Final accepted version

Access to cancer screening by people with learning disabilities in England 2012/13: Information from the Joint Health and Social Care Assessment Framework

Gyles Glover, Public Health England

Anna Christie, Public Health England

Chris Hatton, Centre for Disability Research, Lancaster University

# Abstract

## Purpose

To present information from the Joint Health and Social Care Assessment Framework (JHSCSAF) on reported rates of cervical cancer, breast cancer and bowel cancer screening for eligible people with learning disabilities in England in 2012/13 compared to screening rates for the general population.

## Methods

Between 94 and 101 Learning Disability Partnership Boards, as part of the JHSCSAF, provided information to allow the calculation of rates of cervical cancer, breast cancer and bowel cancer screening in their locality, for eligible people with learning disabilities and for the population as a whole.

## Findings

At a national level, reported cancer screening coverage for eligible people with learning disabilities was substantially lower than for the population as a whole (cervical cancer coverage 27.6% of people with learning disabilities vs 70% of total population; breast cancer screening 36.8% of people with learning disabilities vs 57.8% of total population; bowel cancer screening 28.1% of people with learning disabilities vs 40.5% of the general population. There were considerable geographical variations in reported coverage for all three cancer programmes.

## Discussion

Consistent with previous research, localities in England report cancer screening rates for eligible people with learning disabilities considerably below those of the general population. There is an urgent need to address data availability and quality issues, as well reasonable adjustments to cancer screening programmes to ensure uniformly high rates of cancer screening for people with learning disabilitie across England.

# Introduction

The proportion of people with intellectual disabilities who die from cancer and the prevalence of cancer are currently lower among adults with learning disabilities than in the general population (Glover & Ayub, 2010; Heslop et al., 2013), although people with learning disabilities have proportionally higher rates of gastrointestinal cancer ([Cooke, 1997](#_ENREF_105); [Department of Health, 2011](#_ENREF_148); [Duff et al., 2001](#_ENREF_163); [Jancar, 1990](#_ENREF_347)). The incidence of cancer amongst people with learning disabilities is also likely to be increasing and the distribution of cancers changing due, in part, to increased longevity ([Bonell, 2010](#_ENREF_61); [Cooke, 1997](#_ENREF_105); [Duff et al., 2001](#_ENREF_163); [Jancar, 1990](#_ENREF_347)).

There is increasing and consistent evidence that people with learning disabilities are less likely to access a range of cancer screening services, including:

* Cervical smear tests ([Department of Health, 2011](#_ENREF_148); [Glover et al., 2012](#_ENREF_273); [Osborn et al., 2012](#_ENREF_515); [Pearson et al., 1998](#_ENREF_526); [Reynolds et al., 2008](#_ENREF_556));
* Breast self- examinations and mammography ([Davies & Duff, 2001](#_ENREF_135); [Department of Health, 2011](#_ENREF_148); [Djuretic et al., 1999](#_ENREF_159); [Glover et al., 2012](#_ENREF_273); [Osborn et al., 2012](#_ENREF_515); [Piachaud & Rohde, 1998](#_ENREF_531); [Truesdale-Kennedy et al., 2011](#_ENREF_656); [Willis et al, 2008](#_ENREF_714));
* Bowel and prostate cancer screening ([Department of Health, 2011](#_ENREF_148); [Osborn et al., 2012](#_ENREF_515)).

A recent analysis of a UK primary care database with over 450 General Practices in the UK (Osborn et al., 2012) reported the following Incidence Risk Ratios (IRRs) for people with learning disabilities compared to people without learning disabilities in England: cervical smears IRR=0.54 (95% CI 0.52-0.56); mammograms IRR=0.76 (0.72-0.81); screening for prostate cancer IRR=0.87 (0.80-0.96); and screening for bowel cancer IRR=0.86 (0.78-0.94). Screening rates for people with and without learning disabilities increased for all types of cancer from 1999 to 2009. Disparities between people with and without learning disabilities appeared to be reducing over time for prostate cancer screening, but maintaining or widening for cervical screening, mammograms and bowel cancer screening.

This paper reports information from the Joint Health and Social Care Assessment Framework (JHSCSAF) on screening for cervical, breast and bowel cancer amongst people with learning disabilities in England in 2012/13.

# Method

For the JHSCSAF, each Learning Disability Partnership Board (typically one per local authority area) was asked to provide information on a range of education, health and social care issues concerning people with learning disabilities in England in 2012/13 (see Glover & Christie, 2014, for details). As part of the JHSCSAF, Partnership Boards were asked to report the numbers of people eligible for cervical, breast and bowel cancer screening programmes in the whole population locally and how many of these had learning disabilities. They were also asked how many of those eligible had had a screening test done in within the appropriate period.

Overall, 66% of Partnership Boards were able to report comparative coverage of cervical cancer screening, 63% of Boards reported data on breast cancer screening and 59% of Boards reported data on bowel cancer screening. The North West and North East regions were most consistently able to report these data (more than 80% of Partnership Boards), and the East of England were likely (1 out of 11, or 9%, of Partnership Boards).

# Results

To try and show as clearly as possible the extent of similarities or differences between Partnership Boards the information is presented in a ‘range chart’ format. Information is presented for people with learning disabilities in each former Government Office region, for people with learning disabilities in England as a whole, and for the whole population in England as a whole. The numbers in brackets after the name for each former Government Office region name show the number of Partnership Boards in the region and the number for which usable data were available and that are therefore included in the chart.

All bars report the percentage of eligible people who are reported as having accessed the relevant cancer screening programme. The pale grey bar shows the complete range of responses for the region or for England as a whole. The darker grey bar shows the range for the middle half of included values, the inter-quartile range. The red line shows the median value.

Figures 1 to 3 show the coverage of cervical cancer, breast cancer and bowel cancer screening in people with learning disabilities reported as being achieved by Partnership Boards in each region and nationally. These figures add an additional bar showing the ranges reported for people in the whole eligible population for comparison.

Figure 1 shows the results for cervical cancer screening. The median of the reported proportions of women with learning disabilities being screened for cervical cancer was 26.9%, with high reported proportions in the South West (31.9%) and low reported proportions in the East of England (22.1%) and Yorkshire and the Humber (23.0%). For comparison, cervical cancer screening in eligible women in the total population had a reported median coverage rate of 70.0%

Figure 1 about here

Figure 2 shows the results for breast cancer screening. The median of the reported proportions of women with learning disabilities being screened for breast cancer was 37.6%, with high reported proportions in the East of England (56.4%) and the North East (49.1%) and low reported proportions in London (30.4%). For comparison, breast cancer screening in eligible women in the total population had a reported median coverage of 62.5%.

Figure 2 about here

Figure 3 shows the results for bowel (colorectal) cancer screening. The median of the reported proportions of people with learning disabilities being screened for colorectal cancer was 25.8%, with high reported proportions in the East of England (48.8%) and the East Midlands (43.1%) and low reported proportions in the West Midlands (23.4%). For comparison, bowel cancer screening in eligible people in the total population had a reported median coverage of 39.4%

Figure 3 about here

At a national level, in all cases reported cancer screening coverage for people with learning disabilities was substantially lower than for the generality of eligible people. However there were substantial differences between the programmes. The general population coverage of eligible people was greatest for cervical cancer screening (70.0%). This programme was the one that showed the biggest difference between general coverage and coverage for people with learning disabilities (27.6%). Breast cancer screening achieved the best coverage for people with learning disabilities (36.8%) and a smaller differential, in part because general population coverage was lower (57.8%). Bowel cancer screening reported the lowest coverage in both groups (40.5% in the general population and 28.1% in people with learning disabilities).

# Discussion

Consistent with previous research (Department of Health, 2011; Osborn et al., 2011), information from localities provided as part of the Joint Health and Social Care Assessment Framework (JHSCSAF) reported considerably lower rates of screening for cervical cancer, breast cancer and bowel cancer amongst people with learning disabilities in England compared to the total eligible population. As in Osborn et al. (2011), the national discrepancy in coverage was greatest for cervical cancer, with smaller though still substantial discrepancies for breast cancer and bowel cancer screening. However, it is important to note that smaller differences in cancer screening rates between people with learning disabilities and the general population may partly be a function of poorer coverage in the general population rather than improved coverage amongst people with learning disabilities.

There was also wide geographical variation in cancer screening coverage for people with learning disabilities between regions and between Partnership Board areas within regions. Reported cervical cancer screening rates varied from virtually 0% to almost 70%, breast cancer screening rates varied from 0% to over 80%, and bowel cancer screening rates varied from 0% to 100%.

Some of this geographical variation may reflect differences in data quality between localities (localities need to have both on the number of people with learning disabilities accessing the cancer screening service and on the number of eligible people with learning disabilities in the locality). Of even greater concern is that 34% of Partnership Boards did not provide usable data on cancer screening for people with learning disabilities. In other information for the JHSCSAF, Partnership Boards vary widely in the extent to which they report such data are or are not available (Christie et al., 2014).

Of course, reported geographical information is also likely to reflect actual differences in cancer screening coverage across England. Examples of reasonable adjustments to cancer screening and intervention programmes for people with learning disabilities are increasing although still patchy. It is vital that processes to improve data quality and effective reasonable adjustments to all aspects of the cancer screening process are implemented nationally, to raise the performance of all localities to what is clearly being achieved in the best performing areas (see Turner et al., 2012, for resources and guidance).

# References

Bonell, S. (2010). Neoplasms. In J. O'Hara, J. E. McCarthy & N. Bouras (Eds.), *Intellectual disability and ill health : a review of the evidence* (pp. 127-136). Cambridge: Cambridge University Press.

Christie, A., Baines, S., Hatton, C., Glover, G. & Turner, S. (2014). *Joint Health and Social Care Self-Assessment Framework 2013. Detailed report and thematic analysis*. London: Public Health England.

Cooke, L. B. (1997). Cancer and learning disability. *Journal of Intellectual Disability Research, 41*, 312-316.

Davies, N., & Duff, M. (2001). Breast cancer screening for older women with intellectual disability living in community group homes. *Journal of Intellectual Disability Research, 45*, 253-257.

Department of Health. (2011). *Victorian population health survey of people with an intellectual disability 2009*. Melbourne: State Government of Victoria.

Duff, M., Hoghton, M., Scheepers, M., Cooper, M., & Baddeley, P. (2001). Helicobacter pylori: has the killer escaped from the institution? A possible cause of increased stomach cancer in a population with intellectual disability. *Journal of Intellectual Disability Research, 45*, 219-225.

Djuretic, T., Laing-Morton, T., Guy, M., & Gill, M. (1999). Concerted effort is needed to ensure these women use preventive services. *British Medical Journal, 318*, 536.

Glover, G., & Ayub, M. (2010). *How People with Learning Disabilities Die*. Durham: Improving Health & Lives: Learning Disabilities Observatory.

Glover, G. & Christie, A. (2014). *Joint Health and Social Care Assessment Framework 2013: Detailed report on number questions*. Cambridge: Public Health England.

Glover, G., Emerson, E., & Eccles, R. (2012). *Using local data to monitor the Health Needs of People with Learning Disabilities*. Durham: Improving Health & Lives: Learning Disabilities Public Health Observatory.

Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2013). *Confidential Inquiry Into Premature Deaths of People with Learning Disabilities.* Bristol: Norah Fry Research Centre.

Jancar, J. (1990). Cancer and mental handicap: a further study. *British Journal of Psychiatry, 156*, 531-533.

Osborn, D. P. J., Horsfall, L., Hassiotis, A., Petersen, I., Walters, K., & Nazareth, I. (2012). Access to Cancer Screening in People with Learning Disabilities in the UK: Cohort Study in the Health Improvement Network, a Primary Care Research Database. *PLoS ONE, 7*. doi: 10.1371/journal.pone.0043841

Pearson, V., Davis, C., Ruoff, C., & Dyer, J. (1998). Only one quarter of women with learning disability in Exeter have cervical screening. *British Medical Journal, 316*, 1979.

Piachaud, J., & Rohde, J. (1998). Screening for breast cancer is necessary in patients with learning disability. *British Medical Journal, 316*, 1979.

Reynolds, F., Stanistreet, D., & Elton, P. (2008). Women with learning disabilities and access to cervical screening: retrospective cohort study using case control methods. *BMC Public Health, 8*, 30.

Truesdale-Kennedy, M., Taggart, L., & McIlfatrick, S. (2011). Breast cancer knowledge among women with intellectual disabilities and their experiences of receiving breast mammography. *Journal of Advanced Nursing, 67*, 1294-1304.

Turner, S., Emerson, E., Glover, G. & the Cornwall Cancer Screening Team (2012). *Making reasonable adjustments to cancer screening*. Durham: Improving Health & Lives: Learning Disabilities Observatory.

Willis, D. S., & et al. (2008). Breast cancer screening in women with learning disabilities: current knowledge and considerations. *British Journal of Learning Disabilities, 36*, 171-184.

Figure 1: Range of reported coverage of cervical cancer screening for people with learning disabilities - regional and England figures; England figures for all eligible people for comparison

Figure 2: Range of reported coverage of breast cancer screening for people with learning disabilities - regional and England figures; England figures for all eligible people for comparison

Figure 3: Range of reported coverage of bowel (colorectal) screening for people with learning disabilities - regional and England figures; England figures for all eligible people for comparison





