

# Genomics Video-Assisted Digital Consent Pathways: An Australian First Study in Enhancing Patient Education and Consent Collection

## Summary:

Genomic testing can be complicated, complex, and often done within time constraints at the end of a stressful clinical genetics appointment. Providing parents/families with sufficient information for informed consent is challenging, with the possibility of significant issues arising from genomic testing, such as unexpected paternity and incidental findings, not being given full consideration.

## The Experience:

To overcome this, The CEIH in partnership with the Women's and Children's Health Network, has developed an informational animated video about genetic testing and an online consent form based on a national genetic testing consent form.



Commission  
on Excellence  
and Innovation  
in Health



- ↑ Improved patient literacy and understanding of genomic testing
- ↑ Improved efficiency and effectiveness of patient education
- ↑ Enhanced patient engagement with 97% of patients satisfied with the digital service



## Genomics video assisted consent pathway aims to improve patient understanding of testing.

People can provide consent in the comfort of their own homes, with time to reflect and properly consider the potential impacts.

In addition to making consent more user-friendly, the PRGU at WCH are also digitally collecting personal and family history information needed for a Clinical Genetics outpatient assessment and appointment, using the same platform.

In 6 months, the pathway was completed by 365 parents/patients, 208 completing a digital consent online:

- Improved patient literacy
  - 85% of patients found the pathway provided information they otherwise did not know
- Improved efficiency and effectiveness of patient education
  - 88% of patients responded that having access to the digital service helped them prepare for their clinical visit
- Enhanced patient engagement
  - 97% of patients are satisfied with using a digital service

*"Digital genetic testing consent and digitally collected patient medical history have become critical steps in the patient journey at WCH.*

*This exciting approach to consent and medical information collection has a positive effect on the unit's workflow and can be applied to other units to improve patient experiences."*

### **Professor Christopher Barnett**

Head Paediatric and Reproductive Genetics Unit (PRGU),  
Women's and Children's Hospital (WCH) & Statewide Clinical  
Genomics Lead, Commission on Excellence and Innovation in  
Health (CEIH)