

Scoping Review Summary



Karen

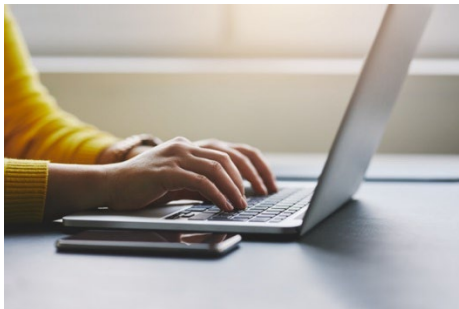


Rhonda



Maria

Karen, Rhonda, and Maria from the University of Queensland are doing the **'We Need to Talk'** research project.



Other people are helping too.

About the 'We Need to Talk' project



This project is about genetics and people with disability.



Genetics is about how genes are passed from parents to children.

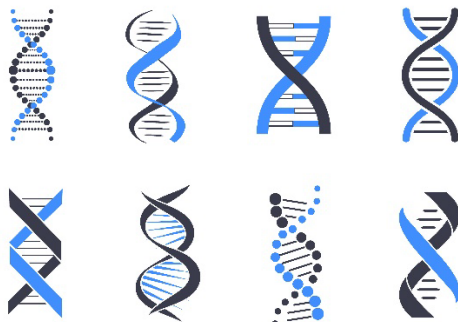


Genes have information that decide:

- The way we look.
- If we might have health problems.
- If we might have a disability.



A person's body is made of lots of cells.



Genes can be found in the cells that make up a person's body.



There are tests that help us understand a person's genes.

These tests are called genetic tests.



A person's blood or saliva is tested.



Some genes can cause a person to have a disability.



Genetic tests can tell us if a person has genes that cause disability.



We want to ask different people if they think that genetics tests can be helpful or not.



We will ask people with disability what they think.



We will also ask other people like parents, doctors, and teachers.



We will also ask the people who do the genetic tests.



With the help of people with disability, we want to make fact sheets about genetic tests.

A fact sheet gives people key information about a topic.

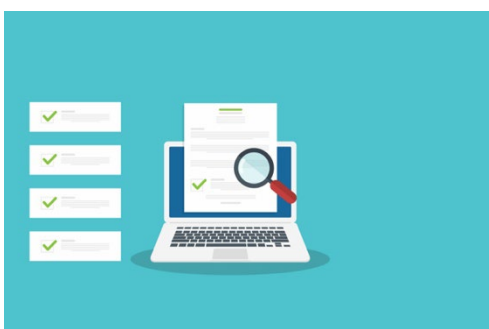
About the Scoping Review



Maria, Karen, and Rhonda searched the internet for research papers to read about genetic testing.



They wanted to find research papers that talked about how genetic testing affects people with disability.



They found 625 research papers.
That's a lot!



They read these papers.

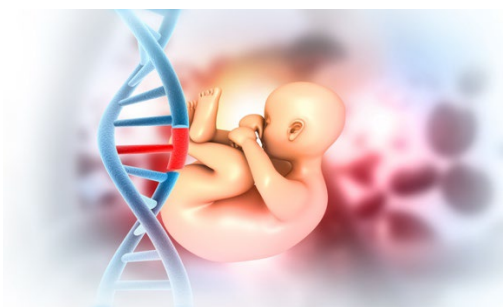


They took notes about what people said in the research papers.

About the Research Papers

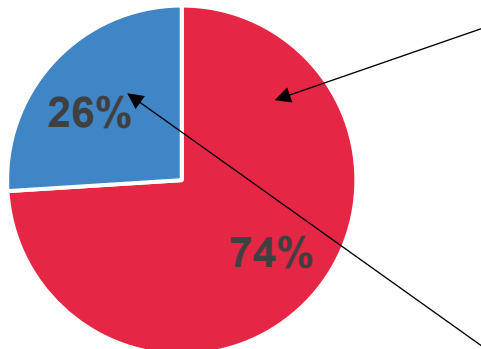


A lot of the research papers talked about genetic tests done on unborn babies.



These tests were done to see if the baby has a disability.

Most of the research papers (the amount in red) talked about one person's ideas.



Only some of the research papers (the amount in blue) talked about a research project.



In the research papers:

- Lots of people were asked how genetic testing affects people with disability.



- People with different types of disabilities were asked.



- Family members, doctors and lawyers were also asked.

What did people say about genetic testing in the research papers?



Some said tests should be used to stop babies with disability from being born.



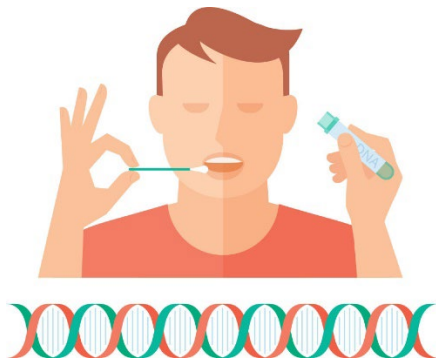
Some said tests can tell parents if their baby has a disability. They can then get help with their baby.



Some said that genetic tests should only look for disabilities that mean a person will die young.



Some said that they were not sure if genetic testing helps people with a disability to live a better life.



Some said that people are using genetic tests more because the tests are now easier to do for doctors.



Some said that genetic testing costs too much money.



Some said that money should be used to help people with disability instead of doing genetic tests.



Some said that all people should have access to genetic tests without having to pay.



New information from research means that genetic tests are changing very quickly.



Because of this, some said that governments need to make new rules about genetic tests quickly.



Governments need to do this to make sure that genetic tests are used properly by doctors.



Some said that genetic testing made them feel sad about having a disability.



Some said that other people made them feel like they were doing something wrong by using genetic tests.



Some think that less people with disability will be born because of genetic testing.



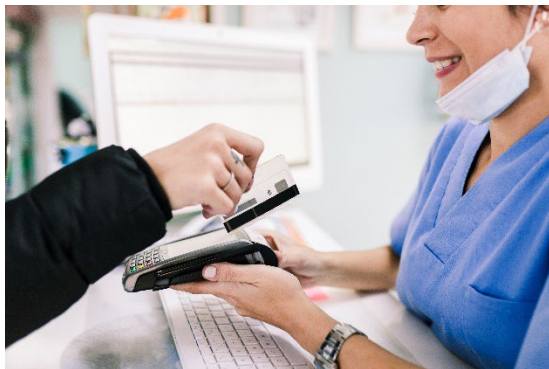
Because of this, some said that they were worried that there will be less help for people with disability in the future.



Some said that genetic testing makes people talk about disability as a health problem that doctors need to fix.



Some said they were afraid that people might not give them a job if they did genetic testing.



Some said they were afraid that they won't be able to get health insurance if they did genetic testing.

Health insurance helps people pay for hospital care and visiting the doctor.



Some said that people might feel like they cannot say NO to genetic testing if doctors tell them about it



Some said that not enough people with disability have been asked about their ideas about genetic testing.



Some said that people with disability want to be asked for their ideas.

How will this information help the 'We Need to Talk' project?



The research team will use this information to come up with questions to ask people.



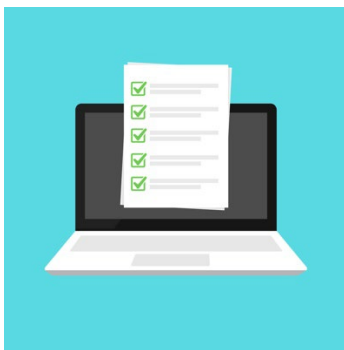
These questions will ask people for their ideas about genetic testing and how it affects people with disability.



We will ask people with disability these questions.



We will also ask other people like parents, doctors, teachers, and the people who do the genetic tests.



People will be able to answer the questions using an online survey.



They will also be able to answer the questions by talking to the research team via Zoom.