

User Experiences of Bladder & Bowel Services during the Pandemic



BABCON
Bladder and Bowel
CONFidence

**Bristol Health
Partners**

Outputs and Outcomes

2020 Healthwatch BNSSG and BABCON HIT collaborative project to investigate the impact that Covid-19 had on people using bladder and bowel services.

About Healthwatch BNSSG

Healthwatch Bristol, North Somerset and South Gloucestershire's (HW BNSSG) statutory duty and remit is to provide a voice for people who use health and adult social care services. We give people an opportunity to have a say about their care, especially those who are not usually heard.

We ensure that their views are taken to the people who make the decisions about services. Our expertise in engagement and coproduction means we can deliver consultancy work to local authorities and other commissioning partners.

We share feedback with national stakeholders Healthwatch England, NHS England and the Care Quality Commission (CQC) to ensure that your community's voice is heard. We make all findings public from our work with patients, families, and Carers.

Vision & Ethos

BNSSG is a place where people's experiences improve health and care. Healthwatch is committed to promoting equality and diversity and tackling social exclusion in all our activities. We aim to ensure equitable access to our initiatives and projects.

About BABCON

The Bladder and Bowel CONFidence Health Integration Team (BABCON HIT) focusses on the geographical area of Bristol, North Somerset and South Gloucestershire, as part of Bristol Health Partners Academic Health Science Centre.

BABCON brings together a network of patient and public partners, health and social care and academic organisations, and charity partners to improve the landscape for people with bladder and bowel leakage: <https://www.bristolhealthpartners.org.uk/health-integration-teams/bladder-and-bowel-confidence-babcon/>.

Introduction

In response to the changing service provision in both adult and children's bladder and bowel services during the Covid-19 pandemic, the BABCON HIT wanted to understand the perspectives of people trying to use these services. They also saw this as an opportunity to learn from a period of rapid innovation, to understand which changes provided advantages and which were considered less suited to the population going forward.

During Autumn 2020, Healthwatch Bristol, North Somerset and South Gloucestershire (HW BNSSG) and the BABCON HIT conducted a collaborative project to investigate the impact that Covid-19 had on people using bladder and bowel services to inform decision making during service recovery and future service innovation.

Executive summary

The pandemic provided an opportunity to document the encounters of those experiencing the consequences of rapid innovation and service alteration in bladder and bowel service provision. Healthwatch BNSSG and the BABCON HIT took the opportunity to capture this period of rapid change and learn from it. Understanding the perceived improvements and avoiding perpetuating changes that were not working well for the population of interest for the benefit of future service provision and those using it.

A clear message of societal underestimation of the seriousness or impact of bladder and bowel leakage was clearly reported, categorised by three themes:

- Reduced access to services or complete lack of awareness of the availability of services was reported due to a lack of visibility and validation that these symptoms are worthy of focus.
- Reliance on informal caregivers for those with bladder and bowel symptoms who are not well supported.
- Lack of public toilets fails to recognise the far-reaching implications for the many people experiencing bladder or bowel leakage, who rely on these vital facilities to enable activity and interaction outside of the home.

Impacts due to service alteration were also voiced clearly within the findings, highlighting:

- Effects on bladder and bowel health and subsequent impact on mental

health for a third of respondents

- The majority of service users require advice and guidance to manage and improve symptoms of bladder and bowel leakage.
- Advantages and disadvantages to largely remote consultations were reported, highlighting that service provision needs to meet the needs of the individual.

It should be acknowledged that this project was a rapid survey, limited by the nature of Covid-restrictions, but it provides insights into patient experiences that would otherwise have gone undocumented. It is acknowledged that wider diversity in the respondents could have provided differing perspectives and is an area for future enquiry.

What we did

A survey was created by the BABCON HIT and Healthwatch BNSSG teams involving all key stakeholders including patients and the public, in response to the emerging changes in service provision that were becoming evident nationally. The survey contained 33 questions exploring aspects such as:

- Characteristics of those completing the questionnaire including symptoms experienced
- Interaction with services
- Perceived advantages and disadvantages to service changes
- Informal care provision
- Preferences for future service provision

A broader approach was included to enable enquiry regarding the impact of public toilet accessibility which had also altered due to Covid-19. Availability of toilet facilities is a key consideration for people with bladder and bowel leakage, and the wider population of all ages.

A framework was devised to reach as many people as possible through the expertise of the Healthwatch Engagement Officer, promoting widest accessibility and inclusivity in the BNSSG area. Widespread dissemination of the survey was undertaken with over thirty organisations including symptom specific charities; groups providing general support for specific communities such as those from black and minority ethnic communities and people with learning disabilities; activity centres; supermarkets; community pharmacies; education

establishments; and through agency & locality newsletters. Opportunities to maximise reach were taken across social media channels and in printed hard copies to promote widespread messaging.

A clear limitation of this study is the lack of social interaction and public engagement that was possible due to Covid-19 restrictions. The survey team were not able to promote the survey using face-to-face techniques that would usually be a leading component of their engagement approach. Similarly, potential respondents to the survey were more restricted in their socialising and interactions outside of the home, so were potentially not as aware of the survey as they might have been outside of the pandemic.

Who we heard from

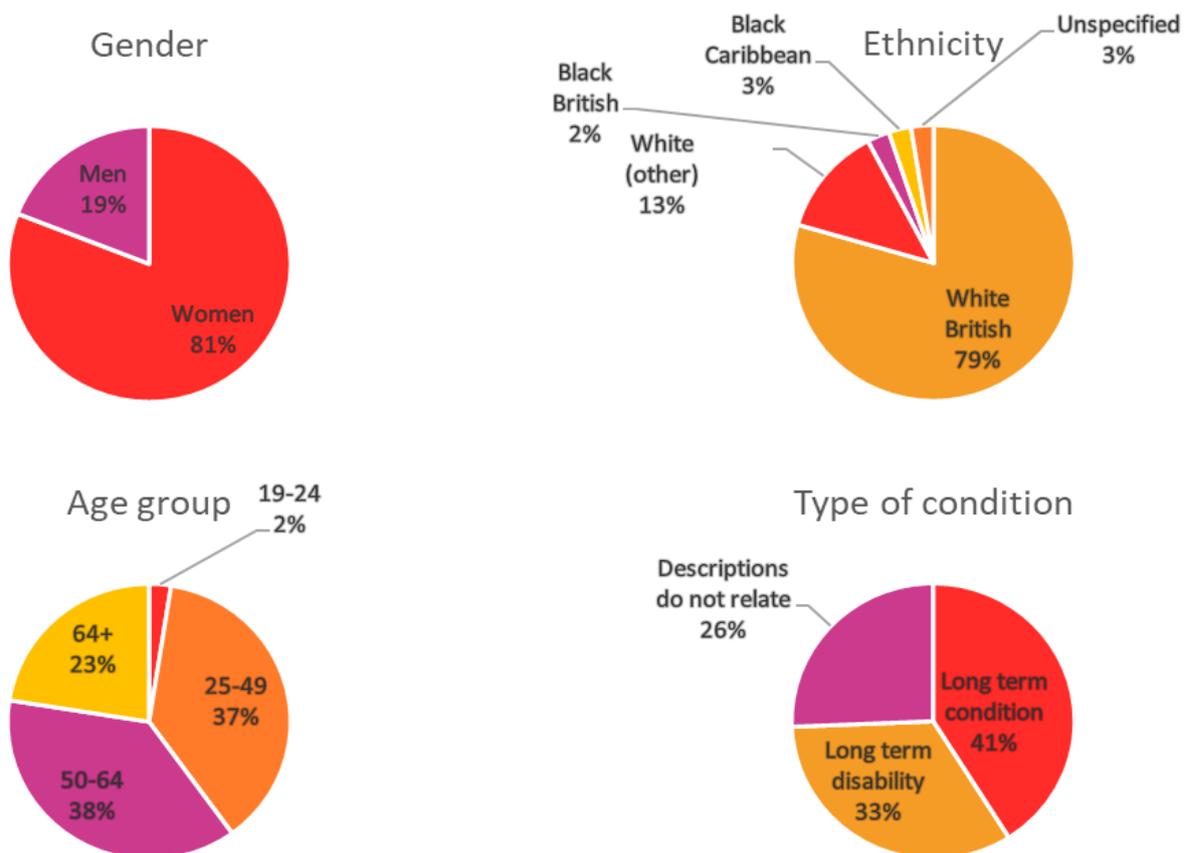


Figure 1

42 participants completed the questionnaire, 34 of whom were women and 8 men. Two of the participants highlighted that their gender was different to that

assigned at birth. Thirty-one participants were White British, five reported to be from a different White background and of the remaining participants who reported their ethnicity, one each reported they were Black British, Black Caribbean and from an unspecified ethnic background.

Fifteen of the respondents reported an age of between 25 and 49, or 50 and 64 each. The remaining participants who reported their age were nine aged over 65 years and one who was between 19 and 24 years of age.

There was a roughly even split between survey respondents reporting bladder or bowel symptoms or both (fig 2).

Sixteen of the survey respondents considered themselves to have a 'Long Term Condition', thirteen a 'Long term disability' and ten reported that they did not feel either of these descriptions related to them. We did not capture information regarding co-existing conditions.

Main Issue Reported

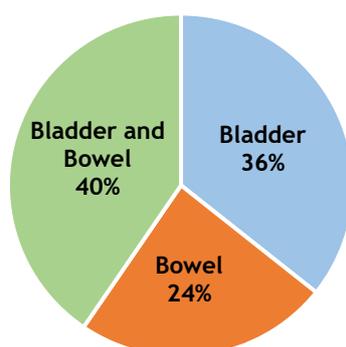
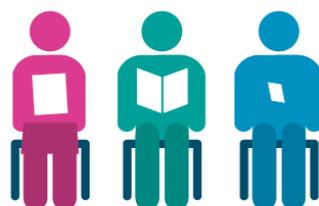


Figure 2

What we found

One in three survey respondents reported their bladder or bowel health had been affected due to service changes. Separately one in three reported that their mental health had been affected by the changes to bladder and bowel service provision during the pandemic, demonstrating far reaching negative impact from these service alterations.



Fourteen survey respondents reported that they receive support from family and friends specifically for their bladder or bowel symptoms. Half of these respondents said their requirement for support had increased during the pandemic. All of these individuals reported that their family or friend providing this care received no support for this role.

Symptom experiences also differed for half of survey respondents during the pandemic due to the requirement to stay at home and interact with others less. The benefit of this imposed restriction for those with bladder and bowel leakage was the proximity to toilets had helped their situation but did not reflect usual life. A choice to deprioritise help-seeking was also described due to feeling that there were other significant demands on services due to Covid-19.

"They're [symptoms] better, as I wasn't as active as before"

"Went from dry to wetting again!"

"I am not on the government list for priority shopping so I have had 'accidents' when I've had to do my grocery shopping".

"Near a bathroom which is better. But totally alone which is worse."

Service accessibility

With regard to direct service access, equal numbers reported that they were waiting to be seen by a bladder and bowel service (13 respondents) or had

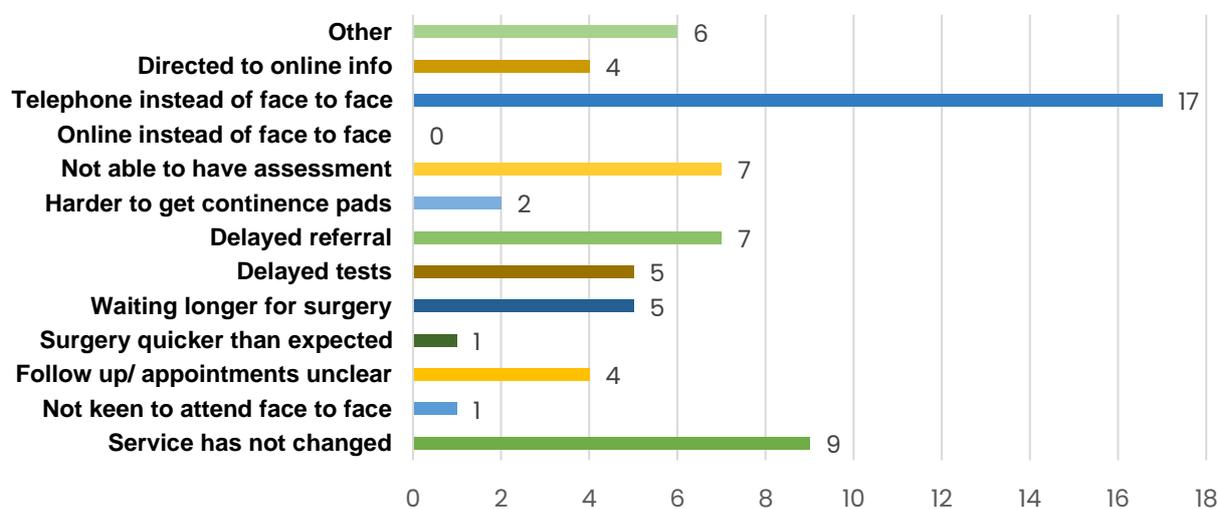
The Impact of covid-19 on people using bladder and bowel services 2020

already been seen by such a service (14 respondents). Eighteen reported that they had had appointments cancelled and only eight said they had received an explanation regarding the current changes.

The nature of service alterations was investigated and almost half (41%, 17 respondents) reported a switch to telephone appointments instead of face-to-face. Nobody reported online appointments as an alternative but 10% (4 respondents) were directed to online resources.

Encouragingly one person reported that their surgery had happened sooner than expected and 22% (9 respondents) that there had been no change to service provision, although it is not clear what level of service interaction they were receiving historically at an individual level. 17% (7 respondents) reported that they had been unable to have an assessment during this time and 29% (12 respondents) reported a delay to their referral or for required clinical tests.

Survey question: Have bladder or bowel services you receive changed due to Covid-19?



Responses provided in the 'other' category referred to broader service impact as illustrated below:

"I was told when he was discharged the service would no longer be available in future due to cutting costs".

"Waiting for referral from my neurologist."

"I've never been referred."

"My GP referred me [for an] endoscopy as I was still under their care but they did not respond or feed back to me or my GP."

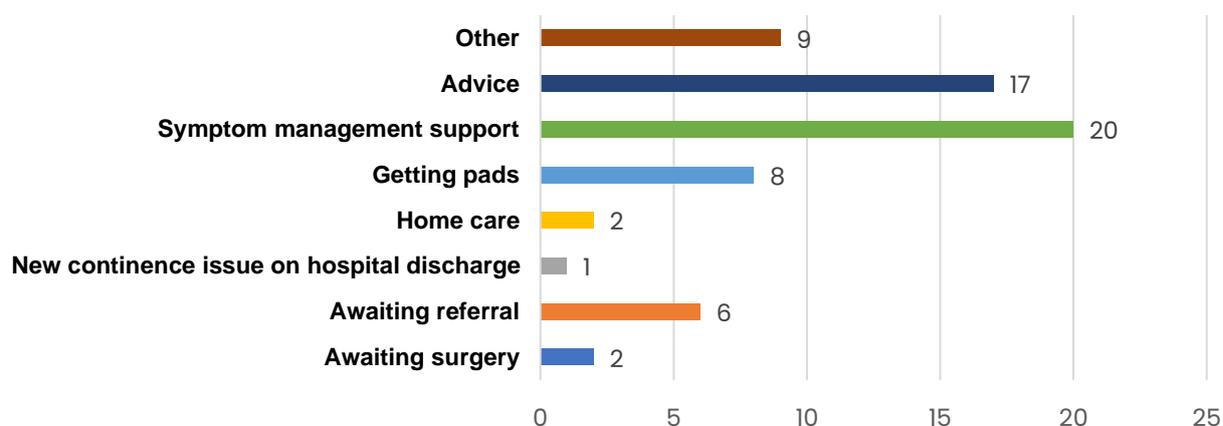
"I had a single telephone appointment during lockdown following which I was discharged."

"Face-to-face meetings have been replaced with twice-monthly phone calls during lockdown and the option to ring a mobile number if we are having problems. My son has been given good support during lockdown."

Nature of service requirements

When asked about the kind of bladder or bowel care people were accessing services for, the most frequent responses were: 40% (17 respondents) reported it was for advice; 48% (20 respondents) for support to manage symptoms; and 19% (8 respondents) to access pads.

Survey question: What kind of bladder and bowel care do you need/use?



Responses provided in the 'other' category referred to more specific

circumstances, but all highlighted some impact on their requirement for services:

“Waiting for initial appointment.”

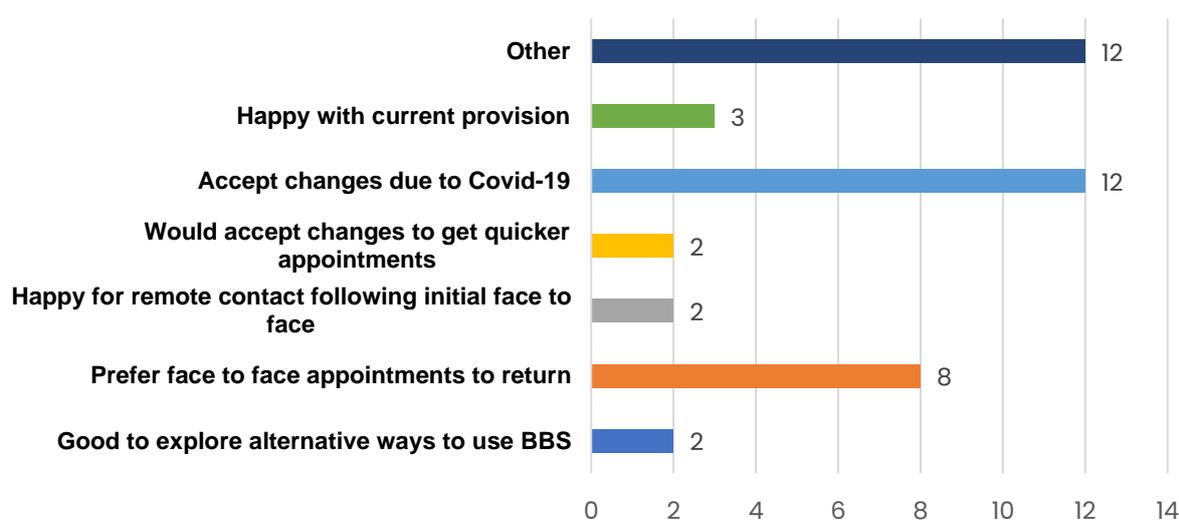
“I was waiting for surgery on my bladder as lockdown happened and all elective surgery was cancelled. My collapsed colon is being self-managed at the moment, to be referred again in a year”.

“Surgeries, physiotherapist and medication seem to have reached the end of the line, so I’m abandoned to manage on my own!”

Future preferences

29% (12 respondents) highlighted that they had only been happy to ‘accept the changes due to Covid-19’ with 20% (8 respondents) stating that they would prefer a return to face-to-face appointments going forward. Collectively, 5% (2 respondents) each stated that it was beneficial to explore alternative ways to use bladder and bowel services; they would be happy for remote contact following an initial face-to-face appointment; and that they would accept these changes to get appointments more quickly.

Survey question: What are your feelings on bladder and bowel care/services during Covid-19?



Responses provided in the 'other' category referred to uncertainties around service provision, some of which predate the pandemic:

"The service I receive at present was resumed last month and I am happy with it for now, but there is a lack of information about how long it will last."

"I feel that I was discharged prematurely due to the restrictions of Covid."

"If anything, the phone calls have been more frequent during lockdown so no real gripes. We have had a review and lots of advice and ideas given to us. My son is less anxious than he was."

"From reading the questions asked, I feel that incontinence pads are available [through healthcare services], I had no idea, I buy mine online @ £57.00 for 48."

Impact of public toilet closures

An overwhelming 71% (29 respondents) reported that they were affected by reduced access to public toilets during the pandemic. Many comments referred to the enduring nature of this issue due to the longstanding reduction in public toilet accessibility. Reduced ability to leave the house, increased requirement for containment products and often emotional accounts detailed a widespread impact that is engendered by this lack of facilities:

"I have been using more pads as a result"

"He's been required to urinate on the street many times."

"It is worse because cafes etc. were closed, but there are never enough public toilets for anyone who has problems to feel relaxed"

"Lack of toilets"

"There are none [Public Toilets]."

Almost got into an argument using a toilet at [private cafe]. It was very embarrassing having to shout to somebody across the place that he has a pee urgency & needed to use it."

"Public toilets being shut during the first lockdown made it much harder to go outside and they remained shut in many outdoor areas throughout the summer".

"Public toilets near where I can go for walks are shut. So, I have to stay near home at all times."

Broader reflections on bladder and bowel care provision

Free text options were used by respondents to describe issues that were problematic aside from the pandemic. These comments fell into three themes: a lack of help-seeking for bladder and bowel symptoms; lack of awareness that such services exist; and an expression of longstanding issues where the importance of bladder and bowel dysfunction are overlooked or deprioritised:

"I just know stuffs wrong, and I've been saying it for years."

Poor help-seeking

"I have never sought advice/help. "

"He doesn't currently have a service, but I believe he needs one."

Lack of service awareness

"Never knew services were/are available till I saw this survey. "

"Just that I feel that it is a rather neglected condition."

"I daren't use toilets elsewhere so if I do feel able to leave the house it can't be for longer than 4 hours."

Deprioritisation of bladder or bowel dysfunction

"They services are clearly stretched and I suspect there's a need for more pelvic floor physios. "

"Service remains over-stretched. "

"Longer term this is going to make many patients much more ill and ultimately cost the NHS a lot more. The situation is dire. I understand Covid is a priority but at some stage the NHS needs support to look after non-covid patients".

"It's rather disappointing and depressing to think that in 30 years there don't seem to have been any advances in treatment for post-natal trauma to the pelvic floor."

What works well?

Descriptive accounts are insightful with regard to perceived advantages of the altered service provision during the pandemic as included below.

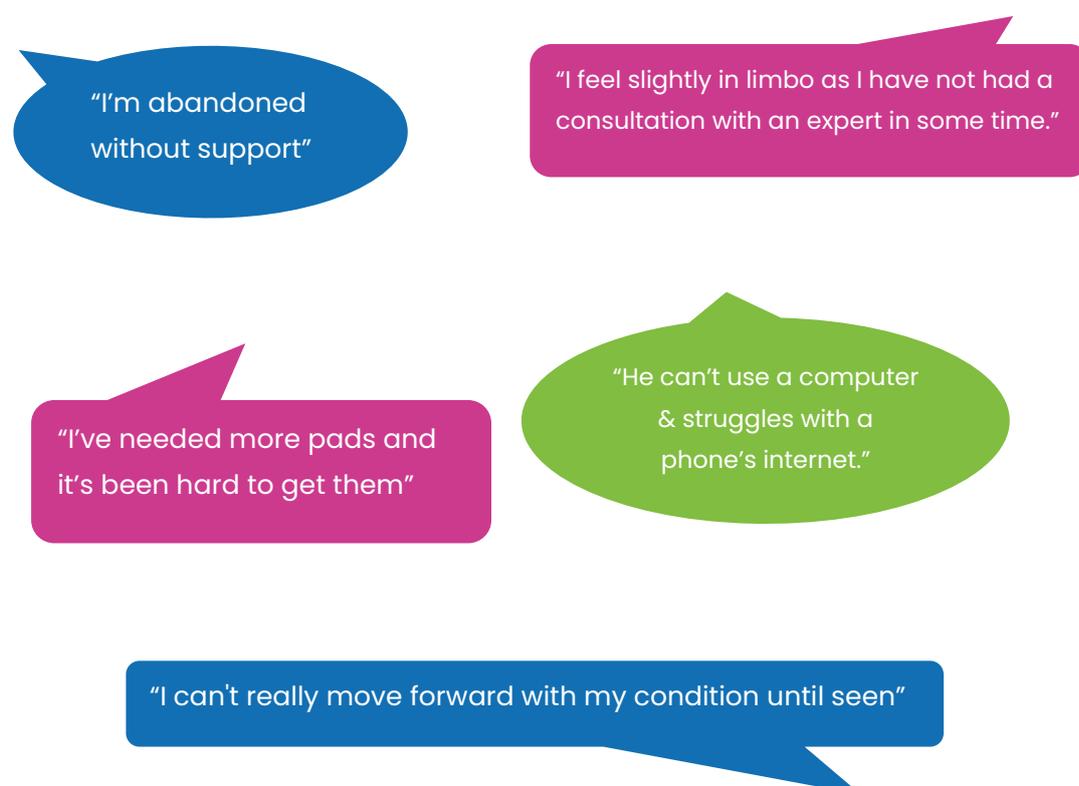
"It is easy on the phone"

"I have found the online support as good as face-to-face"

Further tick box options enabled responders to share other advantages they had perceived during this time of altered provision, including 'preference to not have to attend the clinic' and 'improved accessibility' (4 participants) and some reported receiving care more quickly (5 participants).

What doesn't work well?

A breadth of disadvantages were described ranging from difficulties with technical requirements to feelings of abandonment and stalling progress:



Tick box options again provided quantifiable responses regarding perceived disadvantages, with the main issues being that people feel they have waited longer to access services (14) and that telephone communication is more difficult (7).

Highlights

The pandemic provided an opportunity to document the experiences of those experiencing the consequences of rapid adaptation and service alteration in bladder and bowel service provision. Healthwatch BNSSG and the BABCON HIT

took the opportunity to evaluate this period of rapid change and capture the learning to harness identification of perceived improvements and avoid perpetuating changes that were not working well for the population of interest.

Survey respondents, and the public in general at this time, were understanding of the need to prioritise Covid-19 over other health issues and there was an acceptance of compromised service provision. The global pandemic circumstances were unique, and the alterations were not restricted to continence services alone.

Nevertheless, one in three participants reported that the alteration in service provision had an impact on their physical bladder and bowel symptoms, and separately one third reported an impact on their mental health as a result of these symptoms

Room for innovation was recognised to provide advantages for both service users in addition to service providers by approaching service provision differently. The opportunity to rebuild services that fit the needs of the population is highlighted, rather than returning to traditional healthcare models just because 'it is how services have always been provided'.

Suggestions from the findings are that there is potential for a blended approach to service delivery that suits the needs of the individual, for example a mix of face-to-face and remote appointment accounting for preference, ability and care or assessment requirements. Given that the main requirement of service users was reported to be advice and support to manage symptoms, a blended approach may lend itself well to these requirements.

Clear limitations were evident for some aspects of care provided in largely remote format, such as physical assessment, and it appears that there is not a 'one size fits all' solution. This is important to understand during service recovery and future innovation as digital care provision may provide a more convenient solution but not for everybody on every occasion.

A message of societal underestimation of the seriousness or impact of bladder and bowel leakage was clearly reported, categorised by three themes:

- Reduced access to services or complete lack of awareness of the availability of services was reported due to a lack of visibility and validation that these symptoms are worthy of focus.

The Impact of covid-19 on people using bladder and bowel services 2020

- Reliance on informal caregivers for those with bladder and bowel symptoms who are not well supported.
- Lack of public toilets fails to recognise the far-reaching implications for the many people experiencing bladder or bowel leakage, who rely on these vital facilities to enable activity and interaction outside of the home.

It should be acknowledged that this project was a rapid survey, limited by the nature of Covid-restrictions, but it provides insights into patient experiences that would otherwise have gone undocumented. It is acknowledged that wider diversity in the respondents could have provided differing perspectives and is an area for future enquiry.

Healthwatch recommends

- A review of communication between specialist services and General Practice surgeries and other settings to ensure they have up to date information around bladder and bowel services and available support to give to their patients, providing more effective, safe and efficient care.
- Give patients and carers flexibility for face-to-face and remote Bladder and Bowel appointments with clinicians according to preference and to avoid digital exclusion.
- Further exploration of the impact on carers and the influence of toilet accessibility is recommended to understand the wider impact of bladder and bowel leakage.

Next Steps for BABCON

- Raise the profile of bladder and bowel health nationally.
- Enable those with bladder and bowel symptoms to access high quality advice and guidance to improve symptoms as early as possible, particularly through self-help in the first instance.
- Continue to monitor recovery in bladder and bowel services, in view of the perceived deprioritisation of these services, because of the competing demands of other healthcare priorities as we emerge from the acute

phase of the pandemic.

- Improve awareness and communication of toilet accessibility and identify areas of poor provision.
- Wider engagement, specifically within the following groups: people from non-white backgrounds and men of any ethnicity to understand the perspectives of these less represented groups.

We are extremely grateful to all the survey participants who so openly shared their experiences of bladder and bowel leakage during the Covid-19 pandemic. We are also grateful to all the organisations and outlets that shared the survey to enable it to reach as wide an audience as possible.

Funded by the Bristol Urological Institute, North Bristol NHS Trust and Healthwatch BNSSG.

Contact:

Dr. Nikki Cotterill Director of BABCON HIT and Professor of Continence Care

Email: Nikki.Cotterill@uwe.ac.uk