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A/Prof Julie McGaughran
Chair, Australian Genomics National Consent Working Group
Australian Genomics Health Alliance
50 Flemington Road
Parkville
Victoria 3052

T: (03) 9936 6345

E: australian.genomics@mcri.edu.au

Dear A/Prof McGaughran,

## Re: National clinical consent form for genomic testing - Australian Genomics

The Royal Australian College of General Practitioners (RACGP) welcomes the opportunity to provide feedback and comment in relation to the Australian Genomics Health Alliance's (AGHA) *National clinical consent form for genomic testing*. The RACGP congratulates AGHA in producing these documents on an important and challenging topic.

## **Overall comment**

There are many important considerations for genomic testing, including when it is conducted, how the test is implemented and what to do with the results (especially as costs continue to decrease, and availability and accessibility increase). The development of a clinical consent form for genomic testing is therefore a welcome initiative.

The RACGP understands the focus of the consent form, and supporting information, is for genomic diagnostic testing only. The RACGP therefore suggests making it clear to both the clinician and patient that these documents are predominantly for patients where genomic testing is being performed to help make a diagnosis (usually of a rare condition).

Alternatively, the RACGP encourages AGHA to modify both documents to cover other potential reasons for genomic testing (eg carrier screening, disease-risk assessment, pharmacogenomics testing).

Importantly, the current, and any future, consent form and supporting information should be available for culturally and linguistically diverse communities, and easily accessible for all clinicians. The creation of an interactive PDF would help reduce the need to print and scan the consent forms.



## **Specific comments**

The RACGP provides the following recommendations regarding the form and information sheet:

- Clinical consent form for genomic testing
  - Suggest changing the term 'change' in the third dot point to: 'This test may find a genetic result associated with ...' to provide better clarity.
  - Under the heading 'My results'
    - Suggest changing 'I agree that:' to 'I understand that:' as the patient needs to understand these issues before they 'agree' to the test
    - The use of the term 'others' in dot point four is unclear as it does not clarify who these 'others' are
- Genomic testing information sheet
  - Under the heading 'Genomic testing'
    - It may be helpful to provide a short explanation of what DNA is, including spelling out the acronym to assist in patient understanding.
    - Suggest additional text for the last sentence of the first paragraph: 'Genomic testing is
      done to identify gene variants that do have an impact on a gene's function and that
      cause genetic conditions which may affect your health' as patients are not necessarily
      interested in genetic conditions, but on how these may affect their health
    - Third paragraph: Suggest changing 'A genetic diagnosis provides families with ...' to 'A genetic diagnosis **may** provide families with ...'

Thank you once again for the opportunity to provide feedback and comments. We look forward to hearing about the progress and outcomes of these documents.

Yours sincerely

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Associate Professor Charlotte Hespe

Vice-President