

# Improving Access to Bowel Cancer Screening for Individuals with Learning Disabilities and Autism



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# Introduction

The Learning Disabilities and Autism Focus Group – Bowel Cancer Screening, held on 29th January 2025, was aimed at addressing the specific challenges faced by individuals with learning disabilities (LD) and autism in accessing bowel cancer screening services. The session included educational workshops about bowel health, cancer risk factors, and the importance of early screening. A key focus was understanding how individuals with LD experience barriers in healthcare, especially related to bowel cancer screening and overall medical support.

## Methodology

The focus group consisted of individuals with learning disabilities and autism, who participated in discussions about their experiences with healthcare access, particularly related to bowel cancer screening. Participants were encouraged to share their personal stories and challenges regarding GP services, medical communication, and the bowel cancer screening process. The group was also presented with educational materials and participated in interactive discussions aimed at identifying areas for improvement in healthcare services.

# Key Findings

## **Challenges in Accessing GP Services**

Participants expressed frustration with long wait times to see GPs and reported difficulties in having their symptoms taken seriously. Many felt that their concerns were dismissed by healthcare providers, which created significant barriers to accessing timely and appropriate care.

## **Communication Gaps Between Healthcare Providers**

There was a recurring issue with the lack of communication between psychiatrists and GPs, leading to fragmented patient care. Participants noted that relevant medical information was often not shared between different healthcare professionals, leaving gaps in their care plans.

## **Barriers in the Bowel Cancer Screening Process**

The design of bowel cancer screening kits posed significant difficulties, with many individuals finding it challenging to collect stool samples due to small spaces and narrow openings. There was also confusion around the difference between bowel cancer screening kits and COVID-19 test kits, which led to misunderstandings. Additionally, language barriers exacerbated difficulties in understanding the instructions for using the kits.

## **Lack of Awareness and Education**

A significant number of participants were unaware of bowel cancer and its associated risks and symptoms. There was also limited understanding of the bowel cancer screening process, and some participants mentioned that family members had undergone screening without fully understanding the test's purpose.

## **Impact of Healthcare Staff Attitudes**

Participants felt that some healthcare professionals lacked empathy when dealing with individuals with learning disabilities and co-morbidities. This created a perception that the healthcare system was unwelcoming, with staff attitudes contributing to the stress and confusion faced by patients.

## **The Health Passport**

Many participants were unaware of the Health Passport, which is a tool designed to assist healthcare providers in understanding the specific needs of individuals with learning disabilities. This lack of awareness suggests a need for better dissemination of information about this tool.

# Key Achievements and Positive Outcomes

- Participants appreciated the educational workshops, which provided valuable information about bowel cancer and the screening process.
- The concept of an easy-read email explaining the screening process was highly praised as an effective tool to improve understanding.
- There was strong support for a video guide on interpreting test results, specifically tailored for individuals with learning disabilities.
- The proposal to train carers and support workers to assist with medical communication was recognised as a crucial solution to improving healthcare access.
- Participants emphasised the importance of better public awareness campaigns, with suggestions for TV and online resources, as well as GP surgery-based materials.



# Challenges and Areas for Improvement

- Long wait times and dismissive attitudes at GP surgeries were significant barriers to care.
- Lack of communication between psychiatrists and GPs resulted in incomplete medical records and mismanagement of care.
- Confidentiality policies prevented carers from effectively advocating for patients, especially during out-of-hours services.
- Issues with bowel cancer screening kits, including difficulties with sample collection and confusion with COVID-19 tests, were prevalent.
- Language barriers made it challenging for some participants to understand medical instructions and advice.
- Lack of awareness about bowel cancer and the Health Passport left many patients and families uninformed about essential health issues.
- Negative staff attitudes and insufficient training for handling learning disability patients made healthcare experiences stressful.

# Conclusion & Recommendations

The focus group highlighted significant challenges in accessing healthcare, particularly bowel cancer screening, for individuals with learning disabilities. Key issues included poor communication between healthcare providers, inaccessible screening kits, and a general lack of awareness surrounding bowel cancer.

## **Improved Staff Training**

Healthcare providers should undergo training to improve their understanding of learning disabilities and autism, particularly in communication techniques.

## **Redesign of Bowel Cancer Screening Kits**

Screening kits should be redesigned to make them more accessible, with larger sample collection areas and clearer instructions.

## **Greater Public Awareness**

A public education campaign, including easy-read guides and video content, should be launched to raise awareness about bowel cancer and the screening process



## **Empower Carers**

Carers and support workers should be allowed to assist with medical communications and the completion of screening tests, ensuring patients can access the care they need.

## **Better Integration of Services**

Steps should be taken to improve communication between psychiatrists, GPs, and other healthcare providers to ensure comprehensive care for individuals with learning disabilities.

## **Next Steps**

Moving forward, collaboration between healthcare providers, policymakers, and advocacy groups will be crucial to ensuring the effective implementation of the recommendations. Ongoing engagement with the learning disabilities community will also help to identify additional barriers and refine the strategies for improving healthcare access and outcomes.

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