West of England
Academic Health
Science Network

Create Open Health: Voices for Change

An open innovation project to initiate positive change for people affected by bladder and bowel continence conditions.

Presenting key learnings, insights and real world stories from people with lived experience of bladder and bowel issues.

October 2021 - March 2022

BABCON
Bladder and Bowel
CONfidence

Bristol Health
Partners

Disruptive
thinking

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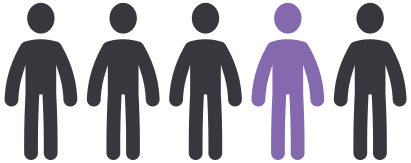
Summary

Create Open Health: Voices for Change

A project to initiate positive change for people affected by **bladder and bowel conditions**

> "This is a condition which doesn't get talked about nearly enough, but so many people are affected. It's perceived as an older person or female issue when in reality, it can affect anyone. Anxiety is always present, the biggest impact is the psychological one."

More than 1 in 5 people in the UK are affected by bladder and bowel conditions



While bladder and bowel leakage can affect anyone at any age, we know that there are a number of groups who are disproportionately affected. We also wanted to ensure a focus on engaging with often under-represented groups, such as:

- People living with, or caring for people with, learning disabilities
- People living with, or caring for people with, dementia
- Postnatal women
- People from ethnic minority backgrounds

Key learnings from people with lived experience

What we did

83 participants

A focus on under represented groups

An inclusive and accessible approach

+

Expert feedback

What we heard

Environmental

People told us they did not feel supported when outside of the home

Perception

People told us there are misperceptions about their condition that has a negative impact on them

Communication

People told us they experience negativity in the way they are spoken to (and that their conditions are spoken about), as well as difficulty speaking to others about their conditions

Mental health and anxiety

People told us their emotional and mental health is significantly impacted

Participation

People told us how their condition limits physical and social activity

Services

People told us they don't feel enough is being done for them individually

What needs to change

1. Address the taboo surrounding bladder and bowel leakage
2. Increase conversations around bladder and bowel leakage
3. Prioritisation for bladder and bowel provisions [by commissioners]
4. Increase access to public toilet facilities
5. Improve access to the right treatments / improve service pathways
6. Support the mental wellbeing of those affected

Background

It is likely we all know somebody who experiences bladder and bowel leakage to some degree, but are probably unaware because it is not openly discussed due to the embarrassment that surrounds these symptoms.

The Voices for Change project was designed to explore some of the challenges faced by those living with the condition, or caring for someone who does.

The project's long term aim is to initiate positive change for those affected, by suggesting improvements to existing information, services and pathways and guiding thinking around developing or identifying innovative healthcare solutions.

The West of England Academic Health Science Network (AHSN) coordinated the project, in partnership with the Bladder and Bowel CONfidence Health Integration Team (BABCON HIT) at Bristol Health Partners and Disruptive Thinking. It is the second in the series of our Create Open Health programme - an 'open innovation' initiative that seeks solutions to key challenges faced by the NHS. The project has been funded by the West of England AHSN and the BABCON HIT.

More than 1 in 5 people in the UK are affected by bladder and bowel conditions

Introduction

As with any healthcare challenge, understanding and articulating the problems and challenges faced by those living with a condition, and their carers, is always the first step in working towards solutions.

We wanted to give people with lived experience the opportunity to share their stories and experiences, and the challenges they face, living directly or indirectly with bladder and bowel control issues. We wanted to give a voice to all those affected.

In doing this exploratory work, we sought as many different voices as possible, from a wide range of backgrounds. We also know, through our network of clinicians, that certain groups are more impacted by bladder and bowel conditions, and we wanted to give under represented groups the chance to be heard.

The purpose of this report is to present the insights and learnings we have gathered and create a springboard for change.

By engaging with those affected, and gathering insight into their experiences, we have a starting point for initiating meaningful and enduring change, with the potential to make a real difference to people's lives.

Key objectives

- To discover and identify common challenges and problems in order to gather insight
- To give an opportunity for under-represented groups to share their experiences and have their voices heard
- To develop succinct 'problem statements' which can be shared with the sector - and innovators - in order to suggest improvements to existing information, services and pathways and guide thinking around developing or identifying innovative healthcare solutions

Foreword

This report provides a powerful voice for the many people experiencing bladder and bowel leakage. It provides honest insight into the experiences of living with incontinence, that so often go unheard - and highlights the impact imposed on many aspects of daily life.

The desire to be heard and to have equal opportunities to live a healthy and active life is something we all aspire to, and these themes are clearly articulated throughout this report. So often this is impeded due to the lack of recognition of the impact of incontinence. It is clear that people who live with these symptoms often feel isolated and alone, further shrouding the topic in secrecy.

Of particular note is the need for increased awareness and recognition of the wider relevance of bladder and bowel health to so many in our society. Here, priority problems are identified, providing a welcome opportunity to drive focussed change and innovation in this area, in order to improve life for all those affected.

The insight gathered in this report enables us to form recommendations for the sector that could create meaningful and enduring change. It also lays the groundwork for future healthcare innovation.

Professor Nikki Cotterill

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Integration Team Director, Bristol Health Partners

Professor Nigel Harris

Director of Innovation and Growth
West of England Academic Health
Science Network

Our approach: Who, how, what?

An inclusive and accessible approach

Who? A focus on under represented groups

We know from our network of clinicians, and from the sector generally, that there are a number of groups who are disproportionately affected by bladder and bowel continence conditions. As part of this work, we wanted to ensure a focus on engaging with these often under-represented groups.

- People living with, or caring for people with, learning disabilities
- People living with, or caring for people with, dementia
- Postnatal women
- People from ethnic minority groups

We reached out to all those experiencing symptoms, including these groups, through multiple channels, engaging with existing contacts with links to these communities, and also building new relationships with relevant groups and networks.

How? A multi-channel methodology

We offered participants three possible channels through which to contribute; group workshops, individual interview and an anonymous survey. This was because we wanted to give people a choice of method, based on individual need, and how they felt most comfortable in sharing their thoughts, feelings and experiences, on what can be a very sensitive topic.

What? Discussion points

We aimed to gather insight around five core discussion points:

1. Why do you want to take part?
2. What is the biggest challenge you face as a person affected by bladder and bowel continence conditions (or as a carer of someone with bladder and bowel continence conditions)?
3. Describe the effect this problem has on you, your life in terms of physical and mental wellbeing.
4. What difference would it make to your life if a solution was found to your main challenge?
5. Are there any more challenges or issues you'd like to raise as a person affected by (or caring for those with) bladder and bowel continence conditions?

A multi-channel methodology

Group workshops

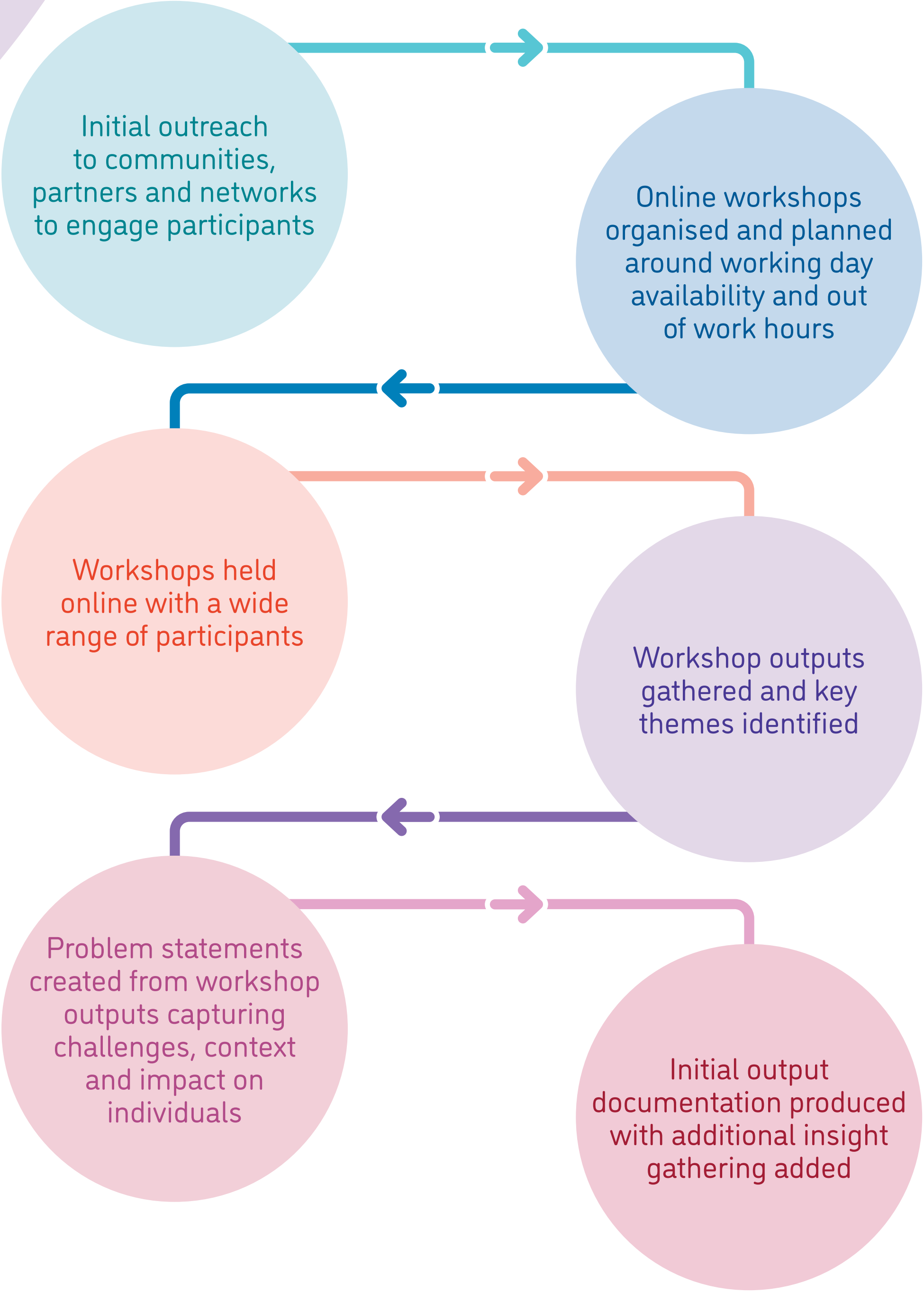
We recruited workshop participants to share their stories and experiences, in a safe space, giving them the opportunity to tell us about the challenges they face living directly, or indirectly with bladder and bowel continence conditions.

A wide range of people took part, including parents, elderly people, those who work in the healthcare sector, young professionals and parents of those with learning disabilities. We heard from both men and women within the groups, in addition to a wide range of ages as well.

We held candid discussions with participants to help understand personal or individual contexts and explore in detail the challenges they faced.

The workshops were held during October to December 2021, each running for approximately 90 minutes.

Please see the appendix for a full anonymised data breakdown of participants.



Initial outreach to communities, partners and networks to engage participants

Online workshops organised and planned around working day availability and out of work hours

Workshops held online with a wide range of participants

Workshop outputs gathered and key themes identified

Problem statements created from workshop outputs capturing challenges, context and impact on individuals

Initial output documentation produced with additional insight gathering added

A multi-channel methodology

Group workshops (continued)

Given the challenges of the Covid-19 pandemic, the project team had to conduct the workshops entirely online. Despite this, there was an evident feeling of connectivity and shared experience during the sessions. For some of the participants, this was the first time they had an opportunity to talk about their challenges in a group that understands, with people who are also going through similar challenges.

Conducting the sessions online and using accessible video chat tools made it easy for the participants to join and take part. This reduced the potential for some individuals to be excluded from taking part. We also provided alternative solutions to accommodate any challenges with access or confidence in using virtual meeting platforms.

The key challenge was creating a virtual environment where participants felt comfortable and safe to share their experiences with the group and team.

By using a relaxed conversational structure, the sessions moved through a format of allowing each participant the opportunity to initially briefly describe their most challenging experiences in turn. We then circled back and explored each individual story in more depth.

This relaxed and empathetic approach meant the participants felt more able to share their stories and to be more descriptive and comprehensive in their recounts.

We also received many positive comments from the participants on the experience of taking part, both in terms of candidness of the conversations and the positive spirit in which they were conducted.

A multi-channel methodology

Individual interview

In addition to the group workshops, we also offered the option of booking an individual interview by telephone.

This was for participants who either did not feel comfortable in a group setting, or who did not feel confident using the internet.

The structure was similar to that of the workshop, with question-answer and discussion, and similar guidelines were followed.

We built flexibility and responsiveness into the way the interview was conducted, in order for the individual to feel fully heard and supported throughout the conversation.

Anonymous survey

The project team also felt that an anonymous option for response would be ideal for those who didn't want to talk about their experiences in a group setting or who would prefer to contribute in writing rather than verbally.

We designed an online survey which echoed the questions asked in the workshops, while collecting key demographic information such as location, age and participant group.

The survey was offered to anyone experiencing symptoms, including those who had expressed an interest in contributing, but who were not able / did not want to attend a workshop.

Discussion points

Q1. Why do you want to take part in this research?

This condition is little discussed as it is embarrassing for most people to talk about. As it seems it is not uncommon, it would be good to be part of change, whereby it is better recognised. Assistance in managing it and information around it should be widely available.

I struggle with bed wetting and would like the opportunity to chat with others in similar positions.

I think this is a subject that doesn't get talked about nearly enough but so many people are affected by. By discussing it, ways of how to avoid problems and cope with them when they do arise can be developed and make a huge difference to the lives of those affected.

I suffered from prostate cancer and had the prostate removed plus a follow up session of radiotherapy. I suffer from bladder incontinence and would like to know what changes may have occurred in both treatment and support.

My daughter suffers from chronic constipation which is now being managed through medication and lifestyle changes. We've faced some difficulties in getting the care we need and I'm willing to provide feedback in this respect.

I am interested to raise awareness having had an intervention as a patient and as an advocate for all patients.

This is a sample of answers provided through the anonymous survey

Discussion points

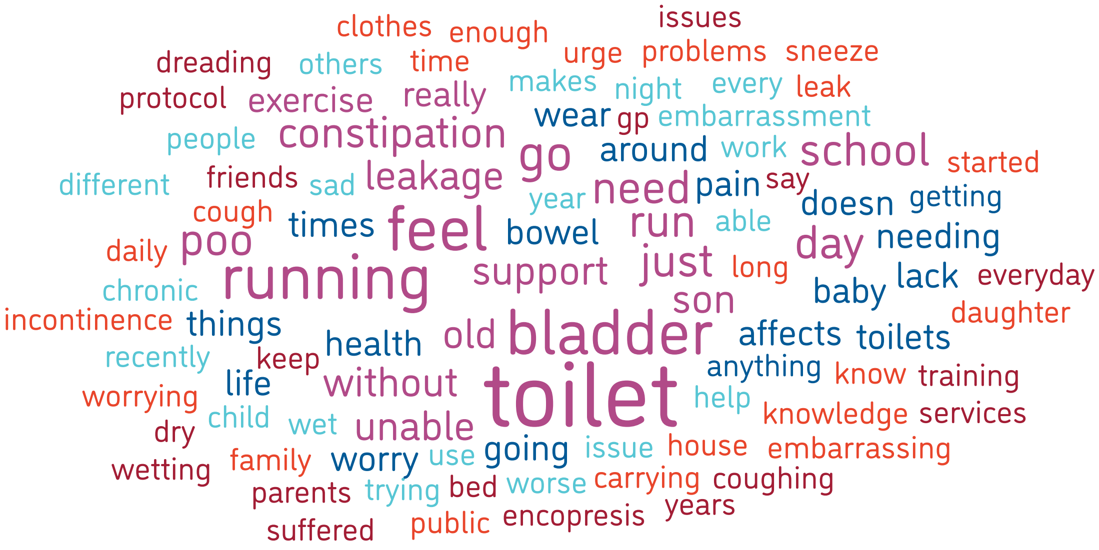
Q2: What is the biggest challenge you face as a person affected by bladder and bowel continence conditions (or as a carer of someone with bladder and bowel continence conditions)?

This question was left intentionally very open for the respondents in order to encourage openness and a variety of answers. When seen as a word cloud (where the larger words are the most frequent across all answers to this question), the overall negative and challenging nature of their answers is apparent. Similar to the workshops, people expressed internal challenges with their thoughts, feelings, emotions and mental health, as well as external challenges when out and about, such as their environment and the people around them.

We heard from a significant number (54%) of survey respondents who are parents of children or young people with continence issues, who largely felt there was a lack of support and solutions (both in service pathways and in schools). Some told us that support services have been cut in their local area and that they had had to push hard for any medical intervention. Others felt that schools did not have the appropriate disability support in place to accommodate their children, with one parent explaining “my six year old son needs to be reminded to go to the toilet or else he doesn’t go”.

We also heard from postnatal women (21.8% of participants) who talked about the inconvenience of leakage and the worry that others will notice. One also mentioned how she struggled with the reduction in support she received after having had her baby, as compared to that received when pregnant. Another mentioned how they don’t drink anything for hours before going for a run just to avoid leakage when exercising.

One young person mentioned how their confidence took a severe hit and how they would worry about going out and using toilet facilities. This echoed the views heard from parents who worried about their children, and how their condition (and others’ perception of the condition) might affect them as they get older.



This data is based on responses given through the anonymous survey

Discussion points

Q2. What is the biggest challenge you face as a person affected by bladder and bowel continence conditions (or as a carer of someone with bladder and bowel continence conditions)?

I feel sad when my daughter is embarrassed after an accident. She's 9 and is at the tweeny age and the upset on her face pains me. Especially when her three year old brother is dry at night and gets praise for doing so. I hug her and keep things positive but she gets so depressed about it. Which in turn makes me feel sad too. I just want to help her.

Inconvenience and frustration. I have slight bladder incontinence after having a baby, if I cough, sneeze or run I can leak. If I'm at home then it's not such a problem, but if I'm out of the house it can be a real inconvenience and I worry if anyone can notice if it's seeped through my clothes etc, it's also quite uncomfortable if I can't deal with the situation promptly.

I was left with leakage after my first child, and now having a second it has only got worse. It is very frustrating that the healthcare system seems to have forgotten me a bit, as soon as you are not pregnant any more the focus is very much on the baby and not on the mother. It is embarrassing when out in public and public loos are awful. I am still carrying pads, spare trousers and supplies around now when the rest of my NCT group seem recovered. I cannot afford things like private mommy MOTs etc and now just feel like this is going to be part of my life forever.

I feel the biggest challenge is the education of others about my daughter's chronic constipation. I have had resistance and misunderstanding from family, friends, GP, health visitor, nursery and school staff. I feel like nobody really understands the chronic nature of it or the impact this has not only physically but emotionally on my daughter and our family as a whole. This impacts every aspect of our daily lives and so many people including healthcare professionals we have dealt with have zero understanding and offer uneducated advice and assume it is because she doesn't eat enough fibre or drink enough fluids or that she will just grow out of it. This is so frustrating and really feels like a daily struggle.

Unable to exercise at the level I would wish to; leakage beyond the level that a pad can hold the contents, results in it being visible to others. Being unable to exercise results in weight gain and a loss of confidence and self esteem.

This is a sample of answers provided through the anonymous survey

Discussion points

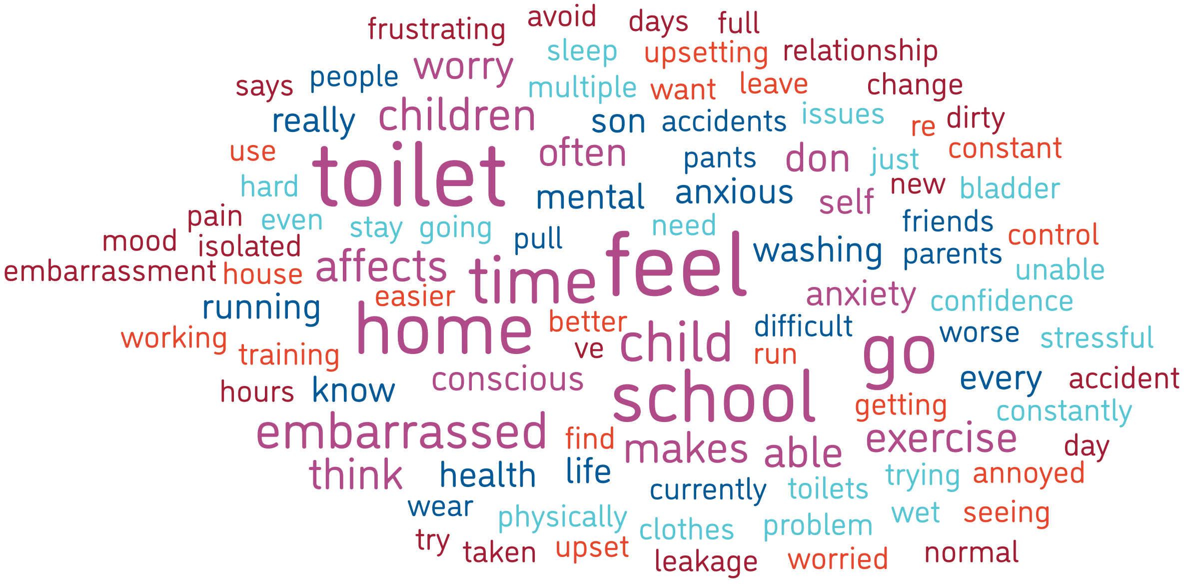
Q3: Describe the effect this problem has on you and your life in terms of physical and mental wellbeing.

When describing the impact, respondents focused on the lack of options when it came to activities and exercise. In terms of mental health - stress, anxiety and embarrassment were mentioned repeatedly. Women in the post-natal group said they simply didn't have the time to manage their own mental health alongside a demanding baby despite their condition being anxiety-inducing; and the parents of children with continence issues mentioned how their children's condition affects every single aspect of their lives.

One respondent said they felt their condition directly caused severe depression, and another purposefully does not hydrate themselves when going out in public purely to avoid any leakage.

The answers here depict a significant impact for those suffering with, or caring for those with bladder and bowel continence conditions. There is a strong mental health impact theme running throughout all answers, with additional frustrations mentioned around how conditions can stop many physical activities.

Many parents are also concerned for their child's development and messaging they are receiving about their child's continence and bowel challenges. Respondents agreed that support and positive education around this topic is frequently lacking , combined with parents and schools often not knowing how to source specialist support.



This is a sample of answers provided through the anonymous survey

Discussion points

Q3: Describe the effect this problem has on you and your life in terms of physical and mental wellbeing.

I cannot really take on any activities as the leakage is triggered by any exercise. Not being able to exercise and to have this hanging over me really affects my mood. I can't be as active for my kids as I want to be, which makes me sad.

Refuses to use pads in school which means this can make her bladder and kidney worse. She becomes anxious, she cries and says she wishes her body was normal.

I sometimes don't go to meet people in a new place for fear of not being able to find a toilet! I cancel plans and make excuses. I also won't hydrate for hours beforehand to avoid needing to urinate.

The constant rigmarole of washing sheets and changing beds when I'm a full time working mum is annoying. Sometimes I don't want to encourage her. I don't show her this but it can be hard to stay positive especially if she has hidden wet clothes from me. Nine years now and no change despite trying everything. It's frustrating and I want it all to be over with for her sake mostly but also for me too!

I need to know where the toilet is and to know it isn't too far. I often need to run out of meetings. Anxious when going out to exercise, that I won't make it home in time. Always have to consider what I can and can't eat makes eating out hard.

Made me go into a shell of my former self. Not confident and not wanting to go out.

This is a sample of answers provided through the anonymous survey

Discussion points

Q4: What difference would it make to your life if a solution was found to your main challenge?

The answers to this question are predictable - all stated what a huge impact it would have, except one respondent who had already undergone life changing surgery to cure their condition. A summary of the answers are as follows:

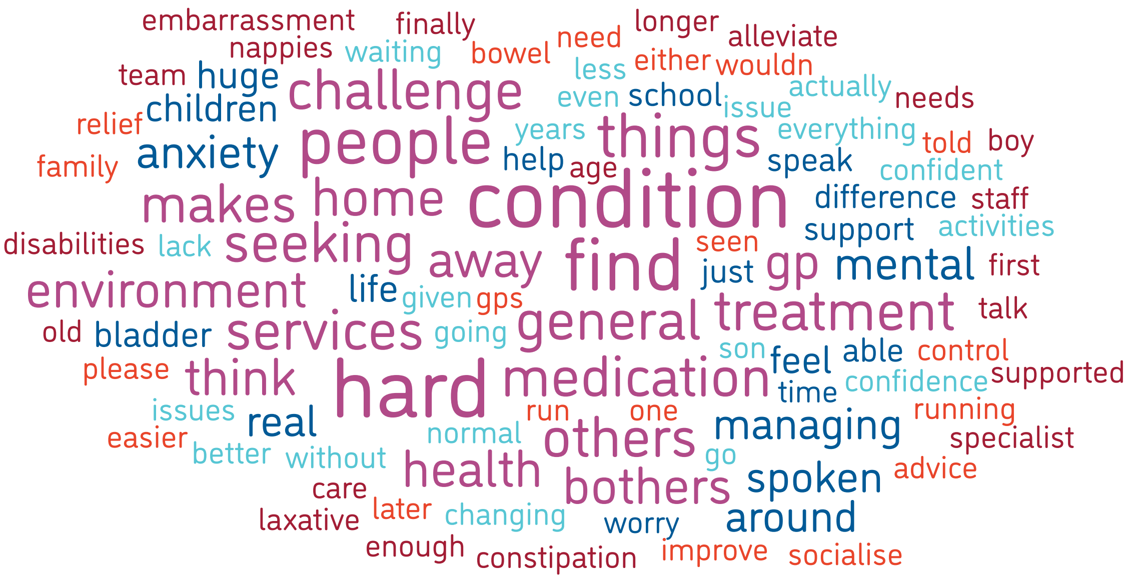
Life changing. Low intervention bladder operations haven't solved the issue but very small incremental changes have already proved to be life changing; to my mental and physical health.

A huge difference. Being able to play with my kids and not worry inside about everything that could go wrong with my bladder control at any given moment would be such a relief.

It could be life changing. My daughter would feel more supported and more accepted and be able to take part in more activities and opportunities.

Could be the same as everyone else. Be able to socialise and meet up with others without having to map out all the toilets. It is actually easier to say no to mixing.

It would make such a difference to just feel supported and like we could actually get somewhere without having to fight.



This is a sample of answers provided through the anonymous survey

Discussion points

Q5: Are there any more challenges or issues you'd like to raise as a person affected by (or caring for those with) bladder and bowel continence conditions?

24 of the 47 survey respondents answered this open question. All of them either referred to challenges accessing support or the perception of their condition. One also spoke of the pain they suffer during the management of their illness. A strong theme arising from the post-natal group was the feeling that having pelvic floor issues after birth was almost expected and that they are made to feel as if their conditions are not valid and fully supported by the service pathways provided to them.

Accessing help & support, cleaning, suitable products for bedding etc, managing school, going out, holidays, mental health, types of products available, male healthcare professionals to talk to male patients - always seen female staff, no teenage suitable literature or support.

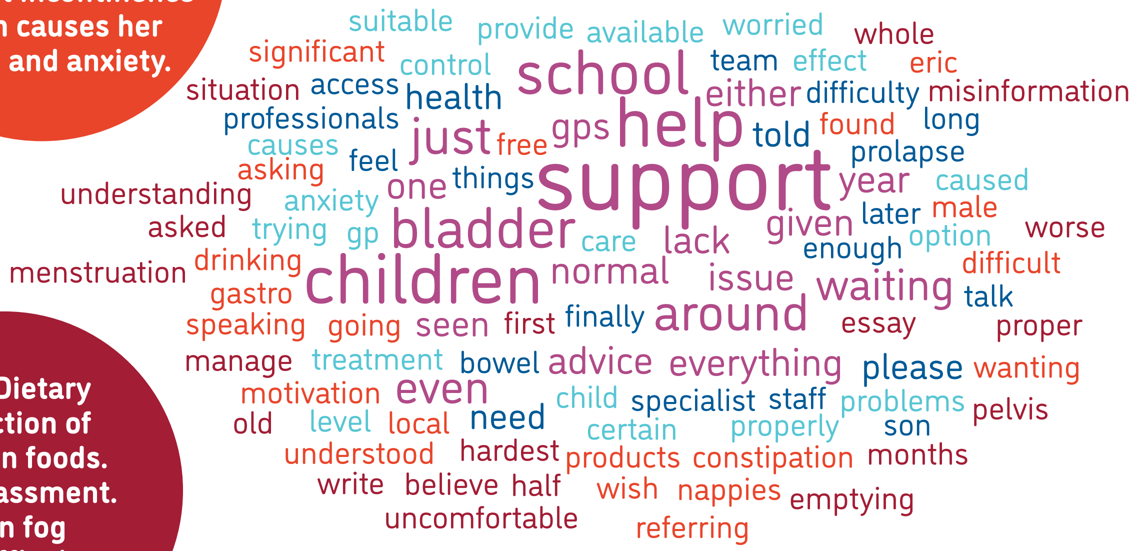
The future looks very bleak for bladder care. In terms of treatment, due to the loss of TVT (Tension-free vaginal tape surgery) as an option, the next level of surgical intervention is significant and all come with significant risks. It can feel a very lonely place to be when it is an issue which isn't openly discussed, even between close family and friends.

I would also like to be able to help my elderly mother who suffers from more frequent incontinence which causes her stress and anxiety.

No support for young children, no groups for them to go to so they can socialise with other children with this condition.

Very difficult to access women's health physiotherapy on the NHS. Very long waiting lists, and expensive "solutions" that may not work.

Pain. Dietary restriction of common foods. Embarrassment. Brain fog and difficulty concentrating.



This is a sample of answers provided through the anonymous survey

Themes and problem statements

Insights and themes

From the survey, group workshops and individual interviews, we have seen a number of important insights and themes emerge.

We used an approach called thematic analysis, where similar sentiments and ideas are grouped together in order to organically generate themes and collections of similar statements.

The following pages show the themes which began to emerge as we analysed the data. We have also included example problem statements which provide clear evidence of the emerging themes.

Problem statements

After reviewing and analysing the data for emerging themes, we also developed a series of 'problem statements'. These are individual statements which succinctly articulate the themes and challenges, seeking to provide meaningful insight and recognition.

These are important communication tools which can help those working on a project or developing a new innovation to better understand the challenge they are aiming to address.

Theme 1
Perception

People often spoke of how they feel their condition is perceived by others in the outside world, and the impact this negative perception has on them.

Quotes from people we spoke to as part of this project

"I'm a clinical specialist and have a bladder issue myself. It's hard accepting you need help, there are so many people out there who don't seek help - because it is so taboo. There's an assumption it is an older person's issue - but it affects many different people."

"It's perceived as an older person or female issue. In reality, it can affect anyone. We need more honest conversations."

"Suffering since teenage years."

"I hid it away from everybody."

"It just doesn't fit into social conversations."

"Being young, it is just not taken seriously."

"..feeling like being an 'inconvenience in a social environment'."

"Public perception is skewed - pad manufacturers messaging makes it harder."

"I have bladder weakness which affects me when I'm running and also sometimes coughing and sneezing. I worry about looking like I've wet myself when I get in from a run."

"The embarrassment that can happen with bladder and bowel issues, the worry about what people say or think, how it can affect everyday life, work and friends."

Perception problem statements

Perception

The misperceptions surrounding bladder and bowel continence conditions is a significant challenge for both people with conditions, and for those who look after them.

When engaging with primary care, those affected report facing preconceptions relating to age, sex and patient grouping which have resulted in delays to treatment or incorrect diagnoses. This leads to frustration and anxiety both for patients and specialist care providers.

Perception

Outside of healthcare settings, the misperceptions surrounding bladder and bowel continence conditions as a taboo subject is a serious issue for both people with conditions and those who look after them. It occurs frequently when those affected feel embarrassed or uncomfortable speaking about their conditions. This may delay seeking treatment, but also has a significant mental health impact on the people affected. People feel like they are isolated and that they need to suffer in silence.

Theme 2
Communication

There were frustrations expressed about a lack of understanding and negativity in the way individuals were spoken to and the way their conditions are spoken about. Many also found communicating with others about their own conditions difficult.

We spoke with the mother of a five year old with chronic constipation resulting in faecal soiling and an overactive bladder. She endured a long period of toilet training described as normal by health professionals, the constipation had irritated the bladder and it took a long time to get help. Eventually she found a Facebook group with thousands of other mums facing similar challenges. The daily accidents at school were damaging to her child's self-esteem, as the child was labeled as "naughty" by the school with their intelligence / maturity being questioned.

"Can't talk to people - as it's embarrassing."

"It's exhausting - remembering everything and having to communicate or explain things again and again, I go from being too embarrassed to talk about it to being too frustrated."

"Not being listened to and understood and therefore not getting the most appropriate treatment."

"I feel the biggest the challenge is the education of others about my daughter's chronic constipation. I have had resistance and misunderstanding from family, friends, GP, health visitor, nursery and school staff."

Communication problem statement

Communication

The difficulty in communicating with non-medical people about bladder and bowel continence conditions is a key challenge. For example, using language that creates a negative response is hard to overcome for parents with children who suffer from these conditions. Use of labelling words such as ‘naughty’ for wetting or treating the child as immature or less intelligent create significant negative feelings and impact on the child’s self esteem.

Theme 3 Environmental

All the groups generally did not feel supported when they were outside of the home, either by the environment (i.e. public toilets) or being in a new place.

“With water infections and incontinence you can feel like a burden, you don’t want to bother doctors, but finding public toilets can be difficult, you feel embarrassed.”

“Plea to have toilets open everywhere and in better condition. It is a public health issue you shouldn’t have to pay. At schools, everyone can have accidents.”

“Journey planning is mentally tiring, having to remember different items including clothing, pads, equipment as well as planning toilet stops and facilities.”

“My daughter doesn’t feel comfortable and is dreading secondary school with a lack of disabled toilets.”

Further comments mentioned:

Disposal of pads is a problem and it can feel unhygienic to use standard household waste

Respondents reported having to drive long distances to find hygienic facilities when out and about

Some reported being reluctant to go to unfamiliar places or where they would be with strangers

Environmental problem statement

Environmental

Even before the pandemic, the problem of the lack of public toilets and the general cleanliness of them posed a real challenge for people affected by bladder and bowel continence conditions. With symptoms including urgency, the scarcity of public facilities and (particularly for males) the general uncleanliness of facilities, mean that making trips out are infrequent or avoided altogether. The fear of an accident in public, or having to apply pads or clean up after oneself in unhygienic cubicles causes stress, anxiety and negatively impact on the ability to get out and about for people affected by these conditions.

Theme 4 Wider health service

Concerns around seeking treatment, GP services, and medication were often raised, with a feeling that not enough was being done for them individually.

“Pelvic floor exercise advice isn’t followed up. Previous surgical procedures led to mess and pain. Lack of improvement from the medical profession even over extended periods.”

“Water infection suffering terribly - had been to A&E, called the GP, had to call back for an appointment the following Monday, they seem like they will accept this, as it’s been going on for 20 years. I don’t want to challenge the “white coats” but I feel often overlooked because of my age and fobbed off.”

“Sad when you hear how long for a referral - symptoms for over five years before they get to a specialist- pads/ life changes. Can’t cure everything but we can often significantly change people’s lives.”

“A huge issue for those with, or caring for people with, learning disabilities and not being treated properly - not being well understood in primary care.”

One participant experienced urinary problems herself, and her daughter with learning disabilities is also doubly incontinent. She has had constipation since birth and suffers from epilepsy, and the neurologist who supported her seemed to have a lack of understanding around bladder and bowel conditions. The parent and daughter saw eight surgeons before eventually needing bowel surgery.

Others mentioned that challenges from the wider health service included:

- The COVID-19 pandemic made in-person support extremely difficult
- Limited advice on managing changes to medication
- Little proactive contact from consultants and care providers
- The products the government recommends are expensive

It was also mentioned that they would like to have knowledge of alternative facilities and services they could be going to for support, rather than relying so heavily on an individual consultant or service.

Wider health service problem statement

Wider health service

The systemic challenges faced by people affected by bladder and bowel continence conditions has a huge impact on early treatment and diagnosis. This occurs frequently with referrals between teams in primary care, where people affected are met with preconceived diagnoses or rigid care pathways resulting in missed opportunities to start or change treatments. This results in frustration and anxiety for people with these conditions and frustration and demoralisation for care providers.

Theme 5
Mental health and anxiety

The group mentioned their feelings and emotional wellbeing being significantly impacted, with many suffering from anxiety and poor mental health as a result.

“None of us can have a full life if we can’t control our bladder.”

“Anxiety is always present, the biggest impact is a psychological one.”

“Managing the condition on your own is isolating and overwhelming. You end up putting it to a side, giving up that anything will change. I’m in the denial stage. Glad I can attend this session to talk about it.”

“Under constant stress, so anything that makes life a bit better would have an impact from a mental health perspective - would love it if people listened to me, as a patient expert.”

“Makes me feel embarrassed and isolated as it makes me feel so self conscious when I’m out running and prevents me from running with friends.”

“My wife had accidents in the care home which weren’t really spoken about - that made her feel ashamed.”

Additional comments mentioned that:

Even though friends can be very understanding, it can still be awkward to talk about incontinence or bowel issues and even more so if an accident occurs

It’s easy to feel isolated and alone

It would be great to find others in a similar position to get support that way

Speaking openly about these conditions without it feeling awkward would be brilliant

It would be good to know where to go for mental health support

Mental health and anxiety problem statement

Mental health and anxiety

The day to day management of bladder and bowel continence leakage has a serious impact on the mental health and wellbeing of people with these conditions. The need to plan ahead for every trip outside the home is a mental burden. The stress, anxiety and panic that is caused by not having an item or the potential of an incontinent episode or disclosure, has a severe psychological impact on sufferers and their carers.

One observation the project team made was around how all of the problems identified in this project contributed negatively on the mental health of those affected.

Theme 6
Participation

The survey highlighted pain and a reduction in physical activities as a consequence of their condition.

"My condition makes me struggle with pain during and after intercourse."

"My son has bowel issues but will not say if he's in pain."

"It affects my ability to do certain things with my baby (i.e. throwing in the air, carrying for long periods, carrying in a sling)."

"I have to make sure I do not drink anything for a few hours before I exercise. This affects my running ability."

"I've been affected by problems when running specifically. I get up extra early before all of my runs to use the toilet and occasionally have trouble needing a poo still whilst running."

"Unable to exercise at the level I would wish to; leakage beyond the level that a pad can hold the contents results in it being visible to others. Being unable to exercise results in weight gain and a loss of confidence and self esteem."

Participation problem statement

Participation

People living with bladder, bowel and continence conditions feel a sense of physical limitation. They describe how their condition limits their ability to take part in activities, such as playing with their children or going for a run. Some also spoke of experiencing daily pain.

Parents of children living with these conditions also worry about their child's development and their ability to keep up with the other children. Postnatal women are also frustrated by how their condition limits their options to exercise and be active post-birth.

All of the above has a direct impact on mental health, with many saying they have experienced anxiety, stress and depression as a direct result of the severity of their condition limiting physical activity.

Further insight

People living with, or caring for those with, dementia and / or learning disabilities.

It should also be noted that the challenges identified within these themes are intensified for some, such as those also living with learning difficulties or dementia.

One individual we interviewed is a carer for her wife (83 years of age), who has had bladder incontinence for three to four years, along with dementia. She also now has bowel incontinence and bowel cancer.

It was evident that her condition added additional complications to an already challenging lifestyle:

“My wife isn’t always aware of when she needs the toilet. This means I need to do the management for her which can cause tension and arguments.”

“Having dementia also makes it really hard for her to keep hydrated.”

We also received five survey responses from those caring for individuals with learning disabilities (either carers or parents). People with learning disabilities can be at risk of bladder and bowel continence conditions. The challenges experienced by this group were long-term and recurrent and had a significant impact on daily life.

The experience of this particular group with respect to their continence needs would benefit from being explored in greater detail, utilising a more individualised approach targeted towards this group of individuals to gain richer insights. (The methodology used in this piece of research was not necessarily accessible for all conditions and severity of disability).

Survey - further insight

Listed below are all of the survey responses given to the question: 'any more challenges or issues you'd like to raise?'. From a project perspective, simply reading these responses highlights how incredibly important it is that we work to support and innovate on behalf of these individuals.

"I wish GPs understood more about it. I have been asking for help for years for my son and it was only after speaking to ERIC [The Children's Bowel and Bladder Charity] that we finally got some help. We are now under the local bladder and bowel team but it is only now, four years later, that there is talk around referring him to a gastro specialist."

"My whole pelvis is uncomfortable, worse during menstruation, and I get difficulty emptying my bladder too. I feel everything is related and having everything split into either bladder, or bowel or reproductive isn't helpful."

"I have to wash clothing more frequently either because I run out of pants or because of the smell."

"We need more information before pregnancy about prolapse/tears/pelvic floor damage, rather than just a pilates teacher telling us to do kegels. It's not that simple."

"There is a lack of interest from professionals around prolapse and the fact that it's almost expected or treated as normal."

"Doctor just prescribed laxido and forgets about us. No advice or support. No long term plan or finding the root problem."

"I have found the lack of understanding from GPs one of the hardest things to manage, and I believe if we had been given proper help and advice when I first asked for it when my son was only seven months old, we would not be in this situation now he is four and a half. I could write an essay on the misinformation I have been given by GPs."

"As an adult it is considered to be one of those things - you have three children what do you expect? For children it is seen as behavioural and something they are too lazy to address."

"Barriers are put in our way and underlying reasons are not properly sought. It is seen as a parenting issue even when it only happens in school or at night time."

"There is nowhere near enough info available, especially to postpartum women & the culture that it's 'normal' to have bladder problems after birth causes a lot of harm."

"I am worried about the effect my problems are having on my kids and those around me. They are worried for me which in itself creates anxiety for them. It is a struggle."

"As a paediatric service user the support and diagnosis is very poor."

Further connections

As the project team went a little deeper into the themes and insights, some connections emerged. Discrete groups frequently mentioned common challenges and we started to see which themes and challenges appeared most important to particular types of people. For example:

1. Parents of young people in particular felt that the system did not support their children's condition adequately. This ranged from healthcare providers through to schools. A lot of parents were frustrated with how much they had to push to feel supported and understood.

2. Postnatal women mentioned how they struggle with being out and about with their condition, and also felt a lack of support with post birth pelvic floor issues.

3. Parents of children with continence conditions had a concern over their lack of ability to do exercise and outdoor activities.

4. Young people felt their confidence levels take a hit - feeling embarrassed and saying that their condition is a strain on their mental health.

Additional themes and insights highlighted in the consultation:

- Prevention: Earlier recognition and support could prevent problems later on
- People we spoke to are often highly reliant on one individual or service. They said they didn't know where else they could get support from - and wanted to be made aware of more options in terms of healthcare, mental health, and community
- Trauma of using toilets for those with learning disabilities
- People with learning disabilities have special needs in this area
- People with very severe problems can find it impossible to get out to clinic
- Men are often overlooked
- People who do not feel confident using the internet or virtual services feel excluded, which caused particular difficulties during the COVID-19 pandemic. As more options become available in terms of support, those who are not digitally savvy may be left out as so much is reliant on how easy it is for people to get on and use the internet
- People spoke about cultural barriers and language differences meaning that seeking help was sometimes difficult
- Learning disabilities may involve challenging behaviours or communication difficulties, which can mask bladder and bowel problems
- Patients sometimes don't feel listened to and supported. They spoke about having to push hard to see the right consultant or not feeling proactive longer term support
- People suffer from a 'circle of anxiety' - they feel anxious in particular situations, and so avoid those situations - which heightens their anxiety further.
- Cost of continence products
- Adverts normalise leakage
- People worried about support when accidents happen at nighttime - outside of normal hours.
- Fluid restriction leads to urinary tract infections
- Male pad users in particular struggle in public toilets due to the lack of suitable disposal bins

Concluding comments from participants

“Thank you for allowing me to be part of such an important subject”

“THANK YOU brilliant work.”

“I am so pleased that the issue of bladder and bowel continence is being talked about and solutions sought to help people affected cope with the issues in a practical sense. This will hopefully help these people to start living full lives again and avoid isolation and shame.”

“Prevention needs to be looked at, what can be done during pregnancy, after pregnancy - stressing need for pelvic floor exercises for life and aids to ensure being done correctly, and at the birth ensuring as little impact as possible is made on the pelvic floor.”

“Education about very basic bowel health should be communicated from birth and during early years health checks.”

“Many caregivers unknowingly suffer from the same conditions their children face and therefore may not spot the signs of abnormal bowel patterns at an early enough stage.”

“Thanks so much”

Reflections and recommendations

Expert reflections

We consulted with our network of experts for their reflections on the learnings in this report.

Learning Disabilities Community Perspective provided by Wiltshire Community Team for People with Learning Disabilities, Wiltshire Health and Care

“Bladder and bowel conditions, especially constipation, are common in people with learning disabilities. Such conditions can be distressing; they impact on quality of life and increase support needs. In some cases, chronic, poorly managed constipation can even be life threatening.

“Many issues can contribute to constipation, such as health conditions, poor or restricted diet, limited physical activity and mobility. Physical changes, including spasticity (overactive muscles) and difficulty walking, can cause practical problems with toileting and personal care. People with learning disabilities may have increased falls or changes in their behaviour or seizures associated with urgency and constipation. Problems with behaviour that challenges, or communication, can also mask bladder and bowel problems.

“The strain on families and support workers may also be immense. This can be due to the effort of practical tasks like cleaning up, assisting with transfers or daily washing of bedding, limitations on activity choices, financial impact, the mental load of planning or distress from watching a loved one struggle.

“Some issues will be particular to this group of people but many are shared by others experiencing bladder and bowel problems, especially in combination with a physical disability. **Inclusion in more widely focussed projects, such as this one, may prompt more research and raise awareness of the challenges and hopefully lead to positive change.**”

Expert reflections

Theme 1 Perception

Societal attitudes and awareness

“Public health awareness campaign to tackle the taboo, de-mystifying / de-bunking through education and awareness. Involvement of role models is needed.”

“System change is needed - there are clearly many barriers to seeking treatment and then being misunderstood – the system is set up to be hard right from the get-go!”

“Cultural change is needed – early intervention is not enough; we need a prevention strategy”.

Funding and service support

“Due to poor perceptions and communication around bladder and bowel health, it is challenging to secure funding to get new projects off the ground and to demonstrate impact. In many areas of health, there is recognition of the unique input of the voluntary and community sector in providing universal tier 1 support, patient support and patient/carer networks, aftercare, influencing ongoing development of services. Yet this is still unrecognised in bladder & bowel care, which tends to be clinically driven and at the behest of the quality of NHS services with little or no sustainable engagement of anyone else.”

Expert reflections

Theme 2 Communication

Expert by experience and confident communication

“Improving patient understanding around the condition, and confidence to communicate about it - finding practical ways to give children and adults the language and confidence to be able to open up and share their problem. To do this, simple messages need to be universally conveyed. This will help people to identify problems and understand they don’t have to suffer in silence. Amazing work and huge strides have gone into making it easier for us to have a dialogue about our mental health. Greater patient confidence and openness would hopefully then lead primary healthcare providers to be more understanding of the nature of the issues and ask the right questions.”

Continence training for professionals in health and education sector

“The misunderstanding and lack of support within the school system must feel like a double whammy for a parent who felt not listened to and dismissed by their GP when they tried to get help. GP education is vital to challenge what they ‘think’ they know - as is education in schools, in order to de-couple continence problems from being seen as a ‘behavioural issue’.”

Women’s health

“We need to improve pelvic health information and education for girls and women in anticipation of childbirth and review the postnatal care pathway. Antenatal education – education at all stages of pregnancy - may help prepare women for any difficulties they experience, along with clear information on where to get further help. We also need to improve postnatal pelvic health provision for women, which will hopefully be achieved through the new national Pelvic Health Centres. A standard follow up postnatal pathway, specifically aimed at reviewing pelvic floor function, should be included in postnatal care.”

Loss of intimacy

“Totally taboo and worth a mention. Most of us find this exceptionally hard to discuss and it affects both sexes. Referral to psychosexual medicine is not available on the NHS so these issues are hard to manage however still worthy of support. Most patients are unaware of some available solutions such as – innovative pessaries that can be removed, consideration of hormone replacement therapy, andrology pumps etc.”

Expert reflections

Theme 3 Environmental

Facilities

“The closure and overall lack of respectable public toilets makes socialising/exercising problematic for individuals with pelvic floor dysfunctions. Council commitment to reopening and increasing provision of public toilets. Commitment from public venues to allow use of toilet facilities. Up to date mapping of all public toilets and those toilet friendly venues?”

Product and service development

“Continence aids are lifelines for many patients. Working alongside these companies there could be improvements in both the products, the ease of their disposal, the sustainability of disposal, in terms of recycling, and the overall advertising of them.”

Expert reflections

Theme 4 Wider health service

Treatment and services

“There is a considerable lack of information about pelvic health, what treatments are available and how these can be accessed.”

“Accessing the correct services appears to have a number of barriers, with significant delays between onset of symptoms and treatment. We need a national requirement for patients to be seen by a specialist within an acceptable time span, having clearly tried all conservative/ pharmacological treatments. Streamlining care with clear pathways from treatment to referral would reduce wasted appointments/travel/ time. The ability to agree these locally and ultimately nationally, with primary care giving greater autonomy to the specialist units to organise tests/treatments and further relevant referrals.”

“Care providers need easy access to the learning disabilities team to support any appointments for patients with pelvic floor dysfunctions as well as a pathway to clinical psychology services for mental health.”

Medical history

“Repetition of history taking can become frustrating for individuals. A method for collating all of the patient information on one platform, that can be accessed by all healthcare professionals, would be beneficial and remove the need for patients to have to repeat the same story over and over. It could contain valuable information regarding previous treatments and their outcome.”

Diagnosis

“Pelvic health professionals need to ask patients about concomitant symptoms (urinary/faecal/prolapse/sexual function). Combined care would help with early diagnosis and treatment, no longer should we be managing continence concerns in isolation but rather we should ask the question and refer on if unable to support.”

Expert reflections

Theme 5 Mental health and anxiety

Mental health

“Better psychological support is needed including information on how to manage the social impact. In the section on physical limitation you have mentioned psychological distress too – anxiety and depression associated with incontinence. It would be great if we could go a step further in future and look at psychological illness. This can involve patients feeling suicidal and asking for stomas which I think is more than feeling anxious. Engagement with clinical psychology could be of benefit.”

Tackling isolation / peer to peer support

“Many of those struggling with pelvic floor dysfunctions feel alone and unheard. Signposting to support groups where they can share concerns and gather information may have an overall benefit for these patients. The query may be related to the regulation of these groups and the information provided. Helping children not to feel alone by giving them a way to network with others in the same situation.”

Theme 6 Participation

Exercise

“The avoidance of exercise is a very clear theme throughout this piece of work. The impact of reduced physical activity is visibly catastrophic for patients’ mental health, and the long-term impacts of reduced physical activity has the potential to increase demand on NHS services in later life. Gym referrals exist for patients with diabetes etc, more could be done to provide gym/work out services with attention of pelvic floor dysfunction.”

Expert reflections

Thank you to our expert contributors:

Wiltshire Community Team for People with Learning Disabilities, Wiltshire Health and Care
Laura Thomas, Clinical Scientist, North Bristol NHS Trust
Kathryn McCarthy, Colorectal Surgeon, North Bristol NHS Trust
Juliette Rayner, CEO, ERIC, The Children’s Bowel & Bladder Charity
Alina Lynden, Communications Manager, ERIC, The Children’s Bowel & Bladder Charity
Davina Richardson, Children’s Specialist Nurse, Bladder & Bowel UK
Professor Marcus Drake, Professor of Physiological Urology, University of Bristol and BABCON HIT Co-Director
Dr Alison Tavaré, Primary Care Clinical Lead, West of England Academic Health Science Network

Reflections and recommendations

For funding bodies, commissioners and service leads, it is imperative that the following is taken into consideration:

1. Navigating the bladder and bowel leakage (continence) healthcare pathway is protracted and unclear. The need for pathways that are accessible and fit for purpose, for all, is evident.
2. Do not underestimate the scale or impact of this problem, please consider prioritising this overlooked area of healthcare to provide for hidden unmet needs.
3. Many more people could benefit from provision of bladder and bowel healthcare services which has farther reaching physical and mental health impact than the symptoms alone.

For clinicians:

1. Supporting sensitive conversations surrounding bladder and bowel leakage is key to demystifying this area of healthcare and enabling access to education and treatments.
2. Early identification of bladder and bowel leakage is needed.
3. Trusted relationships and active enquiry are key to the proactive identification of bladder and bowel leakage.

For innovators ready to tackle these challenges:

1. Innovation is needed to enable people with bladder and bowel leakage to discuss this more openly.
2. Reducing isolation associated with bladder and bowel leakage is an area of unmet need.
3. Providing support for people with bladder and bowel leakage is an area that is ready for new approaches and initiatives, potentially through peer support and community development.

For engagement and inclusion of diverse communities including people with learning disabilities in further work:

1. The association between learning disabilities and bladder, bowel and continence conditions needs to be explored further. It would be immensely valuable for another stage of research which specifically works with, and develops a flexible methodology for, the learning disabilities community.
2. This particular group requires a more specialised and flexible approach, as the methodology used in this piece of research was not necessarily accessible for all conditions (and severity of disability).
3. Participants need an individually tailored approach, that is accessible to each of them, in order to fully support their important contributions.
4. We would recommend that future research is conducted in small groups of individuals (who are either living with, or caring for those with, learning disabilities) to add their important voices to this research.

Recommendations written in collaboration between the West of England AHSN and the BABCON Health Integration Team.

Recommendations

The insight gathered in this report collates and articulates public and patient need in the area of bladder and bowel continence, to be reflected upon by healthcare providers, commissioners, clinicians and innovators. We hope this will lay the groundwork for meaningful and enduring change for those people affected by bladder and bowel conditions. We have pulled the report's key learnings, insights and reflections together to highlight six action points for the sector to consider.

1. **We need to address the taboo** surrounding bladder and bowel leakage to enable proactive identification of symptoms and minimise mental and physical health declines.

2. We need to increase conversations around bladder and bowel leakage to demystify perceptions and allow for supportive actions such as peer support and reduction of feelings of isolation. **This will aid development of supportive communities** rather than negative connotations.

3. We recommend that this report forms the basis of the patient voice in the justification for improvements to support those with bladder and bowel leakage, for example, **supporting business cases and advocating** for the higher prioritisation of bladder and bowel provision.

4. **We recommmend that access to public toilet facilities is increased** to prevent imposed isolation, and meet the needs of all of the community.

5. **We must ensure service pathways meet the needs of those navigating them** and also drive efficiencies in provision to avoid prolonging the journey to access the right treatment.

6. **We should focus on promoting positive wellbeing** for people living with bladder and bowel leakage, to help reduce the mental burden and support mental health.

Project partner contacts

West of England Academic Health Science Network

The West of England Academic Health Science Network is helping to deliver positive healthcare outcomes in the region and nationally by driving the development and adoption of new innovations and enabling patients to play an increasing role in their own care and of others.

www.weahsn.net

Contact: Urszula Kapoulas, Senior Project Manager- Innovation & Growth
urszula.kapoulas@nhs.net

BABCON Bladder and Bowel CONfidence

Bristol Health Partners

Bladder and Bowel CONfidence Health Integration Team (BABCON HIT) at Bristol Health Partners brings together clinicians, academics, patients and carers to focus on improving the lives of those with bladder and bowel symptoms. BABCON includes almost 100 members who are all passionate and enthusiastic to drive change in this fundamental area of healthcare.

www.bristolhealthpartners.org.uk/health-integration-teams/bladder-and-bowel-confidence-babcon/

Contact: Professor Nikki Cotterill, Director
Nikki.Cotterill@uwe.ac.uk

Disruptive thinking

Disruptive Thinking is a consultancy which specialises in programme design & delivery, business development and marketing. Working with a wide range of clients including corporates, public sector and not for profits the team takes on a diverse range of impactful and socially responsible projects and initiatives.

www.hellodisruptive.com

Contact: Amy Wilkinson, Chief Strategy Officer / Director
amy@hellodisruptive.com

Appendix

Data breakdown:
Participant overview and initial analysis

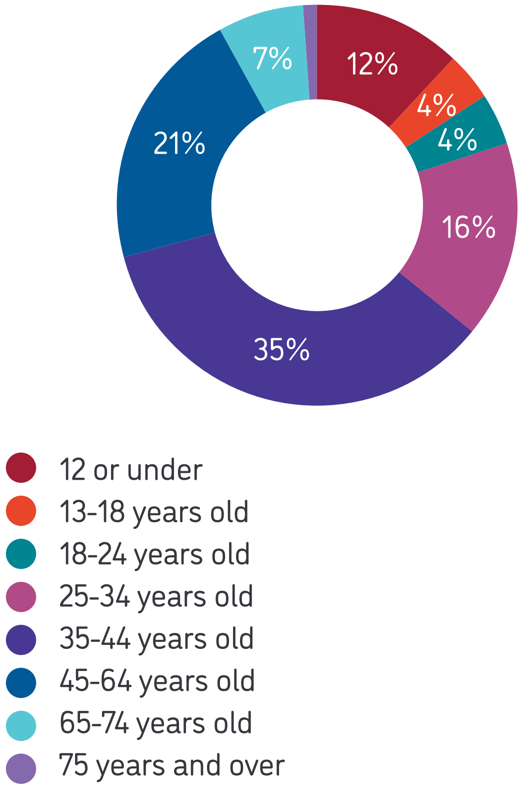
Overall breakdown of respondents

(workshop, one-to-one and survey submissions)

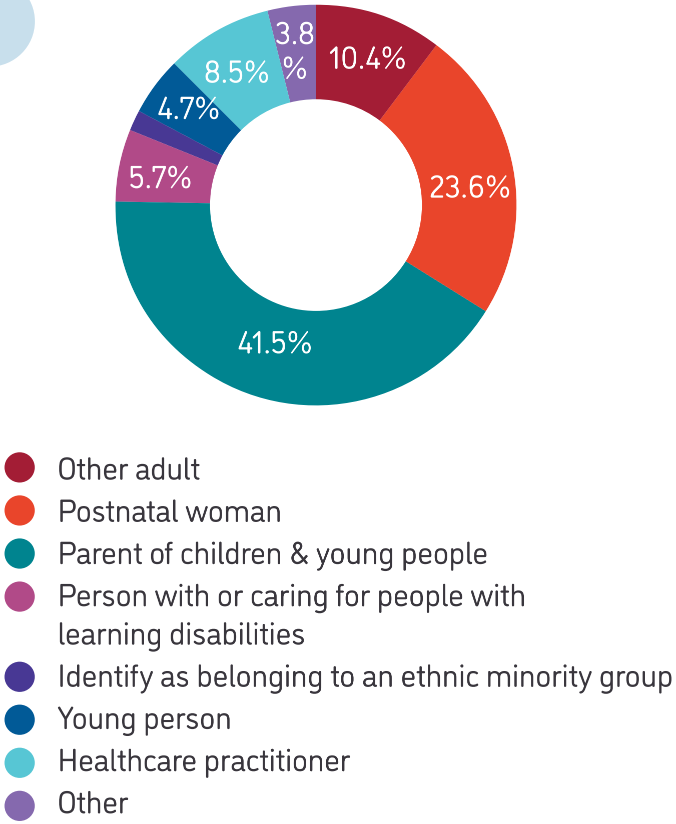
83

Total respondents across workshop registrations and survey

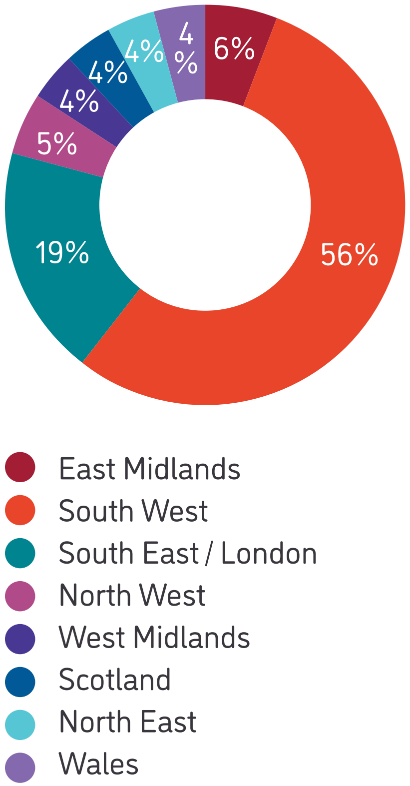
Age



Self description of respondent

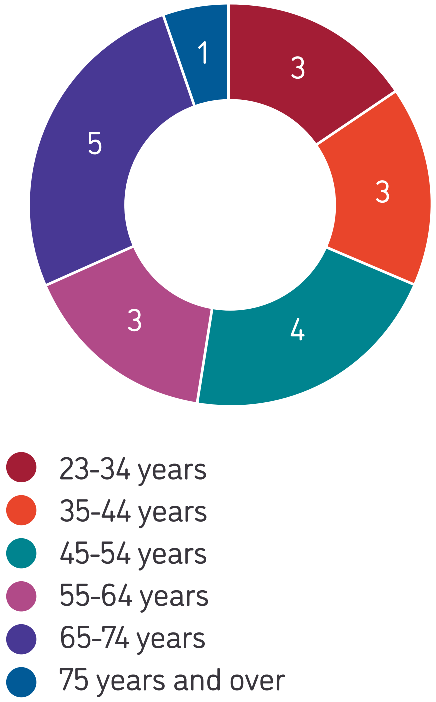


Respondent location

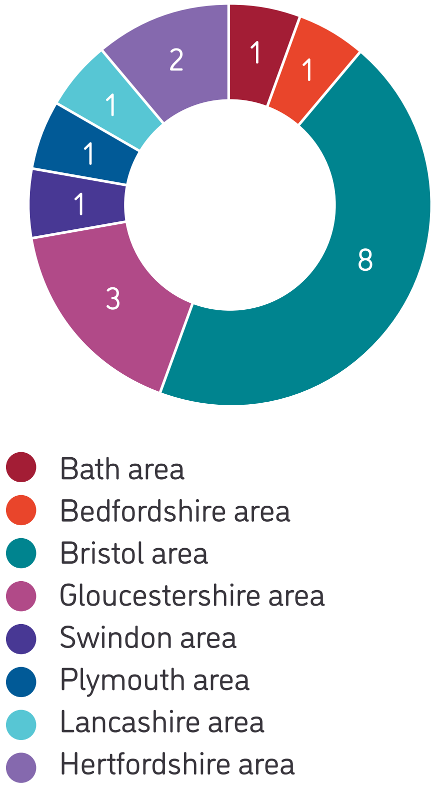


Workshop participation

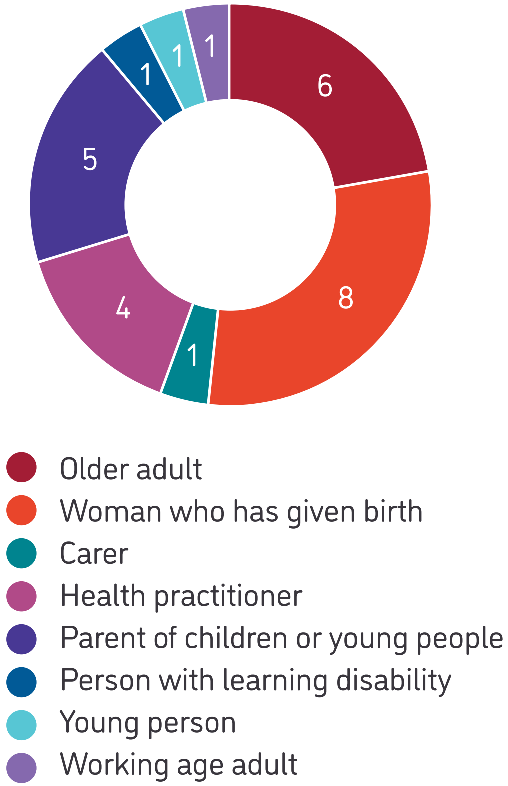
Attendee Age Groups



Location of Attendees



Self Description of Attendee



100%

of attendees use a smartphone or computer

20

attendees across four workshop events

89%

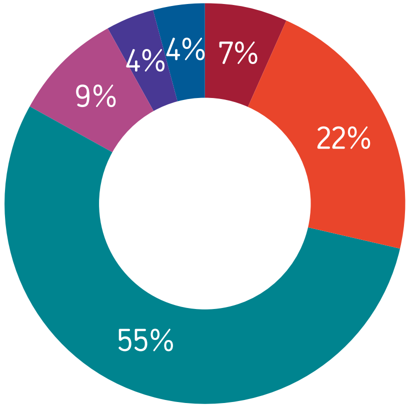
of attendees have been to college or university

Survey respondents

47

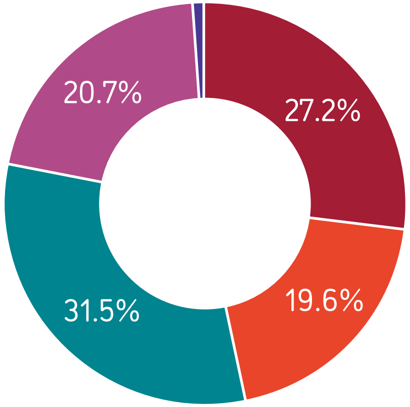
Survey responses in total

Participant profile



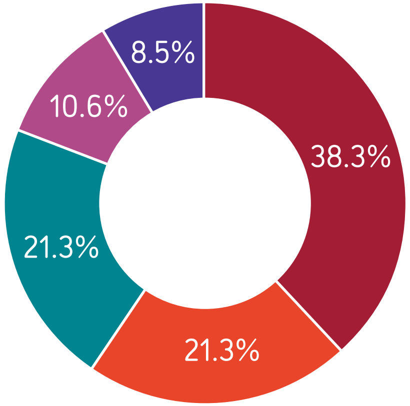
- ● Other adult
- ● Postnatal woman
- ● Parent of children & young people
- ● Person with or caring for people with learning disabilities
- ● Identify as belonging to an ethnic minority group
- ● Other

Setting in which the problem/challenge occurs



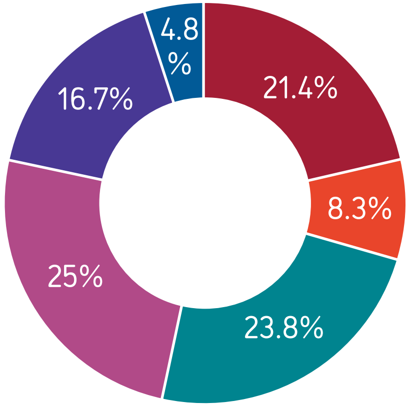
- ● Home based
- ● Workplace/education
- ● Activity based
- ● Socialising
- ● Other

Frequency of problem(s) occurring



- ● Multiple times a day
- ● Once a day
- ● More than once a week
- ● Once a week
- ● Less than once a week

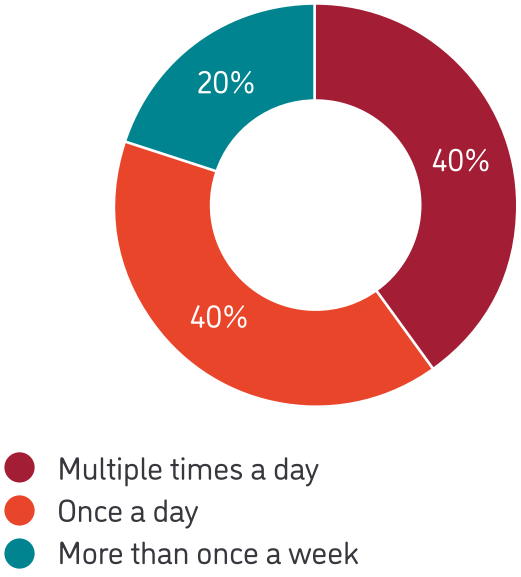
Common themes and challenge areas



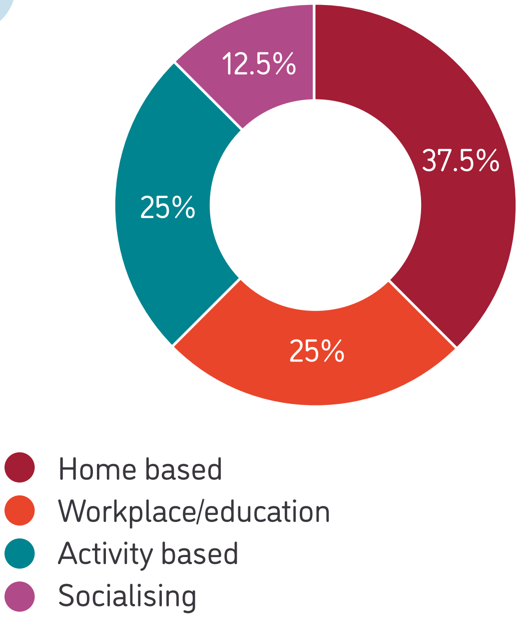
- ● The way others see the condition. It bothers me what people think.
- ● The way people speak to me about the condition. It is a challenge around the way I am spoken to and the way the condition is spoken about.
- ● The general environment when away from home makes things hard.
- ● I find it hard seeking treatment, GP services, or medication.
- ● I find managing my mental health and anxiety a real challenge.
- ● Other

Breakdown of responses specifically from those living with, or caring for those with, learning disabilities

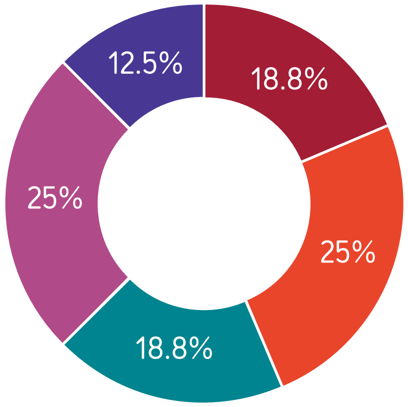
Frequency of problem(s) occurring



Setting in which the problem/challenge occurs



Common themes and challenge areas



- ● The way others see the condition. It bothers me what people think.
- ● The way people speak to me about the condition. It is a challenge around the way I am spoken to and the way the condition is spoken about.
- ● The general environment when away from home makes things hard.
- ● I find it hard seeking treatment, GP services, or medication.
- ● I find managing my mental health and anxiety a real challenge.

West of England Academic Health Science Network

Thank you

A huge thank you to all participants and experts for your essential contributions to this project and report

Create Open Health: Voices for Change

For further information about this project, visit weahsn.net/voices

For confidential support, we would like to highlight the national helplines provided by:

The Bladder & Bowel UK Charity, call 0161 214 4591, or email bbuk@disabledliving.co.uk or visit its website at www.bbuk.org.uk

ERIC, The Children's Bowel & Bladder Charity, call 0808 1699 949 or visit its website at www.eric.org.uk/helpline

You can also download BABCON's free CONfidence app for education and advice from www.bristolhealthpartners.org.uk

BABCON Bladder and Bowel CONfidence

Bristol Health Partners

Disruptive thinking