

Health Services Research Notes 1/2026

Annual National Inquiry 2025

Following the Turin Memorandum

Responses from health authorities in nine European countries
on cancer screening for people with intellectual disabilities

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Co-funded by
the European Union



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Background

Intellectual disability (ID) is defined as significant limitations in intellectual functioning and adaptive behaviour originating before the age of 22 (1) and affects approximately 1% (2) of the population, corresponding to around 4.5 million people in the European Union (3). Despite international commitments, including the United Nations Convention on the Rights of Persons with Disabilities (4), people with ID continue to experience poorer health status and lower utilisation of preventive health services, such as cancer screening (5). Across Europe, participation in organised breast, cervical, and colorectal cancer screening remains lower among people with ID (6–9), reflecting persistent barriers related to limited access to accessible information, anxiety surrounding screening procedures, insufficiently adapted health care encounters, and organisational constraints within screening services (10). Together, these barriers contribute to delayed cancer diagnoses and poorer outcomes compared with the general population (11,12).

To address these inequities, the Turin Memorandum was adopted in May 2025 during a consortium meeting of the EUCanScreen Joint Action, a collaboration of European countries working to strengthen quality and equity in population-based cancer screening (13). Included as an appendix to this Research Note, the Memorandum reflects a shared commitment by experts from multiple countries to improve equitable access to organised cancer screening programmes for people with ID. A central component of this commitment is the Annual National Inquiry to monitor data availability, existing measures, and future plans related to screening participation in this population.

This report presents the findings of the first Annual National Inquiry (2025). Subsequent rounds are planned throughout the EUCanScreen Joint Action and beyond to track progress and support cross-country learning.

Methods

Design and scope

This Annual National Inquiry was conducted as a structured information request within the framework of the EUCanScreen Joint Action (Task 6.5). The objective was to obtain an overview of the current status of data availability, policies, and measures related to cancer screening participation among people with ID in participating European countries.

Participants and recruitment

Experts involved in EUCanScreen Task 6.5 and all signatories of the Turin Memorandum were asked to contact the competent national or regional cancer screening authorities in their respective countries and to request information using a common set of questions.

Data collection

Information was collected via email correspondence between November 2025 and January 2026. Authorities were asked to provide information regarding their national or regional cancer screening programmes in response to four predefined items addressing:

- whether participation rates of people with ID in cancer screening programmes are known or monitored;
- if not, whether there are plans or possibilities to begin collecting such data in the future;
- whether there are any specific initiatives or reasonable adjustments in place to promote participation of people with ID;
- and, if not, whether the responsible regulatory bodies or public health authorities plan to develop such measures in the near future.

Data synthesis

Responses were compiled at the country level and summarised in a comparative overview table, accompanied by a brief narrative summary highlighting the main findings and providing contextual interpretation. No formal qualitative analysis was undertaken. Findings represent a snapshot of reported practices and plans at the time of the inquiry.

Results

Participating countries

In total, experts from 13 signatory countries were approached. In addition, experts from four further countries were contacted. Responses were received from nine countries, all of which were signatories of the Turin Memorandum. Figure 1 highlights the participating countries.

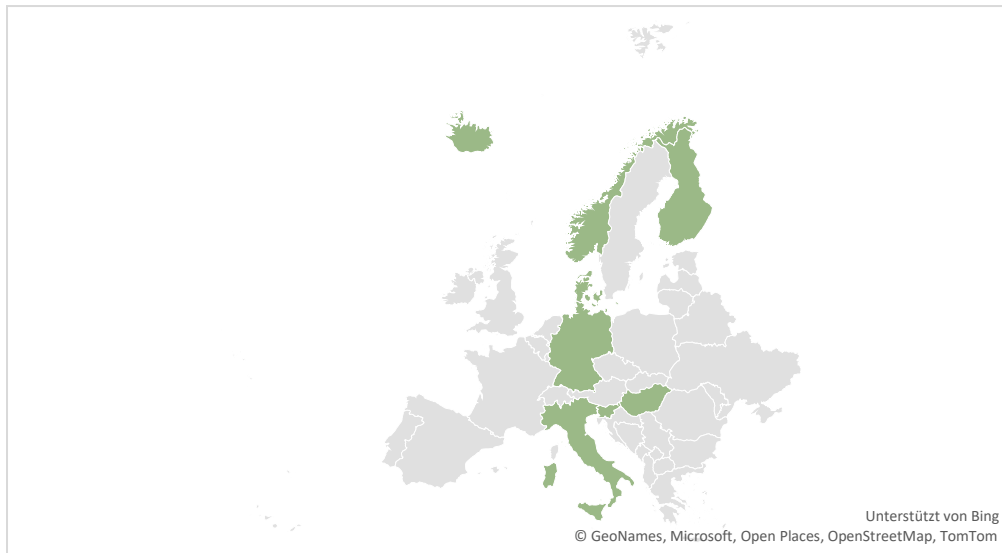


Figure 1. Participating countries in the Annual National Inquiry 2025 following the Turin Memorandum

Cross-country comparison

Table 1 provides an overview of the availability of participation data, existing measures, and future plans related to cancer screening for people with ID, as reported by participating countries. Information refers to organised, population-based cancer screening programmes. Reported status reflects information provided by the responding authorities at the time of the inquiry (2025).

Across all nine countries, participation rates of people with ID are not routinely monitored within national screening registries. Where evidence exists, it is limited to research projects rather than institutional surveillance. Only a small number of countries reported emerging plans for registry linkage or research-based approaches, often constrained by legal, ethical, and data protection barriers.

Most countries reported no ID-specific measures. Some described generic inclusion strategies (e.g., accessibility-oriented information, extended appointments), while explicit reasonable adjustments for people with ID remain rare. Several authorities expressed openness to future action, frequently conditional on improved evidence and capacity, but concrete, funded plans are largely absent.

Discussion

This first Annual National Inquiry conducted under the Turin Memorandum provides an initial overview of how participating European countries address cancer screening for people with ID within organised screening programmes. Importantly, the findings reflect the perspectives of countries that voluntarily

participated in the inquiry and engaged with the topic of equitable cancer screening for people with ID within the framework of the Turin Memorandum.

Across the nine responding countries, participation data for people with ID are not routinely available within national screening registries, and reported measures are largely embedded within broader inclusion or health-literacy strategies rather than being specifically tailored to this population. At the same time, several countries indicated openness to further development, often conditional on additional evidence, resources, or policy prioritisation. As the first Annual National Inquiry conducted under the Turin Memorandum, these findings establish a shared baseline among participating countries. The number of responding countries is expected to increase as awareness of the topic grows. Subsequent rounds will allow developments to be tracked over time and support mutual learning within and beyond the EUCanScreen Joint Action.

Key messages from the Annual National Inquiry 2025:

- No participating country routinely monitors screening participation of people with ID
- Measures remain largely generic rather than ID-specific
- Several countries expressed openness to further development

Disclaimer

Funding

This work was funded by the European Union under the EU4Health Programme (EUCanScreen Grant Agreement No. 101162959). The views and opinions expressed are those of the authors only and do not necessarily reflect those of the European Union or the European Health and Digital Executive Agency (HaDEA). Neither the European Union nor HaDEA can be held responsible for them.

Ethical considerations

The inquiry did not involve individual-level data, human subjects, or sensitive personal information. All information was provided by public authorities or designated experts in their professional roles and analysed in aggregated form.

Table 1. Summary of responses to the Annual National Inquiry (2025) on cancer screening for people with ID

Country	Participation data available	Plans for data collection	Measures/reasonable adjustments	Future actions planned
Denmark	Registry data used in ad hoc research only; no routine monitoring	No	General accessibility-oriented measures for a broader target group (e.g., accessible information, self-sampling options)	No
Germany	No	No	Easy Language materials available	Additional Easy Language materials for breast and lung cancer screening planned (2026)
Estonia	No	Research linkage planned (subject to approval)	No	No
Finland	No	Research linkage planned (subject to approval)	No	Conditional on findings during research project
Hungary	No	No	No systematic initiatives currently (previous local collaborations)	Informal, capacity-dependent
Iceland	No	No	No	Dependent on EUCanScreen results; planned collaboration with disability organisation
Italy	No	No	Position paper addressing disability broadly has been developed	Emerging interest at regional/local level (no formal plans)
Norway	No	Research linkage planned; no routine monitoring	No	Potential future adaptations (e.g., accessible information)
Slovenia	No	No	Non-ID-specific inclusion strategies for vulnerable groups in place	No ID-specific plans

Table 1. Overview of data availability, measures, and future plans related to cancer screening participation of people with ID in participating countries (Annual National Inquiry 2025). Note: Data are self-reported by participating countries and reflect a cross-sectional snapshot at the time of the inquiry.

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Imprint

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Health Services Research Notes

A publication of the Department of Health Services
Research, German Cancer Society (Deutsche
Krebsgesellschaft e. V.)
Publication date: 06 February 2026
DOI: 10.5281/zenodo.18504791
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The Turin Memorandum

Consensus of the EUCanScreen Expert Group on Improving Cancer Screening for People with Intellectual Disabilities

Adopted in Turin, 14 May 2025

The EU Joint Action EUCanScreen *Expert Group on Screening for People with Intellectual Disabilities* acknowledges the fundamental right of all individuals, including people with intellectual disabilities, to equitable access to health care, including cancer screening. In pursuit of inclusive and effective cancer prevention strategies across the European Union, we recognize a significant and troubling gap: the lack of systematic knowledge, data, and targeted approaches regarding the participation of people with intellectual disabilities in organized cancer screening programmes.

Cancer screening programmes for breast, cervical, and colorectal cancer have been widely implemented across the EU. However, evidence (in countries where the information is public) and expert experience suggest that people with intellectual disabilities remain underrepresented, underserved, and often excluded—either by design or consequence. This disparity contributes to preventable suffering and late-stage diagnoses in a population already facing multiple health inequities.

Acknowledging this challenge, the EUCanScreen Expert Group reaches the following consensus:

1. Lack of Data is a Barrier

We acknowledge that, in most EU Member States and regions, there is insufficient data on the participation of people with intellectual disabilities in cancer screening programmes. Without such data, it is impossible to identify gaps, monitor progress, or ensure accountability.

2. Annual National Inquiry

Each member of the EUCanScreen Expert Group commits to contacting their respective national, regional, or local cancer screening regulatory bodies or public health authorities on an annual basis to inquire about:

- Whether participation rates of people with intellectual disabilities in cancer screening programmes are known;

- If not, whether there are plans or possibilities to begin collecting such data in the future;
- Whether any specific measures or accommodations are currently in place to promote screening uptake in this population;
- If not, whether the responsible regulatory bodies or public health authorities intend to introduce such measures in the near future.

3. Promoting Inclusion in Policy and Practice

This recurring inquiry will serve as a tool for accountability, awareness-raising, and policy stimulation. The Expert Group will consolidate responses and identify best practices, gaps, and opportunities for improvement.

4. Future Actions

The group commits to using its collective expertise to support the development of evidence-based strategies to improve screening access for people with intellectual disabilities, including tailored communication, adapted invitation procedures, and cooperation with advocacy organizations and persons with intellectual disabilities themselves.

Through this Memorandum, we affirm that improving cancer screening for people with intellectual disabilities is both a public health priority and a matter of human rights. The EUCanScreen Expert Group calls on all relevant stakeholders—governments, screening providers, researchers, and civil society—to join us in ensuring no one is left behind in the fight against cancer.

Signed,

The Members of the EUCanScreen Expert Group

(The expert group consists of EUCanScreen WP 6 contributors and scientific leaders)

Turin, 14 May 2025