

Why are people with a learning disability less likely to be screened for bowel cancer? A systematic review.

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BACKGROUND

People with learning disability have worse cancer outcomes than the general population (1, 2). Poorer outcomes may result from several factors, including treatment difficulties and later detection, associated with lower screening rates and delayed symptom reporting (3, 4). The fecal immunochemical test (FIT) was introduced in 2019 to increase screening uptake across England and Wales.

The aim of this systematic review is to collate evidence on the reasons why people with learning disability do or do not get screened for bowel cancer.

METHODS

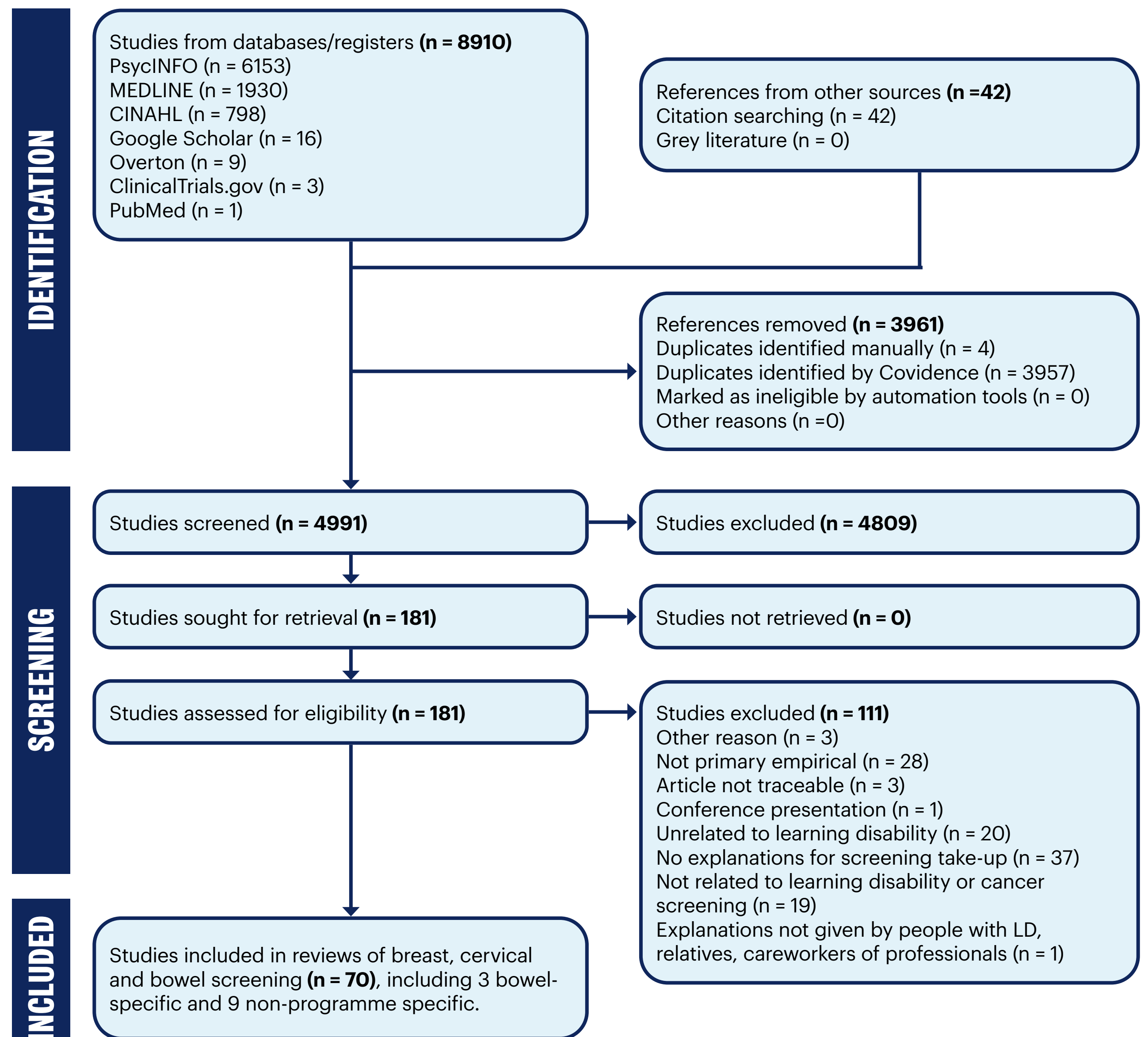
The review protocol was registered on PROSPERO.

Inclusion criteria: primary studies of barriers and facilitators of colorectal screening, as reported by people with a learning disability, relatives, and health and social care staff, published in any language since 2000.

Structured search of six indexed databases in July 2024 for learning disability and bowel, breast or cervical cancer screening (but only bowel studies are reported here).

We used dual independent decision-making on study inclusion and data extraction, then undertook citation searches and a quality appraisal of included studies. Findings were reported narratively.

FIGURE 1. PRISMA FLOW CHART



RESULTS

Searches generated 8,910 hits (Figure 1) and we finally included 12 studies: three that were bowel-specific (from UK, Canada, USA) and nine that were non-programme specific.

The three bowel screening-specific studies in learning disability reported that:

- lack of screening was related to lack of patient knowledge or confidence, and lesser intentions to be screened (5)
- uptake of the fecal occult blood test was more likely if patients were: older, female, living in a more affluent area, enrolled with a family doctor, and making greater use of healthcare services (6).
- most people with learning disability having colonoscopy had inadequate bowel preparation, causing failed examinations and (in two cases) carcinomas that were missed or needed later resection (7).

The nine non-programme specific studies about cancer screening in people with LD (8-16) found that uptake was negatively affected by:

- healthcare practitioners' attitudes to community integration in learning disability.
- practitioners' risk-benefit assessment of screening.
- patients' lack of knowledge of bowel screening.
- patients' procedure fear.
- transport problems.
- tests sometimes not being ordered (or ordered and later refused).
- Screening was increased by the presence of a health advocate.

IMPLICATIONS

Bowel screening in people with learning disability is affected by many factors, some of which are also seen in the general population.

The role of practitioners is key, whether General Practitioners, specialist nurses or support workers.

There is no published research into FIT test screening in people with learning disability, which is an important omission. The effects of learning disability severity on screening decisions, have also not been assessed.

Some factors may be sensitive to intervention (17), including patient and practitioner education, use of Easy Read communication, procedural amendments, and a commitment by services to offer and deliver screening.

References

- Ward L, et al. BMJ Open 2024;14: e084421.
- Mahar AL, et al. Cancer. 2024;130(5):740-749.
- Heslop P, et al. BMJ Open 2022;12: e056974.
- McCowan C, et al. B J Cancer 2019; 121:710-714.
- Gray J, et al. Learning Disab Pract 2021; 24(5):19-26.

- Ouellette-Kuntz H, et al. PLoS One 2015; 10(2): e0118023.
- Fischer LS, et al. Intell & Devel Disab 2012;50(5):383-390.
- Breau G, et al. Inclusion 2020; 8(3):185-193.
- Breau G, et al. J Intell Disab 2022;27(1):250-265.
- Hanna LM, et al. J Intell Disab Res 2011; 55(3):281-291.
- Osborn DP, et al. PLoS One 2012; 7(8): e43841.

- Parish SL, et al. Intell & Devel Disab 2008; 46(6):411-426.
- Rees G. Learning Disab Pract 2011;14(7).
- Stein K. B J Learn Disab 2000; 28(1):9-15.
- Tyler CV, et al. Intell & Devel Disab; 2010; 48(4):271-277.
- Wyatt D, et al. Eur J Cancer Care 2013; 22(3):300-307.
- Ahmed ZS, et al. J Health Inequal 2022; 8 (2): 126-129.

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