

The benefits and harms of cancer screening programmes for adults with intellectual disabilities: A systematic review.

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Abstract

Introduction

Cancer screening programmes are an important public health initiative aimed at reducing morbidity and mortality through the early detection of breast, cervical, and colorectal cancers. The available evidence points towards lower screening participation in cancer screening programmes among people with intellectual disabilities, but the balance of benefits and harms of screening is unknown. The aim of this systematic review is to examine the health outcomes (mortality, morbidity) and harms of cancer screening programmes for adults with intellectual disabilities.

Materials and methods

The review is registered on the Open Science Framework Registries: <https://osf.io/8vmkb>. A systematic search of published peer-reviewed and grey literature was conducted from inception up to 28th February 2025. MEDLINE, EMBASE, Web of Science, PsycINFO, and relevant organisational websites were searched. Additionally, experts in the field were consulted about evidence on the health outcomes and harms of national cancer screening programmes for adults with intellectual disabilities. Two reviewers independently screened titles and abstracts and assessed full texts against the eligibility criteria.

Results

A total of 3,104 records were identified, and 232 full-text articles were assessed for eligibility. No study met the inclusion criteria.

Conclusions

There is a critical lack of evidence regarding the benefits and harms of cancer screening programmes for people with intellectual disabilities. There are numerous studies relating to coverage, uptake, and factors influencing participation in cancer screening programmes. Participation should not be assumed to equate to better outcomes, and there is a real risk of ‘equity-washing’ if this is used as a basis for practice. There is, therefore, an urgent need to examine the full screening pathway continuum for people with intellectual disabilities, along with the associated outcomes, benefits, and harms.

Introduction

Cancer is a major societal, public health, and economic problem, ranking as a leading cause of death worldwide (1). Cancer screening programmes, which detect pre-cancerous or early-stage cancer in asymptomatic individuals are an important public health initiative that increases the chance of survival (2). However, screening is also associated with harms (3) such as discomfort and future health risks (e.g. radiation exposure)(4) from tests, inaccurate results that cause false reassurance (false negative test results)(5) or anxiety(6, 7) (false positive test results)(8), and overdiagnosis(9-11) (the detection of disease that would not have caused symptoms during a person's lifetime) which leads to unnecessary overtreatment. While these are not always avoidable, in an effective screening programme the benefits will outweigh the harms.

Most cancer screening programmes focus on detecting cancers of the bowel, female breast, and cervix, and these cancers contribute substantially to the overall cancer burden (12). Internationally, there is significant variability in how screening programmes are delivered, with non-uniformed approaches likely to mask differences, making like-for-like comparisons difficult. Western European countries typically experience the highest rates of uptake and coverage of cancer screening programmes,(13) with socioeconomic status and social vulnerability factors (14) being known to negatively influence uptake and outcomes (15).

Cancer screening uptake and coverage in people with intellectual disabilities have been reported as being lower than that of the general population (16-19). Increased social vulnerability factors, health inequalities, and inequities regarding access and accessibility are frequently cited as issues that impact healthcare utilisation (20, 21). However, it is not

fully clear how these factors impact the uptake of national cancer screening programmes in their entirety, though the mechanisms are likely similar (22). Despite dying younger, mortality ages for people with intellectual disabilities are increasing, meaning they are more likely to be exposed to the largest risk factor for developing cancers—aging (23, 24). Emerging evidence from Canada (25, 26), Scotland (27), and England (28) highlights that some cancers for which screening programmes exist appear to be occurring at a younger age in people with intellectual disabilities population. Moreover, when these cancers are detected they are often identified at later stages than the general population (26). This limits the chance of having curative treatment. That such inequities exist provides a concerning picture regarding the detection of cancers where population-level interventions exist but do not meet the needs of people with intellectual disabilities.

Screening programmes recognise the need for a more inclusive approach towards screening, with the Irish national screening service developing an equity framework in 2023 (29) and Public Health England developing their screening inequalities strategy in 2020 (30) to better understand and improve equity in cancer screening. Nevertheless, barriers to screening continue to exist for people with intellectual disabilities (20). In parallel with the general literature, it is likely that these barriers follow a health equity gradient influenced by broader general socioeconomic and environmental conditions where people from more marginalised and hard-to-reach groups are more likely to be influenced by the negative factors that also influence the determinants of health and well-being (31-33).

Due to the existing challenges and complex health needs of people with intellectual disabilities, it is important to understand participation in national cancer screening programmes. No attempt has yet been made to synthesise the existing published evidence exploring the relative harms and benefits of cancer screening for people with intellectual

disabilities. Consequently, this review aims to evaluate the health outcomes (e.g. mortality, morbidity) of participation in national cancer screening programmes for people with intellectual disabilities. In doing so, this systematic review aims to provide evidence to help understand the benefits and limitations for this population by identifying gaps and areas for improvement and future practice.

Research questions

1. What are the health outcomes (e.g. mortality, morbidity) of cancer screening programmes for adults who have intellectual disabilities?
2. What are the harms of cancer screening programmes for adults who have intellectual disabilities?

Materials and methods

The review is registered on the Open Science Framework Registries: <https://osf.io/8vmkb>

Identification and selection of studies

Search strategy

We undertook a comprehensive search strategy comprising: (1) searches of electronic bibliographic databases; (2) searches of websites of intellectual disabilities charities and cancer charities; (3) contacting known experts in the field and through discussions during an international workshop in May 2025; and (4) scrutiny of references of included studies and relevant systematic reviews.

The electronic bibliographic databases search strategy was developed in MEDLINE

(Ovid) using terms relating to (1) intellectual disability, (2) cancer, and (3) screening, and was adapted for EMBASE (Ovid), Web of Science (Clarivate), and PsycInfo (Ovid). Copies of the full search strategies are provided in Supplementary file 1. Searches were conducted on the 28th February 2025.

To identify additional/unpublished research, we searched the websites of a sample of charitable organisations that support either (1) people who have intellectual disabilities, or (2) people who have bowel, breast, or cervical cancer and provide research grants. The organisations were either known to the review team or identified through a Google search (“national [breast/bowel/cervical] cancer charities grant funding research”), with relevant returns from the first two search results pages being searched. A list of the organisations searched is provided in Supplementary file 2. Each organisation’s website was searched by entering the term “screening” (intellectual disability charities) or “disability” (cancer charities) into the website’s search box. Searches were conducted from the 7th to the 13th March 2025.

Study eligibility criteria

Studies reporting quantitative data, that were published in the English language, and investigated the health benefits (e.g., mortality, morbidity) and harms of population or targeted bowel, breast, and cervical cancer screening programmes for adults who have intellectual disabilities were eligible for inclusion in this review. We excluded studies of children and young people (aged 17 and under), people who did not have an intellectual disability, and where more than 10% of the study sample did not meet our inclusion criteria. Studies where the method of cancer detection was opportunistic screening, case-finding, one-off testing outside of an organised screening programme or routine examinations were

also excluded, as were studies that provided insufficient information for assessment of methodological quality/risk of bias to be conducted, or no numerical outcome data. Documents not available in the English language, studies where it could not be determined if the inclusion criteria were met, and literature reviews were also not eligible for inclusion in this review.

Review strategy

Study selection was conducted through the Covidence platform (34) for the electronic databases, and directly through the websites of cancer and intellectual disabilities organisations. For both electronic database and website searches, two reviewers independently assessed titles and abstracts. Any paper considered potentially relevant by either reviewer was retained for full text assessment. Full text assessment was conducted independently by two reviewers against the review eligibility criteria, with any disagreements resolved by consensus or through discussion with a third reviewer.

Results

Searching, sifting, and sorting

Full details of the flow of studies through the review are reported in Figure 1. We identified 2,262 unique records through database searches and 842 documents through the websites of cancer and intellectual disabilities organisations. After examination of titles and abstracts, 232 documents were retained for full text assessment (electronic databases: n = 231; websites: n = 1). None met the inclusion criteria for this review. Appendix 3 lists the studies that were excluded at the full text assessment stage of this review.

+++ Figure 1 +++

Discussion

In this systematic review, we intended to examine the health outcomes (e.g. mortality, morbidity) and harms of screening for breast, bowel, and cervical cancers for people with intellectual disabilities. Despite extensive searches of peer-reviewed and grey literature, we did not identify any studies that met the review eligibility criteria. The published evidence in this field broadly relates to the uptake and determinants of cancer screening programmes (16-20). While this is an important consideration, it does not address the overarching aims and objectives of screening, which are to improve morbidity and mortality through the early detection of disease (2). A significant evidence gap exists regarding health outcomes from cancer screening programmes for people with intellectual disabilities, including its relative benefits and harms. Therefore, recommendations from existing research that advocate for increased uptake and coverage need to be fully considered in terms of their overall health benefits for this population.

Cancer screening programmes offer substantial benefits, particularly with respect to mortality reduction from cervical(35) and colorectal screening (36), which may provide a greater net benefit than breast screening (37). For people with intellectual disabilities, the screening process needs to be understood as a continuum, not merely as a single event focused on coverage and uptake. While there is growing evidence in this population around invitation and attendance, greater emphasis must also be placed on exploring health outcomes, test performance, diagnostic follow-up, treatment initiation, positive outcomes, and harms, which are the fundamental to screening (2). Solely focusing on coverage and uptake risks ‘equity-washing’, whereby numerical participation is improved without knowing whether the programmes actually enhance health outcomes for people with intellectual

disabilities. This lack of evidence is particularly concerning given the atypical health presentations in this population, including different baselines for life expectancy and increased multimorbidity (24, 38-40).

People with intellectual disabilities face unique risks related to the capacity to consent, physiological differences, and the invasiveness and validity of some tests (41, 42). For example, in the Netherlands, Banda and colleagues(19) reported higher rates of invalid and inconclusive test results in the breast cancer, cervical cancer, and colon cancer screening programmes among people with intellectual disabilities compared with the general population. Although not reported in the study, these findings may point towards potential harms of screening, particularly increased psychological and physical burden, but further research is needed. Additionally, the experience of screening and its psychological impacts should not be overlooked for this population, who often experience difficulties with self-reporting and health literacy (43, 44). A recent systematic review of general asymptomatic populations reported that while most people view screening positively, those who receive false-positive results often experience increased levels of anxiety (7). A separate study on mammography found that women were less likely to return for future screenings following false-positive results, particularly when short-interval follow-up or biopsy was recommended, raising concerns about ongoing engagement in routine screening (45).

Colorectal screening may offer clear benefits for people with intellectual disabilities, given the high prevalence of these cancers in this population (27, 46). However, when positive results from screening tests (e.g., Faecal Immunochemical Test) or presenting symptoms necessitate further investigation, colonoscopy is typically required and often involves heavy sedation and/or general anaesthesia. Such procedures introduces increased

risks for people with intellectual disabilities and require appropriate adjustments (47). These harm–benefit trade-offs must be appropriately assessed and considered but, as the lack of results in our systematic review demonstrate, there is no current evidence to support people with intellectual disabilities to make decisions about whether to participate in cancer screening programmes.

An recent example of the importance of understanding harm–benefit trade-offs come from a modelling study simulating the benefits and harms of annual, biennial, triennial, and one-time digital mammography screening in women with Down syndrome(48). In this study, screening was assessed to be less favourable for women with Down syndrome compared to average-risk women without Down syndrome, due to their lower baseline risk of breast cancer and reduced life expectancy. While the study was based on a hypothetical cohort, it does highlight that standard screening guidelines developed for average-risk populations may be deficient, or even inappropriate, for people with Down syndrome.

In this context, similar patterns of inequity and have been observed in other underserved groups highlighting the need to understand health outcomes and understanding the benefits and harm of cancer screening programmes. Cancer screening participation rates are reported to be significantly lower among African American, Asian American, Latinx American, and American Indian/Alaska Native populations (49) as well as among transgender and gender-nonconforming adults (50), LGBTQ+ populations (51), and individuals with severe mental illness. (52) While much of the evidence also focuses on coverage and uptake, there is growing documentation of downstream harms, such as poorer cancer outcomes among African Americans (53), and people with mental illness (54). Similar inequalities and inequities in cancer risk and outcomes are now being observed in

the intellectual disability population (28). For example, Heslop et al. (2022) found that 43% of adults diagnosed with colorectal cancer in England were aged 18–59 years, suggesting that the age threshold for colorectal screening (over 60 years) in people with intellectual disabilities may be inequitable.

An example of screening policy being altered to meet the needs of population subgroups comes from the UK cervical screening programme where self-sampling was recently recommended as an alternative to clinician-sampling for under-screened women (55). This example illustrates how recommendations evolve to reflect population-specific risk profiles.

As a priority, we argue for an evaluation of the entire screening pathway for people with intellectual disabilities to determine where processes succeed and where they fall short for this population. This should include assessments of health outcomes, economic efficiency, and benefit–harm balance. Without this evidence, there is a risk that efforts to improve uptake may be interpreted as improvements in outcomes, when they may, in fact, lead to unintended harm. We therefore assert that, collectively, we must explore and understand what happens after people with intellectual disabilities participate in screening, particularly in terms of the balance of benefits and harms. Only then can we consider reasonable adjustments to enhance health outcomes for people with intellectual disabilities when accessing cancer screening.

Strengths and limitations

To our knowledge, this is the first systematic review to examine the benefits and harms of cancer screening programmes for people who have intellectual disabilities. We followed standard methodology for conducting systematic reviews, and the protocol is publicly

available on the Open Science Framework (<https://osf.io/8vmkb>). We searched a broad range of sources for evidence (electronic databases, grey literature in the form of relevant organisation websites, contact with experts), without imposing limits on study design beyond a necessity for studies to present some relevant quantitative data.

Our review has several limitations. First, we did not involve people with intellectual disabilities in this review. This has implications for the applicability of the review as while mortality, morbidity, and harms are essential outcomes of screening programmes they are not necessarily the only outcomes of interest for people with intellectual disabilities themselves. Second, we took a pragmatic approach to determining which websites to search for relevant research. While this is likely to capture the websites of the largest organisations relating to cancer and intellectual disabilities, the results returned are determined by the algorithm used for that search engine; different organisation websites might have been identified by other search engines. There are also numerous other sources of grey literature that we did not explore (e.g., doctoral theses). Finally, we did not search for studies in languages other than English. It is possible that relevant studies in languages other than English could have been missed.

Future Research

This review highlights a significant gap in the evidence relating to health outcomes from cancer screening programmes for people with intellectual disabilities. Existing research has largely focused on coverage and uptake, but not on the benefits and harms associated with cancer screening for this population. From this perspective, research should view screening programmes as a continuum and, using longitudinal data, map the full trajectory from invitation to participation, diagnosis, and outcomes for people with intellectual disabilities.

This would provide a greater understanding of the health outcomes of screening for this population.

Additionally, it be important to estimate the benefit–harm ratio and cost-effectiveness of screening strategies for this population, accounting for different scenarios in terms of this population’s life expectancy and associated comorbidities. It is also important to consider the lived experiences of people with intellectual disabilities, as well as their families and supporters, in relation to participating in cancer screening programmes. This is particularly important to help understand the and psychological impacts of cancer screening programmes.

Overall, it is critically important that future research addresses the potential for 'equity-washing', where increases in coverage and uptake are misrepresented as improved outcomes, without consideration of the actual benefit–harm balance.

Conclusion

In summary, this systematic review highlights a substantial evidence gap concerning the benefits and harms of cancer screening programmes for adults with intellectual disabilities. We found no studies that had evaluated whether cancer screening improves outcomes or causes harm in people with intellectual disabilities. Without this evidence and knowledge of downstream effects, the balance of benefits and harms of cancer screening in people with intellectual disabilities is unknown. cancer screening must be assessed as a continuum of care, not solely through measures of uptake and coverage.

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Supporting information

Author contributions

CRediT authorship contribution statement

487 **Martin McMahon:** Conceptualisation, methodology, validation, investigation, writing - original draft,
 488 writing - review and editing, project administration
 489 **Samantha Flynn:** Conceptualisation, methodology, validation, investigation, writing - review and
 490 editing
 491 **Samantha A Johnson:** Methodology, investigation, writing - review and editing,
 492 **Chris Stinton:** Conceptualisation, methodology, validation, investigation, writing - original draft,
 493 writing - review and editing, supervision

Appendix 1. Database searches

Medline ALL (OVID) 1946-		
#	Search terms	Results
1.	((intellectual or learning or neurodevelop* or development* or mental) adj4 (disabilit* or impair* or handicap or retard* or deficien*)).mp	175422
2.	exp Intellectual Disability/	109278
3.	exp Learning Disabilities/	24548
4.	exp developmental disabilities/	23316
5.	Neurodevelopmental Disorders/	5771
6.	1 or 2 or 3 or 4 or 5	227553
7.	(cancer* or neoplasm* or carcinoma* or tumor* or tumour* or oncolog*).mp	4514628
8.	(colorectal or bowel or breast or mammar* or cervix or cervic*).mp	1248077
9.	7 and 8	816495
10.	exp Colorectal Neoplasms/	253340
11.	exp Breast Neoplasms/	364569
12.	exp Uterine Cervical Neoplasms/	89875
13.	9 or 10 or 11 or 12	910347
14.	((((fecal or faecal) and test) or occult blood test or ((fecal or faecal) and immunochemical test*) or (colonoscop* or endoscop* or sigmoid*) or mammogra* or ((human and (papillomavirus or papilloma virus)) or HPV))).mp	443116

15.	exp Occult Blood/	6652
16.	exp Colonoscopy/	36825
17.	exp Endoscopy/	427442
18.	exp Sigmoidoscopy/	4928
19.	exp Mammography/	34820
20.	(screen* or early detect*).mp	1063010
21.	exp Mass Screening/	149709
22.	exp "Early Detection of Cancer"/	43128
23.	14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22	1680360
24.	6 and 13 and 23	212
25.	limit 24 to English language	206

Embase Classic + Embase (OVID), 1947-		
#	Search terms	Results
1.	((intellectual or learning or neurodevelop* or development* or mental) adj4 (disabilit* or impair* or handicap or retard* or deficient*).mp	222662
2.	intellectual disabilit*.mp. or exp intellectual impairment/	681513

3.	learning disabilit*.mp. or exp learning disorder/	46894
4.	developmental disabilit*.mp. or exp developmental disorder/	72178
5.	(neurodevelopmental disabilit* or neurodevelopmental disorder*).mp	29092
6.	1 or 2 or 3 or 4 or 5	855557
7.	(cancer* or neoplasm* or carcinoma* or tumor* or tumour* or oncolog*).mp	6966647
8.	(colorectal or bowel or breast or mammar* or cervix or cervic*).mp	2167242
9.	7 and 8	1460608
10.	Colorectal Neoplasm*.mp. or exp colorectal tumor/	505106
11.	colorectal cancer.mp. or exp colorectal cancer/	461369
12.	exp breast tumor/ or exp breast carcinoma/ or breast neoplasm*.mp. or exp breast cancer/	721902
13.	exp uterine cervix tumor/ or exp uterine cervix cancer/ or exp uterine cervix carcinoma/ or uterine cervical neoplasm*.mp.	150879
14.	9 or 10 or 12 or 13	1609625
15.	((fecal or faecal) and test) or occult blood test or ((fecal or faecal) and immunochemical test*) or (colonoscop* or endoscop* or sigmoid*) or mammogra* or ((human and (papillomavirus or papilloma virus)) or HPV)).mp	899006
16.	exp Occult Blood/	11512
17.	exp Colonoscopy/	115984
18.	exp Endoscopy/	860222
19.	exp Sigmoidoscopy/	15151
20.	exp Mammography/	73066

21.	(screen* or early detect*).mp	1997579
22.	exp Mass Screening/	343583
23.	"early detection of cancer".mp. or exp early cancer diagnosis/	19261
24.	15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23	3203541
25.	6 and 14 and 24	1945
26.	limit 25 to English language	1912

Web of Science Core Collection (Clarivate), 1900-		
#	Search terms	Results
1.	ALL=(((intellectual or learning or neurodevelop* or development* or mental) AND (disabilit* or impair* or handicap or retard* or deficien* or disorder)))	1,403,762
2.	ALL=((cancer* or neoplasm* or carcinoma* or tumor* or tumour* or oncolog*) AND (colorectal or bowel or breast or mammar* or cervix or cervic*))	1,310,307
3.	(((ALL=((fecal or faecal) and test)) OR ALL=("occult blood test")) OR ALL=((fecal or faecal) and "immunochemical test*")) OR ALL=(colonoscop* or endoscop* or sigmoid* or mammogra*) OR ALL=(papillomavirus or "papilloma virus" or HPV)	659,001
4.	ALL=(screen* or "early detect*")	1,562,020
5.	#4 AND #3 AND #2 AND #1	373
6.	#4 AND #3 AND #2 AND #1 and English (Languages)	361

PsycInfo (OVID), 1806-		
#	Search terms	Results
1.	((intellectual or learning or neurodevelop* or development* or mental) adj4 (disabilit* or impair* or handicap or retard* or deficient*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word])	123456
2.	exp Intellectual Development Disorder/	51650
3.	intellectual disabilit*.mp.	34531
4.	intellectual impairment.mp.	1142
5.	exp Learning Disabilities/ or exp Learning Disorders/ or learning disorder*.mp.	41749
6.	learning disabilit*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	29309
7.	developmental disabilit*.mp.	23352
8.	(neurodevelopmental disabilit* or neurodevelopmental disorder*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	11043
9.	exp Developmental Disabilities/ or developmental disorder*.mp.	23643
10.	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9	165890
11.	(cancer* or neoplasm* or carcinoma* or tumor* or tumour* or oncolog*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	108524

12.	(colorectal or bowel or breast or mammar* or cervix or cervic*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	44603
13.	11 and 12	25199
14.	exp Colorectal Neoplasms/ or Colorectal Neoplasm*.mp.	2698
15.	colorectal cancer.mp.	3347
16.	exp Breast Neoplasms/	12461
17.	13 or 14 or 15 or 16	25199
18.	((fecal or faecal) and test) or occult blood test or ((fecal or faecal) and immunochemical test*) or (colonoscop* or endoscop* or sigmoid*) or mammogra* or ((human and (papillomavirus or papilloma virus)) or HPV)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	8966
19.	occult blood.mp.	468
20.	exp Mammography/	1477
21.	(screen* or early detect*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	167217
22.	exp Cancer Screening/ or exp Screening/ or exp Screening Tests/	28347
23.	18 or 19 or 20 or 21 or 22	173707
24.	10 and 17 and 23	76
25.	limit 24 to English language	74

Appendix 2. Organisations included in the website search (websites and results)

Learning disabilities		
Organisation	Website	Results of searches
Mencap	https://www.mencap.org.uk/	98
IDS Tilda	https://idstilda.tcd.ie/	20
Inclusion Europe	https://www.inclusion-europe.eu/	23
British Institute of Learning Disabilities	https://www.bild.org.uk/	5
Foundation for People with Learning Disabilities	https://www.learningdisabilities.org.uk/	5

Bowel cancer		
Organisation	Website	Results of searches
Bowel Cancer UK	https://www.bowelcanceruk.org.uk/	7
Bowel Research UK	https://bowelresearchuk.org/	14
Fight Colorectal Cancer	https://fightcolorectalcancer.org/	0
Colorectal Cancer Alliance	https://colorectalcancer.org/	32

Breast cancer		
Organisation	Website	Results of searches
Breast Cancer Now	https://breastcancernow.org	31
Breast Cancer Research Foundation	https://www.bcrf.org/	1
Prevent breast cancer	https://preventbreastcancer.org.uk/	0
Susan G Komen	https://www.komen.org/	58
Pink Ribbon Foundation	https://www.pinkribbonfoundation.org.uk/	4
National Breast Cancer Foundation	https://www.nationalbreastcancer.org/	3

Cervical cancer		
Organisation	Website	Results of searches
The Eve Appeal	https://eveappeal.org.uk/	10
British Gynaecological Cancer Society	https://www.bgcs.org.uk/	0

General cancer		
Organisation	Website	Results of searches
Cancer Research UK	https://www.cancerresearchuk.org/	518
International Agency for Research on Cancer	https://www.iarc.who.int/	13

Appendix 3. Studies excluded at full text assessment

Reference	Reason for exclusion
1. Akakpo CW. The relationship between cervical cancer and women living with disabilities in Kentucky. Dissertation Abstracts International: Section B: The Sciences and Engineering 2021;82(6-B):No Pagination Specified.	Wrong patient population
2. Alagoz O, Hajjar A, Chootipongchaivat S, et al. Benefits and Harms of Mammography Screening for Women With Down Syndrome: a Collaborative Modeling Study. Journal of General Internal Medicine 2019;34(11):2374-81. doi: https://dx.doi.org/10.1007/s11606-019-05182-5	Wrong patient population
3. Almohammed HI. Breaking barriers: improving mammography screening accessibility and quality of care for breast cancer women with disabilities in Saudi Arabia. Frontiers in Oncology 2024;14:8. doi: 10.3389/fonc.2024.1398061	Wrong outcomes
4. Almohammed HI. A Systematic Review to Evaluate the Barriers to Breast Cancer Screening in Women with Disability. Journal of Clinical Medicine 2024;13(11):12. doi: 10.3390/jcm13113283	Wrong outcomes
5. Andiwijaya FR, Davey C, Bessame K, et al. Disability and Participation in Breast and Cervical Cancer Screening: A Systematic Review and Meta-Analysis. International Journal of Environmental Research and Public Health 2022;19(15):20. doi: 10.3390/ijerph19159465	Wrong study design
6. Arana E. Racial and ethnic disparities in mammography utilization among women with intellectual disabilities: An exploratory mixed methods approach. Cancer Epidemiology Biomarkers and Prevention Conference: 8th AACR	No extractable data

Conference on the Science of Health Disparities in Racial/Ethnic Minorities and the Medically Underserved Atlanta, GA United States 2016;25(3 Supplement) doi: https://dx.doi.org/10.1158/1538-7755.DISP15-C28	
7. Arana E. Racial & ethnic disparities in mammogram frequency among women with intellectual disabilities: An explanatory mixed methods approach. Racial & ethnic disparities in mammogram frequency among women with intellectual disabilities: an explanatory mixed methods approach. Dissertation Abstracts International: Section B: The Sciences and Engineering 2018;79(1-B(E)):No Pagination Specified.	Wrong outcomes
8. Arana E, Carroll-Scott A, Massey PM, et al. Racial/Ethnic Disparities in Mammogram Frequency Among Women With Intellectual Disability. Intellectual & Developmental Disabilities 2019;57(3):177-87. doi: https://dx.doi.org/10.1352/1934-9556-57.3.177	Wrong outcomes
9. Arana-Chicas E, Kioumars A, Carroll-Scott A, et al. Barriers and facilitators to mammography among women with intellectual disabilities: A qualitative approach. Disability & Society 2020;35(8):1290-314. doi: https://dx.doi.org/10.1080/09687599.2019.1680348	Wrong study design
10. Armin JS, Williamson HJ, Baldwin J, et al. Working with stakeholders to adapt a cancer screening education program for Native American women with intellectual disabilities. Cancer Research Conference: American Association for Cancer Research Annual Meeting 2019;79(13 Supplement) doi: https://dx.doi.org/10.1158/1538-7445.2431	No extractable data

11. Armin JS, Williamson HJ, Rothers J, et al. Refining a breast and cervical cancer screening program for Native American women with disabilities. Cancer Epidemiology Biomarkers and Prevention Conference: 13th AACR Conference on the Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved Virtual 2020;29(12 SUPPL) doi: https://dx.doi.org/10.1158/1538-7755.DISP20-PO-026	Wrong outcomes
12. Bae J, Awammi M, Macnair A, et al. Cervical smear uptake in Black, Asian and minority ethnic and learning disability populations. Clinical Medicine, Journal of the Royal College of Physicians of London 2022;22:S84. doi: https://dx.doi.org/10.7861/clinmed.22-4-s84	Wrong outcomes
13. Banda A, Naaldenberg J, Timen A, et al. Cancer risks related to intellectual disabilities: A systematic review. Cancer Medicine 2024;13(9) (no pagination) doi: https://dx.doi.org/10.1002/cam4.7210	Wrong intervention
14. Bang G, Park M, Seon JY, et al. Comparative analysis of genetic testing utilization rates among people with and without disabilities in South Korea from 2016 to 2019, focusing on malignant neoplasms: A national population-based study. Cancer Medicine 2024;13(9) (no pagination) doi: https://dx.doi.org/10.1002/cam4.7102	Wrong outcomes
15. Bates C, Triantafyllopoulou P. Exploring the impact of mental capacity on breast screening for women with intellectual disabilities. Health & Social Care in the Community 2019;27(4):880-88. doi: https://dx.doi.org/10.1111/hsc.12704	Wrong outcomes

16. Bateson D, Ussher J, Strnadova I, et al. Working together with people with intellectual disability to make a difference: a protocol for a mixed-method co-production study to address inequities in cervical screening participation. Frontiers in public health 2024;12:1360447. doi: https://dx.doi.org/10.3389/fpubh.2024.1360447	No extractable data
17. Bateson D, Woo YL, Kulkarni J. Elimination of cervical cancer: ensuring equity. The Lancet Public Health 2023;8(4):e248-e49. doi: https://dx.doi.org/10.1016/S2468-2667%2823%2900055-5	No extractable data
18. Biggs K, Ouellette-Kuntz H, Griffiths R, et al. Frequency of Missing TNM Stage Data for Adults With Intellectual or Developmental Disabilities in a Provincial Cancer Registry-A Brief Report. Cancer Medicine 2025;14(1) (no pagination) doi: https://dx.doi.org/10.1002/cam4.70579	Wrong outcomes
19. Biswas M, Whalley H, Foster J, et al. Women with learning disability and uptake of screening: audit of screening uptake before and after one to one counselling. Journal of Public Health 2005;27(4):344-7. doi: https://dx.doi.org/10.1093/pubmed/fdi055	Wrong outcomes
20. Bothur S, Knapp I, Kreuzwieser F, et al. Pilot project: Easily said and done: Prevention and early detection of colon cancer and skin cancer. Oncology Research and Treatment 2022;45(Supplement 3):42. doi: https://dx.doi.org/10.1159/000521004	Wrong outcomes
21. Bouchardy Magnin C. Breast cancer screening among women with intellectual disability. Sozial- und Praventivmedizin 2004;49(6):361-62. doi: https://dx.doi.org/10.1007/s00038-004-4088-5	No extractable data

22. Bowler M, Nash P. Learning disabilities: improved bowel screening. Nursing times 2015;111(49-50):14-6.	Wrong outcomes
23. Breau G, Thorne S, Baumbusch J, et al. Family physicians', family practice residents' and nurse practitioner students' attitudes and experiences recommending cancer screening to patients with intellectual disabilities. Journal of Intellectual Disability Research 2016;60(7-8):772.	No extractable data
24. Breau G, Thorne S, Baumbusch J, et al. Family physicians' and trainees' experiences regarding cancer screening with patients with intellectual disability: An interpretive description study. Journal of Intellectual Disabilities 2023;27(1):250-65. doi: https://dx.doi.org/10.1177/17446295211044041	Wrong patient population
25. Broughton S. A review of the literature: interventions to maximize capacity to consent and reduce anxiety of women with learning disabilities preparing for a cervical smear test. Health Services Management Research 2002;15(3):173-85. doi: https://dx.doi.org/10.1258/095148402320176756	No extractable data
26. Brown H, Plourde N, Ouellette-Kuntz H, et al. Brief report: Cervical cancer screening in women with intellectual and developmental disabilities who have had a pregnancy. Journal of Intellectual Disability Research 2016;60(1):22-27. doi: https://dx.doi.org/10.1111/jir.12225	Wrong outcomes
27. Bulova P. Capsule Commentary on Alagoz et al., Benefits and Harms of Mammography Screening for Women with Down Syndrome. Journal of General Internal Medicine 2019;34(11):2581. doi: https://dx.doi.org/10.1007/s11606-019-05295-x	No extractable data

28. Byrnes K. What are the attitudes and opinions of women with a learning disability, family carers, and paid care workers, towards cervical and breast cancer screening programmes? <i>Psycho-Oncology</i> 2019;28(Supplement 2):28. doi: https://dx.doi.org/10.1002/pon.4997	No extractable data
29. Byrnes K, Hamilton S, McGeechan GJ, et al. Attitudes and perceptions of people with a learning disability, family carers, and paid care workers towards cancer screening programmes in the United Kingdom: A qualitative systematic review and meta-aggregation. <i>Psycho-Oncology</i> 2020;29(3):475-84. doi: https://dx.doi.org/10.1002/pon.5311	Wrong study design
30. Byrnes K, Mc Geechan GJ, Hamilton S, et al. Attitudes of women with a learning disability and their carers, towards the NHS cervical and breast cancer screening programmes: A qualitative systematic review and metaaggregation. <i>Psycho-Oncology</i> 2019;28(Supplement 2):10. doi: https://dx.doi.org/10.1002/pon.4994	Wrong outcomes
31. Carlson G. Supporting the health and well-being of people with intellectual disability and high support needs through networking and resource development. <i>Australian Occupational Therapy Journal</i> 2002;49(1):37-43. doi: https://dx.doi.org/10.1046/j.0045-0766.2002.00285.x	Wrong outcomes
32. Carter A, Strnadova I, Watfern C, et al. The sexual and reproductive health and rights of young people with intellectual disability: A scoping review. <i>Sexuality Research & Social Policy: A Journal of the NSRC</i> 2022;19(1):372-90. doi: https://dx.doi.org/10.1007/s13178-021-00549-y	Wrong outcomes

33. Chan DNS, Law BMH, Au DWH, et al. A systematic review of the barriers and facilitators influencing the cancer screening behaviour among people with intellectual disabilities. Cancer Epidemiology 2022;76:20. doi: 10.1016/j.canep.2021.102084	Wrong outcomes
34. Chen LS, Chou YJ, Tsay JH, et al. Variation in the cervical cancer screening compliance among women with disability. Journal of Medical Screening 2009;16(2):85-90. doi: https://dx.doi.org/10.1258/jms.2009.008061	Wrong outcomes
35. Chen Y, Powers J, McDougle CJ, et al. Cervical Cancer Screening and Prevention Uptake in Females with Autism Spectrum Disorder. Journal of Autism and Developmental Disorders 2024 doi: https://dx.doi.org/10.1007/s10803-024-06565-2	Wrong outcomes
36. Chicoine B, Roth M, Chicoine L, et al. Breast cancer screening for women with Down syndrome: Lessons learned. Intellectual and Developmental Disabilities 2015;53(2):91-99. doi: https://dx.doi.org/10.1352/1934-9556-53.2.91	Cannot tell if study meets eligibility criteria
37. Choi JY, Yeob KE, Hong SH, et al. Disparities in the Diagnosis, Treatment, and Survival Rate of Cervical Cancer among Women with and without Disabilities. Cancer Control 2021;28:10732748211055268. doi: https://dx.doi.org/10.1177/10732748211055268	Wrong intervention
38. Cithambaram K, Corby D, Hartnett L, et al. Population-based cancer screening access needs of disabled people: A qualitative evidence synthesis. Journal of Intellectual Disabilities 2025;22. doi: 10.1177/17446295241308708	Wrong study design

39. Clark MA, Rogers ML, Wen XZ, et al. REPEAT MAMMOGRAPHY SCREENING AMONG UNMARRIED WOMEN WITH AND WITHOUT A DISABILITY. Womens Health Issues 2009;19(6):415-24. doi: 10.1016/j.whi.2009.08.001	Wrong patient population
40. Cobigo V, Ouellette-Kuntz H, Balogh R, et al. Are cervical and breast cancer screening programmes equitable? The case of women with intellectual and developmental disabilities. Journal of Intellectual Disability Research 2013;57(5):478-88. doi: https://dx.doi.org/10.1111/jir.12035	Wrong outcomes
41. Cooper D. Supporting a patient with learning disabilities through screening and treatment for primary breast cancer. British Journal of Nursing 2022;31(22):1150-53. doi: https://dx.doi.org/10.12968/bjon.2022.31.22.1150	Wrong study design
42. Cooper SA, Henderson A, Kinnear D, et al. Cohort profile: Scotland's record-linkage e-cohorts of people with intellectual disabilities, and autistic people (SCIDA). BMJ Open 2022;12(5):e057230. doi: https://dx.doi.org/10.1136/bmjopen-2021-057230	Wrong outcomes
43. Cowie M, Fletcher J. Breast awareness project for women with a learning disability. British Journal of Nursing 1998;7(13):774-8. doi: https://dx.doi.org/10.12968/bjon.1998.7.13.5648	Wrong outcomes
44. Cuyppers M, Tobi H, Huijsmans CAA, et al. Disparities in cancer-related healthcare among people with intellectual disabilities: A population-based cohort study with health insurance claims data. Cancer Medicine 2020;9(18):6888-95. doi: https://dx.doi.org/10.1002/cam4.3333	Wrong outcomes

45. Cuypers M, Tobi H, Huijsmans CAA, et al. Disparities in cancer-related healthcare among people with intellectual disabilities: A population-based cohort study with health insurance claims data. Cancer Medicine 2020;9(18):6888-95. doi: https://dx.doi.org/10.1002/cam4.3333	Wrong outcomes
46. Davies N, Duff M. Breast cancer screening for older women with intellectual disability living in community group homes. Journal of Intellectual Disability Research 2001;45(Pt 3):253-7. doi: https://dx.doi.org/10.1046/j.1365-2788.2001.00313.x	Wrong outcomes
47. Davis C. The screen team. Nursing Standard 2008;22(39):20-1.	Wrong outcomes
48. Deroche CB, McDermott SW, Mann JR, et al. Colorectal Cancer Screening Adherence in Selected Disabilities Over 10 Years. American Journal of Preventive Medicine 2017;52(6):735-41. doi: https://dx.doi.org/10.1016/j.amepre.2017.01.005	Wrong outcomes
49. Dibble KE, Lutz TM, Connor AE, et al. Breast and ovarian cancer among women with intellectual and developmental disabilities: An agenda for improving research and care. Women's Health Issues 2024;34(1):3-6. doi: https://dx.doi.org/10.1016/j.whi.2023.06.001	No extractable data
50. Djuretic T, Laing-Morton T, Guy M, et al. Cervical screening for women with learning disability. Concerted effort is needed to ensure these women use preventive services. Bmj 1999;318(7182):537.	Wrong outcomes

51. Evans M, Liu KJ, Rego A, et al. "It's a low-key thing of eugenics": Disability reproductive injustice in barriers to cervical cancer screening during the COVID-19 pandemic. Social Science and Medicine 2025;369(no pagination) doi: https://dx.doi.org/10.1016/j.socscimed.2025.117807	Wrong patient population
52. Fischer LS, Becker A, Paraguay M, et al. Colonoscopy and colorectal cancer screening in adults with intellectual and developmental disabilities: review of a series of cases and recommendations for examination. Intellectual & Developmental Disabilities 2012;50(5):383-90. doi: https://dx.doi.org/10.1352/1934-9556-50.5.383	More than 10% not eligible
53. Gillings-Taylor S. Why the difference? Advice on breast examination given to carers of women who have learning disability and to women who do not. Journal of Learning Disabilities 2004;8(2):175-89. doi: https://dx.doi.org/10.1177/1469004704042705	Wrong outcomes
54. Glover G. Opportunities for using population-level data in health promotion for people with intellectual disabilities in england: Potential and realities. Journal of Intellectual Disability Research 2019;63(7):796. doi: https://dx.doi.org/10.1111/jir.12660	Wrong outcomes
55. Glover G, Williams R, Heslop P, et al. Mortality in people with intellectual disabilities in England. Journal of Intellectual Disability Research 2017;61(1):62-74. doi: https://dx.doi.org/10.1111/jir.12314	Wrong intervention
56. Gray J. Increasing participation of people with learning disabilities in bowel screening. British Journal of Nursing 2018;27(5):250-53. doi: https://dx.doi.org/10.12968/bjon.2018.27.5.250	No extractable data

57. Greenwood NW, Dreyfus D, Wilkinson J. More than just a mammogram: breast cancer screening perspectives of relatives of women with intellectual disability. Intellectual & Developmental Disabilities 2014;52(6):444-55. doi: https://dx.doi.org/10.1352/1934-9556-52.6.444	Wrong patient population
58. Greenwood NW, Wang CT, Bowen D, et al. Testing the feasibility of a DVD-based intervention to promote preparedness for mammography in women with intellectual disabilities. Journal of Cancer Education 2014;29(1):99-105. doi: https://dx.doi.org/10.1007/s13187-013-0554-1	Wrong outcomes
59. Gros SE, Pfaff H, Swora M, et al. Health disparities among breast cancer patients with/without disabilities in Germany. Disability and Health Journal Vol 13(2), 2020, ArtID 100873 2020;13(2) doi: https://dx.doi.org/10.1016/j.dhjo.2019.100873	Wrong outcomes
60. Grzywacz V, Hussain N, Ragina N. Racial Disparities and Factors Affecting Michigan Colorectal Cancer Screening. Journal of Racial and Ethnic Health Disparities 2018;5(4):901-06. doi: 10.1007/s40615-017-0438-x	Wrong patient population
61. Guilcher SJT, Lofters A, Glazier RH, et al. Level of disability, multi-morbidity and breast cancer screening: Does severity matter? Preventive Medicine 2014;67:193-98. doi: 10.1016/j.ypmed.2014.07.025	Wrong outcomes
62. Haider SI, Ansari Z, Vaughan L, et al. Health and wellbeing of Victorian adults with intellectual disability compared to the general Victorian population. Research in Developmental Disabilities 2013;34(11):4034-42. doi: https://dx.doi.org/10.1016/j.ridd.2013.08.017	Wrong outcomes

63. Haire AR, Bambrick M, Jones J. Cervical screening for women with a mental handicap: A court sanctions her sterilisation. What about her cervical smear? British Journal of Family Planning 1992;17(4):120-21.	Wrong outcomes
64. Hall P, Ward E. Cervical screening for women with learning disability. Numbers screened can be optimised by using a focused initiative. Bmj 1999;318(7182):536-7. doi: https://dx.doi.org/10.1136/bmj.318.7182.536b	Wrong outcomes
65. Hall P, Ward E, Djuretic T, et al. Cervical screening for women with learning disability [9]. British Medical Journal 1999;318(7182):536-37.	Wrong outcomes
66. Hanna L, Taggart L, Cousins W. Cancer prevention and health promotion for people with intellectual disabilities: An exploratory study of staff knowledge. Journal of Intellectual Disability Research 2011;55(3):281-91. doi: https://dx.doi.org/10.1111/j.1365-2788.2010.01357.x	Wrong patient population
67. Hasle H, Friedman JM, Olsen JH, et al. Low risk of solid tumors in persons with Down syndrome. Genetics in Medicine 2016;18(11):1151-57. doi: https://dx.doi.org/10.1038/gim.2016.23	Wrong intervention
68. Hassiotis A, Osborn D, Horsfall L, et al. Access to cancer screening in people with learning disabilities in the UK using a primary care database. Journal of Intellectual Disability Research 2012;56(7-8):763. doi: https://dx.doi.org/10.1111/j.1365-2788.2012.01583_10.x	Wrong outcomes

69. Havercamp SM, Scandlin D, Roth M. Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. Public Health Reports 2004;119(4):418-26. doi: https://dx.doi.org/10.1016/j.phr.2004.05.006	Wrong outcomes
70. Herweijer E, Wang J, Hu K, et al. Overall and Cervical Cancer Survival in Patients With and Without Mental Disorders. JAMA Network Open 2023;6(9):e2336213. doi: https://dx.doi.org/10.1001/jamanetworkopen.2023.36213	Wrong intervention
71. Heslop P, Cook A, Sullivan B, et al. Cancer in deceased adults with intellectual disabilities: English population-based study using linked data from three sources. BMJ Open 2022;12(3):e056974. doi: https://dx.doi.org/10.1136/bmjopen-2021-056974	Wrong intervention
72. Honjo S, Ohno S. Colonoscopy for asymptomatic, intellectually and physically disabled persons:equity in medicine. No To Hattatsu 2016;48(Supplement 1):S241.	Insufficient information to assess risk bias/study quality
73. Honjo S, Ohno S. A scheme offering assistance to women with profound and multiple disabilities to receive mammography. No To Hattatsu 2017;49(Supplement 1):S295.	Wrong outcomes
74. Horner-Johnson W, Dobbartin K, Iezzoni LI. Disparities in Receipt of Breast and Cervical Cancer Screening for Rural Women Age 18 to 64 with Disabilities. Womens Health Issues 2015;25(3):246-53. doi: 10.1016/j.whi.2015.02.004	Wrong outcomes
75. Horner-Johnson W, Dobbartin K, Lee JC, et al. Rural disparities in receipt of colorectal cancer screening among adults ages 50-64 with disabilities. Disability and Health Journal 2014;7(4):394-401. doi: 10.1016/j.dhjo.2014.06.001	Wrong outcomes

76. Horner-Johnson W, Dobbertin K, Lee JC, et al. Disparities in Health Care Access and Receipt of Preventive Services by Disability Type: Analysis of the Medical Expenditure Panel Survey. Health Services Research 2014;49(6):1980-99. doi: 10.1111/1475-6773.12195	Wrong outcomes
77. Horsbol TA, Michelsen SI, Lassen TH, et al. Breast Cancer Screening Among Women With Intellectual Disability in Denmark. JAMA Network Open 2023;6(1):e2248980. doi: https://dx.doi.org/10.1001/jamanetworkopen.2022.48980	Wrong outcomes
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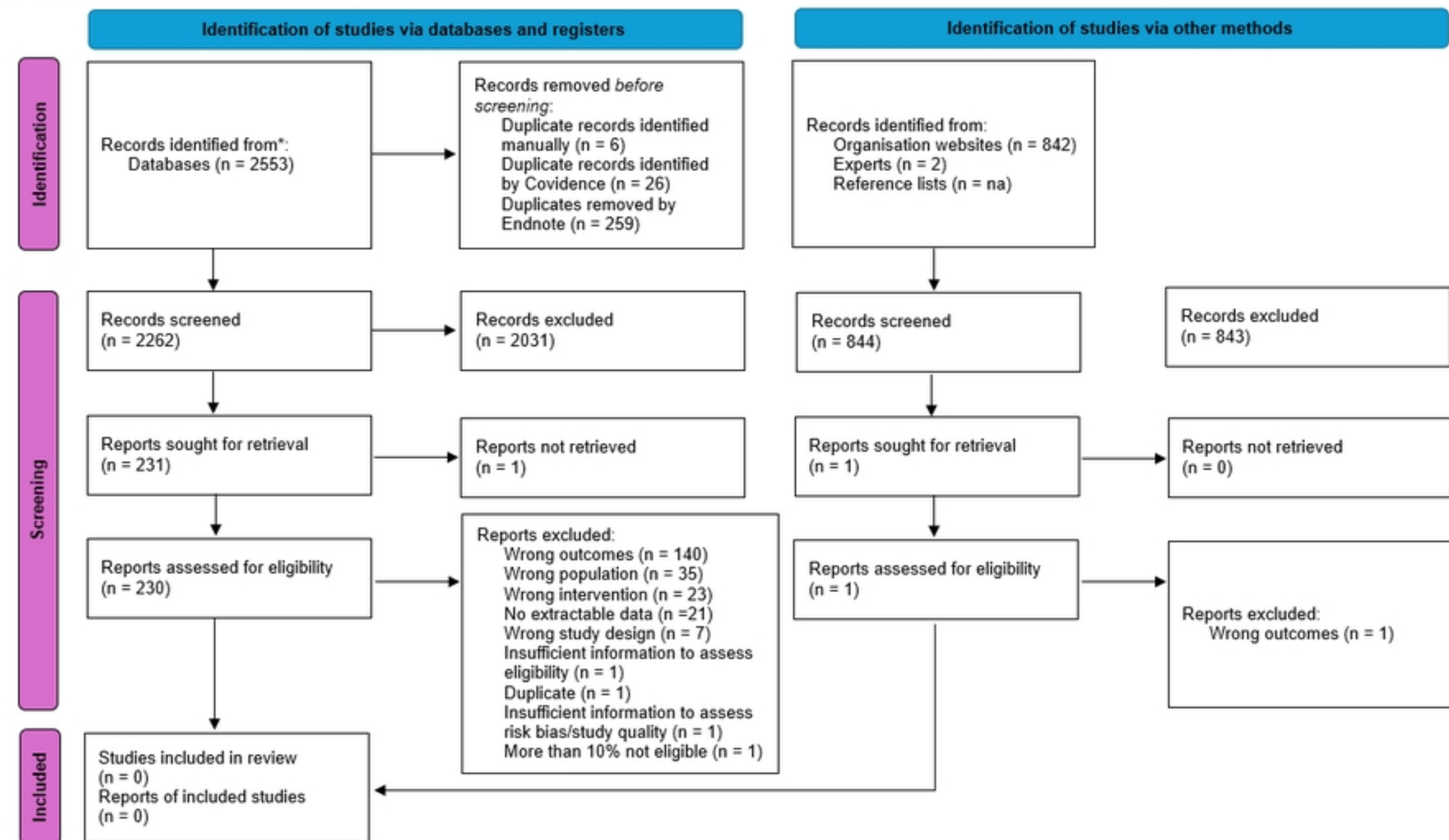
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Note. Studies could be ineligible for multiple reasons, but we only list the first one identified.

Figure 1. PRISMA flow diagram



Source: Page MJ, et al. BMJ 2021;372:n71. doi: 10.1136/bmj.n71.

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PRISMA Figure