EU CanScreen
European Joint Action on Cancer Screening

Reducing inequalities in cancer screening

From identifying barriers to changing screening systems

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Rome

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Framework of population-level cancer screening program

Patients Pathway
What happens to people?

- **Invitation**
- **Screening**
- **Diagnosis**
- **Treatment**

Delivery System
Programme components and interfaces

- Registry/Data Systems
- Workforce
- Laboratories / Imaging
- Communication
- Quality Assurance
- Referral Interfaces
- Governance

Effectiveness
Does it work?

- Benefits & Harms
- Uptake & Participation
- Diagnostic Yield
- Mortality / Incidence
- Differential Outcomes by Subgroup

Value and Policy
Is it worth it, and on what terms?

- Resources
- Affordability
- Opportunity Cost
- Acceptability
- Feasibility
- Fairness & Justice
- Trade-Offs

EQUITY LENS

What makes screening easy for some, but difficult for others?

Three EUCanScreen reviews: 138 unique studies from 23 countries MS41: three papers in preparation

Breast, cervical and colorectal cancer screening

Do I understand why screening matters?	Clear, accessible information about purpose and benefit
Can I fit screening into my life?	Simple pathways, flexible appointments and reminders
What will screening be like?	Respectful care, preparation, choice and control
Who do I trust?	Trusted recommendations and supportive relationships
Does screening work for someone like me?	Sensitive care, accessible options and reasonable adjustments

Many barriers are modifiable through programme design.

What can screening programmes change to make participation possible?

Equity is not a separate activity.
It is a lens across the screening system

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Patients Pathway What happens to people?	Delivery System Programme components and interfaces	Effectiveness Does it work?	Value and Policy Is it worth it, and on what terms?
Who is eligible, invited, screened, diagnosed and treated?	Are governance, registers, workforce, communication, navigation and referral pathways inclusive?	Who benefits, who experiences harms, and do outcomes differ between groups?	Are resources, burdens and benefits distributed fairly?

Across all four pillars

Lorentz Center four-pillar framework, wording supplied by the presenter

Intellectual disability: inequity across the pathway

Evidence from a scoping review

77

studies included

57 quantitative
18 qualitative
3 mixed-methods

Evidence concentrated in a limited number of countries, particularly the United States and United Kingdom.

Barriers

Previous negative experiences with health services

Fear and distress

Inaccessible information and low health literacy

Poor communication

Limited professional training

Insufficient knowledge and confidence in primary care

What facilitates participation

A trusted support person
Preparation before the examination

Inclusive and accessible communication

Easy-read materials and trained staff

Flexible and longer appointments

Helpful clinical behaviour


Koko et al. International Journal for Equity in Health (2026) 25:186
https://doi.org/10.1186/s12939-026-02965-1
International Journal for Equity in Health
REVIEW Open Access

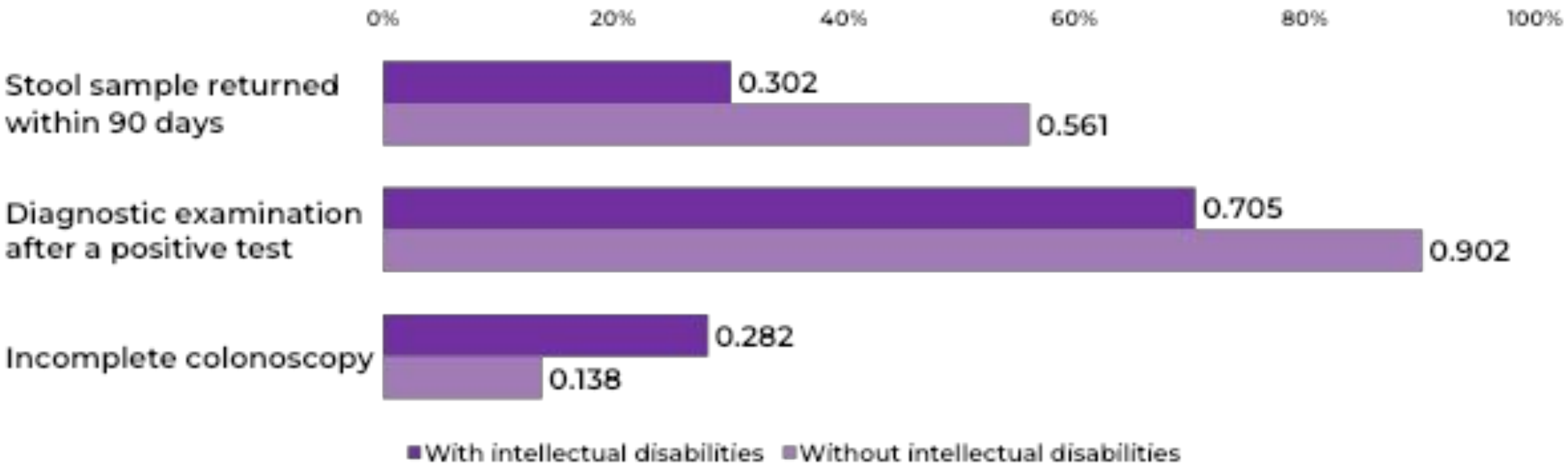
Cancer screening in people with intellectual disability: a scoping review of participation, barriers, facilitators, and improvement strategies within the EUCanScreen initiative

Carmen Koko[1*], Zining Yang[1], Mari Nygård[2], Patrick Martens[3], Eliane Kellen[3,4] and Christoph Kowalski[1]

Inequality was measured across continuum

Colorectal cancer screening

Danish register-based cohort: 17,117 people with intellectual disabilities



Diagnostic examination: within 60 days of a positive test. Higher incomplete-colonoscopy rates indicate worse completion.

External evidence, not a WP6 result. Horsbøl et al. JAMA Network Open, 2026. doi:10.1001/jamanetworkopen.2025.57013

A major barrier is that exclusion is not routinely measured

The Turin Memorandum

Adopted in Turin, 14 May 2025

Consensus developed by the EUCanScreen expert group

25 signatories from 13 countries

Annual inquiry to national or regional screening authorities

2025 inquiry: nine responding countries

No country routinely monitored screening participation among people with intellectual disabilities
Targeted measures were rare

Most countries relied on generic inclusion strategies

Interest in future action existed, but concrete and funded plans remained limited

Lack of systematic knowledge, data and targeted approaches is a central equity problem.

Turin Memorandum and Annual National Inquiry 2025. Signatory count as reported in the supplied WP6 material.

What does this example teach us about equity?

Equity question	Intellectual-disability example
Who is identified?	Intellectual disability may not be identifiable in screening data
Who is reached?	Standard invitations may be inaccessible
Who can participate?	Appointments and procedures may not offer reasonable adjustments
Who completes follow-up?	Lower diagnostic follow-up after positive screening
Who benefits?	Outcomes cannot be evaluated adequately without linked data
Who is accountable?	Responsibilities and funded plans are often unclear

Communication needs accessible appointments, suitable support and usable follow-up pathways.

From inclusion to equitable system design

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To reduce inequalities, screening programmes need to:

Make inequities visible in programme data

Monitor the entire pathway, not participation alone

Provide reasonable adjustments and accessible communication

Train and support healthcare professionals

Co-design services with affected communities

Assign responsibility, resources and accountability

Equity does not emerge by offering everyone the same programme.
It must be designed, measured and maintained across the screening system.

Thank you

Mari Nygård

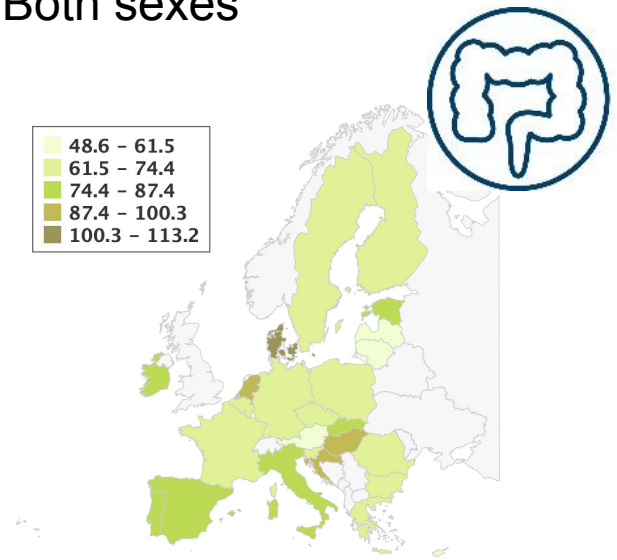
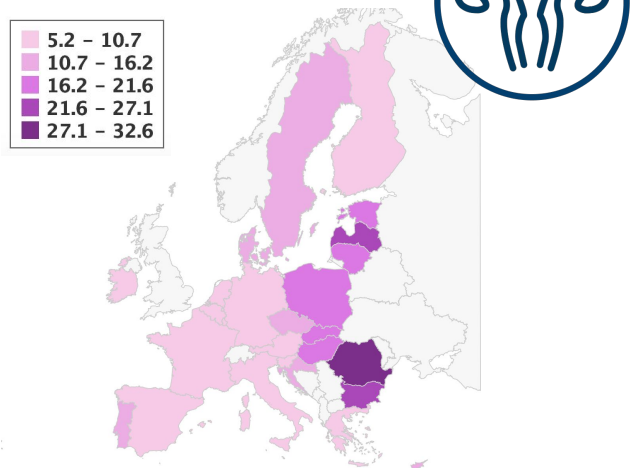
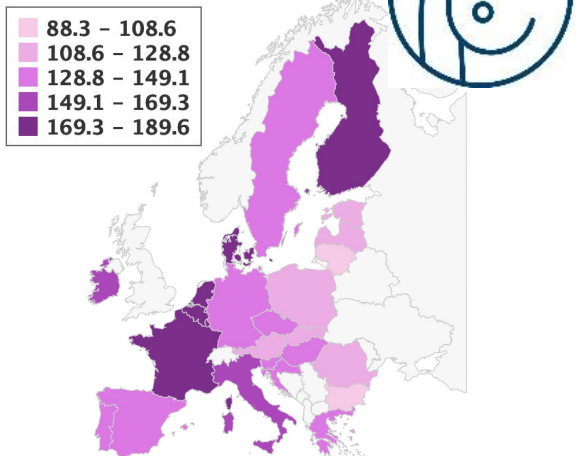
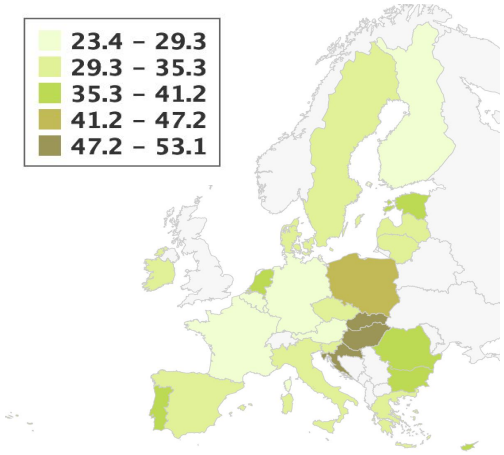
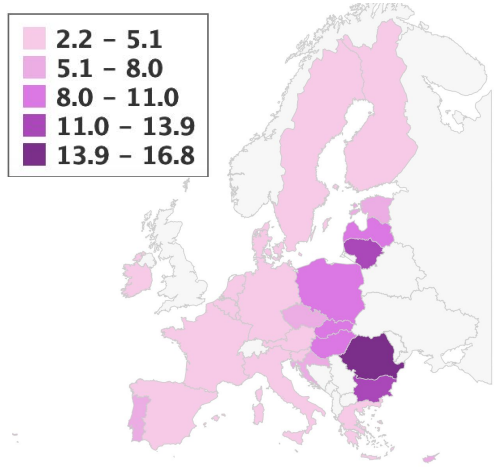
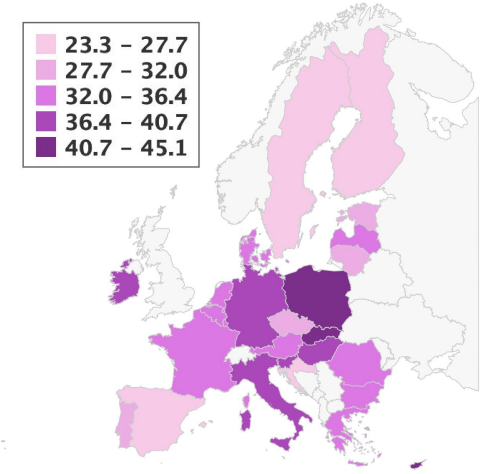
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Unequal cancer burden across the European countries

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	Both sexes	Females	Females
Incidence, age-standardized per 10^5			
Mortality, age-standardized per 10^5			

ECIS - European Cancer Information System, https://ecis.jrc.ec.europa.eu/index.php

Inequalities in utilization of screening test in Europe

FOB-test/ colonoscopy
within the past 2 yrs/10 yrs
N=47,244

cervical exam
within the past 3 yrs
N=68,026

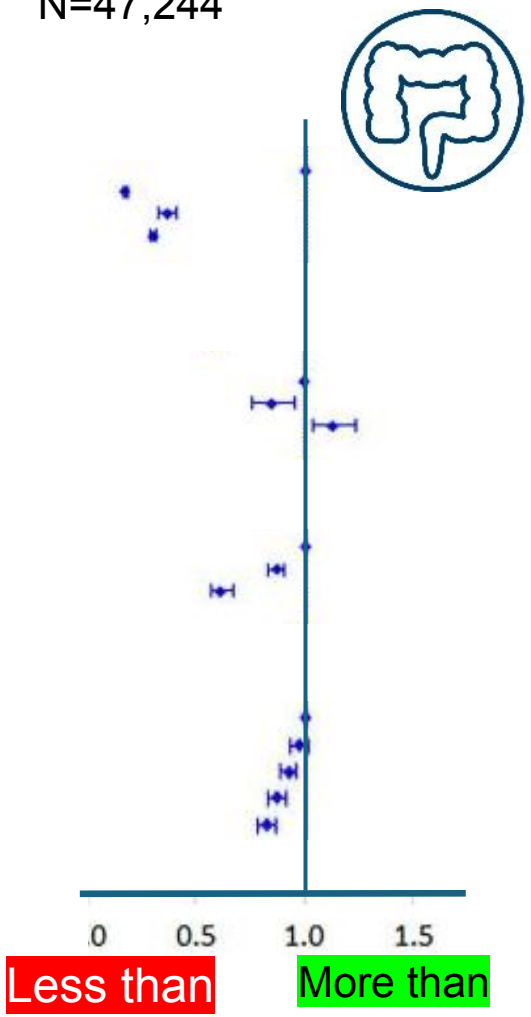
mammography
within the past 2 yrs
N=36,088

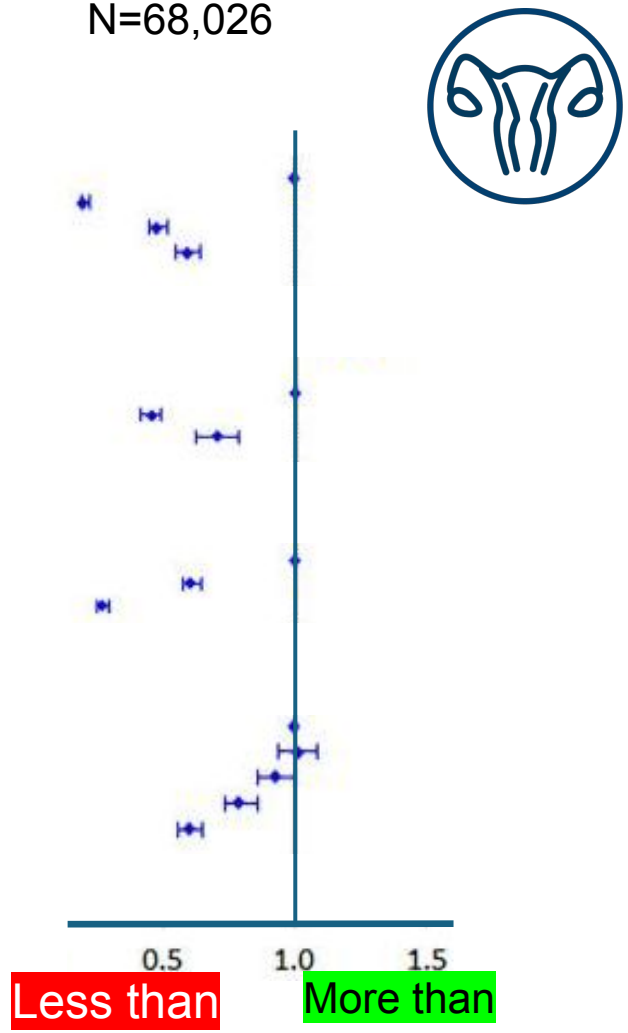
EUROPEAN REGION
- **Western Europe (ref)**
- Eastern Europe
- Southern Europe
- Northern Europe

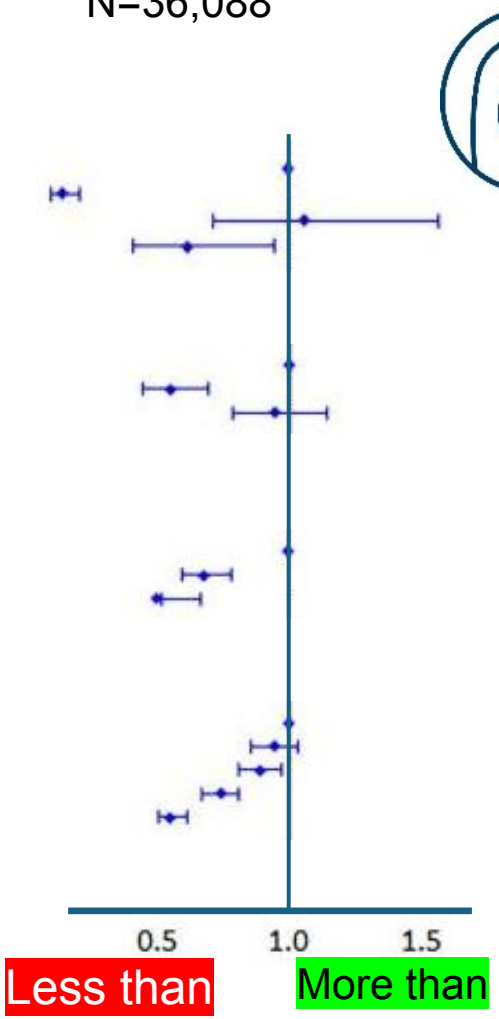
COUNTRY OF BIRTH
- **Native born (ref)**
- Non-EU
- Other EU States

EDUCATIONAL LEVEL
- **High (ref)**
- Intermediate
- low

HOUSEHOLD INCOME
- **4-5th q (ref)**
- 3-4 quintile
- 2-3 quintile
- 1-2 quintile
- <1 quintile







Bozhar et al. 2022, Prev Med Rep 2022 Vol. 26 Pages 101733