital link in supporting our families. We need more of them! We need them to be registered and accredited. They need to be able to provide Medicare and private health insurance rebates and they need to be recognised as NDIS provider.

Question 5. Clarifying the ethical and legal framework

The discussion paper proposes the following actions:

Action 1: Support collaborative research of the ELSI of genomics in clinical practice.

Action 2: Work with consumer advocacy groups and other stakeholders to develop a robust communications and engagement strategy to raise public awareness about the questions raised by the ELSI of genomics.

Action 3: Clarify the ELSI priorities for consideration and action both locally and nationally.

Action 4: Advocate nationally for an update on the implementation, currency and scope of the Australian Law Reform Commission's 2003 report *Essentially Yours: The Protection of Human Genetic Information in Australia*.

Are the proposed actions the right areas to achieve the vision or are there other actions of higher priority that should be considered?

SWAN agrees with the actions outlined around and an ethical and legal framework. Issues that need to be considered are around privacy, health ramifications of not only the gene mutations of the disease trying to be identified, but also of that of any incidental findings that may be discovered in the process and how best to manage these. Individual rights vs family rights will be continued to be debated and then there are concerns over who owns the data/information once it has been discovered.

A review of the Law Reforms Commission's report needs to be updated to include the advances in genetic testing and genomic health. A strategy needs to be developed to ensure consumers have confidence that their personal information is collected in a secure manner, stored in a safe de-identified way and patients understand the consent process including the meaning of "dynamic consent". It is imperative that strategies around the protection of genetic data are developed and communicated at a level the "average" consumer can understand.

Question 6. Adopting the evidence

The discussion paper proposes the following actions:

Action 1: Evaluate the clinically and ethically appropriate role of genomic sequencing in clinical practice and infectious disease surveillance.

Action 2: Develop a decision-making framework to support clinically and ethically appropriate integration of genomic knowledge into Victorian healthcare.

Are the proposed actions the right areas to achieve the vision or are there other actions of higher priority that should be considered?

SWAN agrees with both actions. However, evaluation should not just cease when genomic health is integrated into personalised medicine. Consumer input will be valuable in evaluating the use of genomic health in health care. The Melbourne Genomic Health Alliance should be commended for establishing a consumer advisory group early in their project who offer consumer input around clinical and ethical issues around genomic health.

Victoria is a leader in health care, but that is not to say we cannot learn from other states and other nations. The approach to genomic health care needs to be realistic e.g. you would only order a genome sequencing test if it was economical viable to do so.

A decision-making framework will be needed as a reference point to ensure Victorian health professionals deliver a consistent, collaborative and consumer focused approach to genomic health.

Question 7. Building service system capacity

The discussion paper proposes the following actions:

Action 1: Continue mainstreaming of genetic and genomic healthcare across the service system.

Action 2: Develop a statewide genetic and genomic services design and infrastructure service plan, including workforce capacity.

Action 3: Develop a plan for the integration of pathogen genomics into the state-funded health system.

Are the proposed actions the right areas to achieve the vision or are there other actions of higher priority that should be considered?

SWAN agrees with the action to continue to expand genetic and genomic health care across the health industry. The Melbourne Genomics Health Alliance is leading by example in building a mainstream approach to genomic health care and should be commended in their approach to setting up guidelines and best practice around genomic health care. However, genome sequencing tests have mainly been provided as part of research projects at this point in time and currently the consumer does not pay for them.

A statewide united approach is needed to develop a service design and infrastructure service plan. This can then support training and development of a workforce, which will support genomic health moving forward in Victoria. The Government will need to commit ongoing funding to support geneticists, medical researchers, laboratory technicians, bioinformatians, genetic counsellors and other infrastructure around data management and information systems, and the legal requirements around the genomic health care framework. There is no point in moving forward with genomic testings unless these fundamentals are funded and in place to support them.

SWAN agrees that there should be a plan for the integration of pathogen genomics and it should be state funded. Patients seeking answers should not be limited by cost. At the same time, genome sequencing should only be offered in place of another type of test if it will be a cost saving measure.

Question 8. Driving safety, quality and innovation

The discussion paper proposes the following actions:

Action 1: Establish an independent advisory body to provide ongoing advice on Victorian genomic healthcare provision and drive adoption of innovative practice.

Action 2: Leverage existing state and national research, innovations and biotechnology funding to support translational research in genomic healthcare.

Action 3: Position Victoria's public health reference laboratories to take a national leadership position in the development and implementation of national microbial and infectious disease genomics policy and expertise.

Are the proposed actions the right areas to achieve the vision or are there other actions of higher priority that should be considered?

SWAN agrees with the need for establishing an independent advisory body to provide ongoing advice on Victorian genomic healthcare provision and drive adoption of innovative practice. This independent body should be comprised of; different heath experts, including clinicians and researchers, genetic counsellors, consumer advocacy groups, information management experts and legal representatives.

It is practical to utilise existing state and national research, innovations and biotechnology funding to support translational research in genomic healthcare. There is no point in recreating systems if everything is working. We should be building on existing structures and frameworks. We need a transdisciplinary approach to health care.

If Victoria is to become a leader in genomics, laboratories need to be accredited and operate using the same methods for a consistent approach. Data will have to be stored and analysed using the same methods. SWAN believes our laboratories have the capacity to become a national leaders in genomic health care.

General comments about the document

If the Victorian Government is committed to pursuing excellence in health care in partnership with patients, communities and service providers, they need to involve all parties in the delivery process of developing a framework. SWAN Australia thanks you for the opportunity to provide feedback on this discussion paper and would welcome the opportunity to discuss the State Governments genetic/genomic health care strategy further with you.