**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

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
* 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? |

1. **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? |

1. **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? |

1. **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? |

1. **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? |

1. **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? |

1. **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? |

1. **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? |

**General comments about the document**

|  |
| --- |
| e.g. document structure, use of vignettes, general readability. |