Cancer screening uptake within the female learning disabled population in Gateshead

NHS South of Tyne and Wear
Public Health Directorate
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Acknowledgements

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Executive Summary

**INTRODUCTION:** Equitable health care for people with learning disabilities is an issue currently receiving attention nationally and locally. People with learning disabilities have poorer access to health services, which could leave them vulnerable to poor health and wellbeing both in the short and long term. Screening identifies the early stages of cancer, and reduces the risk of further development of the disease. Breast and cervical screening should be equitably available for all women, however national evidence suggests that they are used less by women with learning disabilities.

**AIM:** The aim of this report is to identify measures to increase uptake of screening services within the learning disabled population, so that future rates of breast and cervical cancer are reduced in this population.

**METHODS:** The study was conducted in two parts. The first was a health equity audit, where the non-attendance data for breast and cervical screening were compared between learning disabled and non-learning disabled populations in Gateshead. The second part consisted of discussion groups with learning disabled women, their parents/carers and learning disabled staff.

**RESULTS:** The health equity audit showed that significantly more women with learning disabilities did not attend breast and cervical screening services compared to the non-learning disabled women. The discussion groups suggested that there were four main reasons for this difference: (1) physical disability (2) learning disability made attending and/or completing the screening difficult; (3) poor decision making about screening on behalf of the woman; and (4) lack of ability to support the woman to screening by parents/carers.

**CONCLUSION:** The inequity in uptake of these screening services could be interpreted as services not being accessible for women with learning disabilities. However the reasons for non-attendance suggest that progress needs to be made not only to improve access for these women, but to improve the decision-making processes for the learning disabled population in relation to healthcare in general.

**WHAT WAS KNOWN BEFORE THIS REPORT:** Attendance at breast and cervical screening services by women with learning disabilities (according to national evidence) is lower compared to the general population. Reasons for this difference include difficulty in understanding the procedures, physical disabilities which may make the procedure difficult to complete, and inappropriate ceasing from the programmes by health professionals.

**WHAT THIS REPORT ADDS:** Local evidence gathered in this report suggests that these national trends are reflected locally. Additionally, this report highlights the lack of implementation of the Mental Capacity Act in assisting appropriate decision-making on behalf of women with learning disabilities with regard to attendance at screening.
1 Background

Equitable health care for people with learning disabilities is an issue currently receiving attention nationally and locally. The publication of the *Healthcare for All*¹ report highlighted the differences in accessing health services for people with learning disabilities, and stated that “The health needs of people with learning disabilities do not appear to represent a priority for the NHS”.

This report was written in response to Mencap’s *Death by Indifference*² report which detailed the deaths whilst under the care of the NHS of six people with learning disabilities. Included in the recommendations was the requirement to add into Core Standards for Better Health: “make reasonable adjustments to the provision and delivery of services for vulnerable groups, in accordance with the disability equality legislation”.

This piece of work strived to understand what adjustments, if any, need to be made in the delivery of services for breast and cervical screening for women with learning disabilities.

1.1 National priorities

The national healthcare strategy for people with learning disabilities (*Valuing People*³) stated that:

> Many people with learning disabilities have greater health needs than the rest of the population. We will ensure that people with learning disabilities, including those from minority ethnic communities, have the same right of access to mainstream health services as the rest of the population.

A review of *Valuing People* in 2005⁴ stated that no reliable information was available about the healthcare of people with learning disabilities, although there was an acknowledgement that health needs are greater than the average population for this vulnerable group. A recommendation was made that “councils, the NHS, the Commission for Social Care Inspection and the Health Care Commission… find better ways to measure results” which are consistent across partners.

1.2 Local priorities

NHS South of Tyne and Wear has a commitment to supporting a longer life, a better quality of life and fair access to services. Improving access to screening services for the learning disabled population is therefore relevant to all corporate aims of the organisation. Within the Annual Reports of the Directors of Public Health⁵, developing and mainstreaming new models of preventative services and better access to physical healthcare for people with severe mental illness and learning disabilities has been identified as a priority in Gateshead. Gateshead currently has a learning disabilities strategy and related health groups which meet regularly.
1.3 Learning disability – definitions

Learning disability is defined as “a significant impairment of intelligence and social functioning acquired before adulthood”\(^6\). This means there is a significantly reduced ability to understand new or complex information, learn new skills (impaired intelligence) and / or cope independently (impaired social functioning).

In most cases of severe learning disability, possible causes can usually be identified. These can be categorised into stages of human development\(^7\):

**Prenatal:** Chromosomal abnormalities; Metabolic disorders; Intra-uterine growth disorders; Cerebral malformations; Infections (Rubella, toxoplasmosis, Cytomegalovirus); Maternal alcohol abuse.

**Perinatal:** Prematurity, and ntrauterine growth disorders; Hypoglycaemia; Hyperbilirubinaemia; Asphyxia; Intracranial haemorrhage.

**Postnatal:** Infection (menningitis, encephalitis); Hypothyroidism

**Childhood and young adults:** Trauma (including accidents); Infection; Intracranial and cerebral neoplasms (neurofibromatosis).

A few syndromes are major contributors to learning disability, but most are rare. Broad categories and their approximate relative contributions to learning disabilities are\(^3\):

<table>
<thead>
<tr>
<th>Genetic:</th>
<th>55-60%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Down Syndrome (33%)</td>
<td></td>
</tr>
<tr>
<td>Other single gene disorders (12%)</td>
<td></td>
</tr>
<tr>
<td>X-linked chromosome disorders (10%)</td>
<td></td>
</tr>
</tbody>
</table>

| Environmental: include maternal infections or substance abuse (e.g. rubella, cytomegalovirus, foetal alcohol syndrome), very low birth weight and putative birth injury; childhood neurological damage possibly caused by infections, such as meningitis, or trauma | 25-30% |

| No cause identified: diminishing with continuing advances in molecular diagnostics | 15-20% |
1.4 Learning disability prevalence

*Valuing People*\(^3\) suggests that 2.5% of the population may have some form of learning disability. The document stated that:

Producing precise information on the number of people with learning disabilities in the population is difficult. In the case of people with severe and profound learning disabilities, we estimate there are about 210,000: around 65,000 children and young people, 120,000 adults of working age and 25,000 older people. In the case of people with mild/moderate learning disabilities, lower estimates suggest a prevalence rate of around 25 per 1000 population—some 1.2 million people in England.

Estimates for England are shown below in Figure 1:

![Figure 1: *Valuing People*\(^3\) estimates of severe and moderate/mild learning disability.](image)

For the first time in 2007, learning disability was included in the Quality Outcomes Framework (QOF) for General Practitioners to record. As this is the first year that data has been gathered by the Information Centre, and recording of a diagnosis of a learning difficulty can differ between GP, data may increase over time.

Using QOF data, Figure 2 shows the average prevalence of learning disabilities for Gateshead, South Tyneside and Sunderland. These figures are much lower than the estimated 2.5%, which suggests that either the recording of learning disability or the *Valuing People*\(^3\) estimate is not accurate:
Average percentage prevalence of learning disabilities within the population

<table>
<thead>
<tr>
<th></th>
<th>Gateshead</th>
<th>South Tyneside</th>
<th>Sunderland</th>
<th>North East</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.28%</td>
<td>0.29%</td>
<td>0.46%</td>
<td>0.43%</td>
<td>0.33%</td>
<td></td>
</tr>
</tbody>
</table>

Figure 2: The average percentage prevalence of learning disabilities within populations, based on QOF data.

1.5 Study aim

The aim of this report is to identify measures to increase uptake of screening services within the learning disabled population, so that future rates of breast and cervical cancer are reduced in this population.

1.6 Study objectives

The aim above was achieved by carrying out the following objectives:

- Complete a health equity audit to establish the uptake of breast and cervical cancer screening in Gateshead in both the general and the learning disabled populations. This will be carried out in 10 GP practices

- Carry out qualitative research to explore knowledge, understanding and experiences of screening services for people with learning disabilities in Gateshead. Additionally, to explore with this community of interest risk factors which limit their ability/choice to access these services

- Recommend changes to current service provision and delivery in order to increase uptake of breast and cervical screening services in the learning disabled population.
2 Breast and cervical cancer and screening

2.1 Breast cancer

2.1.1 Prevalence

One in three of the UK population will develop some form of cancer in their lives, and breast is one of the most prevalent cancers in the UK:

Although the rates over time have been increasing, the death rates are falling:
Breast cancer rates in the learning disabled population can be estimated by relating the prevalence of learning disability in the UK population with the England rate per 100,000 population. Valuing People\textsuperscript{3} estimated that there are over 1.2 million people with learning disabilities in the UK, or 2.5\% of the population. Figure 5 shows rates for both populations, as well as illustrating the positive association between breast cancer and age:

As life expectancy for people with learning disabilities increases, incidence of cancer in this population is likely to rise.
2.1.2 Risk factors
The main risk factors for breast cancer are\textsuperscript{10}:

- nulliparity\textsuperscript{11}
- late menopause
- family history
- age (risk roughly doubles with every 10 years)
- previous benign cancers.

2.2 Cervical cancer

2.2.1 Prevalence
As above, cervical cancer rates in the learning disabled population can be estimated by taking 2.5\% of the national rates to estimate learning disability rates. Figure 6 shows rates for national and regional populations:

![Graph showing cervical cancer rates in the UK population and the learning disabled UK population.](image)

Figure 6: Cervical cancer rates in the UK population and the learning disabled UK population\textsuperscript{12}.

2.2.2 Risk factors
The main risk factors for cervical cancer are\textsuperscript{13}:

- sexual activity (number of sexual partners and age at first sexual intercourse)
- smoking
- biological agents
- hormonal exposures
- dietary factors (protective factors from nutrients in fruit and vegetables)
Although sexual activity is thought to be less common in women with learning disabilities\textsuperscript{14}, this group is vulnerable to sexual abuse\textsuperscript{15,16}. This area has been described as a "...taboo subject, which has been met with resistance and denial"\textsuperscript{17}. However evidence suggests that people with learning disabilities are at higher risk of sexual abuse than the general population\textsuperscript{16}. Additionally, the notion that women with learning disabilities are not sexually active is one that has been challenged\textsuperscript{18}. These factors must be considered when evaluating the risk of cervical cancer in this group.

2.3 National uptake of breast screening

Currently, women between 50 and 70 are invited for screening every three years however from 2008 (to be fully implemented by 2012) screening will be extended from 47 to 73 years to give nine rounds of screening for each woman\textsuperscript{19}.

The national minimum target for uptake of breast screening is 70% of eligible women. As of March 2007, 76% of women aged 53-64 in England had been screened at least once in the previous three years\textsuperscript{20}.

![Breast screening: percentage coverage for women 53-64 and 65-70, England 2002-2007](image)

Figure 7: Coverage of breast cancer screening in England (less than three years since last test). Source: KC63 The Information Centre\textsuperscript{20}.
2.4 **National uptake of cervical screening**

Women between the ages of 25-64 are invited for screening (a 'smear') every three to five years. The target for uptake of cervical screening is 80% of eligible women. Most recent figures show coverage of 79.2% (2006/7)\(^2\).  

**Cervical screening: Coverage of target age group (25-64), England at 31 March, 1997 to 2007**

![Coverage of cervical cancer screening in England](image)

Figure 8: Coverage of cervical cancer screening in England. Source: KC53 The Information Centre\(^2\).

<table>
<thead>
<tr>
<th>Year</th>
<th>% Uptake all ages</th>
</tr>
</thead>
<tbody>
<tr>
<td>1997</td>
<td>82.0</td>
</tr>
<tr>
<td>1998</td>
<td>82.5</td>
</tr>
<tr>
<td>1999</td>
<td>82.3</td>
</tr>
<tr>
<td>2000</td>
<td>82.0</td>
</tr>
<tr>
<td>2001</td>
<td>81.3</td>
</tr>
<tr>
<td>2002</td>
<td>81.6</td>
</tr>
<tr>
<td>2003</td>
<td>81.2</td>
</tr>
<tr>
<td>2004</td>
<td>80.6</td>
</tr>
<tr>
<td>2005</td>
<td>80.3</td>
</tr>
<tr>
<td>2006</td>
<td>79.5</td>
</tr>
<tr>
<td>2007</td>
<td>79.2</td>
</tr>
</tbody>
</table>

*Table A: Figures relating to Figure 8*\(^2\)
2.5 Local uptake of breast and cervical screening

Breast and cervical screening uptake rates in Gateshead, South Tyneside and Sunderland are as follows (2006/2007):

<table>
<thead>
<tr>
<th></th>
<th>BREAST</th>
<th>CERVICAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gateshead</td>
<td>77%</td>
<td>79%</td>
</tr>
<tr>
<td>South Tyneside</td>
<td>72%</td>
<td>78%</td>
</tr>
<tr>
<td>Sunderland</td>
<td>76%</td>
<td>80%</td>
</tr>
<tr>
<td>AVERAGE</td>
<td>75%</td>
<td>79%</td>
</tr>
</tbody>
</table>

Table B: Most recent breast\textsuperscript{22} and cervical\textsuperscript{21} screening rates for NHS South of Tyne and Wear. Cervical rates are taken as coverage less than 5 years from last adequate test.

There is no readily available information about the cervical and breast screening uptake of women with learning disabilities in NHS South of Tyne and Wear. Data are available to identify women who have not had a smear, and data are available to identify women with learning disabilities. Bringing this information together, as this study has done, had not been done before locally.

2.6 Barriers to uptake of screenings services

For the general population: disparities in uptake of and barriers to accessing breast and cervical cancer for the general population have been documented over recent years. Links between deprivation and lower uptake of cervical screening have been found in the North East of England\textsuperscript{23,24}.

A study in Oldham looking at breast screening uptake showed lower uptakes in poorer areas, and lower uptakes by Asian women compared to non-Asian women\textsuperscript{25}. Similarly, socioeconomic disparities in breast screening uptake were also found in North Derbyshire\textsuperscript{26}.

For the learning disabled population: Existing evidence suggests that there are certain barriers for people with learning disabilities accessing health care in general. Issues limiting access may include:

- difficulties with communication
- apprehension of using services
- perceived negative attitudes by health professionals\textsuperscript{27}.

Evidence specifically relating to barriers for breast and cervical cancer uptake is sparse. However a small number of studies have been conducted in England which note a disparity in uptake and/or differences in being offered screening between the learning disabled population and the general population\textsuperscript{28,29,30}. Some barriers identified within these studies include:

- difficulties in using appointment systems and waiting rooms
- uncertainty about who is responsible for routine care
- poor liaison with specialist services
- carers deciding on behalf of the person that screening is not needed
- inadequate training of GPs in communication skills
- being ceased from the screening programme inappropriately
- some physical disabilities making procedures difficult
In addition to barriers to access health services, poor health outcomes have also been evidenced for people with learning disabilities. For example, higher rates of respiratory disease (19.8%) have been shown compared to the general population (15.5%). Also, obesity is more likely – the rate of obesity recorded was 28.3% in people with a learning disability, as compared to 20.4% for the general population.

There is limited research in the area of screening, although it could be assumed that barriers to other health services may mirror any barriers experienced for breast and cervical screening. Therefore new evidence of effective strategies to overcome barriers in order to improve health outcomes for people with learning disabilities is needed.
3 The learning disabled population in Gateshead

3.1 Vulnerability of this population

Individual vulnerability to poor health and wellbeing cannot be measured by the presence of one risk factor such as having a learning disability. It is true that the presence of a learning disability may have a negative impact on particular areas of health and wellbeing (see Section 2.6), however there are varying severities and types of learning disability, and all people with a learning disability will not be vulnerable to poor health and wellbeing in the same way.

An important consideration when planning work around vulnerability is to acknowledge the importance of balancing the health needs of the most vulnerable groups with improving the health of the wider population. An advantage of this combined approach is to reduce stigma usually experienced by vulnerable groups traditionally singled out for interventions or specialist services.

Figure 9 below illustrates a state where five risk factors could intercept to cause vulnerability to poor health and well being. Focussing on the learning disability itself is not adequate enough to address the holistic health needs of an individual. Other risk factors, and the resilience or ability to cope with those risk factors, must be taken into account in order to reduce vulnerability on an individual level.

Figure 9: Many risk factors will leave people vulnerable to poor health and wellbeing in individual ways. More risk factors, and reduced ability of the individual is to cope with these risk factors, will increase an individual’s vulnerability to poor health and wellbeing.
Understanding about these wider factors is important in addressing the risk to poor health and wellbeing of a particular group. In this case, the information was gained from discussion groups with people with learning disabilities, as well as local and national research.

3.2 What is happening locally?

*Being Healthy in Gateshead!* is a comprehensive strategy for adults with learning disabilities in Gateshead. The strategy is based on *Valuing People*, and was written by and for people with learning disabilities. Five objectives are detailed in the strategy, which support the nine key actions within *Valuing People* that are aimed at improving the health of this population. The Gateshead Good Heath subgroup meets once a month to implement these objectives:

This piece of work meets the objectives of the *Being Healthy in Gateshead!* strategy as shown below, and supports the work of the Good Health subgroup:

Objectives of *Being Healthy in Gateshead!*

1. to challenge discrimination faced by people with learning disabilities in Gateshead using mainstream services
2. to reduce health inequalities faced by people with learning disabilities in Gateshead
3. to improve the standard of healthcare received by people with learning disabilities in Gateshead
4. to make health services in Gateshead accessible and person-centred
5. to look for answers to problems and challenges that need to be solved to make our objectives happen.
4 Methodology

4.1 Health equity audit

This part of the study used a health equity audit methodology to ascertain whether the rates of uptake of breast and cervical screening in the general population were comparable with the learning disabled population in Gateshead.

A health equity audit enables PCTs to identify how fairly health services are distributed according to the health needs of different populations and geographical areas. If services or resources are identified as being inequitable across populations or areas, changes should be recommended and reviewed to strive for equity. For a health equity audit to be successful, information gathered should be used to recommend any changes for the future which, when implemented, will bring about improved equity for service users.

Figure 10: The health equity audit cycle.

The objective of this health equity audit was to calculate the proportion of women who have never had a breast or cervical screen in Gateshead in the learning disabled and non-learning disabled population.

Therefore there are two null hypotheses:
1. There is no difference in the non-attendance rates in Gateshead for cervical screening between women with and without learning disabilities.
2. There is no difference in the non-attendance rates in Gateshead for breast screening between women with and without learning disabilities.
GP practices in Gateshead were approached to be involved in this audit. Practices were chosen depending on their age-specific (over 18 years old) and gender-specific (female) prevalence of learning disabilities, as submitted via QOF. Those practices with higher prevalence will be selected, compared to those practices with no identified prevalence of learning disability.

This health equity audit sought to answer the following questions:

- What proportion of non-screened women have learning disabilities?
- Where should work be directed to increase uptake rates if a large proportion of women with learning disabilities are not accessing screening services?

To allow calculation of uptake rates as detailed above, the following steps were taken:

1. A Caldicott request form was submitted to NHS South of Tyne and Wear.
2. After approval was granted, GP practices were approached to be involved in the study (see Appendix A).
3. Once practices had been identified as possible participants, the 10 practices with the highest learning disability prevalence were chosen (see Appendix B). A maximum of 10 practices was chosen (the North East Family Health Services Agency (NEFHSA) had limited capacity to deal with more than this). The practices whose data were not requested from the NEFHSA were thanked for their interest (see Appendix C).
4. The NEFHSA was then approached to supply the following information for each practice:
   - NHS number of women who have never had a breast screen
   - NHS number of women who have never had a cervical screen.
5. Once practice data were obtained, the practices were contacted to provide the following data:
   - NHS numbers of all women in the practice with learning disabilities
   - Ages of the above women to determine eligible learning disabled populations for each screening type
   - The female practice population to determine eligible non-learning disabled populations for each screening type.
6. For each practice, NHS numbers of women with learning disabilities were then matched to the NHS numbers from the NEFHSA. This gave the number of women with learning disabilities who had not had a breast and/or cervical screen before. Using their age, it was possible to determine their eligibility for these screenings.
7. Eligible populations of women with no learning disabilities for both screening types were possible to calculate from the above information gained from the NEFHSA and the practices.
8. Differences in the non-attendance rates for breast and cervical screening were calculated by using Chi-squared and z-score calculations respectively.
4.2 Engagement with the Gateshead learning disabled population

Information about breast and cervical screening knowledge and understanding, and other vulnerability and resilience factors to health and wellbeing were gathered during discussion group sessions at community centres across Gateshead. Discussion groups were held with people with learning disabilities who regularly attend the centres, and were facilitated by a regular member of staff at the centre (the author was present). Parents or main carers of the women were consulted if the woman could not answer due to the severity of learning disability. Staff at the community centres were consulted by the author on a one-to-one basis to explore their knowledge and beliefs about cancer screening in the learning disabled population.

Additionally, a community event to raise awareness of, and discuss issues relating to cancer awareness was held on 30th May 2008 at the Trinity Centre in Gateshead (see Appendix D for the event programme and Appendix E for the press release). This event was advertised to people with learning disabilities, their carers and families. As well as general group sessions designed to inform participants of cancer awareness, there were also separate workshops for men and women to explore in more detail gender-based cancers. This allowed participants and their carers to ask questions to the experts leading the workshops.
5 Results

5.1 Health equity audit

All GP practices in Gateshead were contacted to be involved in this piece of work. Out of the 33 GP practices in Gateshead, 20 (60.6%) agreed to be part of the HEA, and 10 (30%) were finally asked to be involved.

The map on the following page shows where the participating 10 GP practices are located in Gateshead, as well as the location of all other practices in the area:
The percentage uptake of breast and cervical cancer screening for the two populations were as follows:

**Cervical screening**

<table>
<thead>
<tr>
<th>ELIGIBLE POPULATION</th>
<th>NUMBER</th>
<th>NEVER BEEN SCREENED</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>25408</td>
<td>1244</td>
<td>5.0</td>
</tr>
<tr>
<td>Learning disabled</td>
<td>86</td>
<td>40</td>
<td>41.3</td>
</tr>
<tr>
<td>Non-learning disabled</td>
<td>25322</td>
<td>1204</td>
<td>4.9</td>
</tr>
</tbody>
</table>

**Breast screening**

<table>
<thead>
<tr>
<th>ELIGIBLE POPULATION</th>
<th>NUMBER</th>
<th>NEVER BEEN SCREENED</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>11796</td>
<td>1485</td>
<td>14.3</td>
</tr>
<tr>
<td>Learning disabled</td>
<td>31</td>
<td>10</td>
<td>25.4</td>
</tr>
<tr>
<td>Non-learning disabled</td>
<td>11767</td>
<td>1475</td>
<td>14.3</td>
</tr>
</tbody>
</table>

In order to determine any statistical significance between percentage non-attendance in the learning disabled and the non-learning disabled populations, two statistical tests were applied.

**5.1.1 Cervical screening non-attendance**

Calculation of a z-score was applicable for cervical screening data. The z-score allows variance to be expressed in statistical significance. The following formula was used to first calculate the standard error:

\[
\sqrt{ \frac{p_1(1-p_1)}{n_1} + \frac{p_2(1-p_2)}{n_2} } \]

\[
\sqrt{ \frac{0.05(1-0.05)}{86} + \frac{0.05(1-0.05)}{25322} } = 0.023
\]

The standard error was then used to calculate the z score:

\[
\frac{p_1 - p_2}{\sqrt{ \frac{p_1(1-p_1)}{n_1} + \frac{p_2(1-p_2)}{n_2} }} = \frac{0.41 - 0.049}{0.023} = 5.427
\]

The resulting z-score is very large indicating a p value of less than 0.00003. Therefore it is valid to say that the non-attendance of cervical screening by the learning disabled population is significantly higher than the non-attendance by the non-learning disabled population. This disproves the null hypothesis that there is no difference in the non-attendance rates in Gateshead for cervical screening between women with and without learning disabilities.
5.1.2 Breast screening non-attendance

<table>
<thead>
<tr>
<th>ELIGIBLE POPULATION</th>
<th>NUMBER</th>
<th>NEVER BEEN SCREENED</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>11796</td>
<td>1485</td>
<td>14.3 (p)</td>
</tr>
<tr>
<td>Learning disabled</td>
<td>31 (n₁)</td>
<td>10 (r₁)</td>
<td>25.4 (p₁)</td>
</tr>
<tr>
<td>Non-learning disabled</td>
<td>11767 (n₂)</td>
<td>1475 (r₂)</td>
<td>14.3 (p₂)</td>
</tr>
</tbody>
</table>

Calculation of a z-score is not valid for the breast screening data, as \( n₁ \) is too small compared to \( p₁ \).

Therefore the Chi-squared test (\( \chi^2 \)) was used to compare the proportions for statistical significance:

**Observed attendance / non-attendance:**

<table>
<thead>
<tr>
<th>O B S E R V E D</th>
<th></th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Attended?</td>
<td></td>
</tr>
<tr>
<td>Attended?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning disabled</td>
<td>21</td>
<td>10</td>
</tr>
<tr>
<td>Non-learning disabled</td>
<td>10292</td>
<td>1475</td>
</tr>
<tr>
<td>TOTAL</td>
<td>10313</td>
<td>1485</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>E X P E C T E D</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning disabled</td>
<td>27</td>
<td>4</td>
</tr>
<tr>
<td>Non-learning disabled</td>
<td>10286</td>
<td>1481</td>
</tr>
<tr>
<td>TOTAL</td>
<td>10313</td>
<td>1485</td>
</tr>
</tbody>
</table>

The \( \chi^2 \) value is calculated by using the following equation for each of the 4 cells, and then summing the results:

\[
\frac{(observed - expected)^2}{expected}
\]

Therefore,

\[
\chi^2 = \frac{(21 - 27)^2}{27} + \frac{(10292 - 10286)^2}{10286} + \frac{(10 - 4)^2}{4} + \frac{(1475 - 1481)^2}{1481}
\]

\[
= 1.33 + 0.0035 + 9 + 0.024 = 10.36
\]

Using percentage points of \( \chi^2 \) distribution with 1 degree of freedom, 10.36 falls between the 1% (or P-value of 0.01) and 0.1% (or P-value of 0.001) probability that the differences between the observed and expected values above have occurred by chance. Therefore this gives strong evidence against the null hypothesis, and suggests that the non-attendance at breast screening services by the learning disabled population is significantly higher than that of the non-learning disabled population.
5.2 Engagement with the Gateshead learning disabled population

The community event held in Gateshead for people with learning disabilities and their families was attended by 68 people. The feedback was positive and evaluation information from the event is detailed in Appendix F.

Feedback from all sources of information (parents, carers, women with learning disabilities, and community centre staff) are summarised in the themes below. The themes reflect thoughts about going for a cervical or breast screen, and how this could be supported. Additionally, other vulnerability and resilience factors which affected their health were explored. Many of the comments showed a lack of awareness of cervical and breast screening, or a lack of understanding about screening:

Time:

- Long wait whilst at the clinic/hospital to go in for the procedure
- Not a long wait for breast screen, and was completed quickly.

Stress / fear:

- Cervical screening is too distressing
- The procedures can be very stressful
- Fear of hospitals is a barrier to attending screening of either type.

Benefits of attending:

- Breast screening was painful but worth it – better to be safe than sorry
- All women should attend, however some carers may need support to take women to a screen.

Lack of understanding / inability to understand:

- A lack of understanding would make the processes too difficult
- Some women will need a great deal of time and input to understand the procedures, especially cervical screening
- Information retention can be brief with some people with learning disabilities and so needs to be given regularly
- There is a spectrum of learning disability severity, and this will have a bearing on how the woman will cope with either procedure

\* The information has been collated in this way so that identification of individual's comments is not possible.
More understanding of the Mental Capacity Act would help. Some women cannot have the screening as a result of the parent/carers decision. However using the Mental Capacity Act to bring about a group decision about the best option for the individual may result in more women being screened.

Different ways of describing the procedures to women with learning disabilities, such as role play (acting out the procedure visually) may be useful.

Physical barriers:

- Physical disabilities can make the procedures difficult, sometimes impossible for this population.
- An alternative to a mammogram machine would allow a more equitable access for women whose physical disabilities make breast screening difficult.
- Physical disabilities can make the procedures difficult, sometimes impossible for this population.

Resilience factors:

- Support of family to take woman to the procedure was reported once.
- Knowing a person who had contracted cancer in the past.

Other comments:

- The GP advised against cervical screening due to the low risk of contracting cervical cancer compared to the difficulty of the procedure.
- Women with learning disabilities are not sexually active and so cervical screening is not seen as important.
- A letter has been received at the residential home, however no explanation could be given as to why the woman has not attended.
- Some parents are elderly and are not familiar with screening procedures, or the importance of them.
- Some parents are making the decision for their daughter not to have either screen (parents have never attended cervical screening so not something that is considered for the person being cared for).
The following four vulnerability factors give a summary of the discussion group information:

**Vulnerability factors:**

- Physical disabilities make the procedure difficult if not impossible
- Lack of ability for the family/carer to take women to the procedure was reported a number of times
- Poorly supported or poorly founded decision-making by the parent or carer
- Difficulties with understanding information, and retaining information

From the information gathered in this study, one can conclude that in general, the learning disabled population is at higher risk of breast and cervical cancer due to their difficulties with understanding and retaining information. Additionally, if the woman suffers from or experiences (1) physical disabilities, (2) lack of family ability to attend screening, and (3) poorly supported or poorly founded decisions made on her behalf about attending screening, risk will be increased further.
6 Discussion

6.1 Introduction

The health equity audit showed that there are significantly more women with learning disabilities not attending breast and cervical screening services compared to women without learning disabilities. The discussion groups gave some information as to why this may be the case.

Evidence suggests that there may be lower uptake in women with learning disabilities due to a lack of information and understanding. These factors were evident from the discussion groups. However some particular points of information were gathered which were not expected, and need to be reflected on in future service planning and work with this population.

The original vulnerability model can be adapted to reflect the information gained from this study, in relation to the four vulnerability factors identified:

![Venn diagram showing intersecting circles labeled Physical disability, Learning disability, Poor decision making, and Lack of family/carer ability to support at screening.]

The circles are intersecting equally as it was not possible to attribute risk to each factor according to the impact on not attending screening. This could be done in future work, but would require a much more detailed assessment of each vulnerability factor, supported by quantitative information around profoundness of learning and physical disabilities. From this study it is valid only to say that these factors are involved in the non-attendance of screening.
6.2 Equity of access for women with learning disabilities – the future

In Section 2, rates of cervical and breast cancer in the learning disabled were discussed. For both cancers prevalence is estimated at below 10 women in every 100,000. The estimated number of people in Gateshead who are registered (QOF) with a learning disability is 453. Considering that this includes both genders, the number of women within eligible age for both screening types will be very low.

This population is entitled to the same service provision as the general population, however small in number. To alter whole systems of screening for a very small group such as this may not be supported by a cost-benefit analysis, however being able to offer a discreet service for women with learning disabilities which is tailored to their specific needs may be a more appropriate way of enabling equity of access to breast and/or cervical screening.

No decision about health care should be made by individuals on behalf of a woman who has the capacity to decide. Additionally, if the woman does not have capacity to decide, a group of professionals working with the woman should make an informed decision as detailed in the Mental Capacity Act 2005. Poorly informed decision-making which is not adhering to the processes outlined in the Mental Capacity Act 2005 could be putting women at risk of ill health, including cervical and breast cancer in this case.

6.2.1 Cervical screening

The risks associated with contracting cervical cancer may be assumed to be reduced in the learning disabled population as sexual activity is a major risk factor. However given the evidence that sexual activity occurs within this population as well as the increased vulnerability to sexual abuse, lack of sexual activity is not a valid reason for why a woman with learning disabilities should not attend screening.

As cervical screening is mainly delivered through GP practices, specific systems for assisting women to attend could not be centrally co-ordinated. Recommendations to improve cervical screening for women with learning disabilities are detailed in Section 6.3.2 below.

6.2.2 Breast screening

The risks associated with contracting breast cancer apply to all women, however women who have not had children may be at greater risk than those who have given birth. Women with learning disabilities should have equitable access to breast screening services, and this is not being reflected in current practice. Current arrangements for breast screening could take advantage of the fact that this population is relatively small, and put in place specific measures to support women with learning disabilities.
6.3 Recommendations

In all cases below, the assumption is that a woman has the mental capacity to make decisions about her healthcare unless proved otherwise. If this is proved and she does not have capacity to decide, a joint decision should be made (as detailed in the Mental Capacity Act 2005) about whether the woman attends screening, and the ‘Best Interests Checklist’ should be used.

6.3.1 GENERAL

Residential institutions:

1. SUPPORT: Staff should support women to attend screening services if they have the capacity to decide this is what they want. If they do not attend screening, this should be clearly documented, with reasons why.

2. TRAINING: Managers should ensure that staff are adequately trained in the Deprivation of Liberty Safeguards and Mental Capacity Act 2005, and understand its implications in the workplace.

3. AWARENESS RAISING: Managers should make parents, family and carers of the women in residential care aware of the Deprivation of Liberty Safeguards and Mental Capacity Act 2005, and understand its implications for the residents.

Day and community centres:

4. ADVICE: Staff should seek advice from health professionals or independent advocates (such as the Independent Mental Capacity Advocates) if there are concerns about an individual’s healthcare provision.

5. AWARENESS RAISING: Managers should make available educational sessions on relationships between men and women, safe sexual practices, and sources of support and further information if individuals require.

Parents / carers:

6. SUPPORT: Support women wherever possible to attend screening services if they have the capacity to decide this is what they want.

Primary care services:

7. TRAINING: Managers should ensure that staff are adequately trained in the Deprivation of Liberty Safeguards and Mental Capacity Act 2005, and understand its implications in the workplace.

8. SUPPORT: Staff should support women to attend screening services if they have the capacity to decide this is what they want. If they do not attend screening, this should be clearly documented, with reasons why.

9. AWARENESS RAISING: Staff should offer current and accurate information and education to parents, carers and learning disability staff about.
screening. This should include the benefits, as well as an accurate description of what the screening involves.

The Primary Care Trust:

10. AWARENESS RAISING: Sexual health teams should provide training for residential and day centre staff around sexual health. This training could enable staff to train both people with learning disabilities and their parents and carers. This could help to dispel the notion that people with learning disabilities are not sexually active

11. TRAINING: All clinical staff who may have contact with people with learning disabilities should be adequately trained in the Deprivation of Liberty Safeguards and Mental Capacity Act 2005, and understand its implications for their clients. Evaluation of how this training is being used in practice is also recommended

12. SUPPORT: Residential care home managers and day centre managers should be supported in any health-related query relating to the Deprivation of Liberty Safeguards and Mental Capacity Act 2005.

6.3.2 SPECIFIC: Cervical

13. TRAINING: Staff delivering cervical screening in GP practices should have an awareness of learning disability issues, including the Mental Capacity Act. This could be achieved through training sessions at the annual updates for deliverers of screening, and/or through training sessions at the cervical cancer screening mentor\(^c\) meetings

14. FLEXIBLE DELIVERY: Cervical screening could be organised at venues where learning disabled women attend on a frequent basis, such as residential care homes and day centres, however due to the clinical facilities needed for screening, this would not be appropriate. Additionally, providing services outside of mainstream systems does not follow recommended practice\(^d\) within *Valuing People*, or reflect current local practice

15. Considering recommendation 14, women who need additional support to complete a screen successfully should be given this. This could include desensitisation to the procedure by a pre-appointment consultation, longer appointment times, alternative waiting areas for those who are anxious, and information sent to the woman in easy-read format before the appointment

6.3.3 SPECIFIC: Breast

16. TRAINING: Staff delivering breast screening should have an awareness of learning disability issues, including the Mental Capacity Act

17. IMPROVING ACCESS: Breast screening services should continue to support women with learning disabilities to attend screening, and also to

\(^c\) Cervical screening mentors supervise students to carry out smear tests.
\(^d\) *Valuing People* states that people with learning disabilities “…have the same right of access to mainstream health services” as the general population, and we need to “…open up mainstream services, not create further separate specialist services”
support them when they arrive for a screen. Current systems in place to do this are:

- The appointment letter sent out offers assistance for anyone who feels it is necessary. If a woman or her carer rings in for this assistance, longer appointment times are available.

However women with learning disabilities should be recognised by the service and sent an easy-read version of the letter, as opposed to waiting for the woman to contact the service about her disability. Information sharing between primary care and the breast screening service could provide this information.

- Information for the woman and her carer can be sent out on request if she has a learning disability.

However if the service knew of a disability prior to invitation, information could be sent out with the easy-read letter.

- A note is put on the woman’s file that she has learning disabilities for future reference.

18. IMPROVING ACCESS: Women with physical as well as learning disabilities may be more likely to not attend due to worries about being able to stand for the mammogram (as reported in this study). Therefore concerns should be allayed where possible about this. This could be done by: sending out information about what is required of the woman at screening; booking a longer appointment; booking a pre-appointment consultation to go through the procedure with the woman a few days before the actual screen.

**Reflection on the aim**

The original aim of this report was to ‘identify measures to increase uptake of screening services within the learning disabled population, so that future rates of breast and cervical cancer are reduced in this population’.

Reflecting on the study as a whole, a more suitable aim would have been to ‘identify measures to increase informed decision making by women with learning disabilities, so that uptake of screening service is increased and future rates of breast and cervical cancer are reduced in this population’.

If all recommendations above are put into action, informed decision making will be increased, which would hopefully lead to more women deciding to attend screening. This would result in an increase in the uptake of breast and cervical screening, and therefore a reduction in future rates of breast and cervical cancer.

6.4 Ethical considerations

This study involved working with women with learning disabilities to understand their knowledge and understanding of screening. This work requires ethical consideration, because individual concerns may be raised about health and wellbeing, and may not be able to be dealt with in the session. Additionally,
conducting work with individuals who may not fully understand the context around the discussion sessions needs to be considered with caution.

The discussion sessions were always conducted with a learning disabilities staff member present, and their assistance was key to helping women understand what was being discussed and why. If women had profound learning disabilities, a learning disabilities staff member consulted with parents/carers about the information being discussed. Any individual concerns or questions which could not be resolved during the session were followed up afterwards.

Caldicott approval was granted to receive and use personal data. All personal identifiable data on which calculations were based was destroyed after calculations were completed.

6.5 Limitations of this study

6.5.1 Advocacy
This work was carried out by a Public Health Adviser with little experience of advocacy. Examples of individual cases which would have benefited from advocacy input developed over the course of the study, and the author was not able to offer advocacy support. However in these cases any queries or concerns were followed up by sending details of relevant support information / organisations to those involved.

6.5.2 Data limitations
As acknowledged previously, the QOF learning disabilities dataset is a relatively new collection of data and may be open to inaccuracies in the first few years. However this dataset was the best source of learning disabilities data to use at the time, and data will become more robust over time.

The study used non-attendance data rather than attendance data at screening. Time constraints meant that analysing attendance data was not possible, however with more time for data collection and analysis by Public Health, the NEFSHA and GP practice managers, this could be possible in the future. Using non-attendance data in this case was valid as numbers were large enough to support data analysis calculations.

6.5.3 Reasons for non-attendance for the general population
Discussion groups were only conducted with women with learning disabilities, and no control groups of women without learning disabilities were run. Therefore the reasons for non-attendance may not be unique to the learning disabled population. However two of the four main threats to non-attendance (having learning disabilities and poor decision making on behalf of the women) are intrinsically linked to having learning disabilities and were unlikely to have been mentioned in control discussion groups.
6.6 Implications of the HPV vaccination

With the recent introduction of the human papillomavirus (HPV) vaccine for young girls, consideration should be given to how this may affect the learning disabled population. The HPV vaccine will introduce protection from the HPV virus from a young age (delivered in schools with consent from the parent/carer). The vaccine does not remove the necessity to have a smear test in later life, and must be given before any sexual activity has occurred (to ensure that the female has not been in contact with the virus). Girls attending special educational needs schools will receive this vaccine, however girls who are not in the education system may not.

Women who are too old for the introduction of the vaccine could be protected from the virus by the vaccine only if they have not been previously sexually active. This could be an option for women with learning disabilities if there is certainty that the woman has not been sexually active. However the need for a smear would remain if the woman is to be certain of preventing cervical cancer.
7 Conclusion

This study has highlighted that there is an inequity in non-attendance rates for breast and cervical screening between women with and without learning disabilities. Reasons for this inequity have been offered as well as recommendations to reduce this inequity.

Recommendations have been made in two categories – specific and general. The specific recommendations relate to changes in current practice that should enable an increase in uptake of breast and cervical screening for this population.

The general recommendations focus on awareness raising of sexual health issues, training for staff around the Mental Capacity Act 2005, and support for parents/carers and/or staff to attend screening. Additionally, these recommendations should be interpreted in their widest sense, i.e. valid for men with learning disabilities, as well as other health issues apart from screening.

The main area of concern highlighted from this study is the lack of decision-making by the woman herself. Evidence collated here suggests that the decision to be screened is being made by a third party in many cases, although many women may have the capacity to decide themselves. Any decision about health or social care should be made by the individual if there is the mental capacity to decide. If the individual does not have capacity, the decision should be made by a group of professionals and interested parties as detailed within the Mental Capacity Act 2005.

Making progress on correct decision-making would provide a large step to improving the health and wellbeing of people with learning disabilities, as well as helping to treat them with the fairness and respect we are all entitled to. Some individuals will need a great deal of support to make a decision, however if this decision-making is possible for some individuals it must be supported. Following the correct procedures for decision-making for this population will help to ensure that the correct decision about their healthcare is being made in all cases.
Dear X,

RE: Cervical and breast screening uptake by women with learning disabilities

The Public Health Directorate is keen to understand more about the uptake of cervical and breast screening services by women with learning disabilities in Gateshead, as part of our commitment to reducing health inequalities (particularly for vulnerable groups).

As a member of this directorate, I am planning to compare the uptake of these screening services in the general population with the learning disabled population.

In order to do this, I am requesting data from the Family Health Services Agency to identify numbers of women per GP practice who have not been screened within the past 5 years. I will not know which of these women have learning disabilities; therefore I am asking GP practices in Gateshead for assistance.

The FSHA are able to provide NHS numbers of women in your practice who have not attended screening. I am asking for practices to identify the proportion of these women with learning disabilities (this does not require identification of individuals, just a proportion). The numbers should be low and so I expect this to be a small task.

I appreciate this is work over and above your day-to-day commitments, however your assistance will contribute to improving long-term cancer prevention for women with learning disabilities. The Caldicott Guardian for NHS South of Tyne and Wear has approved this piece of work.

I will telephone you soon to follow up this request. In the mean time, please do not hesitate to contact me with any questions.

Yours sincerely,

Lucy Horton
Public Health Adviser for Vulnerable Groups
Appendix B: Prevalence and numbers of people on the QOF learning disabilities register:

<table>
<thead>
<tr>
<th>Practices agreeing to take part in the study</th>
<th>Dr names</th>
<th>National Practice Code</th>
<th>Postcode</th>
<th>Learning Disabilities Register (Ages 18+) MALE AND FEMALE</th>
<th>Learning Disabilities QOF Prevalence (based on QOF list size) MALE AND FEMALE</th>
<th>Learning Disabilities Age-Specific Prevalence (based on PPD list aged 18+) MALE AND FEMALE</th>
</tr>
</thead>
<tbody>
<tr>
<td>OXFORD TERRACE MEDICAL GROUP</td>
<td>DR MORRIS &amp; PARTNERS</td>
<td>A85005</td>
<td>NE8 1RQ</td>
<td>73</td>
<td>0.7%</td>
<td>0.9%</td>
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<td>THE CROFT SURGERY</td>
<td>DR ROONEY &amp; PARTNERS</td>
<td>A85016</td>
<td>NE9 7BJ</td>
<td>40</td>
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<td>CHAINBRIDGE MEDICAL PARTNERSHIP</td>
<td>DR MATHESON</td>
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<td>NE21 5BT</td>
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<tr>
<td>HIGH ST MEDICAL CENTRE</td>
<td>DR ROONEY &amp; PARTNERS</td>
<td>A85015</td>
<td>NE9 7JR</td>
<td>9</td>
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</tr>
<tr>
<td>MILLENNIUM FAMILY PRACTICE</td>
<td>DR ILYAS &amp; PARTNER</td>
<td>A85013</td>
<td>NE8 1NB</td>
<td>11</td>
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<td>WHICKHAM COTTAGE MEDICAL CENTRE</td>
<td>DR MCNULTY</td>
<td>A85020</td>
<td>NE16 4PD</td>
<td>34</td>
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<td>LONGRIGG MEDICAL CENTRE</td>
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<td>A85004</td>
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<td>ROWLANDS GILL MEDICAL CENTRE</td>
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<td>A85003</td>
<td>NE39 1PW</td>
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<tr>
<td>BIRTLEY MEDICAL GROUP</td>
<td>DR STEELE &amp; PARTNERS</td>
<td>A85008</td>
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<td>GLENPARK MEDICAL CENTRE</td>
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<td>A85006</td>
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<td>ST. ALBANS MEDICAL GROUP</td>
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<tr>
<td>HOLLYHURST MEDICAL CENTRE</td>
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<td>FELL TOWER MEDICAL GROUP</td>
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<td>A85001</td>
<td>NE9 5EY</td>
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<td>BEWICK ROAD SURGERY</td>
<td>DR COPE &amp; PARTNERS</td>
<td>A85017</td>
<td>NE8 4DP</td>
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<tr>
<td>PRIMARY HEALTHCARE CENTRE</td>
<td>DR HASSAN</td>
<td>A85024</td>
<td>NE17 7BU</td>
<td>5</td>
<td>0.1%</td>
<td>0.2%</td>
</tr>
<tr>
<td>5 WALKER TERRACE</td>
<td>DR S M IMAM</td>
<td>A85012</td>
<td>NE8 1HX</td>
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<td>0.1%</td>
<td>0.1%</td>
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<tr>
<td>1 RAWLING ROAD, THE MEDICAL CENTRE</td>
<td>DR ORRITT &amp; PARTNER</td>
<td>A85025</td>
<td>NE8 4QS</td>
<td>3</td>
<td>0.1%</td>
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<td>7 ELVASTON ROAD RYTON</td>
<td>DR HILTON</td>
<td>A85605</td>
<td>NE40 3NT</td>
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<td>0.1%</td>
</tr>
</tbody>
</table>
Appendix C: Letter to GP practices thanking them for their interest

18th June 2008

Dear X,

RE: Cervical and breast screening uptake by women with learning disabilities

You may recall that I had a conversation with you about assistance with data collection for the above study. I have had overwhelming support from practice managers in Gateshead to collect this data, which is much appreciated.

The decision has been made to use a sample of GP practices rather than all practices, due to the amount of data handling involved. Ten practices have been able to assist me with this so far, therefore I will not require information from your practice.

This study will be completed in October, and will show whether there is a significant difference in uptake of cervical and breast screening services between women with learning disabilities, and women without learning disabilities. Alongside this, we have conducted consultation events with people with learning disabilities to understand about their experiences of using (or not) cancer screening services. The information and resulting recommendations will help us to improve service commissioning, planning and delivery for people with learning disabilities in Gateshead.

If you are interested in the outcomes of this piece of work, please contact me or Deborah Hunter after October for a copy of the final report (deborah.hunter@sotw.nhs.uk or 0191 529 7028).

Once again, thank you for your interest in this piece of work.

Yours sincerely,

Lucy Horton
Public Health Adviser for Vulnerable Groups
Appendix D: Programme for the cancer screening event

Cancer Screening
Event for People with Learning Disabilities, their Families and Carers

What’s On...

10am – 10.15am
Welcome and Introduction – Lucy Horton, Public Health Advisor for Vulnerable Groups

10.15am – 11am
Workshops:
- Cervical Cancer – Carolyn Garven, Sexual Health Nurse Practitioner, Sexual Health Services Gateshead.
- Cancer Awareness Video, Janis Norris, Gateshead Learning Disability Community Health Team

11.00am – 11.10am
Personal Experiences of Cancer Screening Services
Lynda Rutter and Anne Richardson, New Vision

Please turn over
11.10am–12noon  Gateshead Council Community Health Team – Kay Robson, Community Health Worker

Lumps 'n' Bumps
Do you know what to look for?

NHS South of Tyne and Wear,
Healthy Community Collaborative,
Geoff Graham, Health Improvement Practitioner

12noon – 12.45pm  Lunch

12.45pm – 12.55pm  Personal Experiences of Cancer Screening Services

Lynda Rutter and Anne Richardson,
New Vision

12.55pm – 1.40pm  Workshops:

Breast cancer – Cara Law, Macmillan Health Promotion Specialist, Gateshead Breast Screening Programme

Testicular cancer – Jim Gaynor, Clinical Nurse Lead, Gateshead Learning Disability Community Health Team

1.40pm – 2.30pm  Bowel Cancer – Mary Ritchie, South of Tyne Screening Nurse Lead, South of Tyne Bowel Cancer Screening Programme
Appendix E: Press release for the cancer awareness event held on 30th May 2008:

MEDIA INFORMATION, 27th May 2008

Improving access to cancer screening

A special event aimed at helping to improve access to cancer screening services for people in Gateshead with learning disabilities will be held on Friday (30 May).

They’re invited, along with their families and carers, to a series of workshops at the Trinity Centre, High Street, Gateshead. Each workshop will focus on a different form of cancer – cervical, testicular, breast, prostate and bowel. Experts will give them information on the diseases and the screening available and they will have the chance to ask questions.

The event, arranged by NHS South of Tyne and Wear’s Patient, User, Carer and Public Involvement team, will build upon a recent information-gathering exercise by staff who work locally with people with learning disabilities. They asked their clients what they already knew about screening services and if they felt there were any barriers to them accessing these.

Public Health Advisor Lucy Horton said: “Screening has an important part to play in preventing cancer and, also, in detecting it early so that effective treatment can be given. For example, the NHS breast screening programme, which is free every three years to all women in the UK aged 50 and over, is now saving 1,400 lives every year in England and regular bowel cancer screening has been shown to reduce the risk of dying from bowel cancer by 16 per cent. It is, therefore, vital that we make sure that everyone in our community can access the screening services which are available.”

Friday’s event will be from 10am-3pm. As well as the workshops on the various cancers, there will be a session at Friday’s event by Gateshead Council’s Community Health Team on adopting a healthier lifestyle, including food, diet and exercise. Anyone wanting more information should contact 0191 283 1019 / 283 1405.
Appendix F: Evaluation sheet, and summary of evaluation from the community event held on 30th May 2008:

Cancer Screening Event Evaluation

What did you think?

Thank you for coming today.

We would like to ask you a few questions on this form.

Your answers will help us make sure we are doing things right.

If you need help to fill in this form just ask!
Please put this form in the box before you leave

Questions

1. Did you think the event was

☐ Good    or    ☐ Bad?

✓ 100% of respondents chose 'Good'

2. Did you find out lots of good information?

☐ Yes    or    ☐ No?

✓ 100% of respondents chose 'Yes'
3. Did you feel that people listened to you?

☐ Yes  or  ☐ No?

✓ 100% of respondents chose 'Yes'

4. Do you think what you said will make any difference?

☐ Yes  or  ☐ No?

✓ 100% of respondents chose 'Yes'
5. Is there anything else you would like to say about the event?

Specific comments from this question were:

1. Enjoyed taking part in the examination for males
2. Good information and workshops
3. Ideas from participants were useful to health professionals, and hopefully they can be taken forward
4. Very good information
5. Good event. Made me more aware
6. It was alright
7. I enjoyed the day
8. It has been a very good day. I enjoyed it
9. I learnt a few things today. Thank you
10. It was canny. I enjoyed it.
11. to 17 No comment

Attendance and evaluation of the event

A total of 67 people attended the event (not including health professionals) – 40 females and 27 males. A small number of professional carers attended (about 8) however no family carers.

Main points from the community event

Understanding and awareness of screening services was varied across the participants in the workshops. Some people had attended screening, and were keen to share their positive experiences, however not all participants volunteered information. Some carers voiced concerns about some screening services (e.g. do females need cervical screening if they are not sexually active?), and these were answered by the professionals leading the workshops.
9 References


4 Care Services Improvement Partnership (2005) Valuing People – what do the numbers tell us? Department of Health.


