

## **REPORT & RECOMMENDATIONS**

### **[Based on Patient Survey]**

The following report and recommendations is on Improving the Cervical Screening Appointment Process for Patients with Learning Disabilities and/or Autism, with a focus on reviewing the current pathway and related information for transformation to AIS.

### **Introduction**

Cervical screening is an essential public health service that helps detect early signs of cervical cancer.

However, for individuals with learning disabilities and/or autism, accessing and understanding the screening process can present multiple and significant challenges.

This report provides an analysis of survey data related to the cervical screening appointment process for individuals with learning disabilities and/or autism and offers recommendations for improvement, in line with AIS compliance.

All the patients surveyed, for this project, attend Wandsworth GP Federation surgeries or PCNs.

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### **Survey Data Summary and Analysis**

Our easy read survey was created to assess the accessibility, understanding, and support provided before, during and after the cervical screening process.

In terms of the individuals surveyed, 100% of respondents identified as female, with 80% considering themselves to have a disability.

However, the survey reveals several key issues and challenges experienced by patients with learning disabilities and/or autism.

### **Key Findings:**

#### **1. Invitation Format and Understanding**

- 80% of respondents did not receive their cervical screening appointment invitation in a format they could easily understand.
- Only 20% of patients received the invite in an accessible format.
- 60% found the invitation content easy to understand, but 20% found it challenging.

**Recommendation:**

GP surgeries must ensure that cervical screening invitations are consistently provided in accessible formats such as easy-read letters, large print and or verbal communication, if and when required.

Offering a choice of accessible formats can accommodate varying preferences and needs. This in turn will provide a much more equitable process of accessing cervical screening appointments for those with a lived experience.

**2. Booking the Appointment**

- 60% of respondents booked their appointments independently, but 20% required help and the other 20% needed help but did not receive it.

**Recommendation:**

GP surgeries must offer clear instructions [in the required accessible formats] on how to book appointments and provide accessible support for those who need further assistance following the instructions.

Additionally, offering telephone support must be considered, along with online chat services to help those who need help navigating the online booking system.

**3. Explaining the Cervical Screening Appointment and Test Process**

- While 100% of respondents were informed about the purpose of the cervical screening appointment, 60% reported that no one explained what would happen during the test.

**Recommendation:**

GP Surgeries must ensure that both the appointment and the test procedure are thoroughly explained to patients, ideally in a visual and or verbal format that is easy to follow/understand.

This may include using simple language, diagrams and or easy read resources that can be sourced by visiting or contacting <https://www.easyhealth.org.uk/>.

#### 4. Chaperone and Comfort during the Cervical Screening Appointment

- 60% of respondents were offered a chaperone, but 40% were not.

##### **Recommendation:**

GP surgeries must always offer the option of a chaperone to individuals, with a lived experience, who may feel anxious or uncomfortable during the test.

At all times they must ensure that this option is clearly communicated before and during the appointment in a format the patient understands.

#### 5. Support During and After the Cervical Screening Appointment

- 60% of respondents needed support to access their appointments, and all respondents received the necessary help.

##### **Recommendation:**

GP surgeries must continue providing the required support for patients, with a lived experience, who need help accessing appointments, whether through transportation, communication, or understanding the appointment process.

Additionally, they must ensure that support is consistently available throughout the entire process, including post-test support and required signposting for additional support.

#### 6. Understanding and Accessing Cervical Screening Test Results

- 60% of respondents needed help understanding their results, but all received the necessary support.

##### **Recommendation:**

GP surgeries must ensure that results are communicated in an easy read/accessible format, and provide support for understanding the outcomes.

This can include offering explanations in person, via phone, or using visual aids or simplified language for individuals with learning disabilities or autism.

If test results are abnormal then an in person consultation, preferably with support is highly recommended.

If the Wandsworth surgeries need help with communicating test results in accessible formats for those with a lived experience they can contact Generate opportunities for assistance.

## 7. HPV Vaccination

- 80% of respondents received the HPV vaccine, while 20% did not.
- Additionally, 20% of respondents indicated they were not offered the vaccine at all!

### **Recommendation:**

GP surgeries and PCNs must ensure that all individuals with learning disabilities and/or autism are consistently made aware of and offered the HPV vaccine.

They must provide clear and accessible easy read information about the vaccine's benefits, risks, and availability.

Easy read/accessible information and resources on HPV are freely available, on request from Generate Opportunities or by joining <https://www.easyhealth.org.uk/>.

## 8. Cervical Screening Appointment Logistics

- 80% of respondents received information on what to bring and wear.
- Whilst 20% did not.

### **Recommendation:**

GP surgeries must always provide clear, accessible information on what to bring, wear, and how to prepare for cervical screening appointments.

This is especially important for individuals with autism, who may require additional details [in an accessible format] in order to feel comfortable and be prepared for their appointment.

Generate Opportunities can create easy read leaflets and resources on cervical screening appointment logistics for Wandsworth GF Federation surgeries and PCNs.

## 9. Transportation and Access to Cervical Screening Appointments

- 60% of respondents received directions to their appointment,
- Whilst 40% did not.

### **Recommendation:**

GP surgeries must provide detailed, accessible directions to the appointment location, ensuring that individuals with learning disabilities and/or autism can easily navigate the transportation process, along with support, if requested or required.

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## **Recommendations for Improvement of the Current Cervical Screening Appointment Pathway.**

Based on the collected survey data, the following is recommended to enhance/improve the cervical screening appointment process and experiences for individuals with learning disabilities and/or autism:

### **1. Ensure Invitations are Accessible**

All invitations should be sent in easy read/accessible formats that are easy to understand. Offering multiple options, such as easy-read letters, phone calls, or video invitations, can help cater to the diverse needs of patients and in turn this will improve take up and early detection/treatment for those with a lived experience.

### **2. Improved Communication of Appointment and Test Process**

Surgeries must ensure that patients receive a full explanation of what to expect during the appointment and the test procedure, ideally using clear, simple language, and visual aids if needed. Additionally, support workers, relatives and carers, must be involved in this process, where possible.

Patients should, also, be encouraged to ask questions, and resources should be provided for further clarification, if needed.

### **3. The Need for Consistent Offering of a Chaperone**

A chaperone should be offered to every patient and this should be clearly communicated that the option is available, whilst patients should, always, be able to select the gender of their chaperone, if preferred.

### **4. Cervical Screening Booking and Support Services**

Booking appointments should be simplified, in line with the needs of patients with a lived experience and those who need assistance should be offered different booking options, along with dedicated/specialist support, such as a helpline or online assistance.

This will, in turn ensure that individuals with disabilities can access services without unnecessary barriers.

### **5. Support Post-Test and Results**

After the cervical screening appointment, patients should receive help understanding their results in an easy read/accessible format that works for them.

The support may include follow-up appointments, phone calls, an explanation using a easy read resource or in-person consultations, with their support network present, to ensure clarity and understanding of information communicated.

**6. HPV Vaccine Access and Information**

Surgeries must provide all individuals, with a lived experience, with clear, accessible information about the HPV vaccine, and ensure that they are routinely made aware of and offered the vaccine during their cervical screening appointment.

**7. Comprehensive Travel and Appointment Information**

Surgeries must ensure that patients are provided with full details about what to bring, where to go, and how to get there.

This will help reduce anxiety, especially for patients who are unfamiliar with the screening process and who may not attend their cervical screening appointment due to their fears related to travelling.

**8. The Importance of Regular Reviews and Feedback**

Surgeries must regularly gather feedback from individuals with learning disabilities and/or autism to assess whether improvements are being made and to identify any new barriers that may arise.

This in turn will also improve their understanding of those with a lived experience, improve their communication and put them in a better position to adequately assist those patients whilst at the same time adhering to current AIS Compliance requirements.

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## **CONCLUSION**

Improving the cervical screening appointment process for individuals with learning disabilities and/or autism is essential to ensuring equal access to vital healthcare services and addressing health inequalities, within the London borough of Wandsworth.

By implementing these recommendations, healthcare providers can create a more inclusive and accessible cervical screening experience that promotes better understanding, accessible information, comfort, support and overall quality of experience for all patients.

In order to achieve this, providing a cervical screening appointment process that promotes a transformation to Accessible and Inclusive Services (AIS) is crucial in improving access to appointments and related cervical screening information for patients with learning disabilities and/or autism.

Individuals with these conditions face multiple barriers such as communication difficulties, anxiety, and sensory sensitivities, which can make accessing and navigating the traditional screening process challenging, overwhelming and inaccessible.

By adopting an AIS approach, healthcare services can create an environment that is tailored to meet the specific needs of these patients, ensuring they feel supported, understood, and empowered throughout the process.

AIS provides the essential tools for communication, self-expression, and interaction with others.

Therefore, based on this project's report findings and recommendations, it's extremely important for all surgeries to adopt an AIS based approach as it would promote and encourage;

### **1. Improved Communication:**

As, AIS helps many individuals with learning disabilities or autism who struggle with verbal communication and allows them to express their thoughts, needs, and feelings, which can reduce frustration and improve their ability to interact.

### **2. Increased Independence:**

By making resources and information accessible by translating appointment material into easy read, along with using alternative communication methods (such as symbols, communication devices, or sign language) will allow patients to communicate more independently, without always relying on support workers, caregivers or others to interpret their needs.

### **3. Emotional Expression:**

For individuals who have difficulty expressing their emotions verbally, AIS can provide a way to convey feelings of happiness, frustration, or distress, which is crucial for managing one's mental health and physical well-being.

### **4. Increased Community Engagement & Inclusion:**

Effective and accessible communication tools can facilitate greater community engagement especially amongst those with a lived experience, increase social interaction and inclusion in activities, which in turn, breaks down barriers that might otherwise isolate individuals who need to access vital health information and services.

### **5. Behavioural Improvement:**

Many behaviours that are seen in patients with autism or learning disabilities (e.g., aggression or withdrawal) can stem from the frustration of not being able to communicate effectively.

AIS can help reduce these behaviours by enabling more effective and inclusive communication.

## **6. Person-Centered Care:**

Providing the right AIS tools ensures that care is individualized to each patient's needs, allowing them to have more control over their daily life, choices, and overall experience.

This transformation to AIS can include clear, easy-to-understand information [like easy read], flexibility in appointment times, and providing additional support such as trained staff, advocacy services and or consulting local organisations that specialise in supporting people with a lived experience, like Generate Opportunities.

The process may also involve reasonable adjustments, such as modifying the physical environment [to suit], offering sensory-friendly options, or using alternative methods of communication, such as visual aids, easy read resources and or sign language interpreters.

These adjustments not only enhance accessibility but also promote equity by addressing the health inequalities that exist for people with learning disabilities and autism, ensuring they receive the same level of information, care, attention, treatment and overall experience as those without such conditions.

By ensuring that the cervical screening appointment process is made and remains accessible to all, we can reduce the risk of under-screening in vulnerable populations, which can lead to undiagnosed conditions and or delayed diagnoses.

In turn, this would contribute to better health outcomes, increased engagement with healthcare services, and a reduction in health disparities for individuals with learning disabilities and/or autism.

Ultimately, transforming the current cervical screening appointment process amongst Wandsworth GP Federation surgeries into a more accessible, inclusive and supportive experience, based on AIS, is a key to advancing health equity and improving the overall health and well-being of those with a lived experience of learning disabilities and or autism.

In addition, Involving support workers, care providers, guardians, appointees, and family members in the cervical screening appointment and procedure process, for patients with learning disabilities and/or autism, is crucial to ensuring that these individuals receive the necessary support and care in an environment that is both safe and respectful of their needs.

There are several key reasons why involving all these people, within the patient's family, care and support network is essential:



### Communication and Understanding:

Support workers, family members, and guardians are often familiar with the individual's communication style and can act as advocates, ensuring that the healthcare provider understands the patient's preferences, triggers, or specific needs.

This can significantly improve the effectiveness of the cervical screening appointment process by facilitating clearer communication and reducing anxiety, whilst improving patient's understanding of medical procedures, ability to express discomfort and or communicate their needs

### Emotional Support and Comfort:

The process of cervical screening can be stressful and anxiety-inducing for anyone, let alone a person with a lived experience. Having trusted individuals present during the appointment can offer emotional reassurance, alleviate fear, and help manage stress.

This comfort and support can increase the likelihood of the patient attending the screening and feeling more at ease throughout the procedure.

### Personalized Care Plans:

Each patient with learning disabilities or autism is unique, and a one-size-fits-all approach may not be effective in ensuring their comfort or compliance.

Therefore, support workers and family members who know the patient's routines, preferences, and sensory sensitivities can help tailor the screening experience.

This may involve making reasonable adjustments, such as scheduling appointments during quieter hours, using specific language or methods of communication, or ensuring the environment is familiar and sensory-friendly to prevent overwhelming stimuli.

### Ensuring Consent and Understanding:

For patients with learning disabilities or autism, understanding the purpose and importance of cervical screening may be more challenging.

Guardians, appointees, or family members can help explain the process in a way that aligns with the patient's level of understanding, and they can provide informed consent on behalf of the individual if necessary.

Their involvement in the decision-making process also ensures that the patient's rights and autonomy are respected to the fullest extent possible.

### Increased Attendance and Compliance:

Research has shown that individuals with learning disabilities and autism are less likely to attend cervical screening appointments without appropriate support.

Therefore, involving family members, care providers, or support workers in the process can encourage attendance and compliance. These individuals can help with reminders, transportation, and any additional preparation needed for the appointment, ensuring that the patient follows through on necessary healthcare.

#### *Safeguarding and Advocacy:*

Support workers, guardians, and family members can also play an important role in safeguarding patients during the cervical screening process.

They can advocate for the patient's dignity, comfort, and emotional well-being, ensuring that the procedure is carried out in a manner that prioritizes the individual's rights and respects their autonomy.

If the patient feels uncomfortable or unable to consent, their appointed advocate can speak up on their behalf, ensuring that their needs are met throughout the process.

#### *Holistic Care Approach:*

Healthcare for patients with learning disabilities and autism should be person-centered, addressing not only the physical health needs but also the emotional, psychological, and social aspects of care.

By involving those closest to the patient, including support workers and family members, the healthcare staff can take a more holistic approach to care, ensuring that the individual's health needs are met in a way that respects their choices and overall well-being.

#### *Long-term Health and Well-being:*

Involving the patient's support network can have a lasting impact on the individual's health outcomes, whilst it can also contribute to the development of a trusting relationship between healthcare providers and patients, which is critical for ongoing medical care.

By adopting the AIS approach and making the cervical screening process accessible and supportive, it fosters a positive experience with healthcare services, which can have long-term benefits for the individual's health and well-being.

Therefore, the involvement of support workers, care providers, guardians, appointees, and family members in the cervical screening process for patients with learning disabilities and autism is essential for providing compassionate, individualized care.

It ensures that the patient feels supported, understood, and respected, while also facilitating better communication, improving attendance, and enhancing the overall quality of healthcare delivery.

This approach not only helps to make the screening process more manageable and comfortable but also supports the patient's long-term health and well-being.

In summary, AIS offers patients with learning disabilities and autism a voice, promoting communication, independence, and social integration, which are fundamental aspects of their quality of life