



Screening people with learning disabilities

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Equality Act 2010

All public bodies are required to make reasonable adjustments to ensure that people with learning disabilities can use their service.

The Health and Social Care Act (2012):

Legal duty for public authorities to reduce inequality in the benefits people can obtain from the health service.

Public Health England Screening Inequalities Strategy (updated 2020):

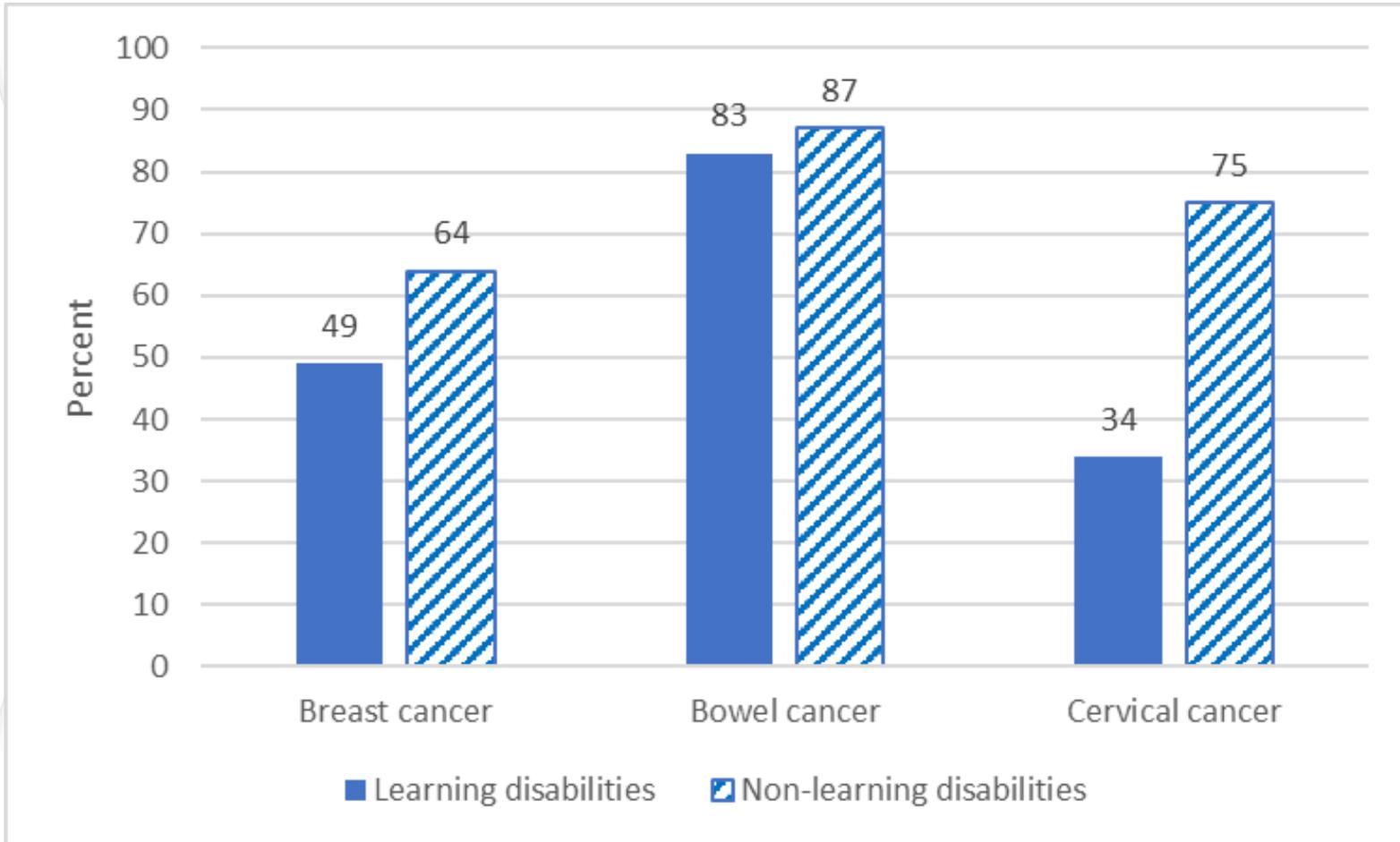
Seeks to address the 'unwarranted and unfair barriers that may mean people do not engage with an offer of, or participate in, screening or who are disadvantaged in maximising the benefits of screening'. <https://www.gov.uk/government/publications/nhs-population-screening-inequalities-strategy/phe-screening-inequalities-strategy>

Introduction

What do we know about recent screening rates in England?

Overall, 54% of patients registered in England (as at 31 March 2019) are represented within this dataset. However, coverage varies by CCG. There are some CCGs that have no data contained within the dataset.

<https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2018-to-2019/cancer-screening>



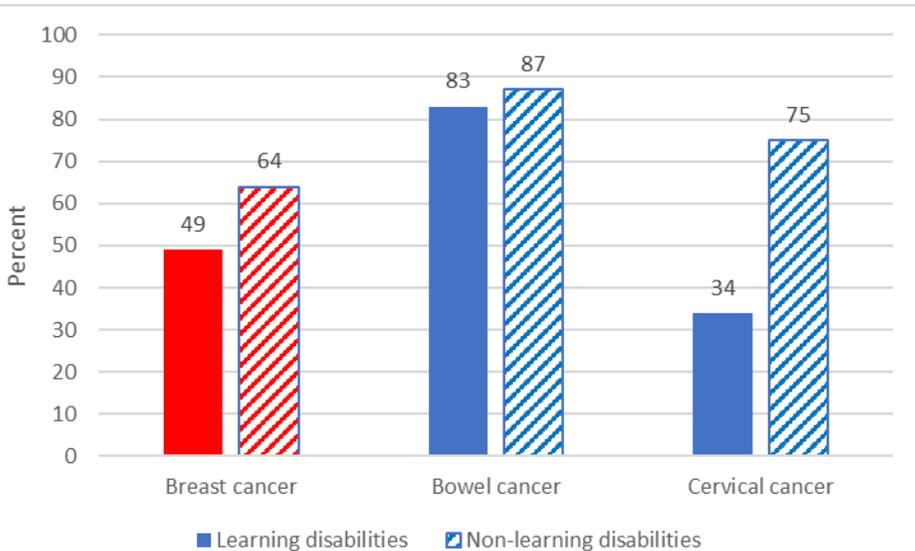
Breast cancer screening (England)

Data from NHS Digital (2018/2019 data)

Percentage of patients on the learning disabilities register (cf not on the LD register) eligible for breast cancer screening who received breast cancer screening in the last 5 years.

Women with learning disabilities = 49%

Women without learning disabilities = 64%

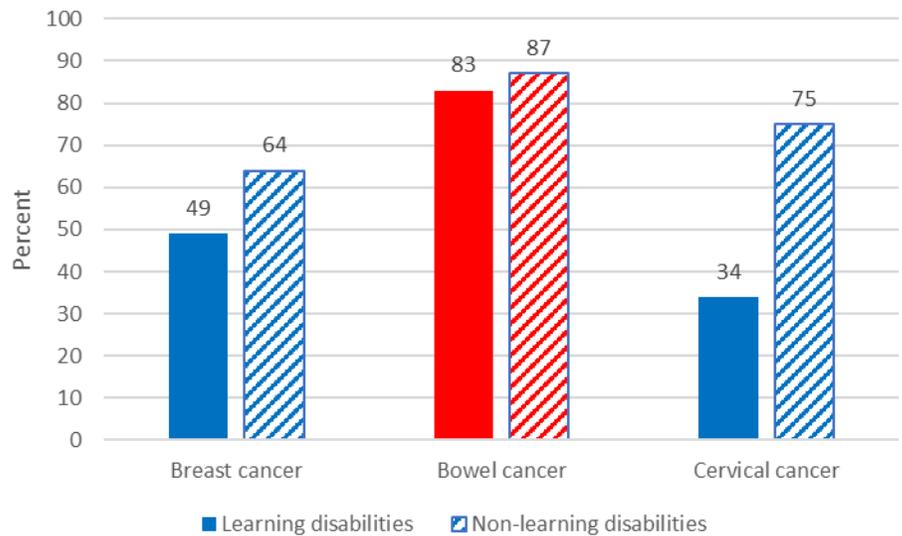


15% difference between people with learning disabilities compared to people without learning disabilities in England.

Between 2014/15 and 2018/19 there has been a slight decrease in coverage of breast cancer screening in people with learning disabilities (52% to 49%).

<https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2017-to-2018>

Colorectal cancer screening (England)



Data from NHS Digital (2018/2019 data)

Percentage of patients on the learning disabilities register (cf not on the LD register) eligible for colorectal cancer screening who received screening in the last 5 years.

People with learning disabilities = 83%

People without learning disabilities = 87%

Difference of 4% between people with learning disabilities compared to people without learning disabilities in England.

Between 2014/15 and 2018/19 learning disability coverage has improved from 69% to 83%.

Non-learning disability coverage has also improved but less than learning disability coverage, so the gap in coverage has reduced.

<https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2017-to-2018>

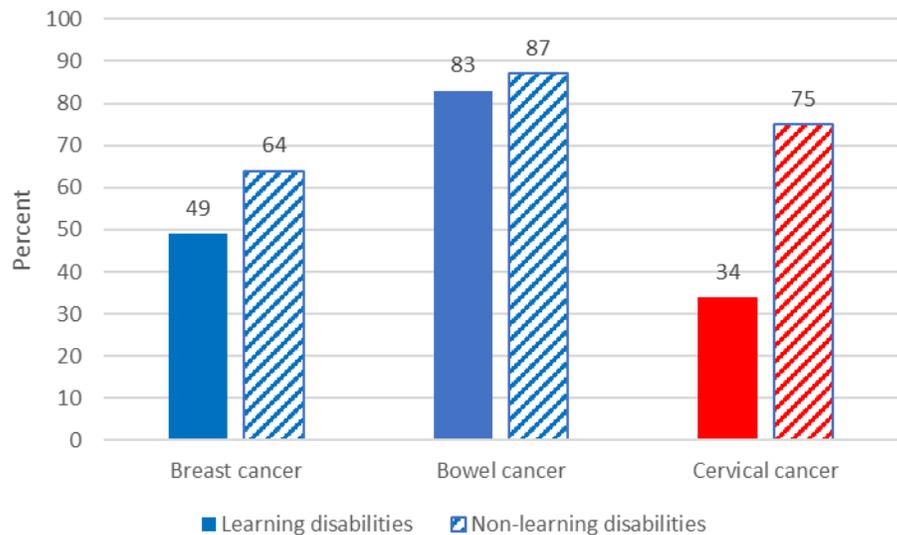
Cervical cancer screening (England)

Data from NHS Digital (2018/2019 data)

Percentage of patients on the learning disabilities register (cf not on the LD register) eligible for cervical cancer screening who received cervical cancer screening in the last 5 years.

Women with learning disabilities = 34%

Women without learning disabilities = 75%



Cervical screening coverage is significantly lower (by 41%) in women with learning disability compared to women without learning disability.

Between 2014/15 and 2018/19 learning disability coverage has improved slightly (from 30% to 34%).

<https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2017-to-2018>

Learning Disabilities Mortality Review (LeDeR) programme



Learning Disabilities Mortality Review
(LeDeR) Programme

Supports local areas to review the deaths of all people with learning disabilities aged 4 years and over.

Data from completed reviews is collated nationally.

Data relates to people who have died, which may affect screening rates.

Reviewers often unable to identify whether age appropriate screening has taken place (approx. 45-50% of cases are unknown).

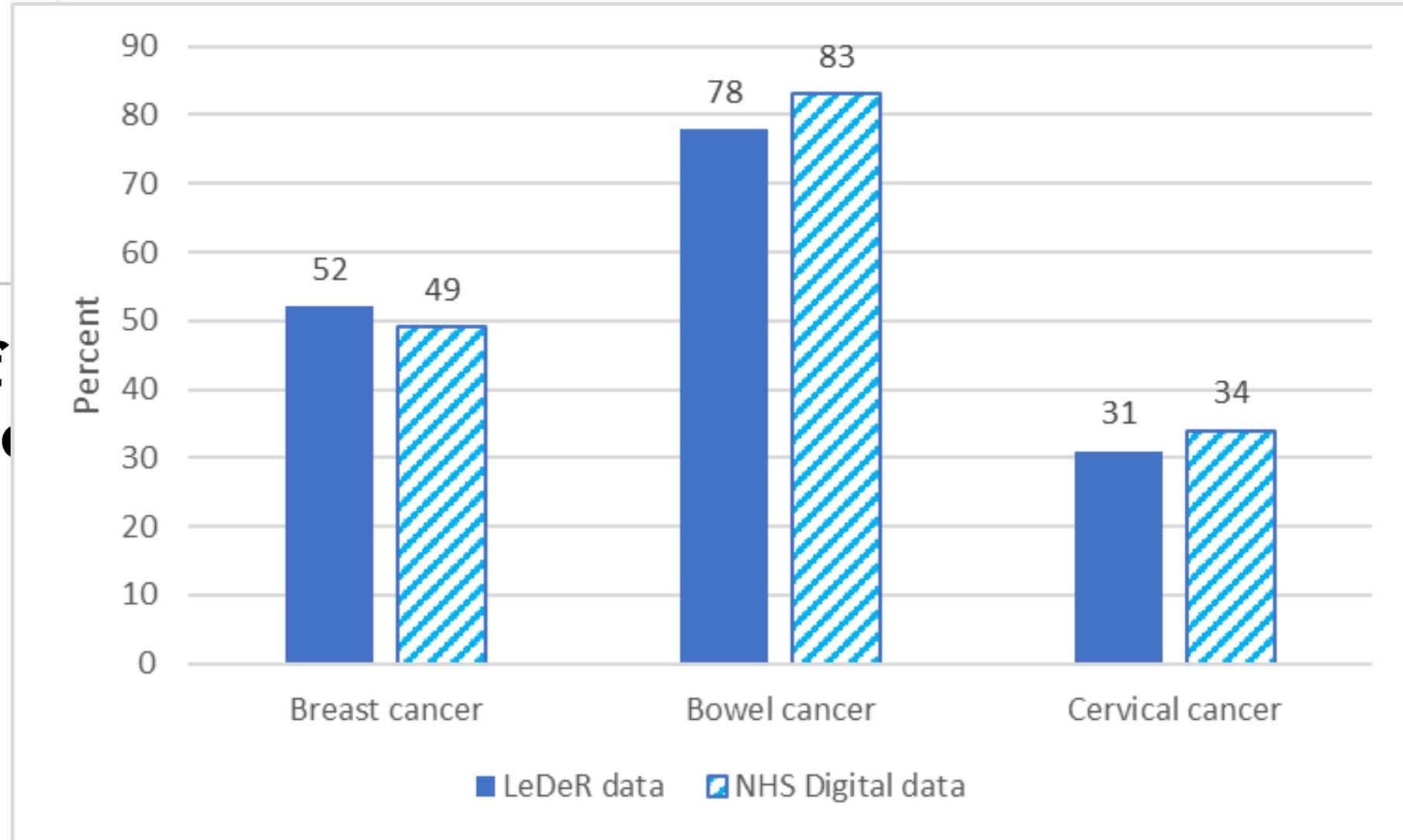
Q. Had the person received age and gender appropriate health screening? (2019 data)

Breast cancer = 52%

Colorectal cancer = 78%

Cervical cancer = 31%

Comparison of NHS Digital and LeDeR data



Barriers to uptake: mammography



Systems issues

Issues of informed 'consent' and 'vulnerability'^{4,7}

Breast awareness not promoted²,

Practical barriers e.g. transport and timing of appointments^{4,7}

Care provision

Limited knowledge of paid carers^{5,7}

Staff attitude⁷

Communication issues¹³

Lack of training in cancer prevention⁸

Unaware of family histories^{8,10}

People with learning disabilities

Inadequate knowledge^{1,2,4,6,9}

Embarrassment^{1,2,6}

Fear and anxiety^{2,6,9,10}

Don't check breasts regularly or know what looking for³

Put off by previous experience of mammography or hospital^{3,9,10}

Barriers to uptake: cervical screening



Systems issues

Issues of eligibility, informed 'consent' and 'vulnerability'^{10, 11}

Practical barriers e.g. time pressure^{11, 12}

Inadequate resources and invitation letters^{11, 13}

Call and recall system¹³

Care provision

Assumptions that people are not sexually active¹⁰

Negative attitudes of paid carers^{11, 12}

Limited knowledge of paid carers¹²

Competing demands of paid carers¹²

Limited exposure to people with learning disabilities¹²

Lack of appropriate knowledge, attitudes and skills¹²

People with learning disabilities

Limited health literacy¹³

Strategies to improve screening rates



Prepare people psychologically for screening - to enhance understanding, increase predictability and minimise anxiety.

- The provision of procedural and sensory information^{1, 12, 16, 17}
- The use of pre-exposure and desensitisation to familiarise people with the procedure, the equipment used and the setting in which the screening takes place^{12, 16, 17}

Optimise people's experiences

- Preparation work with paid carers^{10, 16}
- Positive attitude^{15, 17}
- Provision of emotional support¹
- Have appropriate knowledge, attitudes and skills^{12, 17}
- Maximise flexibility with reasonable adjustments^{12, 17}

Interdisciplinary working^{7, 14, 17}

Working with families^{14, 15}

Conclusions



Large gaps in our knowledge about rates of screening for people with learning disabilities.

Most complete data is for breast, colorectal and cervical cancer screening....but this only covers 54% of patients registered in England.

Data suggests disparities between people with learning disabilities and those without learning disabilities.

Largest disparity for cervical cancer screening.

Breast cancer screening in people with learning disabilities has been decreasing slightly since 2014/15.

Colorectal cancer screening for people with learning disabilities is approaching that of people without learning disabilities.

Many of the barriers to uptake are remediable.

Strategies to improve uptake should include working with people, their families and paid carers to optimise their experiences and ensure they are well-prepared.

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