

Breaking down barriers: research to find out about the needs of disabled people using screening services in Ireland





This is Plain English information about a research study.

What is the National Screening Service?

The Irish National Screening Service, or NSS, is part of the HSE.

Screening services look for diseases, such as cancer, at the early stages.

Screening can help us to find diseases early and treat them.

There are 4 main screening programmes for people in Ireland.

The screening programmes

1. BreastCheck

This screening service looks for cancers in the breast.

2. CervicalCheck

This screening service looks for cancers at the early stage in the cervix.

3. BowelScreen

This screening service looks for cancers at the early stage in the bowel.

4. Diabetic RetinaScreen

This screening service is for people with diabetes. It looks for changes in the eyes.

What is this study about?

This study is about screening services for disabled people. It is the first study of its type in Ireland.

Disabled people have the same rights as others to use screening services.

Around one in five people that could use BreastCheck or BowelScreen have a disability.

Less disabled people use screening services than non-disabled people.

This study looked at what disabled people need to use screening services successfully.

Staff members from the NSS helped to plan this study.

Researchers from Dublin City University worked on this study.

This study had an advisory group with disabled people.

What happened in the study?

We asked disabled people about their experience of using screening services.

We asked what supports them to go to their screening appointments.

20 disabled people took part in interviews and group discussions.

People with different disabilities took part.

5 healthcare staff took part in the study.

5 family members took part.

We collected the information from the interviews and group discussions.

We looked at this information carefully.

Before screening

Some people with intellectual disabilities said they did not get an invitation to screening.

Some people need support to make an appointment or go to a screening service.

Many disabled people find it hard to understand the information they are given.

Some disabled people find it hard to travel to screening appointments that are far from their home.

During screening

Some disabled people had a good experience of screening services. For example, longer appointments, support from staff, accessible information.

Some people worried about the attitude of staff working in screening services.

For example, they worried that staff thought screening services were not suitable for people with intellectual disabilities.

Some disabled people prefer to have the screening test at a place they know, with people they know.

It can be hard for some disabled people to give their consent.

To give consent means you agree to have the screening test.

Sometimes, disabled people do not have enough space to get into and around the building.

During screening

Sometimes, the right equipment is not available, or it is hard to use the equipment.

Some people need support to do the screening test, for example, the BowelScreen test.

After screening

Some people find it hard to give information about their disability.

Some people prefer to give information about their disability and needs in online forms.

Some disabled people do not want to speak to screening staff about their disability and support needs.

Disabled people said they got their screening test results in a way that they could understand.

They had to ask for this.

What would make the service better for disabled people?

Disabled people should take part in designing and planning all screening services.

There should be disability awareness training for all staff working in screening services.

This training should be planned and given with disabled people.

There should be advice for staff on the best ways to support disabled people during screening.

Appointment times should be longer.

There should be caring staff that give good support.

There should be information to support disabled people, their family members, and staff to learn about the screening services.

This information should tell them what to expect when they come to a screening service.

What would make the service better for disabled people?

Information should be easy for everyone to understand.

Information should be given in different ways.

For example, in Braille, with pictures and easy words, or bigger writing.

There should be a video showing a disabled person at the screening tests and follow up.

Disabled people should be given clear information on how to get in and out of the buildings.

The NSS must think about how people give information about their disability and needs.

After the screening appointment, there should be a way for people to say what worked well and what needs to change.

The NSS must check why some disabled people did not get invited to screening.

What will happen next?

The NSS has tried to make their services easier for everyone to use.

Disabled people still experience challenges when they use screening services.

The NSS, Disabled People's Organisations, and disability services need to work together to make access better.

We must collect information when disabled people use screening services.

This could help us make services better in the future.









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