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Engaging with Disabled People on Experiences of - and Barriers to - Accessing NHS Screening Programmes



Final Project Report

October 2019



**Manchester Health & Care
Commissioning**

A partnership between
Manchester City Council
and NHS Manchester CCG



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This is the final report from this engagement work. It covers key points and themes raised by disabled people via interviews, group discussions and surveys. Our report makes recommendations for inclusive good practice based on disabled people’s lived experience of NHS screening programmes, the barriers they face to accessing them and their suggestions for improvement in Manchester.



Foreword

As I write this, another high profile story has hit the media, sharing the impact of inaccessible healthcare on a disabled woman who was unable to access a colposcopy for 6 months to determine whether she has cervical cancer.

We clearly still have lots to learn collectively about how we can do screening better.

‘Appropriate and accessible health and social care provision’ is rightly listed one of the 12 basic rights of independent living. These are the things which disabled people require to live in equity with non-disabled people so that we have the same choice and control over our lives. The strong evidence from the disabled people who took part in this project shows that there is still some way to go before there is full equality of access to NHS screening programmes, both locally and further afield.

However, this is also a great opportunity for Manchester to lead the way in offering a fully inclusive, barrier free range of screening programmes, which ensure that no-one is unable to access potentially life-saving or life-changing screening. We hope that Manchester’s lead on this will also encourage other areas of the country to level up to our great practice.

There are a number of quick wins which can be implemented swiftly, others will require some patience. The experiences of disabled people also show how critical the importance is of enforcing both the reasonable adjustment duty of the Equality Act and the full implementation of the Accessible Information Standard.

This work is complementary to other initiatives and research, both local and national. For example the excellent work of Jo’s Trust in highlighting entrenched barriers to cervical screening – nationally for disabled people and locally for BAME communities - and the new Answer Cancer programme operating across Greater Manchester to ensure equality of access to cancer related screening,

We look forward to sharing Manchester’s ground breaking practice in this field.

Michele Scattergood, Chief Executive Breakthrough UK



Project Outline

Tackling health inequalities is a key priority for Manchester Health and Care Commissioning (MHCC). The uptake of NHS screening amongst disabled people in Manchester is the lowest in Greater Manchester and more needs to be understood about the reasons for this. Nationally, Public Health England are also addressing the low health screening uptake by some groups of disabled people, as well as low uptake amongst members of some BAME groups and of people living in deprived areas.

MHCC wished to understand further what the experiences, issues and barriers are for local disabled people across the whole life course when accessing local NHS screening programmes.

Breakthrough UK was commissioned to conduct a number of engagement conversations with disabled people* across Manchester to explore this. Breakthrough also ran a survey to further gather disabled people's experiences and advice on removing barriers to accessing screening programmes.

The types of NHS screening considered in this engagement were:

- Screening in pregnancy
- Cervical screening
- Breast screening
- Bowel cancer screening
- Eye Screening for people with Diabetes
- Abdominal Aortic Aneurysm (AAA) screening

*Disabled people includes people of all impairments and self-definition using the [Social Model of Disability](#).

The engagement took place between summer 2018 and September 2019.

Breakthrough is a Manchester based disabled people's organisation. We are led by disabled people, and we support other disabled people to work and live independently.

Breakthrough works to make positive changes at an individual, regional and national level. We provide disabled people with person centred



support to develop their independence and gain access to training and employment. We advise employers, policy makers and other organisations to understand and remove barriers that disadvantage disabled people.

Our aim is to bring about a society where disabled people can participate fully in all areas of life.

At the core of including disabled people as full and equal citizens in society is the Social Model of Disability. The Social Model of Disability came about as Disabled People and our organisations challenged the traditional view that we are disabled by their individual conditions of mind, body or senses (impairments). The idea originally came from a group of people with physical impairments in the 1970's and was named by the late Mike Oliver in 1983. Subsequently disabled people with other impairments have found this model to be a useful way to describe their exclusion and the solutions to this. In the Social Model:

- Disability is the loss, limitation or denial of rights by society, to a point where someone is restricted or completely excluded
- Disability is an experience, not a medical condition
- A Disabled Person has an impairment, not a disability

This means that the focus of work shifts towards identifying and removing disabling barriers. Discrimination is addressed by examining policies, systems and the physical environment.

As a disabled people's organisation working within the Social Model of Disability, we believe that adequate, personalised and holistic health services are necessary to preserve the dignity, independence and human rights of all participants. Disabled people also want to be involved in the design, delivery and evaluation of services.

Methods

We engaged with disabled people about access to screening through:

- Discussions with Breakthrough UK clients
- One to one interviews



Breakthrough UK – Accessibility of NHS Screening

- Focus groups with existing organisations of disabled people and impairment specific groups across the city, at different times of day.
- Drop-in conversations at public places and events taking place across the city. This proved very difficult in practice because of the sensitive nature of the subject matter.
- Virtual engagement and awareness raising of the screening programmes for those who found it accessible.
- Surveys cascaded through social media and community organisations
- Meetings which were specific to the type of screening because of the sensitive nature of some of the programmes.

We held group and individual discussions with **107** disabled people at:

- Abraham Moss Centre, Crumpsall
- Windrush Millennium Centre, Moss Side
- Stroke Café Harpurhey (Manchester Youth Zone)
- Stroke Café Gorton
- Stroke Café Northenden
- Breakthrough Peer Group
- Members of the Greater Manchester Coalition of Disabled People (GMCDP)
- Manchester People First
- Manchester Deaf Centre 50+ Group
- Via surveys (47 people in total)

Some groups also included family members, Personal Assistants (PAs), interpreters, advocates and/or organisational staff (not included in totals). Overall, approximately 70% of participants were from Manchester.

In practice, most of the conversations operated by 'piggybacking' onto existing established group meetings already taking place, rather than through stand alone meetings. The latter were not well attended.



Barriers to engagement

This was a challenging piece of work.

Our initial approach was to arrange widely advertised single-issue sessions for people who were eligible for a specific type of screening so that people could talk freely and tailored information could be provided. This was also done so that the sessions were inclusive of people of all genders and none.

However, these stand alone sessions were poorly attended and we found that people were more prepared to engage anonymously, or via broader sessions with people they knew. We also attempted conversations at public events, but this was quickly found to be inappropriate because of the subject matter and lack of privacy, so were discontinued.

Discussions at broader, mixed sessions inevitably were less detailed on specifics of sensitive and intimate screening experiences and focused more on the wider barriers to accessing health screening. More detailed feedback came via surveys and one to one interviews.

Many groups in the city were contacted and expressed enthusiasm for the work, but this did not readily translate into participants. Members of one contacted group fed back to us that “we don’t want to talk about cancer at our coffee morning!”.



Conversation format and aims:

- Provide accessible information on the screening programmes available, and how to access them.
- Gather disabled people’s lived experience of accessing health screening.
- Seek to understand the barriers to accessing screening programmes - and what works well.
- Understand the reasons why disabled people might choose not to go to screening.
- Develop and understand the particular information and communication requirements of disabled people around health screening, and how the Accessible Information Standard is working in practice.
- Try to understand the cultural and other intersectional factors which may also influence disabled people’s uptake and experience of screening.
- Seek ideas, proposals and enablers for ‘accessible’ screening programmes across the six screening areas.

Engagement approach

Breakthrough made contact with a range of organisations across the city. In addition to disabled people working with us, disabled people’s organisations and impairment specific groups we also contacted women’s groups, BAME groups, groups working with refugees and asylum seekers, LGBTQIA+ groups, older people’s groups, contacts within the Our Manchester Disability Plan Health and Social Care Workstream and community groups with a health and wellbeing focus.

We also liaised with organisations involved in promoting screening locally – e.g. Jo’s Cervical Cancer Trust, Answer Cancer and Manchester University NHS Foundation Trust.

This was backed up by an ongoing social media campaign.

Some survey respondents referred to screening which had taken place outside of Manchester, but is included here where it reinforces points made by local participants, or gives examples of good practice.



Summary of Key Themes Emerging from the Engagement Work

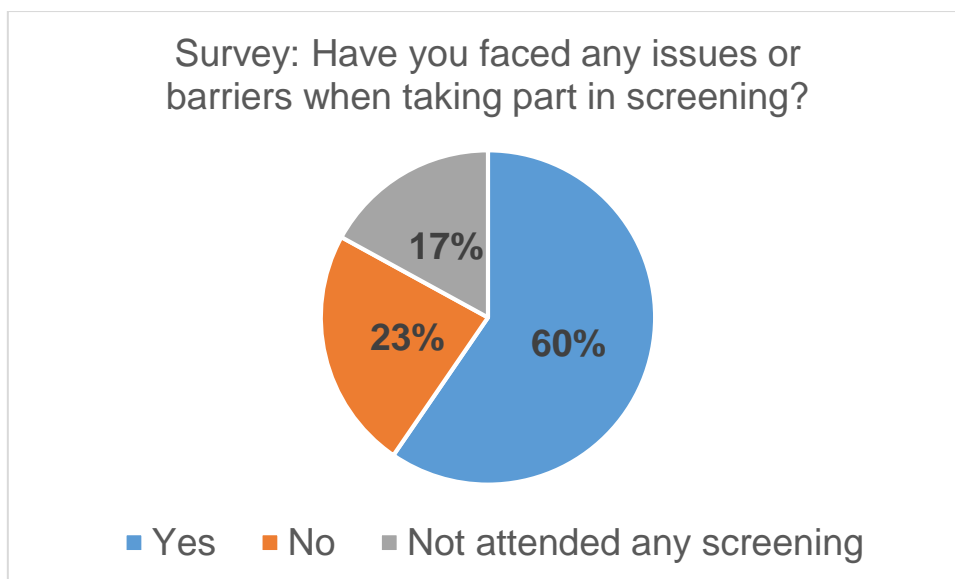
Health inequalities often start early in life for disabled people. Difficulties in getting effective and appropriate healthcare when it is needed can make a person's health worse and affect their quality of life. Broad barriers resulting in health inequalities experienced by disabled people across the population include:

- Limited availability of accessible services
- Access barriers
- Inadequate skills and knowledge of health workers
- Poverty
- Inaccessible transport
- Poor communication
- Negative attitudes
- Diagnostic overshadowing and under-shadowing

Across Britain, disabled adults report much lower rates of good health overall compared with non-disabled adults. A report from the Equality and Human Rights Commission ('Being disabled in Britain 2016: A journey less equal') states that:

“Disabled people are more likely to experience health inequalities and major health conditions, and are likely to die younger than other people. The extent of these health inequalities is difficult to assess because of limited data on outcomes for disabled people collected by NHS providers and commissioners. Accessibility of services is problematic, and disabled people are less likely to report positive experiences in accessing healthcare services.”

Timely access to preventative screening is therefore essential to avoid compounding the health inequality already faced by disabled people.



Key issues raised by disabled people participating in this work were:

- The majority of disabled people who took part had faced barriers to accessing screening, or had not attended any.
- Lack of effective implementation of the [Accessible Information Standard](#) was a big problem, alongside inadequate sharing information of access and communication requirements across services. Many of the barriers described in this report would not have happened if information about people's access and communication requirements had been shared.
- Several participants were aware of the Accessible Information Standard and Equality Act, and didn't feel either were being implemented fully.
- Some people felt that they weren't asked access questions because their impairments were hidden, so assumptions were made which created problems for them further down the line.
- Attitudes and assumptions led to people not getting tested, or being encouraged not to have tests. These attitudes and assumptions can come from family members and support workers as well as from health professionals.
- Inaccessible mainstream tests were a big issue, coupled with lack of easily available information on the accessible alternatives and how to get them.
- Overreliance on websites for information on screening, digital by default etc. NHS screening leaflets in different formats and print can



only be ordered in bulk by NHS organisations. Otherwise people require internet access.

- Poorly trained front line staff on helplines and reception using scripts and forms which do not include questions about access and communication requirements.
- Intersectional factors, for example language barriers, PTSD from abuse or trauma, caring responsibilities, gender role assumptions.
- The role and availability of support workers and Personal Assistants (PAs) was a recurring theme, with providers being asked to ensure that supporters are accommodated and welcomed. Some people were unable to attend screening because they didn't have this support in place, or because their support providers were unwilling or not funded to assist them.
- Potentially poor access was the biggest deterrent to people attending appointments, followed by difficulties getting an appointment, previous bad experience and transport barriers.
- Other key reasons for non-attendance were fear, and lack of accessible home testing options coupled with rising numbers of disabled people effectively isolated at home due to barriers leaving the house and impairment related issues.

Findings

For each section under the headings below we have listed the barriers described along with enablers/solutions that would remove or prevent these.

At the end of the report is a list of recommendations from participants, followed a list of recommendations for action listed under the 12 pillars of independent living. We suggest that these are followed up in a report to the Our Manchester Disability Plan Health and Social Care Reference Group by May 2020.

12 Pillars / Basic Rights of Independent Living

These basic rights cover the minimum that disabled people have identified that we require to have choice and control over living our lives:

- Appropriate and Accessible Information
- An adequate income



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- Appropriate and accessible health and social care provisions
- A fully-accessible transport system
- Full access to the environment
- Adequate provision of technical aids and equipment
- Availability of accessible and adapted housing
- Adequate provision of personal assistance
- Availability of inclusive education and training
- Equal opportunities for employment
- Availability of independent advocacy and self- advocacy
- Availability of peer counselling (peer support)



Breast Screening

For Breast Screening, the most commonly reported barriers raised by participants were around the inflexibility and inaccessibility of equipment offered at some screenings, poor information on options, and access requirements not being communicated or acted upon. Enablers being the opposite of these – accessible and well publicised centres catering for a range of access requirements, great communication with a range of contact options, equipment that can be tailored to individual's requirements and a process that passes people's access requirements on seamlessly.

Barrier – X-ray machine not accessible

“I was unable to have mammogram as can't sit up long enough.”

Enablers – Information about accessing alternative methods of having the test if possible e.g. at more accessible units. Good communication with individual about what would be accessible to them. Advice on mitigating risks if it is really the case that no current screening options are accessible. Consideration of viability of alternative testing options, e.g. ultrasound.

Barrier – poor communication and lack of adjustments

“Breast screening: failure to have the access adjustments in place when I turned up for my appointment; lack of consideration as to how and where I could, and couldn't, move parts of my body e.g. pushed my arm into the position they thought necessary without checking/asking first = pain then and impact lasted 2 days.”

Enablers – Always check with the person about what works for them before taking any action. For example:

“At the last breast screening the staff were much more accommodating and didn't 'pull' my body into the position they wanted it without checking whether I would be able to do that/be caused unnecessary pain.”

Barrier – gender specific requests denied

“My initial screening was with a male consultant - when I said I only wanted to see a female they said I could rebook but would have to wait. As I was already really anxious and didn't want to wait I had to let the male consultant examine me which was awful.”



Enabler – offer preferred gender wherever possible for sensitive screening types

Enablers - diagnosis and treatment:

“Mammogram screening picked up that I had breast cancer early so it was effectively dealt with”

“Usually positive, last screening was for breast cancer”

Enabler – adjustable equipment:

“Excellent practice at hospital - well trained staff and height adjustable chairs to make mammogram easier for wheelchair users- you don't want to fall if your breast is clamped for screening!!”

Barrier – poor communication and duplication. Potential discrimination.

“Breast cancer runs in my family. Mum, aunt and Nana had it. Nana died of it. They leave it up to me to find out, they don't offer services. I want to be listened to and not shoved to one side and not taken seriously. My non-disabled sister has been getting a mammogram every year since she was 30. I have been told I have to wait until I'm 40 to have one. We have different GPs but live in the same area and have the same level of risk. I have now got a referral to the family history team. They are looking at the family history from scratch, even though my sister volunteered to share the info they already have for her. They are not joining up me and my sister. It feels like a barrier. I don't want to wait until I'm 40. I'm very anxious. It's hard for me to check my breasts. Can't someone help me to check my breasts?”

Enablers – Good communication. Sharing information where consent is given. Provision of information in clear English which meets people's known access requirements. Extra time to talk through concerns and options. Accessible explanation of clinical decisions re testing younger women. Information about what to look out for when self-checking is not accessible.

Barrier – steps and poor communication

“Breast screening in mobile units, often with stairs & no previous warning.”

Enablers - Access information provided about all testing centres. Easily available information about accessible testing units and how to get an appointment there. Ensuring that the Accessible Information Standard



works well enough to flag up people's access requirements in the call up process so they are not referred to an inaccessible testing unit.

Barrier – lack of options when can't attend external appointments

“Too ill to attend post cancer mammogram.”

Enabler - Flexible and widely promoted options to rearrange appointments to allow for health or impairment related gaps. Follow up to ensure people are not lost in the system.

Barrier – delays in getting results

One person at a focus group said she had to wait for 5 months to get the results from her breast screening at Wythenshawe.

A participant at another focus group went for breast screening and had not had any results. She rang her doctor 2 weeks before the session and still had not heard anything. This was worrying her.

Enabler – results sent to person in their preferred format within standard timescales.

Barrier – Standard equipment not designed to be used seated.

“Difficulty with standing for mammogram. Was able to sit between screenings.”

Enablers – Machines which allow for seated screening. Better promotion of accessible screening centres where these are available. Screening centres welcome discussion beforehand about how a person's access requirements can be met whilst also taking an effective image.

Barriers – no support, no at home testing options, perception of test

“I haven't had breast screening due to not being able to get out. And I don't have anyone to support me. I don't want my boob squashed to smithereens and they didn't used to have these things in the past so why now?”

Enablers – Follow up assistance and information offered to people who have never attended screening.

Barrier – Poor communication

“Breast screening refused because my wife is confined to a wheelchair”



Enablers – Widely promote accessible testing centres and ensure that people know that they can be in touch in advance to check access.

Barrier – poor access, insufficient parking, poor information.

“Screening was in a prefab, up steps, at the back of the hospital. All parking was staff only. Paid parking was at the front - walk from there to hospital, through hospital, out back - maybe 15 minutes for a healthy person, 30 minutes+ for me.”

Enablers – Clear access information available on each testing centre in a range of formats. Accessible parking available at all sites.

Barriers – Poor access and poor information.

“There were steps up to the breast screening mobile unit. I asked about accessibility & was told that wheelchair users or women with mobility impairments would need to have their screening at the hospital.”

“Ghastly car park mobile vans, external creaky lifts and tiny screening rooms.”

Enablers - Clear access information available on each testing centre in a range of formats. Widely promote accessible testing centres.

Barriers – Lack of easy read information and map. Reported inappropriate behaviour.

A participant who requires easy read information said she didn't know where she was going on the day of her mammogram. The letter didn't say where it would be on the site. She didn't know it would be in the van outside and she spent a lot of time trying to find the right place when she got to the hospital.

She was also not happy about the way she was touched at the appointment - she said there was a handprint on her breast that lasted all day. She said they did not seem interested in helping when she told their reception about this. She then complained about the member of staff and “they made her stop working”.

Enablers – Invitation letter send in appropriate accessible format with a picture based map. Information about the process and what to expect provided in a clear way. People treated with respect and dignity. Disability Equality Training.



The table below is a contribution from a participant based on their own experience of breast screening, much of which tallies with the barriers and enablers identified above and throughout this report.

“Breast screening (and bra fitting) some of this applies to non-disabled women too. Also, some of it applies to other medical interventions:

Good Practice - Enablers	Poor Practice
Checking person’s preferred method of communication i.e. text, email, telephone call, use of an advocate or interpreter at the point of referral – this can easily be added to patient notes on NHS database	Not asking at all or, asking at first appointment when person has arrived and maybe feeling nervous.
Sending out information about what to expect – make this available in different languages and use individual’s preferred communication method as above.	Handing out a leaflet on arrival or giving a verbal explanation that may be overwhelming.
Having designated staff wearing badges that say what their expertise is like Dementia aware, able to use BSL (Marks & Spencer do this for bra fitting staff). At Harry Potter World they have staff trained in Autism who will lie on the floor or, do whatever is needed to help).	Having limited disability awareness training and not having people who know what to do to help those with certain conditions e.g. anxiety, Poor mobility.
Treating people as individuals - e.g. all deaf people are different.	Assuming that all people with the same condition have the same needs
ASK the person or their helper what assistance they need and prefer	Not asking and not listening
DIGNITY & RESPECT always	Remembering that this may be routine to the practitioner, but it is a big deal for the patient.
Check if individual prefers to see a man or a woman	Not checking if they prefer to see a man or, a woman



Offer assistance for undressing	Do not put person in a small cubicle alone and expect them to undress and put on a back-fastening gown unaided
Offer scans in accessible, clearly signed buildings, have free wheel chairs at entrances and volunteers on hand to push or help visually impaired people etc from the outset.	Do not offer scans in large vehicles in random car parks like pubs, shopping centres. The creaky outside lifts are unsafe and uncomfortable and often the changing rooms are too small
Have adequate, free, proximate parking	Do not charge for parking and ensure that there are enough spaces.
Welcome the patient and ask their preferred name, check their details in a confidential way.	Ask people to verify personal details in front of a queue of others.
Give an indication of approx. waiting times in large letters or verbally if required	Leave people waiting with no clue if they have time to go to the toilet etc
Courtesy counts! 'Hello, I'm Dr Jane Brown, this is Nurse John Smith, may I call you Jan or, do you prefer Mrs Mortimer?' Acknowledge the person who is with them.	Don't disrespect! 'Hello Jan, I'm Dr Brown and this is my Nurse'
Read notes before patient is seen	Sit reading notes whilst ignoring patient.
Ask permission before you do anything.	Just start touching patient
Offer help to get on/off couch, chair or, scanner	Let patient struggle.
Warm your hands	Cold hands can be especially painful for some conditions like arthritis.
Use a height adjusting wheelchair to get patient close to mammogram scanner – asking a nurse to gently position the breast and arms to the required position.	Force patient to stand – falling with one breast in what feels like a large tight waffle maker is very, very painful



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Listen to patient's breathing and if they make any sounds, pause if they are in discomfort, offer reassurance, explain how long it will take, pause if needs be.	Carry on regardless of how patient might feel.
Offer help when patient needs to get dressed again	Leave patient to struggle
Explain exactly what will happen next and check if patient has any questions	Just say that you will write to G.P.
If breast ultra sound is required, try to do it on same day. Check what is most comfortable for patient e.g. Sitting up, lying down, pillow or not.	Do ultra sound in the same position for all patients
Check if patient has any questions	Don't check if patient has questions.
Say something kind as they leave	Ignore patient once exams are done"



Cervical Screening

The key issues raised here related to flexibility to respond to people's individual requirements - taking a person-centred approach, using the right, accessible equipment, and having provision for home testing if possible.

Barrier – insensitivity to people's preferences and impact of trauma

“For some things like cervical screening, where the patient has severe PTSD around that area, GPs should not keep pressuring the patient. I have the right to refuse treatment that I know for a fact I cannot cope with, and shouldn't be bullied into it.”

Enablers – Respect people's stated choices not to have screening. Consider alternatives to tests in a clinical setting.

Barriers – Inflexibility of attitude and inaccessible approach

“Cervical screening. The doctor refused to change the equipment and methods, despite me trying to advocate and explain how I had a successful screening (I go on my side and use different equipment) Dr was insistent that they knew better "Other people with CP can open their legs." Eventually she used the method I suggested but by that point I was very distressed and results were inconclusive. A subsequent screening was good as people were careful to listen and take my lead. However this would not have been needed if people had listened at the original appointment.”

“Cervical: the tools used were inappropriate for how my vagina and cervix are actually positioned and the width of instrument that was needed to do the job effectively. Due to my impairments it is no longer possible to get in far enough to take a sample (whole of that bit of my body has collapsed/folded on itself, due to nerve damage). I'm also very narrow in that regard so a. the standard width is too big, causing me immense pain, and b. the narrow option is for very young adults and does not reach far enough, I was told. Also concerning is that no-one even suggested the narrower tool until the last screening I attended (I am now 60!) so I've had several decades of people causing great pain without succeeding in taking a sample.”

Enablers – Listening and following the person's lead about what will work for them. Using a wider range of equipment and promoting centres where this is available if not possible at each GP surgery.



Barrier - Lack of home testing option

“Too ill to attend GP for cervical screen.”

“Not being able to access screening when housebound particularly cervical smears”

“I’m currently overdue one because I’m mostly housebound and going for the test can take a lot out of me. Home visits would be useful.”

Enabler – consider whether DIY smear tests or home visits could be an option for some people who face significant barriers to leaving the house.

Barrier – Inflexible systems

“Cervical screening- trying to get to an appointment. Having to wait until I have a small window of strength to be upright, in the car etc”

Enablers – home testing options or flexible appointment slots for smear tests available in different centres across the city.

Enabler – positive outcome

“Before I became disabled I had unhealthy cells removed that was found in routine smears.”

Barrier – lack of alternative approaches promoted or known of

“I’ve declined some screening mainly because of my back issues – they want you to lie on a bed e.g. smear. I can’t do it. They don’t offer an alternative. I’ve asked them but they don’t give a different option. I’ve not had a cervical smear for 20 years because first I couldn’t get out – people had to come to me e.g. chiropody. Now I can go out I have some caring people to assist and give me more time at certain appointments. But I can’t lie down for a smear.!

Enablers – awareness of accessible options for people who cannot access a standard test e.g. referral to hospital or accessible centre.

Barriers – impairment related assumptions, attitudes, infantilisation

“I almost didn’t have one until they realised I was in a relationship. Was that because I have learning difficulties?”

At one session, a woman said that she had been refused a smear test because “you did not bring a carer with you”.



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“My Mum told me not to bother with a smear test and that I shouldn’t have to be put through all that on top of everything else.”

“They did too many intimate tests at the GP. They wanted to do four tests, I just had two in the end but I only wanted them to test for the thing I came in with. I wasn’t comfortable and I couldn’t get anyone to go in with me at the time. I just wanted them to do the one test and then make a different appointment for the others. I had a smear test in the past and it was painful. I don’t want to go again because of what happened at the GP, I was not in control.”

Enablers – Listening. Disability equality action training for frontline staff. More easy read info e.g. the popular booklet from Jo’s Trust circulated through community organisations so people can make informed decisions about their health without family influence.



Bowel Cancer Screening

Some people said that they experienced no issues with bowel screening:

“Bowel cancer was ok as just posted off stool sample.”

The main barriers raised for this type of screening were around the accessibility of the home testing kit (the now discontinued FOB kit), and the information accompanying it. Very few comments were received about scoping.

Implementation of the Accessible Information Standard is key here as staff sending kits out did not know what people’s access requirements for information were, or ask, or act on what they were told. This requires better training for the regional centre staff also so that they can ensure that people know that more accessible testing options such as pots and bowls can be made available to accompany the newer FIT kit, which still present barriers to many disabled people when collecting samples and putting them into the bottle.

Lack of assistance to complete the kit in any format was also a recurring theme, with reported refusals from some PAs and Support Workers to assist with this. This is an issue that may need to be addressed in contracting arrangements and support planning. People were not generally aware that a referral for endoscopy can be made if the kit is inaccessible in any form.

Barrier – standard kit not accessible

“Bowel cancer. As a wheelchair user I have no leg movement and little back balance so, although sitting on the toilet normally is fine, anything extra like taking a mid-stream urine sample or faeces sample is extremely awkward.”

“The bowel screening is the hardest, the container and the spatula is cardboard which bends. Not easy. I worked in pathology 11 years, the plastic containers and plastic spatula was easy to collect 3 days or 3 different faeces with. But not environmentally friendly. And costly. I have arthritis, hard to collect now.”

“Bowel cancer - testing kit was very hard for me to use because of my disability”

“Bowel cancer testing was difficult”



The lack of accessibility of the bowel screening kit was also raised by Stroke survivors. People said it is very difficult, if not impossible, to do with one arm, for example.

Enablers – provide information about accessible alternatives or additions to the kit – pots, bowls etc. Provide support for people to collect samples if they wish.

Barrier – information not accessible and alternatives not promoted

“Five of the attendees at one focus group had had the bowel cancer screening kit and only one had completed it. Reasons for this related more to embarrassment or not being able to follow the instructions with the kit (which are lengthy and complicated). One person said ‘If we could do it at the doctor’s I’d do it.’”

And at another: “They don’t send enough information on alternatives to the test and on the different formats available. The writing is too small and complicated. Therefore people don’t do the test.”

“September / October I received a notification about scoping in standard print – they didn’t know about my preferred format. In November I asked for an appointment (rang the North West/West Midlands Bowel Screening Centre) and told them my access requirements for large print information. They sent me out a letter in standard print. Then I said to them I needed large print and what font and they sent me the A5 colour booklet photocopied to A4 doubled. This was poor contrast and still wasn’t big enough. So I rang up and said I still can’t read this. They said well there’s nothing we can do, we can send you a DVD for people with learning difficulties. And that’s what they did.

So then they sent me the pack and it was a standard print leaflet for the enema. So my daughter ended up reading it out to me. And she said “Mum – TMI!” And even then I got the results in standard print.

So I have challenged them on this and RNIB are helping me with it. They are having conversations with them on their failure to provide accessible information that might end up in proceedings – breach of Equality Act and Accessible Information Standard.

I’ve got a friend and they failed to provide the information to her in Braille. And I know a number of people who haven’t done the test, they just literally shoved it to one side. One said “Oh I found the kit” That says it all.



There seems to be a huge variation between centres because as soon as this person in the North East told them they were blind, they sent them the pots instead. Apparently in the South they are good – someone I spoke with said they do x, y, and z and they are really good on access. You get a different experience. Pots are more accessible but then you've got issues about labelling. Do they give you sticky labels and do they have Braille on them? You should have your instructions in Braille / audio. But when you ring up the staff don't know, it feels like you're in a call centre. Unless they've come across it they haven't thought about it. It wasn't just a member of staff, he actually referred it to a team leader who then sent me the video out for people with learning difficulties.”

Enablers – enforce the Accessible Information Standard and additionally pass on details of people's access requirements for information. Ensure that all formats can be catered to, including Braille labelling. Provide training on disability equality to regional centre staff so that they provide people with appropriate formats.

Barrier – alternatives to using kit not promoted widely

“I am blind and live alone since my wife died in 2017. Prior to this she helped me with my bowel cancer kit which came in the post. I have grown up daughters but am too embarrassed to ask them to take a sample from my stool.”

Enabler – Promote support options for people who do not have anyone to assist them to do the kit.

Barrier – kit assumes people can access post

“Can't post back bowel screening test as house bound.”

Enabler – courier testing kits back for people who have identified that they face barriers to leaving the house and have no support

Barrier – Inaccessibility of kit and lack of promotion of alternatives

The lack of accessibility of the bowel screening kit was raised by Stroke survivors. People said it is very difficult, if not impossible, to do with one arm. Also that they don't send enough information on alternatives to the test and on the different formats available. The writing is too small and complicated. Therefore people don't do the test.

The information below came from a disabled person who does not have access to the internet:



Breakthrough UK – Accessibility of NHS Screening

“This is about the ‘shit kit’ for bowel cancer screening. It is not accessible to disabled people, including people with visual impairments like me.

They (NHS England) won’t deliver a commode for one person to use to do the test. They say it’s a ‘waste of money and resources’. The test has changed from 3 samples to one, but it’s still inaccessible.

I’ve got the backing of my GP practice. I’ve sent a letter to my MP. I’ve spoken with other people with visual impairments. District nurses won’t do it. Fortunately my PA doesn’t mind handling shit, so I can arrange something to do the kit.

I’ve been passing blood so I’m getting a colonoscopy anyway this time.

It should be as comfortable as possible for the person, never mind the cost. Say no to poo pots – what if someone’s PA won’t do it? The only potential way for most people who find the test inaccessible is a colonoscopy.

The GP wrote to me to say it’s available (the colonoscopy). The regional health authority, they ignore me.

Update on above:

I’ve now found out that anyone who receives an unusable home kit can request through their GP to go to hospital and they give a laxative, the nurses help and the next day they do an endoscopy. This is available to anyone who is a disabled person who does not find the test accessible.

If NHS England had not been so stupid they could have told me that. I found out through a booking clerk. The NHS didn’t tell me. GPs can refer people but they did not know either. They only referred me for an endoscopy because of other medical reasons. I’m amazed how many other practices don’t know. These organisations are so stupid, we have to work our guts out to find out these things.

Two years ago they had to deliver me a commode and I was lucky as my district nurse would help me do the kit.

NHS don’t communicate and they probably didn’t know I was a visually impaired person. They don’t share the information as they should under the Accessible Information Standard.

Further update:



NHS England are developing a new kit which would involve putting a cardboard bowl inside the loo, then dip a stick in the sample, then put it in a bottle and send it back. I suggested a commode to them as a bowl is not accessible to me.

I'd want to send the whole bowl back at the very least, as the stick/bottle won't be accessible. They are going to send me one of the new kits to try and I will report back. So I'm not going into hospital now.

I found this out through the NHS helpline North West & Midlands 0800 707 6060. I had to do a lot of ringing around to get that contact. NHS England will need to adapt the kit.

Feedback afterwards - The bowl placed in the toilet worked much better than the pots. It is much more practical. It was still difficult for me to get the sample into the bottle via the stick though. You need three hands.

People need to know that you can ring and ask for a more accessible kit, they don't offer it and GPs don't know about it."

Enablers – Disability Equality Training for all front line staff in the bowel cancer screening regional centre. Wide promotion of the range of accessible options available for completing the bowel screening test. Thorough implementation of the accessible information standard and sharing access requirements. Support options for completing the test. Ensure information is available in a range of formats and doesn't rely on internet access.



Abdominal Aortic Aneurysm Screening (AAA)

Fewer comments were received on this type of screening. The main barriers were around lack of information on the test itself and on next steps, and also about barriers related to getting the invite on the test sent out in the correct format – implementation of the AIS is again a factor here.

Barrier – lack of follow up information and support

“AAA screening was done on me and I was told I had an enlarged aneurism and then was just handed a two paged leaflet? Really bad I thought as I was given little or no other info by the screening nurses.

Then 12 months later I was screened again and told it had grown bigger. And just told I would be screened again in another 12 months. And just told I then might be referred to the hospital? Nothing as to what might help it, say slow this down or such. And strangely on the first screening I was prescribed Aspirin, then one the 3rd screening I was told ‘Well it’s now controversial about using Asprin for an AAA’. God they even confused me more. Really poor and shoddy practice and info given to me.

Lack of decent info as regards my AAA. Nurses seem too busy to sit and talk one’s AAA over with you, especially as to how or what might help slow its growth down or such? A poor show I feel as regards the AAA screening process”

Enablers – extra time to talk through concerns. Accessible information on next steps.

Barriers – not receiving accessible invitations or knowing about the test.

People with learning difficulties in the city are not being accessibly called up for (or getting) their AAA screening. There were several men over 65 at the People First focus group who should have had that check done and hadn’t had it yet.

The AAA screening was not widely known about at any focus groups. One person said that they don’t know whether they are screened for that or for different things. Their GP does an annual health MOT, with lots of things covered. They recommended that process.

Enablers – Targeted accessible publicity campaign about the test and what it is. Implementation of the accessible information standard.



Breakthrough UK – Accessibility of NHS Screening

Ensuring that PAs and support workers are accountable for ensuring that people receive invites and are supported to attend screening.



Screening in Pregnancy

Although seven survey respondents said that they had been tested in pregnancy, no barriers or enablers connected to this were highlighted by participants at all.

The following are the recommendations from a Breakthrough commissioned work from disabled academic and mother Alison Wilde. These are from her 2011 paper “Great Expectations”. Her paper specifically addresses the pressures that families / parents may face, during a pregnancy, to terminate a life due to either impairment of the un-born child (foetus) or the mother’s impairment. It details the author’s findings, highlights good practice and finally outlines recommendations for health professionals, policy makers, media practitioners and academics.

Although some of the recommendations for health professionals are outside of the remit of this work, all are reproduced here for completeness. Please contact Breakthrough for the full paper.

Recommendations for Health Professionals, Policy Makers, Media Practitioners and Academics:

1. Prenatal testing should be carried out in a sensitive manner; the parents should be given full information regarding risks and accuracy of testing, and should not feel pressured into undergoing tests. Counselling services should be available, and should be informed by a social model of disability perspective.
2. Advice to terminate, or suggestions that children should be removed from their parents, should be seen as a last resort, after all other options, including extended support to the parents, has been considered.
3. There should be shift in emphasis from a medical to social model of maternity. Women should have access to midwife-led care, including Birth Centres and home births if appropriate. Risk management should not be the most important element of obstetrics.
4. Health professionals should be trained in the social model of disability
5. A comparison with a supposed ‘normal’ mother or birth experience should be avoided; the aim should be for good enough parenting and the mother should be supported in, and validated, for achieving this.



6. The mother (and father) should be provided with appropriate information so that she can make informed choices. Peer support should be available wherever possible.

7. All health and social care providers should have a protocol on disabled mothers' potential needs, based on the social model, ensuring reasonable adjustments are anticipated and professionals are well-informed.

8. There should be access to necessary equipment and support, including access to personalised education classes.

9. Disabled parents should have access to a PA in order to support their childcaring role. The PA should be facilitated in assisting the mother in the birth process if appropriate.

10. There should be developed and integrated aftercare support services, and these should be linked to the maternity services.

11. There should be a reassessment of the term 'young carers', referring to children caring for their disabled parents. This should be in three parts: 1. increased support given to disabled parents to decrease expectations of support from children; 2. ongoing awareness campaigns to highlight problems facing children and offering support where appropriate; 3. focus on some of the positive sides to being involved in caring, emphasizing that it is ok for children to have some caring responsibilities, and highlighting that most disabled parents have positive relationships with their children.

Social care and health professionals should be made aware of the social model approach to the issue of 'young carers' and help families to build resiliency.

12. Particular care should be taken by the media when representing and reporting on 'young carers' with the emphasis shifted to the resiliency and value of disabled families, highlighting social barriers to inclusion.

13. There should be greater awareness in the media of how disabled women are negatively represented – this includes both fiction and journalism. It would entail using disabled writers, directors and producers, and maintaining a greater awareness of the reality of the lives of disabled people, and a committed and ongoing reluctance to resort to easy negative stereotypes.



Breakthrough UK – Accessibility of NHS Screening

14. There is a need for a greater number and range of disabled mothers in all forms of media.

15. More research should be carried out, from a disabled positive perspective, with the aim of objectively assessing the reality of disabled parents' lives, avoiding deficit model assumptions.



Eye Tests for People With Diabetes

The main barriers described by participants around the annual eye tests for people with diabetes were around lack of knowledge of the test and poor administration/communication. However, most people who had attended these tests found them well organised.

Three people with diabetes at one focus group had been for the annual eye screening. One was awaiting laser surgery as a result.

“Retina checking for Diabetes seems very well organised”

Barrier - Lack of accessible information, especially in BSL

The main screening type that members of Manchester Deaf Centre’s 50+ group did not know about was the annual eye test for people with diabetes. One man with diabetes said he had never had an eye test and did not know about it. Another person with diabetes agreed with this.

Enabler – Ensure that there is information available on eye screening in local dialect British Sign Language and in easy read.

Barrier – admin communication breakdown

“Diabetes eye screening – bad episode this year. The first time they didn’t tell me it was in a different place from the usual clinic. I queued and waited for an hour there past my appointment time and took a picture of myself as proof. The next time they made an appointment in this new suite. They told me the right suite but the wrong time. They’ve sent me another appointment now but I’ve got DNA on my file. I’ve had the DNA removed. It’s taken three visits. It puts a lot of onus on myself. I turned up twice but I got a DNA!”

Enabler – accurate communication.

Barrier – inaccessible equipment used resulted in relapse

“Need Stretcher ambulance, and equipment to be designed to accommodate patient lying down. Sitting up just a minute or so at ophthalmology appointment just long enough to look in each eye, caused severe relapse for several months.”

Enablers – availability of options to conduct eye tests from a reclining position. Knowledge of access requirements.



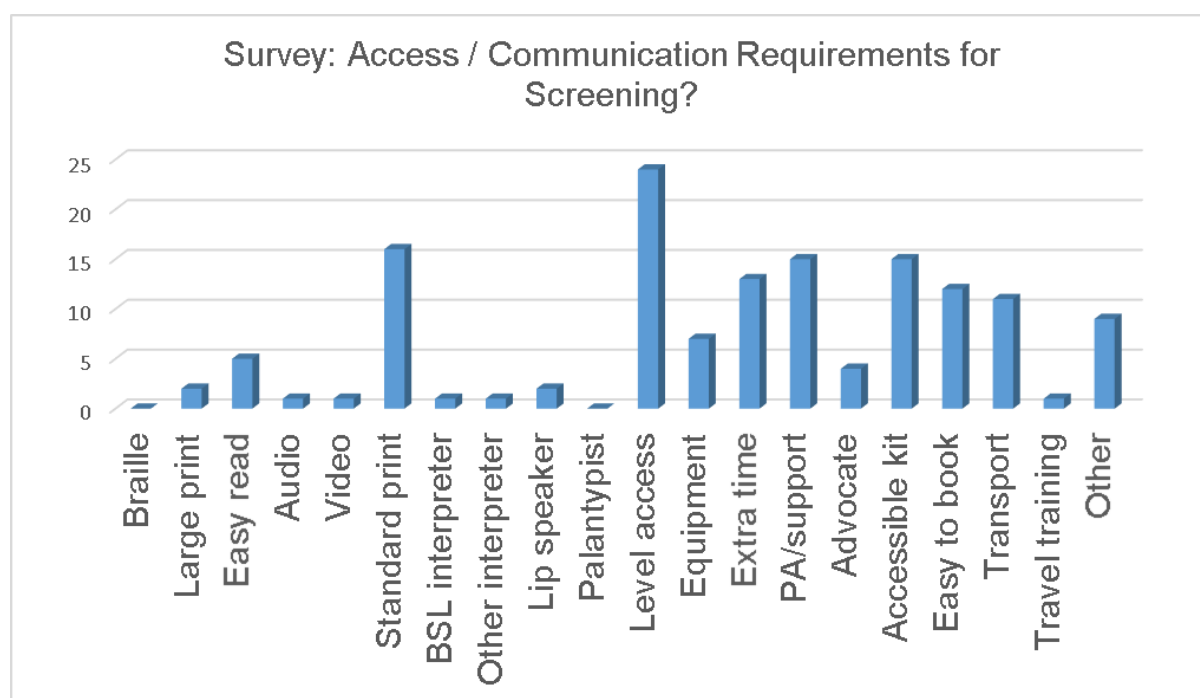
Access Requirements

This section covers some of the broader access requirements which are applicable across different screening types. At some mixed sessions, people talked more generally about what would make screening accessible to them, and this feedback is captured here also.

Survey responses were weighted towards access requirements which remove physical barriers, but a broader range of access requirements were discussed in the face to face meetings and interviews.

Many of the enablers below were participant’s feedback on what works for them. People generally commented positively about staff – their experience was let down by access barriers: “Staff lovely, accessibility is the problem despite the accessibility standard.”

The role of support workers and PAs was a recurring theme, with providers being asked to ensure that supporters are accommodated and welcomed. Some people were unable to attend because they didn’t have this support, or because their support providers were unwilling or not contracted to assist them.



Enabler – hoist and welcoming environment for PAs. Provision of accessible equipment and knowledge of adjustments required.

“I’m a wheelchair user & I need PA support & a hoist for any transfers”



It is important to note that several people who responded to the online survey said that they were unable to take part in screening programmes because they could not leave the house. At Breakthrough, we are aware of the huge issue of social isolation amongst disabled people, and offer community connecting services to support people to challenge the structural barriers they face to accessing the community. In addition to the health reasons described, restrictions to support packages mean that some disabled people do not have the holistic assistance available to leave home.

Barrier – lack of home visits/tests or the means to return kits

“Unable to take part in NHS screening programmes as I'm housebound and can't travel.”

“I am housebound and mostly bedbound. Ideally I require home visits. Visiting the doctors' surgery severely deteriorates my condition for days or weeks following.”

“I'm house bound, so it is rare that I am well enough to get to a surgery. I need home visits, otherwise my health is significantly affected.”

“Home visits on a bad day. I fluctuate so no knowing til the day how I will be.”

“Difficulty managing with immune issues (not wanting to be exposed to infectious illness).”

Enabler – Home appointments:

“Generally someone to come to my home or conduct appointments by phone (occasionally by Skype though I have difficulty with internet access). Please note that the internet is not always accessible to people with disabilities/health conditions - it can cause many problems.”

Enabler - Close, accessible parking

“Ability to park close enough that I can walk.”

Enabler – range of accessible formats and equipment on site

“Hearing loop”

“If no lip speaker then an induction loop that works, staff who can use a loop, the microphone, Filling forms in before screening in large print. Not too many words - easy read or similar.”



“Text message facility”

Enabler - Flexibility

“Mostly helpful at rearranging appointments etc. to make things more accessible.”

Barriers – difficulty getting to and navigating around venues:

“Locations that took triple the time by public transport than they would take by car.”

“Constant lack of or poor signage.”

Enablers – screening locations close to good public transport stops, with good, pictorial signage.

Enablers – ask person what works for them, self advocacy, advance information about access facilities:

One person at a focus group found that she was not getting the right support to get on a bed. She said she was expected to manage. There was a discussion about knowing how to ask for support and the medical staff needing to know exactly how to support you as it can be different for each person.

A participant said that they had an appointment coming up and had called in advance to check access. She was asked if she could transfer out of her wheelchair onto the bed and walk up a step. No information on access was given in the letter and it would have been a wasted journey if she had not called in advance.

Enabler – extra time

Another issue facing some participants at the Stroke Cafe is the lack of time given for people to get themselves dressed after tests like smears and mammograms, which people felt was undignified and stressful.

“People need a bit of extra time. Just 5 more minutes means the world.”

Enabler – share access requirements with provider. Ensure that there is extra time and space available for disabled people who require this after appointments.

Information and Communication

This was a big area of discussion with some strong views. Several participants were aware of the Accessible Information Standard and



Equality Act, and didn't feel either were being implemented fully. Some people felt that they weren't asked access questions because their impairments were hidden, so assumptions were made which created problems for them further down the line. Also included within these comments were concerns about poor administration.

Enabler – ensure that the infrastructure is in place to support the full implementation of the Accessible Information Standard and additionally transfer of access requirements from GP through to third party provider where applicable.

“Everything comes back to the poor implementation of the AIS.”

“Have they asked access requirements at the doctors and shared this?”

“People are not flagged up on the NHS systems when they need particular types of information or support (they should be under the Accessible Information Standard). Or this information is not shared between the doctor, receptionist and other NHS organisations.”

Enabler - ensure that information is gathered on access requirements, allowing the recording of personalised requirements (open field) e.g. extra time, accurate timings, quiet waiting space, preference for staff of a particular gender etc.

“Accurate appointment time (no waiting) on my good days.”

“There's a lot of paperwork already so why can't they ask about hidden impairments? A lot of people don't have a voice. The staff are under so much pressure and having the information in the first place would be useful. It's not rocket science. It would make me so elated that somebody thought about me. More empathy in the patient doctor relationship! It's important that people care when you go to these things. Staff become complacent because they are used to it but for that patient it's the first time they've been in that environment.”

Enabler – provide a range of staffed contact and communication options e.g. voice, text, email or letter in preferred format. Don't rely on one single medium such as the internet or phone, and ensure that people's communication requirements are always passed on:

“Communication by email/letter/text NOT voice call.”

“Everything being web-based in terms of communication.”



Enabler – provide Deaf awareness training and Disability Equality Action Training:

“Not deaf, hard of hearing aware.”

Enabler - provide a smooth, clear system for the booking of interpreters and confirmation of appointments. Ensure providers are accountable for booking appropriately qualified interpreters accurately and in a timely way:

“Getting an interpreter for the screening was problematic. Once done yes, but took four attempts to make the booking due to difficulties in booking an interpreter.”

Enabler – provide easy read, jargon free information on screening to key community groups and partners who have built up a trusted relationships with individuals. Accessible signage:

“Some people in the People First group (a small number) said they would be ok to look for info about screening on Google, but most others would ask their doctor or get the information from People First.”

“Information about screening should be in plain English, no jargon and pictures of where you’re going and what is going to happen.”

“A hospital changed the name of the fracture clinic to ‘Orthopaedics’ and people didn’t know what it was. A picture of a skeleton would be good instead. Sometimes the pictures used in hospital signage are strange –a shopping basket for a coffee shop! The Christie is a good example because they give you the number of the department, rather than its name.”

Transport and Travel

Transport was one of the more common barriers raised in the survey, with key enablers being venues close to accessible public transport routes, travel training, and clear maps and accessible directions. Some people found that the venues they had to travel too were a very long way from their home, and this made it very difficult. Accessible parking needs to be available close to venues.

“Travelling to screening appointments is a big barrier for the disabled people we spoke with. People reported at focus groups that they don’t know where the tests are held. Sometimes they are very far away – in a



completely different part of Greater Manchester e.g. being expected to travel from Wythenshawe to Rochdale.”

Enabler – ensure that all appointments are accompanied by an easy to understand map, with access information about the venue in Clear English. This should include information on accessible parking and local public transport options. Arrange appointments close to the person’s address wherever possible. Ensure that people are contacted by phone about appointments if this is their preference.

“One person’s letter didn’t say where to go and it was hard for them to read and understand. She was advised in the meeting to bring the letter in to People First.”

Broader NHS Communication Issues

Highlighted by members of Manchester Deaf Centre’s 50+ Group:

Enabler – Effective interpretation booking services

Several people talked generally about the lack of effective interpretation service at hospitals (not specific to screening). Interpreters not turning up, hospital saying they had booked them. People waiting for hours because they could not speak to a doctor without an interpreter. “Waste of time”.

One person spent 7 hours waiting in hospital, in pain, for an interpreter to turn up so they could be treated.

Another person said that they often had issues with unqualified interpreters turning up to medical appointments which is inappropriate as they cannot communicate at the level required. Several others agreed with this. People booking - especially for gender sensitive, personal issues – should ensure that the interpreter booked is also of the same gender as the Deaf person having the treatment/screening.

“They are often a trainee, wrong gender or not booked at all – or come but it’s very late.”

People agreed that this sort of thing “happens every day”

Another member elaborated that it’s very difficult when critical information has to be communicated in sequence and an interpreter is not there all of the time. “They can really put you at risk”



One member said that the hospital would not provide an interpreter themselves, but then refused to allow her adult son, who was present, to interpret as it was against their protocols even though she had consented.

A member had a letter from the hospital saying his interpreter had been booked. When he arrived he found out the booking had been cancelled. He was not advised of this. He loses control of his time. No-one gets back to you. Just get an interpreter in the first place. Appointments all say that they will cost the NHS £160, but don't consider the loss to the person if booked without an interpreter.

NHS staff need more training on Deaf awareness.

One member works at the MRI on each ward. None of the community language posters give info on how to book a BSL interpreter. Deaf people should be equal. She also mentioned that she keeps being asked to informally interpret at the hospital. She says this is not fair on her or them as she is not an interpreter.

Other Points Raised

Enabler – make information easily available on testing procedure for Prostate Cancer in easy read and British Sign Language.

A 50 year old Deaf man went to see his GP about his treatment for prostate cancer. He was told he did not need an interpreter for this and the info about his condition was not provided in an alternative way.

Another participant queried why prostate cancer is not one of the 6 statutory tested things “When it's the number one killer of men”?

One person at People First also asked a question about prostate checks and whether they were covered by screening. His concerns were answered by a male member of staff who had had all of the tests recently.

Attitudes

Comments about attitudinal barriers mainly related to providers being advised to take the lead from the person themselves about how to make the screening work for them. They also linked to a need to be flexible



about approach (remove bureaucratic barriers), and not making assumptions about someone's requirements based on appearance.

Enabler – the person themselves is the expert on their requirements and their body. Always ask the person what they require:

“Staff trained to ask, not assume what I need.”

Enabler – Listen and offer flexibility wherever possible. Signpost to advocacy and / or support. Provide quiet waiting areas and predictable timings.

“Had issues with not being given enough time as I have autism and mental health issues and physical health problems. No advocacy. Feeling scared... Long waits in noisy environments which gave me panic attacks. Inaccessible buildings or unsuitable appointments then bullied if I ask for it to be changed to more suitable time.”

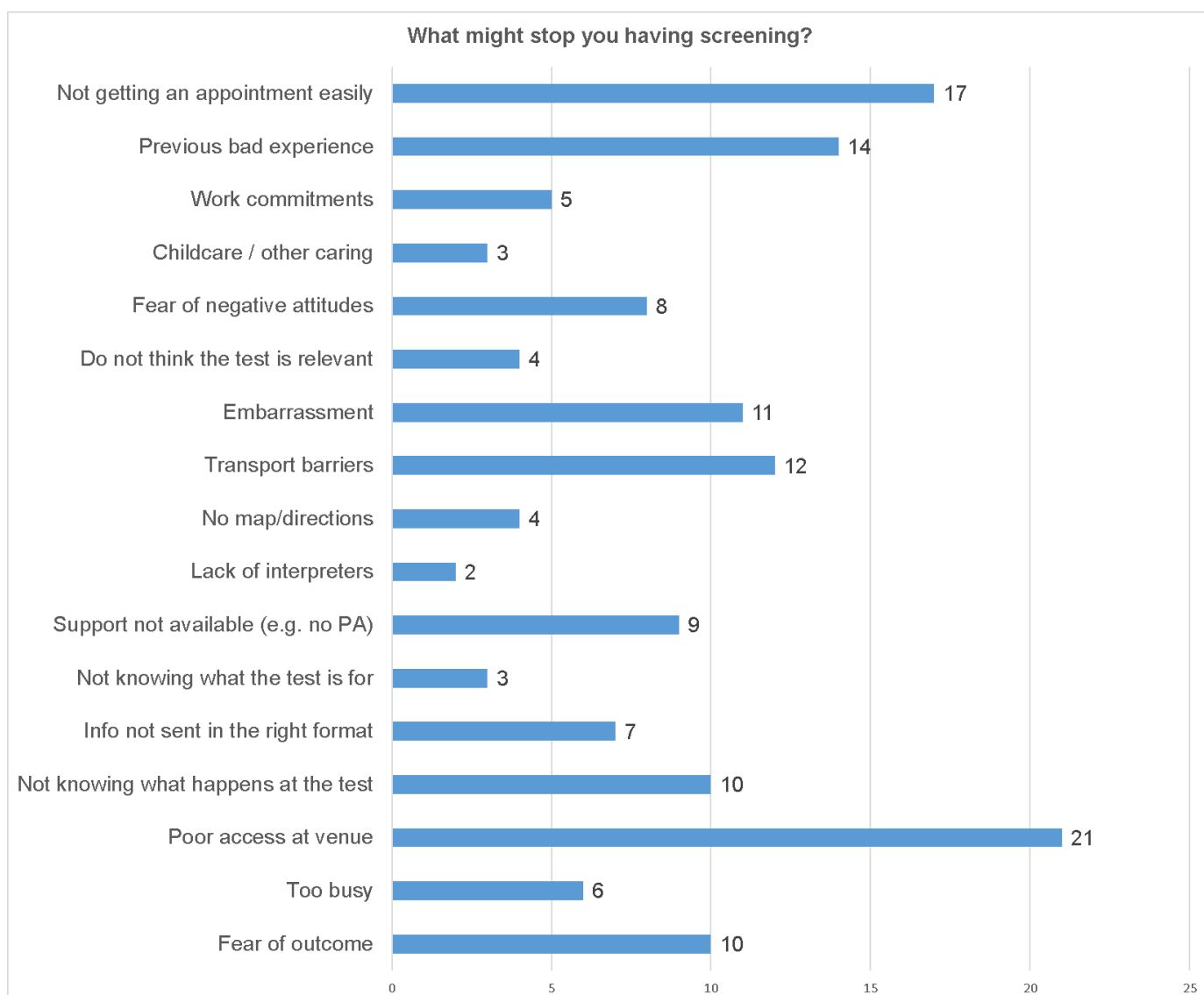
Enabler – knowing that many disabled people have hidden impairments and may face a range of barriers that are not obvious:

“The main thing is people don't see me as a disabled person as I have hidden impairments – I have to tell them. Some are not welcoming when I ask for support such as a cushion. They don't ask enough questions to find out what I need in advance. I'd like to be able to unhook a wristband or lanyard as I go in – a bright one, then they would know I need a bit of extra time/patience.”

Enabler – being open to the impact of other aspects of a person's identity:

“I just want someone to understand about my anxiety. Sometimes people can't speak up for whatever reason and that's how they end up missing appointments. No-one takes into account I have two lives to run as a carer. It's hard work. Befriending is not the answer as I'd need time to get to know someone first to feel safe.”

Reasons for Non Attendance



Some people wanted to reinforce that they had positive experiences of the testing process here, although they might not if they faced other barriers:

“Positive experiences at screening at my GP's practice.”

“I was ok but accessibility issues could put some people off.”

Potentially poor access was the biggest deterrent to people attending appointments, followed by difficulties getting an appointment, previous bad experience and transport barriers.

In the comments for this questions health or impairment-related issues were the biggest reasons for non-attendance, particularly when this was coupled with barriers to leaving the house:



- “Relapsed badly for months after ophthalmology appointment to check if glaucoma”
- “Not able to attend due to illness”
- “Not been able to attend screening since ME became severe.”
- “When I was well enough to travel absolutely zero notice was taken of my illness and no additional arrangements could be made. I either did what they said or didn't get screened.”
- “Due to the inability to access screenings or even appointments at home, every event causes further worsening of my health ie, seizures, paralysis, being unable to speak or move, increased pain, decreased cognitive ability, due to severe Post Exertional Malaise in M.E.”
- “I need home visits”
- “Not had any screening planned since I became ill but they will be due soon.”
- “Multiple stays in hospital, often for months at a time. Have never attended cervical or breast screening appointments.”
- “I'm usually housebound with overlapping energy limiting chronic illness issues. If I do go out I need support getting there.”
- “I have ME and any GP /hospital appointments are extremely tiring.”
- “Not being well enough to attend screening.”
- “Too ill to get to appointment.”
- “Being well enough to get to the doctors' surgery.”
- “I am chronically ill with a fluctuating condition. Mostly housebound. Would need home visit preferably. Might make clinic appointment but might have to cancel last minute several times.”
- “Pain issues; stress of physically taking part; usefulness of screening - follow-up treatment?”
- “What effect it might have on health e.g. MRI scans may be deleterious. How far I have to travel (only local travel i.e. less than 10 miles is generally possible). Lighting, infectious illnesses/privacy etc. at venue.”
- “If I were in a bad relapse.”
- “If I deteriorate I may be unable to stand at all.”
- “Birth trauma, uncomfortable examinations.”

Enabler – Home testing / home visit screening options where possible.



For some people this was also linked to a requirement for support, and for appointments to be more flexible. As funding for personal assistance is now so restricted, many disabled people struggle to prioritise appointments which are not already accounted for in their support plans.

- “I have to be lying down on a stretcher or bed.”
- “Negative impact on other health issues from the exertion of attending.”
- “Not being able to get an appointment that fits with my support or change it easily.”
- “Screening may be difficult without physical assistance.”
- “There was not much room in the breast screening mobile unit so would be a bit difficult for anyone who needed a PA.”

Enabler – flexible appointments at non-standard times for disabled people requiring personal assistance. Ensuring that screening venues have space to accommodate a PA, supporter, interpreter or advocate.

Some participants said that not knowing enough about what the screening was for, or would involve, is a barrier:

Enabler - this work highlights a need to make accessible information on screening more readily available across the board. At the moment, there is a strong onus on getting information off the internet or through services which people may not be engaging with. Our experience is that many disabled people are still fully or partially digitally excluded.

“Little leaflets on each type of screening would be useful.”

“Information on the main screening types in local dialect BSL” (rather than the ones made in Scotland on You Tube)

Enabler - As highlighted in the section on cervical screening, it is essential that providers have access to a range of well promoted equipment to meet people’s access requirements – for example, different sized speculums, rise and fall beds, height adjustable chairs, hoists. When these routes are not accessible, alternative ways to complete tests should be used and publicised widely.

“The unsuitability of the equipment for meeting my needs. Consequently I no longer go for cervical screenings.”



Barriers - Fear or embarrassment

- “I will not take part in most screening because I could not tolerate the tests needed if there is a problem.”
- “I have now opted out of breast cancer screening, before the cut off date.”
- “Scared of Smear Test.”
- “Previous psychological trauma, sensory overload.”
- “Eligible for both breast and cervical screening but never attended because of fear of pain and lack of knowledge about what’s happening at the test. More time at the beginning with a nurse would be good so you know what could happen. I find out what happens about the test from friends who are mainly also refugees. More information needs to be sent in different languages and more about other people’s experiences. It’s embarrassing.”
- “I just can’t do the bowel cancer screening, I feel too embarrassed.”
- “People at focus groups were worried more generally about what they would be told - what they would find out at a screening check. This fear puts some people off from going.”
- “I will not have ongoing tests unless I am under general anaesthetic. Will not have mammogram because of too many false positives.”
- “Fear of the unknown. Not getting straight answers.”

Enabler – Myth busting sessions and accessible information from partners such as Cancer Research, Answer Cancer, Macmillan, Jo’s Trust, culturally appropriate community organisations and peer groups. Person-centred approach.

Barrier - Inaccessibility of screening

This is a recurring theme, highlighted in more detail in the sections above.

“I cannot collect the stools. I cannot turn around due to arthritis. The instructions are not clear and easy to understand.”

Enabler – wider promotion of alternative, accessible ways to complete tests.

Reiterating the above, Manchester People First staff observed at our workshop there that the main barriers to screening were:



1. Fear
2. Getting inaccessible information about the test and where it is, then people don't turn up or get lost.
3. Support staff not interested in supporting people to do the bowel screening kits or to turn up to appointments – an example was given of a member who completed the bowel kit when he lived independently, but has not done one since he moved in with Shared Lives.
4. Individuals not knowing what to look out for e.g. symptoms of cancer. People not knowing how their bodies work and what is or isn't ok.

Additionally, People First reported that:

- People are scared.
- People don't know about all the different types of screening.
- People are often relying on support staff when they are invited for a test, and not all of the support staff do what they need to do to make it happen – e.g. reading the letter and making the appointment.
- The annual health checks for people with learning difficulties are superficial. Low uptake and just cover the basics. Other tests should be included in them automatically – why not do a PSA (Prostate) test whilst there as they are doing a blood test anyway?
- People with learning difficulties often find it hard to self diagnose. Lack of access to easy read information or knowing about their own bodies and what is 'normal'.
- There can be a tendency for people who rely on support workers/PAs to be seen as a 'nuisance' when things are going wrong medically – e.g. the man who keeps having to get up to go to the loo. Things get overlooked.

People feel confused by it all.

“Unsympathetic staff. Not sure of what to do - silly things like wearing a gown, do I fasten it etc.”

“Understanding it”

Enablers – requirements to assist people with statutory screening programmes should be written into contract standards for support providers – it's not just about getting people to their annual health



checks (for people with learning difficulties). It should include other screening too. Accessible information about screening and why it's done, cascaded through trusted community groups.

Barrier - Poor admin and bureaucracy

“Poor information or invitations that come too late to organise attendance. Lack of contact details to check out things prior to attendance.”

Enablers – ensure appointment notifications arrive at least two weeks before appointments so that appropriate support or interpretation can be arranged. Access information should be provided, along with contact details to check specific queries.

Barrier - previous bad experiences

“Experiencing bad attitudes makes it harder to motivate yourself to go back. It can be difficult to find someone you trust enough to support you.”

“Lack of mental health understanding by staff and how to put bad news across to mental health patients. I feel training is required in this. As we are not idiots and simply need to be sat down and it explained slowly and fully (probably with one's wife/partner or carer. As the talk I received was for 1 minute. And I was so confused and my stress levels went high. Mostly because I was told next to nothing about my AAA screening except it had grown??? And see you in 12 months???? That was it ????”

“Fear I can't handle it. Fear from other people's bad experiences.”

“Time of day - I prefer early as this helps with anxiety.”

Enablers - reassurance, convenient time and information

Barrier - waiting

“Wait times”

“Waiting”

“Anxiety and making me wait.”

Enablers – Appointments with dependable timings

Barrier – insensitivity and lack of information about process

Barrier – trauma and discomfort



“Hatred of body parts being touched”

“I do take part but some times it is arduous and upsetting”

“Two women present at a focus group both said they found cervical cancer screening unpleasant and invasive. The breast screening was also uncomfortable for one of them.”

Enablers – Sensitivity to impact of trauma. Promotion of support services, including peer support if appropriate.

Barrier - attitudes

“A staff member doesn’t have to say anything. Being deaf - raised eyebrows, even eyes say enough when working with profoundly deaf.”

“How I am treated by staff.”

“People’s assumptions and attitudes.”

Enablers – Disability Equality Training. Deaf Awareness Training

Barrier – inflexible appointments

“Hours and availability of nurse as I work full time.”

Enabler – flexible, out of hours appointments



Recommendations from Participants

- “Better information about practicalities such as accessibility, transport options, suitable clothes to wear, what will happen at the appointment etc.”
- “More training, treat people as experts on themselves. Ask people about access needs in appointment letters or phone calls.”
- “Accessible venue, support from the medical team, understanding what they are saying. Treat me as a human, as a person.”
- “Need good attitudes. Need reassurance. If you have an appointment you could hear more about what is going to happen and other people’s experiences would be really useful.”
- “The front line staff at the Bowel Screening Centre have a script/a pathway. Maybe they should put something about accessibility in the script. What disability awareness training is delivered to them so they understand the impact of barriers – e.g. for people who are ‘print disabled’? If you’re lucky you get someone with personal experience, otherwise they stick to the script. We either have to experience something or you have to learn it so it becomes part of your practice.”
- “Encouragement to take part in spite of the physical difficulties present.”
- “Home visits”
- “Screening done in home visits where possible.”
- “Combine screening into one accessible visit.”
- “Do more at home. Make sure you have other formats than web for communication. Do more by phone. Have venues that are accessible (flat ground etc) and also be aware that other issues such as lighting and risk of infections may be involved - so private access and a request form that asks about access issues would be useful.”
- “Cater for stretcher bound patients who cannot sit up.”
- “Have awareness training. Don’t ignore people. Listen. Don’t treat people like a kid.”
- “Bizarrely as it's the NHS -understanding of disability. To treat patients as people rather than cogs in a machine. To accept that people have long term illness and stop treating them as if they are deliberately out to cause problems.”



Breakthrough UK – Accessibility of NHS Screening

- “Home visits for chronically ill/ housebound patients who are generally neglected and therefore not accommodated fully or compassionately or respectfully.”
- “Offer home visits, or home testing. Someone to help with pushing a wheelchair.”
- “Home visits if at all possible. If clinic visits - no waiting, go straight in. No penalties for cancelling last minute.”
- “Home visit smear tests for women who are housebound.”
- “To be able to book appointments easier.”
- “Don't treat people as sacks of flesh to be roughly manipulated for the purposes of the screening. Be prepared to give extra time to people who have physical and/or communication impairments that affect how long the screening might take. Follow a procedure of: Ask, listen, have a gentle try, check if ok, do. Get with the times and be reliably contactable by email and make sure you've advertised/said what the email address is. Far too many letters come with (if you're lucky) a telephone no. to contact if you need to and far too few with an email address.”
- “Choice of setting; clean air (I have COPD); full knowledge and understanding of my other long term conditions; better use of IT.”
- “Ask how people will get there, where they can park - even buses dropped off quite a long distance from the location.”
- “Being able to specify gender of person that you see. Being fully informed about what will happen and how long it will take.”
- “Maybe if more was done at local GPs or pharmacists.”
- “In my case I would like a nurse to visit my home on the 3 days necessary to take a sample with a bowel cancer testing kit.”
- “More information about help available with screening.”
- “When the nurses or doc have to give bad news to the patient, especially if they suffer from anxiety or poor mental health. Need to 1 try and make sure a person they know is there. 2 explain exactly what the prognosis is to them. And 3 What might help to slow an aneurism down. Say such as do not lift heavy objects or strain ones self. In certain ways I had to go on line and Google help? That in my opinion says some people are not doing their jobs right.”
- “To make breast screening more accessible, have some screening for disabled women in GP's surgery in an accessible venue so they don't have to go to hospital.”



- “Wheelchair access.”
- “More accessible parking, footrests and comfortable chairs in waiting room.”
- “Online booking for smear tests.”
- “Telling patients by post what is available to them and what format”
- “Consult disabled people”
- “Putting the information in websites and even on the TV with a person signing in BSL. Enabling all disabled people to be aware. Have audio on websites. There is an accessibility standard. The national Macmillan website has people signing which helps people be aware. The ‘please ring if you need to ask any question’ needs an accessible option for Deaf and hard of hearing people. Implement the accessibility standard.”
- “How do people know how to get the accessible mammogram in Wythenshawe if they are not on the internet?”
- “‘Access requirements’ is jargon. Give examples of what you mean e.g. easy read, large print etc.”
- “Have GPs actually listen to their patients, who are in fact well equipped to advocate for themselves.”
- “Proper consideration of access needs.”
- “To treat people as individuals and understand their circumstances and needs.”
- “Allowing to use text message to make the appt. more information in BSL about the screening.”
- “Some alternative procedure for bowel cancer testing.”
- “Consideration for disabled users.”
- “People need to learn how to self advocate and be assertive.”
- “Why is it so difficult to get accessible information? Culture change is needed. Their IT systems don’t work with each other. There is no mandatory field for access requirements on the GP’s database – this needs to be changed. There needs to be manual intervention to the systems. People’s requirements are not currently transferable across systems. They need to ask what works for people.”



Overall Recommendations under the 12 Pillars of Independent Living

We suggest that these recommendations are followed up by Manchester Health and Care Commissioning, with a progress report by May 2020 to the Our Manchester Disability Plan Health and Social Care Reference Group.

Appropriate and Accessible Information

Ensure that the infrastructure is in place to support the full implementation of the Accessible Information Standard (AIS) - and additionally the collection and transfer of access requirements from GP through to third party providers.

Share information on people's requirements for language interpretation / other communication support.

Share accessible information format requirements with screening providers and the administration staff who are scheduling appointments.

Provide front line staff with Deaf Awareness Training and Disability Equality Training so that appropriate information is given, the right questions are asked, support is offered appropriately and a culture of the person being the expert on their own requirements and being in control is respectfully maintained.

Provide information in a range of formats and media about accessible ways to get screened. Don't rely solely on online information.

Provide a range of staffed contact and communication options e.g. voice, text, email or letter – in the person's preferred format.

Ensure that up to date Access Statements are available for each screening centre.

Provide local dialect British Sign Language and community language information on each screening type and disseminate through community groups.

Offer myth busting sessions and accessible information from partners such as Cancer Research, Macmillan, Jo's Trust and culturally appropriate community organisations.

Ensure guidance sent to people about to have screening is a) in the right format / language and b) written in easy to understand language.



Ensure that home kits can have Braille labelling if required.

Prenatal testing should be carried out in a sensitive manner; the parents should be given full information regarding risks and accuracy of testing, and should not feel pressured into undergoing tests.

Create a targeted accessible publicity campaign about the AAA test and what it is.

An adequate income

Reimburse travel costs where this is a barrier to attendance.

Appropriate and accessible health and social care provisions

All recommendations!

Offer extra time at appointments where this is an access requirement.

Go above the requirements of the AIS to ensure that known access, as well as information requirements, are passed on to screening providers in advance.

Promote options for alternative screening methods where conventional tests are not accessible.

Offer appointments at flexible times.

Provide a smooth, clear system for the booking of interpreters and confirmation of appointments. Ensure providers are accountable for booking appropriately qualified interpreters accurately and in a timely way.

Add information to community language posters on how to book a BSL interpreter.

Consider the viability of at-home screening.

A fully-accessible transport system

Arrange appointments close to the person's address wherever possible.

Provide accessible parking close to centres, with level access to the building.

Make sure screening locations are close to accessible public transport stops.



Appointments offered at times when people can use their concessionary travel passes.

Full access to the environment

Have a rolling programme of access audits for screening centres.

Provide directions in the right format and easy to follow, pictorial maps.

Ensure that screening centres are within accessible reach from outside the building from transport and parking locations.

Adequate provision of technical aids and equipment

Ensure screening centres with a range of access equipment – e.g. hoists, rise and fall beds etc. are widely promoted.

Encourage people to contact screening centres beforehand to talk through their access and support requirements.

Provide height adjustable chairs for mammograms.

Offer eye tests in a range of positions.

Have differently sized speculums available for cervical screening.

Consider the implementation of a pilot for DIY home conducted smear tests.

Adequate provision of personal assistance

Promote support options to disabled people who do not have anyone to assist them to do the kit.

Commission support to assist people with completing screening if required, particularly for bowel screening.

Welcome and provide space in screening centres for Personal Assistants.

Make contracted PAs and support workers accountable for ensuring that people receive their invites and are supported to attend screening.

Requirements to assist people with statutory screening programmes should be written into contract standards for support providers, including Shared Lives.

Availability of independent advocacy and self-advocacy

Welcome advocates and provide space in screening centres for them.



Check whether people require an advocate at the point of referral.
Ensure providers know how to signpost people to advocacy options.

Ensure self advocacy organisations have full information on screening types in a range of formats, especially easy read.

Provide information on options and venue accessibility in a range of formats so that people can self advocate, including on risks of not having screening.

Provide accessible information on self checking in a range of formats (and physical models for groups, if available).

Offer follow up assistance to disabled people who have never attended screening appointments.

Involve disabled people in the design, development and evaluation of new screening services and centres.

Respect people's stated choices about screening participation.

Availability of peer counselling (peer support)

Peer support groups should be available and should be informed by a social model of disability perspective.

Provide easy read, jargon free information on screening to key community peer groups.

Contact

For more detailed background on this work and reading list, please contact:

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