

A whole organisational approach to support cancer screening among people with intellectual disabilities

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An tSeirbhís Náisiúnta Scagthástála
National Screening Service


BreastCheck
An Clár Náisiúnta Scagthástála Cioch
The National Breast Screening Programme


CervicalCheck
AN CLÁR NÁISIÚNTA SCAGTHÁSTÁLA CEIRBHEACS
THE NATIONAL CERVICAL SCREENING PROGRAMME


BowelScreen
An Clár Náisiúnta Scagthástála Putóige
The National Bowel Screening Programme


Diabetic RetinaScreen
An Clár Náisiúnta Scagthástála Reitiní do Dhiaibéitigh
The National Diabetic Retinal Screening Programme

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- More information and contact information





What is screening

“Screening refers to the use of simple tests across a *healthy population* in order to identify individuals who have disease, but do not yet have symptoms”

World Health Organisation (2004)

Overview of National Screening Service (NSS)

We run 4 national population screening programmes:

3 that screen for cancer, and 1 that screens for diabetic retinopathy.

[BreastCheck](#)

[CervicalCheck](#)

[BowelScreen](#)

[Diabetic RetinaScreen](#)





Overview of National Screening Service (NSS)

Our programmes focus on looking for early signs of disease in healthy people, so that we can:

- detect health issues early
- help prevent disease
- ensure that anyone who does develop the disease being screened for has the best chance of early, more effective treatment
- reduce people's risk of developing a disease or its complications
- support people in making informed decisions about their health



Screening people with ID

In the context of
population
screening, we aim
for people with an
intellectual
disability to:

- understand what screening is and who it is for
- have a clear understanding of the screening process and what it can and can't do
- make an informed decision about taking part in screening-screening is a choice
- access screening if they decide to take part
- understand what results mean and how to act on any follow-up needed.



Research: Cancer Screening among people with ID

- Irish Studies: Reduced participation in breast cancer screening among women with intellectual disabilities. Poor awareness about breast cancer warning signs, risk factors and BreastCheck among women with mild to moderate intellectual disabilities.
- Swedish study: women with a specialist diagnosis of intellectual disability had lower degrees of cervical screening participation.
- USA study: A systematic review and meta-analysis to compare bowel screening participation in individuals with and without disabilities. Individuals with intellectual disabilities had significantly lower rates of bowel screening participation especially for 'Home' Kits.

<https://doi.org/10.1111/bld.12225>

<https://doi.org/10.1177/1744629514521067>

[https://doi.org/10.1016/S2468-2667\(23\)00026-9](https://doi.org/10.1016/S2468-2667(23)00026-9)

[10.3390/curoncol31110517](https://doi.org/10.3390/curoncol31110517)



TILDA Findings:

- IDS-TILDA is a longitudinal study researching ageing in Ireland among people with an intellectual disability aged 40 and over.
- Breast: 71.1% (n = 165) people of eligible women (50-69) were invited for a mammogram in the previous two years. Of these, 77.9% (n = 127) attended.
- Cervical: 272 participants were eligible (40-65) to be screened, **150 (63%) reported they were not invited**. Of those invited, 26 attended (30%).
- Bowel: Out of 156 people who were eligible for screening in the previous two years (those aged 62 - 69), 68.1% (n = 96) had a bowel screen.



Barriers for people with ID (Chan et al, 2022)

- Fear, distress, and embarrassment
- Unpreparedness for screening
- Negative interactions with healthcare professionals
- A lack of knowledge about cancer screening
- Mobility issues
- A high severity of ID
- Lack of ability to provide consent and communicate verbally



**How the NSS are supporting people
with ID to access screening**



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National Screening Service

Choose Screening

Together we can make a difference

National Screening Service
Strategic Plan 2023-2027



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National Screening Service

National Screening Service

Improving equity in screening

A STRATEGIC FRAMEWORK 2023-2027



Both reports available on www.screeningservice.ie



Approach Across the NSS

Strategic-long term	Operational-day to day
Access officers for all programmes	Reasonable accommodations offered such as longer appointment times, support person accommodated, pre-visit, pre-meet with screener, information in other formats, call-back
Access & Consent project team-supporting implementation of Assisted Decision-Making Act (ADMA)	Training offered to services and ongoing support provided to services
Partnerships with many disability organisations	Audit of BreastCheck buildings
Partners in European research projects such as CUPID and EUCanScreen-NSS to assist in development of a strategic framework on improving equity for screening for people with ID	Lectures to 3 rd level students who will support people with ID in their roles
NSS Strategic Plan 2023-2027, NSS Equity Strategic Framework 2023-2027. Disability Needs Assessment report launched end of 2023	Suite of accessible resources for each programme-plain English, photo stories, videos, translated literature and videos, ISL



About Breast Screening



This is an Easy to Read information leaflet about breast screening.



About Breast Screening



This is a Plain English information leaflet about Breast Screening.



These screening programmes are **free of charge**

are free of charge.



Going for a Cervical Screening Test

A Plain English Story



Going for a Cervical Screening Test

A Photo Story



About Bowel Screening



This is an Easy to Read information leaflet about bowel screening.



About Bowel Screening



This is a Plain English information leaflet about bowel screening.



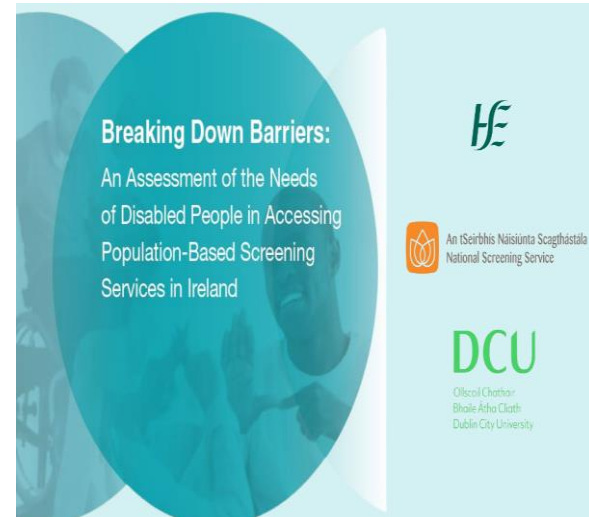
Breaking Down Barriers report overview

- Views and experiences of disabled people in accessing screening
- Access barriers and enablers to participate in screening
- Focus groups and interviews-Qualitative

36 recommendations across:

1. Training and Education
2. Person Centred
3. Communications
4. Accessibility
5. Further Research

Full report available on website: www.screeningservice.ie





Implementation of recommendations

1. Almost 200 NSS staff have completed disability awareness training covering disability awareness, effective communication and reasonable accommodation
2. All 4 access officers have completed access officer training
3. Further training for managers on reasonable accommodation processes
4. Reviewing NSS reasonable accommodation processes
5. Collaboration with users to develop carers resource to support carers to help people they care for access screening



Implementation of recommendations

6. Information in different formats being developed (e.g. Videos in ISL)
7. Access sections on website being updated-Accessibility Statement
8. Campaigns include people with disabilities
9. Call out for people with disability to be part of NSS Public Patient Partnership (PPP)
10. Assisting to offer appointments close to home



How to support people with ID to access screening

- Check our registers and update or add as required; you can do this online, by email or by contacting freephone number 1800 45 45 55
- Use our Easy to Read resources and videos available online for all screening programmes
- Contact us to let us know of any reasonable accommodations required
- Use our carers resource
- Always be aware of possible symptoms and direct to GP



Symptoms Bowel Cancer

Call your GP TODAY if you notice any of the following



A change in your bowel habit for more than 6 weeks, such as looser poo, pooing more often or constipation



Feeling like you need to pass a bowel motion even when you know your bowel is empty



Unexplained bleeding from your back passage



Unexplained pain in your tummy or back passage



Unexplained lump or swelling in your tummy



Unexplained weight loss



Feeling very tired all the time, more than is normal for you



Breathlessness more than is normal for you



Symptoms Cervical Cancer

Call your GP TODAY if you notice any of the following



Vaginal bleeding or spotting between your normal periods or after the menopause



Vaginal bleeding, spotting or pain during or after sex



Abnormal vaginal discharge (may be bloodstained or smell unpleasant)



Unexplained pain in your lower tummy or your lower back



A change in your bowel or bladder habit, e.g. constipation, peeing or pooing more often than usual, or blood in your pee



Unexplained pain or swelling in one or both legs



Symptoms Breast Cancer

Call your GP TODAY if you notice any of the following



A new lump that you can feel in either of your breasts.

A new lump that you can feel in either of your armpits.



A change in the size, shape or feel of one or both breasts or armpits, e.g. a new area of thickened tissue or lumpiness in either breast or armpit that was not there before.



Skin changes on your breast such as puckering or dimpling (the skin may look like orange peel).

An abscess (infected boil) in your breast – this may appear as a red, tender area on your breast.



A change in the appearance of your nipple, such as the nipple flattening or sinking into your breast or turning inwards.



Bloodstained or watery discharge from either of your nipples.



A rash or eczema on or around your nipple.



More information and contacts



- Website: www.screeningservice.ie



- E-mail: info@screeningservice.ie

- Freephone: 1800 45 45 55

- Contact our Access Officers

access@bowelscreen.ie

access@breastcheck.ie

info@cervicalcheck.ie





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Thank You

Questions



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#choosescreening

About the National Screening Service



An tSeirbhís Náisiúnta Scagthástála
National Screening Service



The National Screening Service screen for 3 types of cancer; breast, bowel, and cervical cancer. We also screen for diabetic retinopathy caused by diabetes.

We try to find diseases early so people can get the best treatment.

We know from research many people with an intellectual disability do not have screening.

We want everyone to have a fair chance to come for screening. This is called equity. We have an equity plan.



About the National Screening Service



We did some research about our screening services in Ireland for disabled people.



We wanted to look at the things that stop people from taking part in screening.



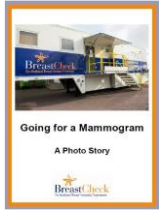
The results of our research are available in easy to read.



We are now working on ways to improve how we support people to come for screening.

What you can do

Check our registers and to update or add your name address and date of birth.



Use our easy to read resources and photo stories available online for all screening programmes.

Contact us to let us know if any reasonable accommodations are needed.



It is important to see your doctor if you have symptoms that could mean cancer.

For more information or to contact us



For more information check online:

www.breastcheck.ie

www.cervicalcheck.ie

www.bowelscreen.ie



Phone us for free on 1800 45 45 55



Email us at:

info@breastcheck.ie

info@cervicalcheck.ie

info@bowelscreen.ie

Contact our access officers:

access@breastcheck.ie

info@cervicalcheck.ie

access@bowelscreen.ie