

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

Name	Country	Role in EUCanScreen Joint Action
Christoph Kowalski	Germany	Lead Task “Improved cancer screening for people with intellectual disabilities (IDs)”
Carmen Koko	Germany	Co-lead Task “Improved cancer screening for people with intellectual disabilities (IDs)”
Mārcis Leja	Latvia	Project Coordinator/ Scientific Project Manager
Yelena Tarasenko	Latvia	Scientific Project Management
Mari Nygård	Norway	Lead Work Package “Addressing barriers and facilitators in cancer screening”
Ágúst Ingi Ágústsson	Iceland	Partner in Task “Improved cancer screening for people with intellectual disabilities (IDs)”
Maarit Lamminmäki	Finland	Partner in Task “Improved cancer screening for people with intellectual disabilities (IDs)”/ Co-lead Task “Outreach strategies to other vulnerable populations, including transgender populations”
Silvia Deandrea	Italy	Partner in Work Package “Implementation research to improve the existing screening programmes”
Ulrik Deding	Denmark	Lead Task “Individual Barriers”
Paola Mantellini	Italy	Partner in Task “Improved cancer screening for people with intellectual disabilities (IDs)”
Natalia Usenko	Ukraine	Partner in Work Package “Addressing barriers and facilitators in cancer screening”, Head of the Ukrainian team
Viktória Naszvadi	Hungary	Co-Lead Task “Strategies to increase health literacy in cancer screening”
Bernd Kerschner	Austria	Co-Lead Task “Strategies to increase health literacy in cancer screening”

Eliane Kellen	Belgium	Partner in Task “Improved cancer screening for people with intellectual disabilities (IDs)”
Livia Giordano	Italy	Partner in Task “Improved cancer screening for people with intellectual disabilities (IDs)”
Mykyta Pepenin	Ukraine	Partner in Task “Improved cancer screening for people with intellectual disabilities (IDs)”
Yurii Kondratskyi	Ukraine	Partner in Task “Improved cancer screening for people with intellectual disabilities (IDs)”
Andrii Horodetskyi	Ukraine	Partner in Task “Improved cancer screening for people with intellectual disabilities (IDs)”
Oleksii Dobrzhanskyi	Ukraine	Partner in Task “Improved cancer screening for people with intellectual disabilities (IDs)”
Maija Vahteristo	Finland	Partner in Task “Improved cancer screening for people with intellectual disabilities (IDs)”/ Co-lead Task “Outreach strategies to other vulnerable populations, including transgender populations”
Urška Ivanuš	Slovenia	Lead Work Package “Sustainability”
Maiju Pankakoski	Finland	Lead in Task „Implementing data collection with open-source software and standardised data model for screening to produce key quality and performance indicators”
Cindy Simoens	Belgium	Partner in Task “Improved cancer screening for people with intellectual disabilities (IDs)”/ Co-lead Work Package “Facilitation new screening implementation”

Signatories as of 24 June 2025