

## Easy Read Version

### Health care choices for people with intellectual disability:

- what helps
- what does not help



This booklet is about

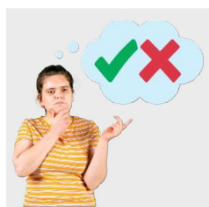
- people with intellectual disability
- and their **health care choices**.

### What we know



**Health care choice** means you can choose

- what happens to your body.



Examples of health care choices are to

- take medicines
- have a surgery
- have a blood test.



Many people

- can
- want to

make their own health care choices.



There are rules that say

- everyone should have health care choices
- everyone should get information they understand
- health care workers must give this information.



The Australian Charter of Healthcare Rights

Each country has different rules.

In Australia, one of the rules

- is the Healthcare Charter of Rights.



To read it you can go to

**[www.bit.ly/healthcare-rights-A4](http://www.bit.ly/healthcare-rights-A4)**

or scan the QR code.



Or you can ask your doctor

- to look at it together.



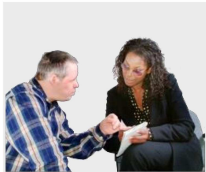
Health care workers should help people

- make their own health care choices.



Health care workers are

- doctors
- nurses
- other health care people.



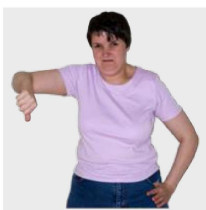
Health care workers must give information

- that people can understand.



This helps people

- make their own health care choices.



People should make choices they want.

Saying no is also a choice.



Many people with intellectual disability

- have bad experiences with health care
- do not get to make health care choices.



We need to find out

- why these problems still happen
- how we can fix them.



This way we can make health care better

- for people with intellectual disability.

## What we did



GeneEQUAL looked at what researchers

- already know about how people make health care choices.



GeneEQUAL is a program to

- help people with intellectual disability get better health care.



You can find out more about GeneEQUAL

- on our website

**[www.geneequal.com](http://www.geneequal.com)**



or scan the QR code.



GeneEQUAL wanted to know what

- helps
- does not help

people make their own health care choices.



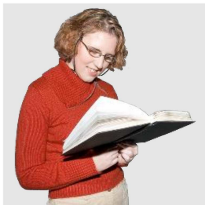
## Researchers are people

- who find more about different things.

Researchers have already asked different people

- about health care choices.

GeneEQUAL looked at this research.



We looked at 88 research studies.

23 studies were about

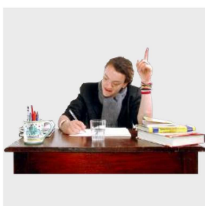
- how people make their own health choices.

From these studies we found six ideas.



We worked with researchers with intellectual disability to

- check the ideas
- make this Easy Read summary
- plan how to share our ideas



We will now talk about the ideas we found.

## What we found out

### Idea 1 is about health care workers.



Many health care workers do not

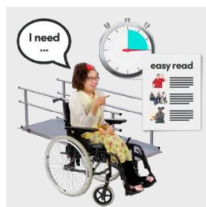
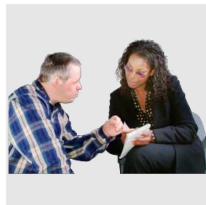
- know how to support people
- treat people fairly
- give options to people

when they make health care choices.



There are rules that say health care workers

- should help people make their own choices
- must treat people as equals
- must give information to help people make choices
- must make **reasonable adjustments**.



**Reasonable adjustments** are things health care workers

- can do to make things easier for people.



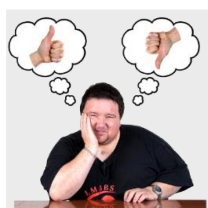
Examples of **reasonable adjustments** are

- give Easy Read information
- book longer appointment times
- use plain English
- explain things in different ways.



Many health care workers do not

- follow these rules
- give health information that people can understand
- treat people with respect
- give people choices.



This makes it very hard

- for people to make a health choice.



Health care workers need more training to

- do good health care
- explain things in plain English
- help people make their own choices.

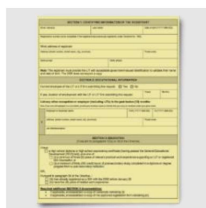


## Idea 2 is about health information people can understand.



People need information they can understand

- so they can make their own health care choices.

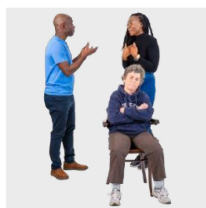


Many people are given

- no information
- not enough information
- information that is hard to understand.



This makes it hard to make health care choices.



Some health care workers give information

- to carers or a support person but not to the person.



Health care workers should give information

- to the person
- that the person can understand
- in many different ways

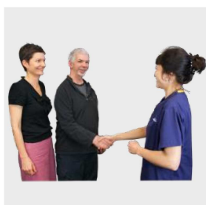
so the person can make health care choices.



One way is to give Easy Read information

- to help people understand their health care choices.

### **Idea 3 is about the choice of a support person.**

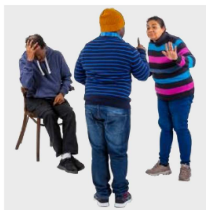


Support people can help

- talk to health care workers
- explain health information to the person
- support people's feelings
- remember important information.



This can help people make health care choices.



But some people with intellectual disability think

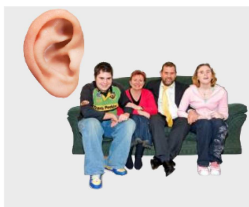
- support people can make it harder

to make health care choices.



Some support people

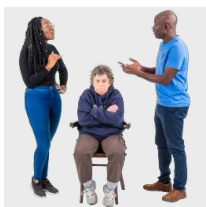
- think the person can not make choices
- do not listen to the person's choices
- do not let the person make a choice.



Some doctors and nurses

- only talked to the support person
- only listened to the support person

when making a health choice for someone else.



Lots of people did not like this.

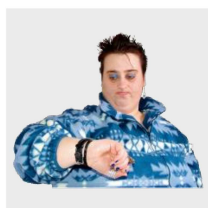
## Idea 4 is about problems in the health system.



People sometimes need more

- time to think
- appointments

to make health care choices.



Health care workers need more time to

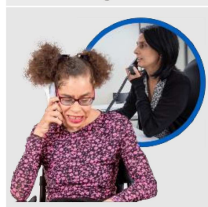
- explain things in plain English
- help people make their own health care choices.



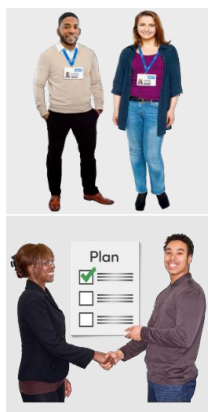
People want support to make health care choices.

Such as

- a telephone number to call
- a website



for more health care information.



### Health care workers want more

- time to spend with people
- training about how to explain things
- resources
- health system rules

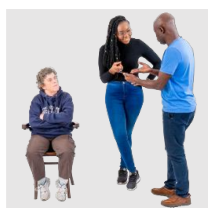
to help people make health care choices.

### Idea 5 is about how to support the needs of different people.



### Some people find it harder than others

- to make choices.



### This can be because they

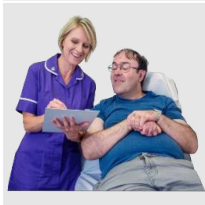
- did not make health choices before
- did not know they can make health choices
- had bad health care experiences in the past
- find it hard to speak up.



### People might

- say they understand information
- agree with a choice

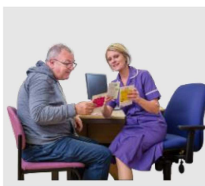
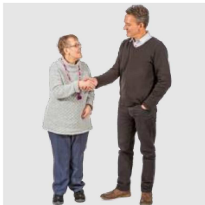
when they actually do not.



### Health care workers should

- check people understand the information
- remind people they have choices
- ask people if they need extra help
- give extra help to people who find it hard

to support them to make health care choices.



### Health care workers can

- give people a chance to speak up
- give choices people can understand
- respect people's choices
- listen to people, not just their support person

to give extra help.

## Idea 6 is about how health care workers should know how to communicate.



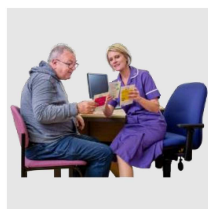
Health care workers must know how to

- talk with people.



This means they give information the person can

- understand
- use to make health choices.



For example health care workers can

- use simple and short words
- say important bits many times
- use pictures to explain things
- use Easy Read booklets.



Health care workers should

- communicate in different ways

to support the person's needs.



They can use

- words to talk
- sign language
- picture boards
- body language



to help people make their own health choices.

## How we can make things better



It is important that we teach health care workers

- how to support people

to make their own health care choices.



We must teach health care workers how to

- use different ways to communicate
- give choices to people
- explain things so people can understand
- check people understand the information



so people can make their own choices.





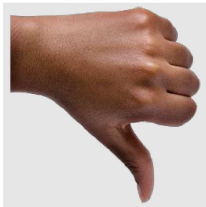


Health care workers must

- ask people how they prefer to communicate.



Many people have bad experiences with health care.



Because of this they

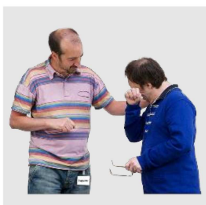
- do not trust doctors
- avoid going to the doctor
- find it hard to talk about health care.



Health care workers need to

- understand how bad experiences can affect people
- support people after bad experiences

when they make their own health care choices.



We call this **trauma-informed care**.



For example, doctors and nurses need to

- tell people they have choices
- ask people what they want
- get to know the person
- use words that are respectful and positive.



Health care workers need to be taught how

- they can do trauma-informed care
- to do reasonable adjustments
- use Easy Read health information



to better help people make choices.

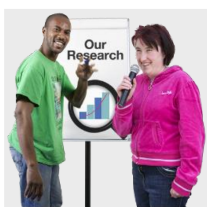


We also need to find out more about

- how people make health choices
- what people think about health choices.



This should be **inclusive research**.



**Inclusive research** is when researchers

- work together with people with intellectual disability

to find out more.



This will mean we can

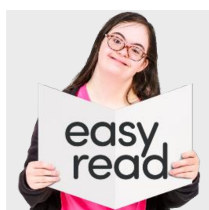
- teach health care workers to support people better
- help people make their own health care choices.

## More information



The GeneEQUAL team made this booklet.

It was made with Photosymbols.



This booklet is an Easy Read summary about

- some of our research.



The full article is called:

**Equitable and Accessible Informed Health Care Consent Process for People with Intellectual Disability: A Systematic Literature Review.**



The GeneEQUAL website has

- the full article
- more information



Go to

[www.geneequal.com](http://www.geneequal.com)

or scan the QR code.