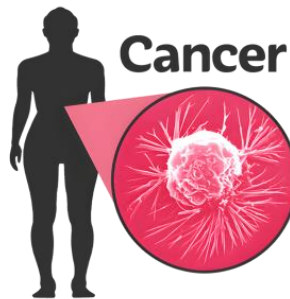


Cervical Screening Appointment Pathways Project



A review of the current pathway and related information for transformation to AIS, as commissioned by the Wandsworth GP Federation.

Cervical Screening Appointment Pathways Project

Background

In the UK women with learning disabilities have significantly lower rates of cervical screening compared to those without such disabilities. Key statistics include:

- **National Average:** As of March 2021, only 31.5% of women with learning disabilities were up to date with cervical screenings and this is compared to 69.9% of women without learning disabilities.

SOURCE: https://www.nationalworld.com/health/cervical-cancer-prevention-week-women-with-learning-disabilities-half-as-likely-to-get-smear-tests-with-just-32-screened-3537073?utm_source=chatgpt.com

- **South West England:** Only 25% of women with learning disabilities attended their cervical screening appointments when invited, according to a study in Exeter .

SOURCE: https://www.england.nhs.uk/south/2019/01/23/study-shows-only-1-in-4-women-with-learning-disabilities-attend-cervical-screening-in-the-south-west/?utm_source=chatgpt.com

Factors such as assumptions by healthcare professionals that women with learning disabilities are not sexually active, staff who lack the required training to support these patients , with learning disabilities effectively and the lack of accessible information and resources all contribute to these disparities.

Public Health England has made efforts to address this issue by developing accessible resources like "The Smear Test Film" by Public Health England.

In addition, until the summer of 2024, Jo's Cervical Cancer Trust was active in informing women with learning disabilities about the importance and process of cervical screening. However, they no longer exists!

Learning disability is defined by the NHS as *"the way a person learns new things throughout their lifetime, which means they can have difficulty understanding new or complex information, learning new skills and coping independently"*.

There is a spectrum from mild to profound and at its greatest severity, a profound learning disability leaves a person with multiple disabilities, including learning, sensory and physical impairments .

Local Authorities are required to meet a person's needs holistically, under The Care Act 2014, which encompasses an acknowledgement of the wider determinants of wellbeing, such as employment or socialisation.

This legislation is strengthened by the Mental Capacity Act 2005 which protects the right of individuals and their families to make their own decision.

Afterall, everyone deserves the right and opportunity to be active citizens, live a meaningful life, and make contributions to the community.

SOURCE: NHS (2018) Care Act 2014 Mental Capacity Act 2005

See https://www.wandsworth.gov.uk/media/9758/wandsworth_jsna_vulnerable_groups.pdf

Learning Disabilities in The London Borough of Wandsworth

In Wandsworth there are over 6,000 aged 18 or older with learning disabilities and the highest proportion of people with a learning disability are those aged 35-44. The lowest proportion of people is 85+.

This reflects the comparatively low life expectancy of adults with a learning disability, within the borough. This is also applicable to adults with a moderate or severe learning disability.

Around 800 people with a learning disability are supported by Wandsworth Council through a variety of mechanisms, including block contracted services , Direct Payments and spot-purchased services.

In general, people in Wandsworth live longer than the national average. However, life expectancy at birth and at 65 years of age tend to be higher in other London boroughs.

Despite females in the borough living 3.6 years longer than males, there has been a recent decline in healthy life expectancy in women which sees them spending longer in poor health than previously and spending longer in poor health than men.

However, in Wandsworth variations in life expectancy across are driven by inequalities between more deprived and less deprived areas, in particular among the 60 to 79 age group, who have a higher incidence of cancer and cardiovascular disease.

In Wandsworth the proportion of people screened for conditions such as cancer is low compared to the national average, but the number of people attending NHS Health Checks was better than the national average.

Adults (18+ yrs) with learning disability receiving long- term support from local authorities (per 1,000 population): In 2019/20 was the 5th highest in London, 2.5% lower than the

SOURCE: https://www.wandsworth.gov.uk/health-and-social-care/public-health/public-health-publications/jsna/jsna-people/#17_Non-UK_Born_Population

In Wandsworth the average life expectancy for service users with a learning disability is currently 65.1 years for women and 65.5 years for men

SOURCE: (Health and Care of People with Learning Disabilities: Experimental Statistics: 2015 to 2016, NHS Digital 2017).

it is, therefore, essential for local healthcare providers, within the borough, to implement strategies tailored for patients with learning disabilities and or autism.

These strategies may involve offering longer appointment times, providing information in accessible formats, and ensuring that staff are trained to support patients with learning disabilities effectively.

Cervical Screening & Why it's Important

For most women, cervical screening is a part of routine healthcare that helps monitor and maintain their reproductive health.

Cervical screening tests are important because they help detect changes in the cells of the cervix that could lead to cervical cancer.

They are also known as Pap Smears or Pap tests and can detect abnormal cells early on the cervix before they turn into cancer. Early identification of changes allows for treatment to prevent cancer from developing.

Cervical screening can, also help the detection and treatment of precancerous conditions, before they become cancerous. The risk of cervical cancer is significantly reduced by early detection.

The test can also detect the presence of Human Papillomavirus (HPV), which is a virus that can cause changes to the cells in the cervix and is strongly linked to the development of cervical cancer.

Most importantly, regular cervical screenings reduce the number of women who develop advanced stages of cervical cancer, leading to better survival rates and improved health outcomes.

Therefore, regular cervical screening, based on risk factors and age is of paramount importance for women to detect any issues early when they are more treatable.

This, in turn, reduce the risk of developing cervical cancer.

There are ways women can reduce the risk of developing cervical cancer, For example, by:

- **Practicing Safe Sex.** The risk of being infected with HPV can be reduced... In particular the use of condoms is encouraged.
- **Not Smoking** – On average the risk of developing cervical cancer can be reduced by half if you are a non-smoker.
- **Attending [cervical screening](#)** aids early detection of cervical abnormalities and HPV infections before they are able to develop into cervical cancer.
- **[Vaccination](#):** If you are eligible (for girls at school in Year 8) getting the **HPV Vaccination** will protect you from the high-risk HPV types 16 and 18 that cause 70% off all cervical cancers.

Despite smear tests being an embarrassing and challenging subject for some, cervical screening remains the most effective method of checking for and preventing the spread of the disease.

For those with learning disabilities, cervical screening also helps to ensure their health is monitored by their guardians, along with those who care for and support them.

In the UK, 9 women everyday are diagnosed with cervical cancer and unfortunately 2 women will lose their battle against the disease. However, despite being largely preventable thanks to cervical screening and the nationwide HPV vaccination programme, in women under 35, cervical cancer is still the most common cancer.

As a result of the NHS screening programme as well as improvements in treatment, the number of women dying from cervical cancer has halved over the past 28 years.

However, Liz Mearns, NHS England Medical Director South West, however, said:

“Cervical cancer is still one of the most serious illnesses affecting women. The NHS encourages all women to attend their screening appointments, but we are particularly keen to encourage women with learning disabilities to have this vital health check.

*“We know that many women, and particularly those with learning disabilities, are embarrassed or afraid to have the check done, but Jo’s Trust has a leaflet and a short film** specifically for women with learning disabilities that can help explain what’s involved why it is so important.”*

In 2019-20, compared to patients without a Learning Disability, a significantly smaller proportion of patients with a Learning Disability had a breast, cervical and or colorectal cancer screening test.

In order to have cervical screening patients must first give their consent to the procedure and this is known as [informed consent](#).

Methods for screening vary depending on the type of cancer, for more information go to the NHS website <https://www.england.nhs.uk/cancer/early-diagnosis/screening-and-earlier-diagnosis/>

Cervical Screening Statistics

According to NHS England statistics, compared to patients without a learning disability, overall patients with learning disabilities are less likely to receive screening for the three types of cancers.

This difference is, evidently, greatest for cervical cancer screening. Nonetheless, patients with a lived experience's ability to give informed consent to such invasive procedures should be considered when interpreting the data.

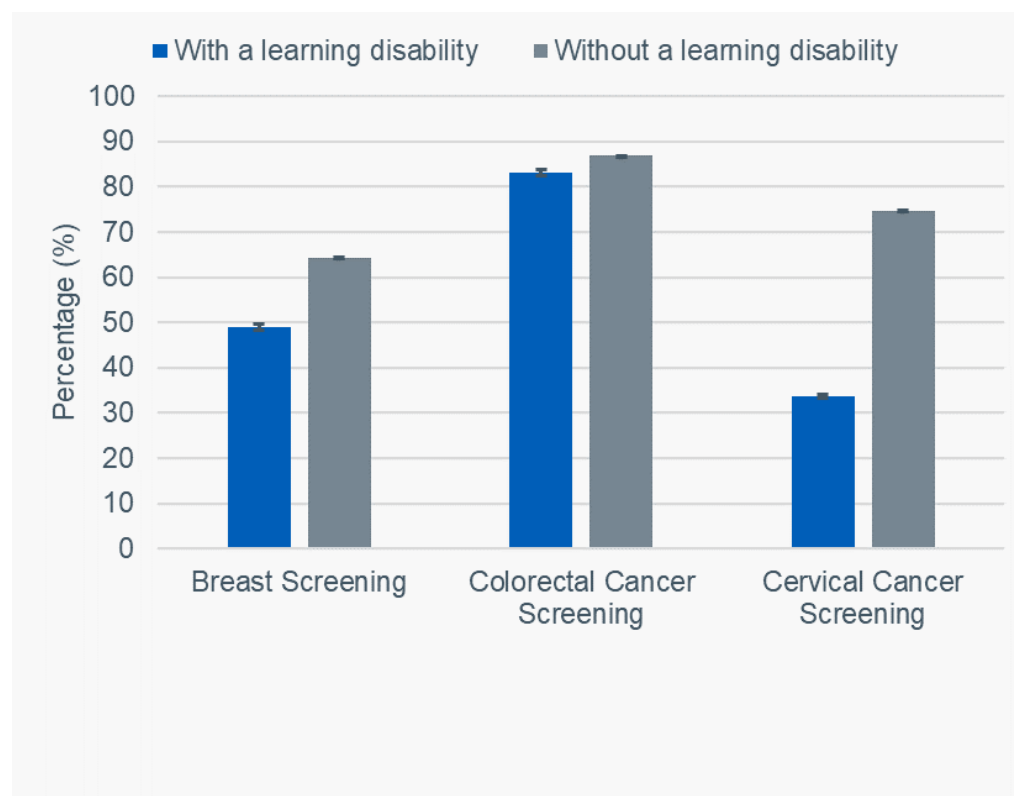


Figure 1: Shows the Percentage of patients eligible for cancer screening, who have had a cancer screening test in the five years prior to 31st March 2019

SOURCE: NHS England

<https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2019-to-2020/cancer-screening#:~:text=In%202019%2D20%2C%2040.0%25,patients%20without%20a%20learning%20disability.>

In addition, Jo's Cervical Cancer Trust gathered data that shows women with learning disabilities are 45 per cent less likely to be screened for cancer compared to their counterparts without learning disabilities.

However, the proportion taking up the offer of cervical screening, in the South West, may be even lower and a study in Exeter found that only one in four of women with learning disabilities attend their cervical screening appointment when invited.

SOURCE: Jo's Cervical Cancer Trust

<https://pcwhf.co.uk/>

This is a serious issue affecting already vulnerable people and it needs to be addressed by firstly looking at the appointment process, which is key if attendance for cervical screening tests among patients with learning disabilities is to be increased.

The Significance & Importance of Accessible Information Standards [AIS]

The **Accessible Information Standard (AIS)** is crucial for healthcare providers because it ensures that patients with disabilities or other communication needs can access and understand the information they need about their care.

Listed below are a few reasons why AIS is important:

- 1. Promotes Equality and Inclusivity:**

The standard helps ensure that people with disabilities, including visual, hearing, cognitive, or learning impairments, have the same access to healthcare information as everyone else.

Therefore, AIS supports the principle of equality by preventing discrimination and ensuring all patients are treated fairly.

- 2. Improves Patient Care:**

By providing information in accessible formats like braille, large print, easy read, or digital formats, healthcare providers can enhance patient understanding, which ultimately leads to better health outcomes and helps address health inequalities.

When patients are well-informed, they are more likely to follow medical advice, understand their condition, and make informed decisions.

- 3. Legal Compliance:**

In the UK, the Accessible Information Standard [AIS] is part of healthcare regulations, meaning healthcare providers are legally required to follow it.

This ensures they are meeting the needs of individuals with disabilities and are complying with relevant laws like the Equality Act 2010.

- 4. Supports Effective Communication:**

The standard helps healthcare professionals identify and address any communication barriers, improving interactions between patients and providers.

This, in turn, leads to more effective diagnosis, treatment, and follow-up care.

- 5. Enhances Trust and Satisfaction:**

Patients are more likely to trust healthcare services that accommodate their needs.

Therefore, by following the AIS, healthcare providers can demonstrate their commitment to patient-centered care and recognising individual needs, which can lead to increased patient satisfaction.

In summary, the Accessible Information Standard is vital for healthcare providers because it ensures that all patients can access, understand, and act upon the information necessary for their health and well-being, fostering equality, trust, and better healthcare outcomes.

Easy Read

[It's significance, with regards to AIS and Patients with Learning Disabilities]

Easy Read is a format of written information that is simplified to ensure it's accessible and understandable for people with learning disabilities, autism and other neurodiverse conditions.

It focusses on using clear, simple language, short sentences, and includes visual aids such as pictures or symbols to support comprehension and aid overall understanding.

Easy read's significance in relation to the Accessible Information Standard (AIS) is that it ensures people with learning disabilities can access important health and social care information in a way that they can understand.

As already mentioned, the AIS requires organizations to provide information in accessible formats, like Easy Read, so individuals with learning disabilities are better able to make informed decisions about their care, which in turn can improve overall health outcomes and promote greater inclusion.

The Current Cervical Screening Appointment Process

The current NHS process for booking a cervical screening appointment is as follows:

"You'll be sent an invitation letter in the post when it's time to book your cervical screening appointment."

Your invitation letter will tell you where you can go for cervical screening and how to book.

Most cervical screening is done in a GP surgery by a female nurse or doctor.

Call your GP surgery to book an appointment with them. You might be able to book the appointment online."

SOURCE: <https://www.nhs.uk/conditions/cervical-screening/how-to-book/>

This service is essential for ensuring public health, but the current NHS cervical screening booking has multiple issues that may contribute to delays, confusion and reduced participation, which may also contribute to ongoing health inequalities.

Here's an outline of some of the main issues:

1. Inconvenient Appointment Scheduling

- Limited Appointment Availability:

Many report difficulty in booking appointments due to limited availability of slots at their local GP or clinic.

This is particularly problematic in rural or underserved areas where fewer clinics offer cervical screening.

- Long Waiting Times:

In some cases, patients may face long waiting times between booking and attending their appointment. Such delays discourage some from participation and result in missed opportunities for early detection of cervical cancer.

2. Lack of Flexibility

- Limited Hours for Appointments:

Cervical screening appointments are usually available only during standard working hours, which makes it difficult for people who work full-time or have other commitments.

- No Out-of-Hours or Weekend Options:

There is often a lack of out-of-hours or weekend screening options, which would make it easier for individuals with busy schedules to get screened.

3. Communication Challenges

- Confusing Letters or Notifications:

Some patients find the language or format of their invitation letters unclear, leading to misunderstandings about how to book an appointment or what the process entails.

- Lack of Follow-up Reminders:

While some people receive a reminder for their screening, others do not, or they only receive a reminder too late to book an appointment in time.

- Inadequate Information:

Patients may not always receive accessible or enough information about the screening process, what to expect, or why it's important, leading to unnecessary anxiety or reluctance to participate.

4. Accessibility Issues

- Digital Barriers:

Many people, particularly older individuals or those without access to the internet, may struggle to navigate the online booking system or might not have access to it at all.

- Language Barriers:

Non-English speakers may find it difficult to access information or make appointments, leading to lower participation rates among these groups.

5. Stigma and Discomfort

- Fear or Anxiety:

The prospect of having a cervical screening can cause anxiety for many, and the process of making the appointment can be a barrier. Some individuals avoid screening due to fear of the test or concern about potential results.

- Lack of Privacy:

Some people feel uncomfortable discussing their screening needs with a receptionist, leading to reluctance in making the appointment altogether.

6. Inconsistent Data Management

- *Difficulties with Rescheduling:*
If a patient needs to reschedule, the process can be cumbersome and may result in delays. Inconsistent data management systems across clinics can make rescheduling difficult.
- *Missed Invitations:*
Some patients may not receive invitations due to administrative errors or system flaws, missing the chance to schedule a screening.

7. Underrepresentation of Certain Groups

- *Disproportionate Barriers for Vulnerable Groups:*
Individuals with disabilities, lower socioeconomic status, or from minority ethnic backgrounds may face additional barriers, including lack of tailored support or culturally sensitive communication.
- *Lack of Inclusivity in Booking Systems:*
Certain people, such as trans men or non-binary individuals, may feel excluded or misunderstood in the current system, which is primarily designed for cisgender women.

8. Inefficient Use of Technology

- *Limited Integration Between Services:*
The booking system may not be integrated well with other health services, creating confusion about which provider to contact or when to schedule the screening.
- *Technical Issues with Online Systems:*
The online booking platforms can experience glitches or downtime, frustrating users who may not be able to book their appointments.

9. Low Participation Rates

- *Cultural and Societal Factors:*
Some people are less likely to engage with the process due to cultural beliefs or stigma around sexual health, even if they receive invitations or reminders.
- *Lack of Engagement Strategies:*
There may be insufficient efforts to engage people who are hesitant or less aware of the importance of cervical screening, leading to low participation rates in certain demographic groups.

It is clear that the NHS cervical screening booking process faces a variety of challenges that can hinder accessibility, convenience, and engagement.

Addressing these issues could involve improvements such as more flexible appointment scheduling, clearer/more accessible communication, better digital accessibility, and more inclusive practices for underrepresented groups.

The Case for Adopting Accessible Information Standards [AIS]

Here are the main reasons why transforming the current cervical screening appointment system in line with AIS will benefit everyone involved:

1. **Communication Barriers:**

Patients with learning disabilities may struggle to understand the typical process of making and attending appointments.

A complicated booking system or unclear instructions can be overwhelming, leading to missed appointments.

Hence, simplifying the process and providing clear, accessible information is crucial for encouraging attendance.

2. **Support Needs:**

Many individuals with learning disabilities may require additional support during the appointment process. This could include assistance with making appointments, understanding the purpose of the screening, or requiring an advocate or carer/support worker to attend with them.

The appointment system needs to be flexible to accommodate these support requirements.

3. **Anxiety and Fear:**

Patients with learning disabilities might experience heightened anxiety around medical appointments, especially for intimate procedures like a cervical screening.

Understanding this, and providing a more supportive and less intimidating environment, can improve attendance.

Also, ensuring that the appointment process includes reassurance, time for questions, and a friendly atmosphere can help reduce this anxiety.

4. **Accessibility of Appointment Scheduling:**

If the process of booking appointments is not accessible (for example, if it is only available through online portals or during inconvenient hours), individuals with learning disabilities may face barriers in accessing care.

Hence, the system should offer multiple ways to book appointments, such as through phone calls, accessible websites, or in-person scheduling, and be sensitive to the needs of those with varying abilities.

5. **Transport and Accessibility:**

Practical concerns like transportation to the clinic, physical accessibility of the facility, or the need for assistance navigating the healthcare system can all contribute to low attendance.

The appointment process needs to consider these factors and ensure that arrangements can be made to support the patient's needs, such as providing information about accessible transport and or also offering home visits.

6. **Follow-Up and Reminders:**

Patients with learning disabilities might need extra reminders and follow-up communication to ensure they remember their appointments.

Setting up simple, repeat reminders—through various channels like phone calls, texts, or letters in easy-to-read formats—can help improve attendance rates.

It can be argued, therefore, that by adopting the AIS approach and tailoring the cervical screening appointment process to address these specific needs, healthcare providers can help ensure that patients with learning disabilities are more likely to attend their cervical screening tests, ultimately leading to better health outcomes for this group.

Aims & Purpose of this Project

In the London borough of Wandsworth there are 38 GP practices who are all Wandsworth GP Federation [WGPF] shareholders.

The federation holds an Annual General Meeting to update shareholders on activities during the year and to discuss ways of working in the future

All decisions are agreed through discussion with the GP surgeries.

The WGPF operates between primary care providers and the wider health and care system to ensure primary care retains a strong voice in the borough. Their activities play a significant role in helping the local primary care system to be organised and supported to provide effective and efficient leadership, management and service delivery.

SOURCE: <https://wandsgpfed.co.uk/>

Our Research & Resources

The Wandsworth GP Federation asked Generate and Easy Health to engage local patients, with learning disabilities and or autism, who have accessed cervical screening appointments at their Wandsworth GP surgery and or a Primary Care Network [PCN].

GP practices played a significant role in this process as they were asked to instruct their surgery PACT Administrator to do an EMIS run to get a list of patients with the following characteristics/ - code:

- Cervical Screening, 25-65 years old,
- Mild Learning Disability,
- In assisted or Independent Living.

The GP surgeries and PCNs then had to instruct their Healthcare Assistants

- To help fill out the survey with patients from that list :
[This was done over the phone or online]
- To, also, assist the patient in filling out the survey after their cervical screening appointment.

If the healthcare assistants were unavailable or busy, Generate and Easy Health were available to provide the required support and assistance.

We co-created an easy read/accessible questionnaire for patients with a lived experience, in Wandsworth, who have attended cervical screening appointments.

Alongside that we also created a questionnaire to be completed by 2 GP surgeries, chosen at random from the 38 Wandsworth GP Federation surgeries.

To assist in the process, communication with surgeries was facilitated and coordinated by the Wandsworth GP Federation [WGPF] to, also, help generate uptake by surgeries.

Our accessible survey enabled us to gather invaluable information and gauge patients with learning disabilities and or autism's opinions and experiences of the cervical screening appointment process in Wandsworth.

We then actively engaged with the chosen GP practice/ Primary Care Network [PCN] to review the invite to appointment approach for cervical smear and review their current pathway and related information for transformation to AIS.

This process, of AIS adoption, shall involve assessing and possibly refining how patients are contacted or invited to schedule appointments for specific services, ensuring the process is effective, accessible and ultimately provides more integrated care.

Finally, a pathway will be implemented with at least one GP practice to improve access to appointments for patients with learning disabilities and or autism.