Easy Read Version

Making genetic health care decisions together

This booklet is a summary of an **academic article**

An **academic article** is something that experts write

- about what they know

The experts in this article know about

- people with intellectual disability
- genes
- medical health care

The full academic article is called

“Shared decision-making for genetic tests with children and young people with intellectual disability: Considerations for inclusive, person-centred and respectful approaches”

This academic article has recommendations

- for doctors

We want doctors to

- help people with intellectual disability

make decisions about their health

Why we made this academic article

We all go to the doctor sometimes

People under 18 years old go to the **Paediatrician**

A **Paediatrician** is a doctor that knows more about children and young people under 18 years

At the doctor everyone has the right to make decisions about

- their health
- medical tests

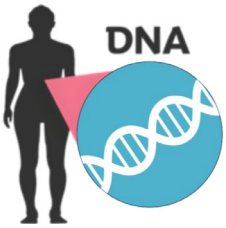
Children and young people need help making decisions

People with intellectual disability also might need help

- making decisions

Sometimes people need to get more medical tests

- to understand what might be different



These tests can be a **genetic test**

Doctors do a **genetic test** by taking a

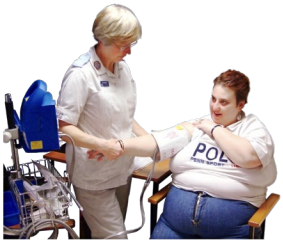
- blood sample

- saliva sample.

A genetic test will look at our **genes**

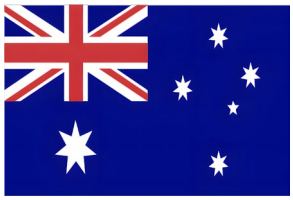
Our **genes** are small things in our body

That make us the way we are



Our genes can explain why we have

- medical issues
- intellectual disability.



In Australia doctors can do different tests

Some of these tests are

- chromosomal microarray
- Fragile X PCR
- genome sequencing.

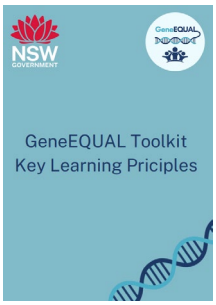
We can tell our doctor if we

- want a genetic test
- do not want a genetic test
- are not sure about a genetic test

Making decisions about genetic test is hard

Explaining what a genetic test is also hard

We have a resource to help



The name of the resource is

- GeneEQUAL Educational Toolkit

A lot of people helped with the resource

- people with intellectual disability
- academics
- teachers

- doctors

People that helped with GeneEQUAL Educational Toolkit wrote this article.

Recommendations

We want doctors to

- help people with intellectual disability

make decisions about their health

This includes Paediatricians

Paediatricians talk with

- children
- young people
- families

Paediatricians sometimes talk about

- genes
- genetic tests
- genetic test results

We have 5 ideas for Paediatricians to make things better

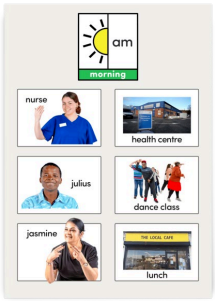
Idea 1 is to make changes in how they explain things to

- children
- young people
- families

This means to use different ways to give information

Paediatricians can

- talk
- show something written
- use **visual supports**



Visuals supports are when pictures are used

- to help explain ideas.

Idea 1 also means to have more time

- to explain

And to make sure the person understands.

We can check if someone understands

- by asking to repeat the information

Idea 2 is to give accessible information

When the doctor asks if we are Okay

- we need to give **informed consent**

Informed consent means we understand why we

- say yes
- say no

We need accessible information

Paediatricians can ask people

- about their preferences for accessible information

Some examples of accessible information are

- Easy Read booklets
- videos
- better verbal explanation.

Idea 3 is let support people help only if needed

Support people or caretakers can help us with

- transport
- emotional support
- appointment coordination

Paediatricians have to ask people

- if they want their support person to be there

Our support person

- can help us make choices
- cannot make choices for us

Our support person can also

- help the Paediatrician explain information

Our support person has to make sure we

- understand the information
- make our own choices.

Idea 4 is that everyone has to feel safe at the doctor

Sometimes young people feel scared at the doctor

Doctors do not ask about their

- opinions
- preferences

But they have to ask

Doctors can also help by

- learning about intellectual disability
- use plain English
- be kind

Doctors can also help by not using bad words

- mutation
- risk
- disorder

Idea 5 is to better explain genetic test results

A genetic test result is hard to understand

It is also hard to understand

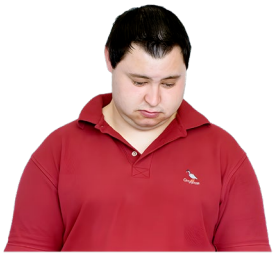
- what to do with a genetic test result
- what happens next
- what it means for our family

To understand a genetic test we might need

- extra support

- more time

- Easy Read information

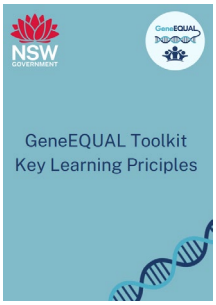


Sometimes we might need support

- that the doctor cannot give

But the doctor can help us find it

- emotional support
- financial support
- peer-support groups



The GeneEQUAL Toolkit has more ideas

- for doctors
- for Paediatricians
- for people with intellectual disability

Some of the ideas are

- send information before the appointment

- have a quiet space

- introduce yourself

More ideas are

- get to know the person

- give choices

- explain what will happen

Mofe information

The GeneEQUAL team made this booklet

We use Photosymbols

The GeneEQUAL website has

- the full article and
- more information

Go to

www.genequal.com

or scan the QR code.