



WATERSTOWN MEDICAL



# Supporting Cancer Care for People with Intellectual Disabilities

A GP's Approach to Detection and Ongoing Care

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# Overview of Talk

- Context and Background.
- Cancer Risk in people with Intellectual Disabilities.
- Screening.
- General Practitioner's Role.
- Final Thoughts.

# Context and Background

- Stewarts Care – Mission Statement.
  - ‘to empower and support individuals with different abilities to have an enriched life experience based on their own decisions and life choices’.

# Context and Background

- Residential and Community Based Service Users.
- One whole-time equivalent GP.
- Annual Medical Review.
- Ongoing Primary Care.

# Cancer Risk

- In Ireland, the lifetime risk of developing invasive cancer is approximately 1 in 2 (CSO, 2023).
- Invasive malignancies account for nearly one-third of all deaths in Ireland (Department of Health, National Cancer Strategy 2017–2026).

# Data specific to people with intellectual disabilities

- Relative **lack** of contemporary data on the cancer experiences of adults with intellectual disabilities.
- Mortality studies suggest a **lower** proportion of cancer-related deaths in this group compared to the general population.
- Cancer remains one of the **five most frequently** recorded causes of death among adults with intellectual disabilities (Heslop, BMJ, 2022).

# Data specific to people with intellectual disabilities

- **Digestive system cancers**—such as colorectal, gastric, and pancreatic—are the most common cancer-related causes of death in this group,
- General population, lung cancer predominates.

*Heslop, P., Cook, A., Sullivan, B., Calkin, R., Pollard, J., & Byrne, V. (2022). Cancer in deceased adults with intellectual disabilities: English population-based study using linked data from three sources. BMJ,*

ICD-10 Code	Cancer Type	Males	%	Females	%	Total	%
C15–C26	Digestive organs (e.g. bowel, stomach, liver)	131	28%	92	23%	224	26%
C50	Breast	†	†	103	26%	105	12%
C43–C44	Skin (melanoma and other skin cancers)	56	12%	32	8%	88	10%
C00–C14	Lip, oral cavity, and pharynx	52	11%	13	3%	65	8%
C30–C39	Respiratory/intrathoracic organs (e.g. lungs)	39	8%	21	5%	60	7%

† Data suppressed where numbers are very small for confidentiality.



# Screening.

- Ireland
  - **Bowel** cancer screening (59–70)
  - **Breast** cancer screening (50–69)
  - **Cervical** cancer screening (25–65)
  - [Diabetic retinopathy screening].

# Screening.

- . Bowel screening participation was notably high in IDS-TILDA Wave 5 compared to both earlier waves and the general population.
- . Cervical and breast cancer screening uptake was lower than in previous waves and general population.

# Findings from Dr. Pauline Hislop's 2022 Study

Dr. Pauline Hislop's 2022 UK study examined 1,096 adults with intellectual disabilities who died between 2017 and 2019.

- Cancer Diagnosis route.
- Stage at Diagnosis.
- Types of Cancer.
- Potential Impact for Screening Age.

# Findings from Dr. Pauline Hislop's 2022 Study

Cancer diagnosis route:

- . 35% (n=162) of cancers in adults with IDs were first diagnosed via **emergency presentations**.
- . In the general population, emergency cancer diagnoses are significantly lower — approximately 20%.

(source: National Cancer Intelligence Network).

# Findings from Dr. Pauline Hislop's 2022 Study

Stage at diagnosis:

- . 45% (n=228) of cancers in people with IDs were diagnosed at **Stage 4** (advanced/metastatic).
- . In the general population, 20–26% of cancers are diagnosed at Stage 4.

# Dr. Pauline Hislop's 2022 UK study

## Digestive system cancers

- Accounted for 36% (n=309) of all cancer-related deaths in adults with IDs.
- Digestive cancers are a major cause of cancer mortality in the general population too, but not to this proportion
  - Typically accounts for about 10–13% of all UK cancer deaths.

# Findings from Dr. Pauline Hislop's 2022 Study

## Screening age and eligibility:

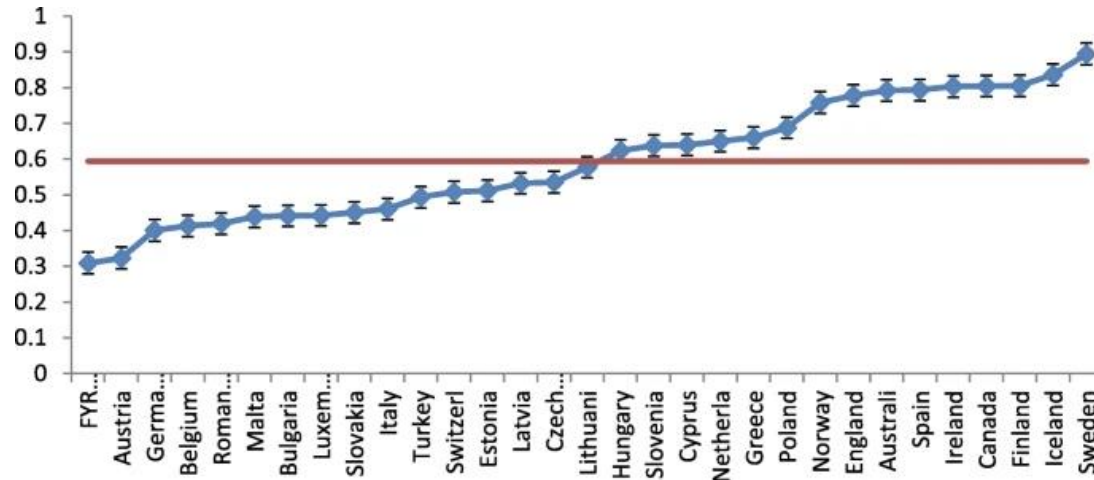
- 43% of those with IDs who died from colorectal cancer were **younger** than the screening age threshold.
- The UK offers colorectal screening from age **50**
- Ireland currently offers screening from age **59**, plans to expand this gradually to 55–74.

# Barriers to GP access for people with intellectual disabilities

- Hoists/Mobility Aids: Lack of space for hoists, inaccessible equipment, or unsuitable toilets.
- Communication: Lack of accessible materials, easy reads, potentially complex language used.
- Time: Limited consultation time for adequate communication and addressing needs (15 minute consultation).
- Steps/Stairs: No ramps, narrow doorways, uneven steps.



# Barriers to GP access for people with intellectual disabilities



- Step-free access
- Door width
- Elevator access where necessary
- Accessible Toilets
- Other physical features important for accessibility
- Combined into a single "accessibility score" using a statistical model.

Groenewegen, P.P., Kroneman, M. & Spreeuwenberg, P. Physical accessibility of primary care facilities for people with disabilities: a cross-sectional survey in 31 countries. BMC Health Serv Res 21, 107 (2021). <https://doi.org/10.1186/s12913-021-06120-0>

# Barriers to GP access for people with intellectual disabilities

Third-Person Interaction: Staff member or relative acts as an advocate.

- This can subtly **shift the focus** away from the individual's needs
- Potentially affecting their comfort and **autonomy** in the consultation.

# Barriers to GP access for people with intellectual disabilities

## Assisted Decision-Making (Capacity) Act

- **Empowers** individuals by promoting autonomy and providing tailored support, while safeguarding rights through legal frameworks.
- However, it is a **new approach**, there is practical **complexity**, potential lack of competence and confidence, resource limitations, may lead to confusion, delays, or disputes over decision-making between the different healthcare settings.

# Barriers to GP access for people with intellectual disabilities

- BMJ study, adults with intellectual disabilities may experience up to a **2-week delay** in receiving healthcare compared to the general population.
- This delay may be attributed to
  - Caregiver coordination
  - Transportation issues,
  - Waiting for adapted medical services.

Sakellariou, D., & Rotarou, E. S. (Year). Access to healthcare for men and women with disabilities in the UK: Secondary analysis of cross-sectional data. *BMJ Open*

# Risks for People with Intellectual Disabilities

## Delayed or Missed Diagnosis

- Communication challenges
- **Atypical** presentations, potential diagnostic overshadowing

## Participation in **Screening** Programs

## Risk of Gastrointestinal Disease and Cancers

- **Constipation**, Reflux

# Risks for People with Intellectual Disabilities

Polypharmacy and Long-Term Medication Use

Lifestyle, Environmental Factors

- Obesity
- Sedentary Lifestyles

# GP at Stewarts Care

- Dedicated MDT offering Primary Care to Service Users
- Near Frictionless access to facilities
- Same day appointments is the norm
- Paperless, E-medicine model, telemedicine and e-scripting
- High level of **familiarity** between MDT, service users, advocates and families.

# GP at Stewarts Care - Annual Medical Review

Pre-AMR document, outlining [service user concerns](#), stakeholder concerns

## Physical Exam

- Dermatological inspection, Otoscopy: Ear Wax,
- Oropharyngeal, Dental Inspection
- Respiratory, Cardiovascular, Abdominal Examination
- Breast Examination
- Peripheral Vascular & Lower Limb Assessment



# GP at Stewarts Care - Annual Medical Review

- Constipation
- Medication Review
- Bloods: Iron Stores, Bone Profile (Calcium), Vit D, HbA1c, Lipids, Renal, FBC, LFTs, PSA (where indicated)
- ECG (where indicated),
- Ambulatory Blood Pressure Monitoring
- Bone Density
- Specific Reviews within subgroups: T21, Diabetes and CDM.

# Final Thoughts/Discussion Points?

- Dedicated Primary Care Centers/Clinical Hubs for people with Intellectual Disability
  - SafetyNet Primary Care, Spirasi Clinics, Addiction Services
- Screening ages
- ICGP Module/ ID Specific Training for GPs
  - Highlight specific 'Challenges' for People with intellectual Disabilities
- Building Capacity, Accessibility
- Patience

# Accessible Summary

**Cancer is sometimes a serious illness.**

Anyone can get cancer, including people with intellectual disabilities.

**Doctors, Nurses and Family can help.**

They can help find out if you have cancer and help you get the right treatment.

**Everyone should be treated fairly.**

Doctors must make sure everyone gets good care and is included.