



It's time to talk continence

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healthwatch
North Yorkshire

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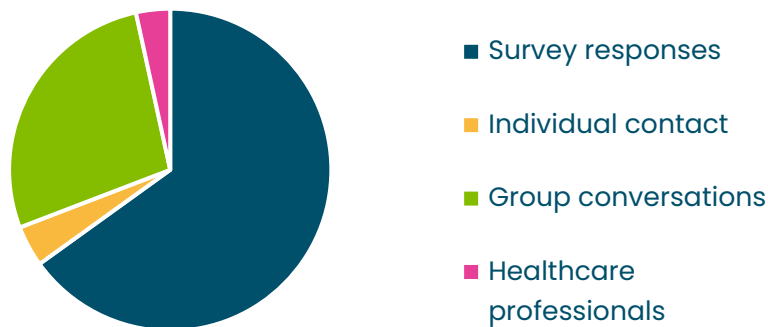
Introduction

From conversations with groups, organisations, and individuals, we realised that continence issues affect many people of all ages across the UK¹, including North Yorkshire. We found that too often issues to do with wee and poo are seen as taboo and are not talked about. This means people are reluctant to seek support and help. Therefore, we decided to undertake a research and engagement exercise to understand what continence services are available to adults living in North Yorkshire and to hear their experiences accessing continence services and living with bladder and bowel issues.

In developing this report and recommendations, we worked in partnership with local and regional organisations. This work would not have been possible without: [Up for Yorkshire](#), [North Yorkshire Council](#), [Tadcaster Volunteer Community Support Association](#), [Second Chance Ostomy](#), [Everyday Enable](#), [Salts Healthcare](#) and our volunteers.

Together we heard from more than 146 people through surveys, conversations with individuals and five healthcare professionals and discussions with groups. We also undertook a services mapping exercise².

How we heard from people



¹ <https://www.bbuk.org.uk/continence-problems-in-the-uk/>

² See appendix for demographic information of survey respondents

What are the key issues?

Stigma

Our research and engagement has shown that there is a significant stigma that needs to be addressed to enable people to lose any embarrassment in talking about wee and poo and particularly their bladder and bowel habits and issues.

Information

We heard about the importance of information for people at every level. This includes more information about how to maintain good bladder and bowel health, where to go if you have an issue, how to get the most from pads and pants and how to live well with your stoma or catheter.

Continence services

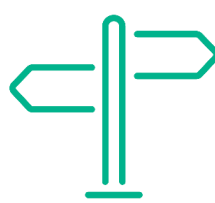
We heard some good practice from healthcare professionals and particularly from continence or long-term condition specialists, but we also heard about areas where things could be improved to ensure people get a better service and support.

Impact on people

There is no avoiding the impact that continence issues have on all aspects of people's lives, from their ability to travel and socialise, the physical discomfort and stigma that people have, the financial worry of having to purchase products, to the isolation that many people experience with continence.

Awareness

Continence issues can affect anyone at any stage of their life. We heard from people about how important it is that we all talk about wee and poo and break down the barriers to enable everyone to have better bladder and bowel health or quickly get any issues treated.



Recommendations

From the feedback and insight gathered, we would encourage the following actions for organisations to help improve public awareness of continence, help reduce the stigma and improve services and information provision.

What we can all do together

- Develop continence information in a range of formats and share this widely through all communication mechanisms including in health and care settings and public venues.
- Encourage NHS & social care staff, the voluntary sector, volunteers, members of the public, and service users to talk about wee and poo, to share information, start conversations and be open to discussions individually and collectively.

GPs

- GPs, practice nurses and others should have proactive conversations about continence even if someone isn't presenting with any issues. This would help people raise concerns.
- Ensure people who are susceptible to urinary tract infections (UTIs) have a flag on their health record so that if an infection is suspected, urine is quickly tested, and appropriate antibiotics are rapidly prescribed to address any infection and prevent exacerbation and possible hospital admission.

Continence services and secondary care

- Follow York and Scarborough Teaching Hospitals NHS Foundation Trust's example and ensure there is a range of continence products available through local formularies in response to people's needs.
- When someone is admitted to hospital, support them to manage their continence themselves, rather than them using pads and pants when they are not necessary.
- Provide an information pack for every new stoma patient before they leave hospital to help them use the products safely and correctly.
- Ensure hospital website information and leaflets are up to date and provide clear information about how people can access services including self-referral where available. Any contact information must

include a range of contact methods to ensure everyone can access the information and service.

- Promote existing peer support groups, such as Second Chance Ostomy, and work with the voluntary sector and patients to develop peer support groups as appropriate.
- Provide the necessary training for staff working in emergency departments and on hospital wards regarding stomas, ostomies and catheters or have information about who to contact for immediate advice if they are not sure of how to support someone.

North Yorkshire Council

- Encourage care homes and domiciliary care staff to have up-to-date information and training on continence. This should include identifying UTIs, using continence products and supporting people with catheters and stomas.
- Encourage social care and other client facing staff to start conversations with people about good bladder and bowel health.
- Work with the voluntary community and social enterprise sector across the county to help collect and redistribute continence products that are no longer needed to support people affected by continence poverty.
- Ensure that public toilets, particularly accessible ones, are open all year round.

Social care providers

- Support people to manage continence themselves for as long as possible. Do not encourage people to use pads and pants when this is not needed.
- Work with NHS continence teams and North Yorkshire Council to ensure all client facing staff are aware of continence issues including identifying UTIs, using continence products and supporting people with catheters and stomas.
- Support continence poverty initiatives encouraging people or family members to donate unused continence products for redistribution.

We are committed to improving continence services, increasing information, and tackling stigma. We would welcome the opportunity to work in partnership with organisations to help make this happen.

What is continence?

Continence is a broad term and can cover many different conditions and issues. It generally refers to a person's ability to control their bladder and/or bowels. Incontinence is when a person does not have that control.

Continence issues can be part of a pre-existing long-term condition like multiple sclerosis, Parkinson's or different types of dementia or it can be a standalone issue. Continence can affect anyone of any age and any time.

What are the continence issues?

Continence issues can include (but are not limited to):

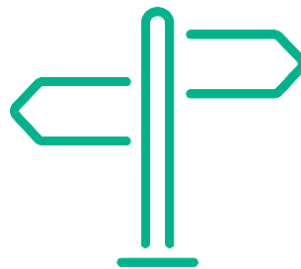
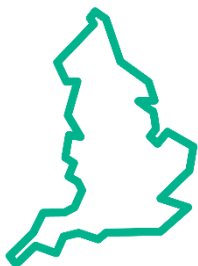
- Urinary incontinence
- Faecal incontinence – can range from the passing of a poo when passing wind to the complete loss of control of your bowel.
- Stress incontinence – the involuntary leakage of urine – often happens when coughing, sneezing and laughing.
- Urge incontinence – the inability to control the sudden urge to wee.
- Mixed incontinence – a person can have both stress and urge issues.
- Overflow incontinence (or drip) – this comes from a failure of the bladder to empty fully and can be common with prostate problems in men.
- Functional incontinence – the bladder is working properly, but there are other reasons that you might not get to the bathroom on time. These could include mobility restrictions, dementia etc.
- Reflex incontinence – occurs due to spinal or neurological trauma or disease.
- Chronic constipation – impacted (hard) stool that is too hard to pass remains in the rectum.
- Diarrhoea – is one of the major causes of faecal incontinence.

There are many reasons for continence issues. For more information, visit the [Bladder and Bowel UK](#) website.

Where are services and support available?

Healthwatch North Yorkshire volunteers carried out online research to identify continence services and support available for people in North Yorkshire. In carrying out this work, they noted:

- It was difficult to find information about continence specific charities. The suspicion is that information for those with linked long-term conditions sits with the overarching charities, for example the [MS Society](#), [Multiple Sclerosis Trust](#) or [Prostate Cancer UK](#).
- Many NHS continence services mention the option of self-referral but no explanation of how to do this.
- Website information for services and support is not consistent, even within the same NHS Trust.
- A lot of continence services, products and advertising are aimed at women, which does not recognise that continence affects people of all genders.
- Many continence services are provided via hospital trusts. It is not clear if the services are available in the community, particularly in rural areas. This is vital as travel could put people off accessing services and support and be particularly problematic when there is worry about access to toilets during journeys.



NHS services

Service provider	Service provider	Districts covered	What does the service offer?
Specialist continence advisory service	York and Scarborough Teaching Hospitals NHS Trust	York, Scarborough, Bridlington, Ryedale, Selby and Easingwold communities	Continence services for adults and older people, including assessment, treatment and management. Also offers advice and support to health care professionals and carers on continence issues.
Integrated prevention, community care and support service	NHS Humber Teaching Foundation Trust	Scarborough and Ryedale	Continence service and continence products.
Continence advisory service	South Tees Hospitals NHS Foundation Trust (Friarage Clinic)	Hambleton and Richmondshire	Takes referrals from hospital urology and gynaecology departments, GPs, district nursing teams, case managers, social services, nursing homes and patient self-referrals. Continence assessment, diagnosis and treatment.
Continence advisory service	South Tees Hospitals NHS Foundation Trust	Middlesbrough, Redcar and Cleveland	Takes referrals from GPs, any health and social care professional and self-referrals. Team specialist adult nurses, specialist occupational therapist and specialist physiotherapy.
Community continence service	South Tees Hospitals NHS Foundation Trust	Middlesbrough, Redcar, Hambleton and Richmondshire	Referral required by GP or self-referral for adults. Children referred by GP, school nurse, health visitor or paediatrician or any health care professional. Assessment, treatment and management of continence.
Specialist continence service	Harrogate and District NHS Foundation Trust	Harrogate District	Information, support and treatment for adults with bladder or bowel problems. Training, education and advice to carers and health professionals.
Specialist continence nurse service	Airedale NHS Foundation Trust	Craven District	

Charities and voluntary sector

Service provider	Districts covered	What does the service offer?
Continence specific charities		
<u>Second Chance Ostomy Yorkshire</u>	Yorkshire	Practical and emotional support for anyone who is about to have or has had an ostomy as well as their families and carers. Runs online and face to face peer support groups.
<u>Association for Continence Advice</u>	Yorkshire	Support for health care professionals.
<u>Bladder and Bowel UK</u>	UK wide website	A national helpline, advice and support in liaising with your GP and other services. Advice to health care professionals. Signposting. Able to order a 'Just can't wait' card, giving accessibility to toilets.
Other charities		
<u>Scarborough and District Age UK</u>	Scarborough and Filey with signposting for Whitby and Ryedale	Social prescribing, advocacy for referrals and support which includes continence assistance.
<u>Closer Communities</u>	North Yorkshire and East Riding	A charity/community started in the pandemic, for families with children with complex medical and behavioural and learning needs. Offers local support, to the children, and families. Continence may be an issue that they advocate and help with. Including access, assessments and funding/prescriptions for continence aids and equipment.
<u>Bladder Health UK</u>	UK wide	Support for people with bladder problems.
<u>Age UK</u>	UK wide	Offers purchasing of continence products, and advice to clients. The profits of products go to the Age UK charity.
<u>Scope</u>	UK wide	Helping individuals and their families lead an independent life, with personal activities of daily living helped with and promoted. Offers advice on continence for all ages.

Please note the information above is not exhaustive and we may have missed some services and voluntary sector support groups.

Stigma and people's experiences

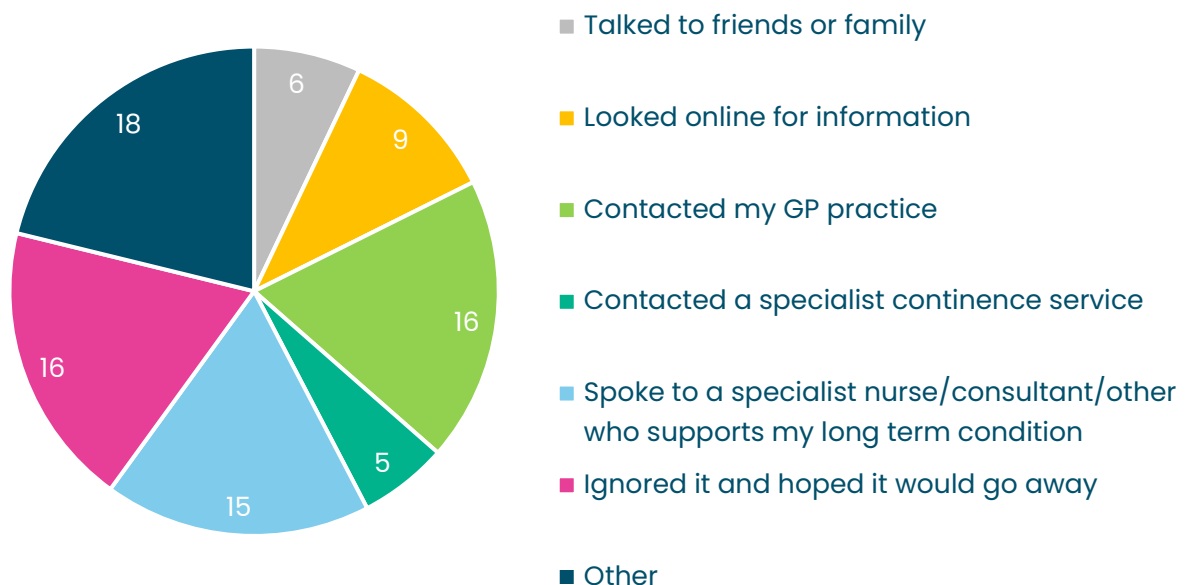
Talking about wee and poo is not common, and the stigma attached affects how people respond to issues they experience.

Information is key to breaking down stigma and we found that information provision could be a lot better across the board. Information also needs to reflect the fact that anyone can be affected.

We asked people who have continence issues what they did when they first realised they had a problem. While many got in touch with healthcare professionals, a significant number ignored the issues and hoped they would go away. The responses in the 'other' category reflect this too.

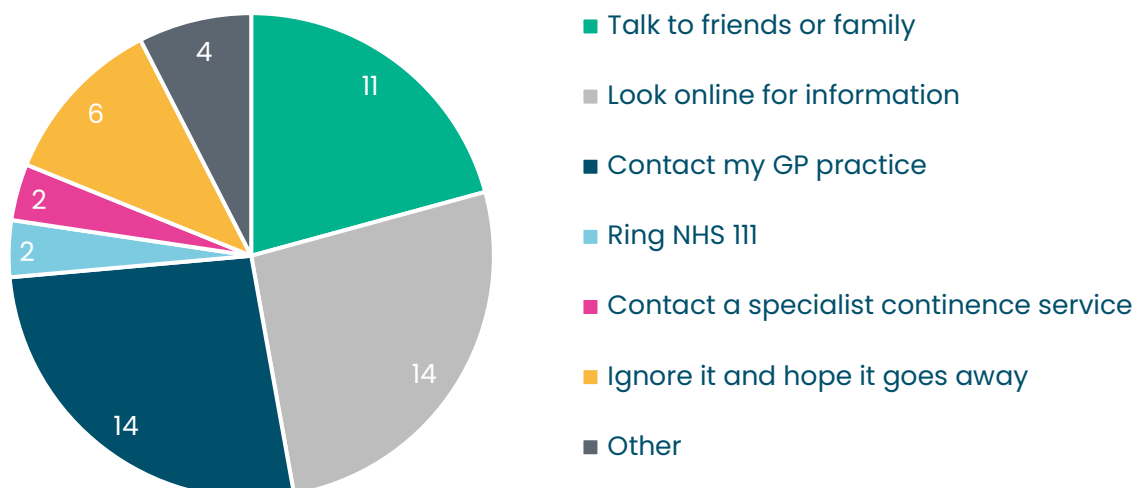
Many respondents said they just bought products (pads and pants) from the supermarket. Others said they had started pelvic floor exercises or adjusted what they were drinking.

Action taken when people noticed a continence issue



The results from the survey for people who haven't experienced a continence issue echo the above response. We asked if people were to have a problem with wee or poo what they would do? There was a mix of responses, but a significant number would also ignore it and hope it would go away or (in the 'other' category) buy products from a supermarket.

If you were to have a continence problem, what would you do?



More than a third of those who responded but did not have an issue said that they knew someone who has a continence issue. This may mean they are more likely to talk about the issue to family, friends, or a healthcare professional.

When we asked what would make it easier to talk about continence the comments received show there is still a lot to do to break down the stigma and embarrassment associated with wee and poo.

"If it didn't seem a taboo subject [it would be easier to talk about]."

"If it was not so embarrassing due to not being spoken of more openly until you get into your 70s and 80s."

"Being able to say poo and wee without everyone becoming embarrassed."

The extent of the stigma is also reflected in the way people talk about continence products. In responses to our survey and in conversations, many people talked about pads and pants as 'nappies', a term that seems to reflect embarrassment or a lack of appropriate vocabulary.

It is clear from our survey responses and conversations with the members of the Second Chance Ostomy community group and the Harrogate Parkinson's UK group that peer support is important. One person said: "It's

helpful when someone has similar issues and knows what to do about it and shares it in a kind way.”

However, there are not many support groups for continence issues. One respondent said: “[Its] good to know it's common. But [it is] difficult to find support groups”. Others recognised the importance of informal support: “Not official peer support but I have a friend with a husband with advanced Parkinson’s and it has been very helpful to talk to her about how to manage the transition to nappies - both practically and emotionally.”

Other people told us it is key to hear other people talk about their issues and how refreshing it is when you see people go to the toilet on TV programmes. However, media and television programmes could do a lot more to show people living positively with continence issues with the right support. As this report was written, it was positive to see a Channel 4 programme about poo: Know Your S**t: Inside Our Guts³.



³ <https://www.channel4.com/programmes/know-your-st-inside-our-guts>

Case study: Jackie

“It was horrendous. When I got to the hospital, I told the surgeon to operate.”

Jackie first noticed an issue as she had stomach upsets every evening. She then found blood in her poo and was experiencing pain. The doctor said it was piles even though Jackie knew it wasn't. Things got worse and Jackie returned to the GP who still insisted it was piles. She had blood tests and was eventually (after about five months) referred to a specialist.

In the meantime, Jackie collapsed and ended up in hospital where she had tests, including a colonoscopy, and was diagnosed with inflammatory bowel disease. She was discharged with medication. It worked for two months, but her symptoms came back. At the worst, Jackie was going to the toilet up to 50 times a day and couldn't leave the house to collect her six-year-old son from school. Different treatments didn't work so surgery was mentioned.

She went, by bus, to York Hospital for an appointment and doesn't know how she got there. The surgery went well. Jackie was in a lot of pain afterwards and was shocked at the length of the wound and by the clear bag that was her first stoma.

The impact of having a stoma is life changing. Jackie's symptoms had gone, and she could go out without a toilet close by. However, she struggled with the emotional impact and saw the effect on her family, particularly her son. At no point was Jackie offered mental health support or counselling. She didn't even have the option to talk to someone who was living well with their stoma to learn from them, and all the online groups were full of problems and negativity.

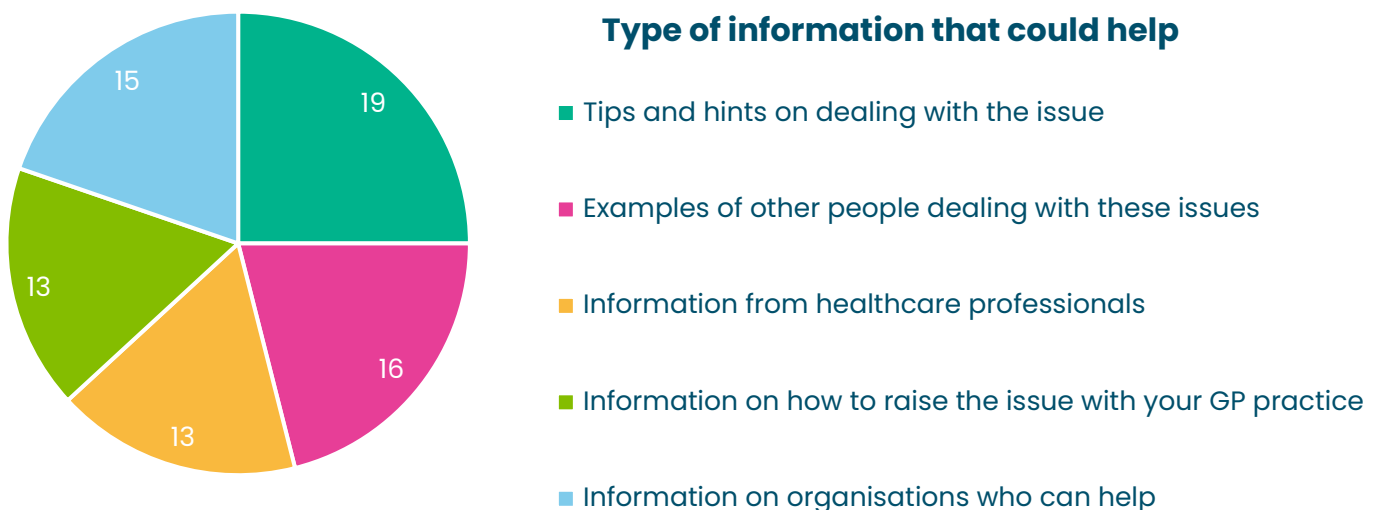
That feeling of isolation after her operation was one of the main reasons Jackie set up Second Chance Ostomy, a community group for people with a stoma. The first meetings took place in 2020 which were online with face-to-face group meetings starting in 2021, after COVID lockdown was over. It has grown incredibly from there with online members around the world and everyone delighted to find somewhere their questions would be answered by people who understood.

Good bladder and bowel health

We heard from specialist continence healthcare professionals about how important good bladder and bowel health is. There are plenty of things everyone can do to improve their bladder and bowel health, but very few people know about what to do and often only find out after they have a problem.

One person said they only got information about the foods and drinks that could help or make things worse because of a physiotherapy appointment. They felt this information would have been more useful when their issues started or even before that. Another person mentioned: "I have read that there are 'pelvic exercises' that can strengthen the muscles controlling the bladder." However, the person did not know where to find any information about this.

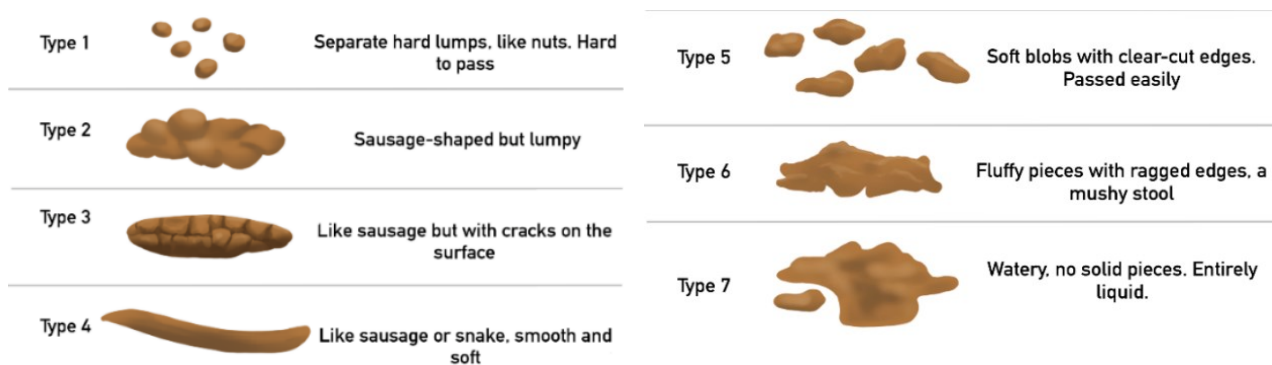
We asked people who hadn't experienced any continence issues what kind of information they think could help if a situation arose. People had the chance to select as many options as appropriate for them but out of 25 respondents to this question, the majority (76%) said tips and hints on dealing with continence issues would be helpful.



People identified keeping a bladder or bowel diary to understand your body's normal patterns is a good way to help identify issues. However,

unless someone has a continence problem, there is no information or advice that this could help.

We found very few people, apart from healthcare professionals, know what the Bristol Stool Chart⁴ is. However, this is important for us all to identify if we might have an issue.



Continence professionals at York and Scarborough Teaching Hospitals NHS Trust have begun to provide training and awareness for staff and residents at care homes about continence. This has been very well received and the team hopes to continue and expand its educational work depending on staffing and financial resources.



⁴ <https://publicdocuments.sth.nhs.uk/pil3883.pdf>

Case study: Allyson

“I’ve never had a problem talking about wee and poo – it is part of a natural process and it is important for people to talk about it.”

Allyson was a nurse working with people with a learning disability including talking to them about continence. Since retiring, she has had cancer and her own experience of continence issues as a result.

“When you talk to people about cancer, constipation is common. In a national NHS survey, it was in the top five things that people needed information about or support with. When I was diagnosed, I had a health needs assessment. The only related question I was asked was about bowels, i.e. ‘have you been?’ Nothing else. When you have chemotherapy, you can have problems with diarrhea or constipation. A pharmacist gave me medication, but a nurse never followed it up. A phone call from a nurse would have been helpful, just to check everything was OK.

“When you are diagnosed with cancer, there is information there (particularly from Macmillan) and there is a clinical nurse specialist you can ring if you have problems. But women are often not raising anything as wee and poo is still seen as taboo.

“In my work, we used to get people to keep charts to understand what was normal for every person, because it is different. It matters what people eat and drink and exercise is important.

“The Bristol stool chart was part of conversations as it is important for people to know about their poo and what’s normal. People also need to understand what the colour of their wee means. It matters. Questions about wee and poo need to be regular questions. They give an opening for people to share any problems or worries. GPs should ask.

“There needs to be information about where people buy products – e.g. In chemists or supermarkets. Tips and hints on good bladder and bowel health would be good. We need to give ideas about what people can do – eating, drinking enough, doing exercise etc. – to keep bladder and bowels healthy.”

What to do if you have a problem and who can help

Some people that we heard from who hadn't experienced any continence issues said that they would still be interested to find out who could help or how to raise issues with healthcare professionals in case they needed help in the future.

Many respondents said more information would help them feel they are in control. Our respondents said that there needs to be more information on what is normal, what issues you might experience if diagnosed with cancer, up to date information on treatments, tips for good bladder and bowel health and information about who you can talk to about continence issues.

"We need more information about bowel and bladder issues when diagnosed with cancer."

"Women's physio roles still exist but it is not always clear who funds them and how people get referred."

"More information with up-to-date treatments and procedures should be readily available and easily accessed."

"Medication and tips on how to empty bladder better are required, as well as being advised about some foods that are known triggers for bladder incontinence."

"A symptom checker is needed to get an idea what and why it happens."

"More information is required about 'what is normal?'."

We have heard from continence specialist services across North Yorkshire that they have or are developing screening tools for people to use to help identify issues. This is a positive step; however, these are currently not always well publicised or known about. Our mapping exercise showed what services are available, but where and how to get in touch with specialist services is not always clear. This was reflected in feedback from people about how information could be better.

“We need information about local continence services – these are different depending on where you live and some services have self-referral, others are via the GP. Need to be clear what is there and how to access it.”

“I seem to be in the minority that knows that there is a continence advisory service available. Many people I have spoken to are totally unaware that there is help there or how to access it.”

Continence products

Continence products can include pads and pants (from a supermarket or via the NHS) as well as catheters, stomas and more. Our feedback shows that often people don't feel that they have enough or the right information about the products and how to use them, even for those supplied by the NHS after an operation or procedure. This includes a lack of awareness that there are different products for women and men. Feedback from continence specialists also highlighted the need for people to have more information about how to use pads and pants. For example, just taking them out of the packet and putting them on means people do not get the best from them.

Many people attending the Second Chance Ostomy peer support group said they did not get enough, or sometimes any, information about their stoma before leaving hospital. Almost everyone said people need a full information pack while in hospital. Ideally, a nurse or other healthcare professional would go through the key elements with them, but having a comprehensive information pack, including links to useful websites and contacts for stoma helplines would be a starting point.

Such information is already available. All stoma product companies provide booklets. However, people must go and find the information for themselves, so it would be better if this could be ready for them when they leave hospital.

Stoma information pack

The kind of information people would like to see in a pack includes:

- Information about different products and how to order new products after leaving hospital.
- Links to helpful websites or advice lines providing advice on changing bags, good stoma hygiene, information about helplines where people can go to get questions answered etc.
- Information about the ostomy, potential side effects and things to watch out for.
- Advice on diet, such as what you can and can't eat or what to be careful with.
- Advice on exercise and activity and what you should or shouldn't do.
- Information about how to reduce the likelihood of a hernia. Hernias are common after bowel surgery, but no one we spoke to had received any information about this and very few people realised the increased risk.

People attending the Second Chance Ostomy group also suggested follow up after surgery would be helpful. Very few people had any contact with a stoma or continence nurse after they had left hospital.

We also received feedback about pads and pants as some people struggled with NHS provided products. Some of the issues may result from people not having good information or guidance about how to use them, but some feedback highlighted how the products provided were not always appropriate.

"The pads the NHS supply are not easy to use and not comfortable to wear. They are sent by a supply company in huge quantities which are difficult to move and store."

"The pads that we get on the NHS are useless and often don't give enough coverage."

"I live alone in a wheelchair, so it took time to learn how to put on the products and how to avoid leaks etc."

“The continence products (pads and pants) that you get on the NHS are useless. When I rang to see if I could have something different, I was told to try the pads for longer. I think most people would give up and buy their own, but these are expensive.”

“I was appalled by the only NHS continence pad provision, which was cutting chunks off a roll. They were very visible and very insecure.”

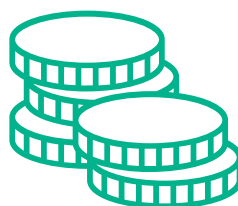
We heard from the continence team at York and Scarborough Teaching Hospitals NHS Trust that they have ensured that there are three continence products (pads and pants) available on the formulary (list of recommended medicines or medical devices). This is a positive step forward as often there has only been one option that is not appropriate for everyone.

We also heard about continence poverty, an issue that has been raised by several people and organisations who are supporting people buying products themselves. Where people buy products themselves, the increasing cost of living could mean people having to choose between continence products or other essentials or using products for far longer than intended, which could increase infection risk.

“You need to recognise a difference depending on people’s income, but also people using [individual] products for longer than they should due to costs.”

“My husband dislikes how much money my pads cost. Free ones from the continence nurse are too thick.”

“Rushing to the toilet, changing pants etc is very tiring so I don't change as often as I should – it saves money too! I am told this is not good for me, also they leak after a while and ruin the chair.”



Case study: Esta

“It wasn’t normal for someone my age. I was embarrassed and didn’t want anyone to know. I bought continence pants to wear, which felt like wearing a nappy, and hoped it would go away.”

Esta was 18 and at university when her bladder issues started. She had issues with retention and weeing with no control and no knowledge until it happened. She didn’t know what to do.

Whilst in hospital with sepsis, they fitted a urethral catheter to try to help with the bladder issues and referred her to urology at the local hospital. They ran a number of tests, but they were inconclusive. So, Esta was referred to Bradford Royal Infirmary where she had more tests.

One test saw Esta drink to fill her bladder, which immediately emptied. They knew something was seriously wrong. The consultant said they could try Botox to stimulate the bladder, but it wouldn’t work in the long term. He suggested a urostomy and a stoma which could not be reversed. During this time, Esta was fitted with a suprapubic catheter as she had been having a number of urinary tract infections (UTIs) which they hoped a different type of catheter would help.

The catheter wasn’t working, and Esta still had leaks. She had extremely painful bladder spasms multiple times a day, had to have the catheter changed under general anaesthetic every month or two due to the pain and was still getting a lot of UTIs. She said: “I had missed out on so much at university and was very low with my mental health. If I hadn’t had the operation and stoma at that point, I don’t know what I would have done.”

The operation is rare, and Esta was the youngest person to have the procedure at Bradford Royal Infirmary. Esta urged them to remove her bladder, which they found was completely ruined. The surgery was a success. The recovery was hard, but it has made a huge difference to Esta’s life.

There is no pain now, the infections are gone. From being in hospital every few weeks, Esta hasn’t been for a few years. She can go out to concerts and events without thinking about it and doesn’t have to plan journeys round where the nearest toilets are. She and her family even have birthday parties for her stoma. Once she got used to it, Esta became proud of her stoma. She wears it outside her clothes for comfort and has specially designed bags to cover it. She has even blogged about as [#itsinthebag](#) and fifty shades of wee.

Esta said: “Being told you need a urostomy and a stoma forming is a scary prospect. It can be a big operation depending on how it is done. Worries and fears about the future are natural, but once you have recovered and settled into a new type of life with a stoma it becomes normal. My quality of life is so much better now with the stoma after all it’s only a bit of wee and we all do it. Stomas are life saving and life changing – mine is.”

Continence and childbirth

Continence issues resulting from childbirth are not common but do happen. Working with Maternity Voices Partnership groups across North Yorkshire, we asked for feedback from women who are pregnant or had given birth in the past 12 months. We wanted to know if people had been given advice about possible continence issues resulting from childbirth, what information they would have liked and people's experiences.

We only had five responses, however, all of those said they would have liked information about continence before getting pregnant, during antenatal classes and/or at pre-birth discussions with healthcare professionals. Of the five responses, only two people had received information before giving birth, one person from an antenatal class and the other from her mother.

The type of information people wanted to find out about was how common it is to experience incontinence because of childbirth; that it can happen; why it happens and what you can do to improve matters; and exercises to do while pregnant.

Of the five respondents, four had experienced continence issues after giving birth. These issues had some impact on three people's lives and quite a lot of impact for one person. In all instances, the respondents said that they had not had much, if any, support for the issues.

While it is a very small sample, we also had responses to the general survey from people who had experienced issues due to poor healthcare during childbirth.

"I had an operation to repair the problem which had been brought about by poor care during childbirth."

"My dilemma was avoidable; it was due to inexperienced midwifery care."

Experiences of continence services

We asked people who had experienced continence issues about the support they received.

Of the 60 respondents, 32 people said they had received support and 28 had not. It is not clear whether this is because they had not asked for support or had asked and not got any support.

We then asked people to rate the service that they received help from. As shown below, a mix of ratings was received for the different services listed.

Views of continence services



GP practices

Positive

One person said they went to their GP about a urine retention issue. This was severe, so they were referred to get a catheter to address the immediate issue, which worked well.

One person said they had blood in their urine so went to their GP and were seen on the same day. They were fast tracked for a cancer two-week pathway. They had an ultrasound and CT scan, which ruled out cancer. The whole process was excellent, the GP and Harrogate Hospital were very helpful and supportive.

There was praise for allied health professionals, such as dieticians, who have helped people get useful prescriptions from their GP.

"A dietician was willing to listen, research and advocate with my GP for prescription probiotics."

Negative experiences

Several people said their GP was dismissive of their continence issues.

"I mentioned it to GPs repeatedly, but they don't seem interested."

For people with a stoma, GPs are often not helpful. One person saw their GP who said, 'I don't know anything about it' and referred the person back to the surgeon who operated on them.

Several people who went on to have stomas said their GP had initially said it was piles, even though the person knew, and said, it was not.

"It could have been explained better and in the beginning, I should have been referred to the hospital sooner, instead of keep saying it was piles."



Specialist continence services

Positive experiences

There was praise for continence specialists and nurses when people were able to see them.

“The incontinence specialist at Selby Hospital was excellent and gave life changing suggestions.”

“The incontinence specialist was so helpful getting me to try so many things and finding things that helped like anal irrigation. My husband also has MS and had constipation and she sorted him out and now rarely has issues.”

Negative experiences

Issues were raised that local staff do not always have the skills or experience to do some of the more complicated procedures and treatments that people may need.

“The local incontinence nurse is brilliant and totally approachable and easy to talk to. Unfortunately, locally we have none of the skills or experience to do any of the more complicated procedures or treatments, so I have to be referred to the specialists in London. The waiting lists are enormous, and the travel is exhausting and I have to manage it all myself.”

“Speaking to the incontinence professionals who deal with this everyday [is good] as they get it, but the frustrating thing is the local ones are not sufficiently trained to be able to help beyond nappies.”

One person said the nurse they saw was not very helpful and did not make use of their care plan, meaning their continence issues have continued.

“Initially (about seven years ago) [it was] very good. Latterly, very poor. I needed reassessment for specialist incontinence pads. The current Tena nurse was most unhelpful, didn't consult my care plan that specifically states not to be rolled due to dislocated hip and various other issues that needed addressing. Consequently, my wheelchair cushion was wet daily and soiled several times a week.”

There were also comments about the long waiting times to receive continence support via the NHS, which has led some people to seek private treatment where they can afford it.

“The gastroenterologist was brilliant. [I was] seen quickly as a private patient. NHS was a two-year wait, and I was permanently incontinent. A specialist sent a treatment and medication plan to my GP which took another three months to start. The specialist had to chase the GP repeatedly for them to issue the prescription.”

One person said her son has epilepsy and Type 1 diabetes. At one point, he was having four or five seizures every night and wetting the bed as a result. He saw the continence nurse who suggested pads rather than trying to find the cause (his epilepsy wasn't diagnosed at that time). Since his epilepsy diagnosis, medication means his seizures are rare and he no longer has continence issues.

Long-term condition support (e.g. MS, Parkinson's)

Positive experiences

There was praise for the medication and support some people have received via other organisations that help people with long-term conditions such as MS and Parkinson's.

“Medication to make my poo firmer. Stopped that now as my pelvic floor control has improved and used the techniques suggested by continence nurse referral from MS nurse, with positive effect.”



Negative experiences

Some people said they have not received any support for their continence issues that are a result of other long-term conditions they have.

“I understand there are not enough people with my condition to commission local NHS services of sufficient competence, but it would be really helpful if the need was at least recognised and there were established pathways to refer us out of area to the specialists who can actually help.”

“Although not much can be done about my condition, it would’ve been good to have at least yearly appointments with continence services to monitor situation and bladder health.”

Several people also mentioned poor communication and coordination between different services. For example, one person said they have experienced confusing communication between York and Leeds hospitals where they were told by York hospital about next steps, chemotherapy and timings, but then saw the surgeon in Leeds who told them something completely different. Another person said they were told by the Macmillan nurse in York there was ‘no point in getting in touch with me as I won’t know what’s been done’ for a York patient who had surgery in Leeds.



Case study: Dorothy

“Shame is the biggest thing. I can’t control my own body and I am ashamed. It is particularly bad for wee and poo as they are such private things and so fundamental.”

“Having continence issues stifles my social and work life. There is so much embarrassment. I don’t accept invitations for some activities like walking and outdoor things as I don’t know where the nearest toilet is. And I know if I’m stressed it aggravates the problems. I once read a definition about disability as affecting your daily living. I never thought I was disabled, but in that definition, I am.

“I have memories of urgency at primary school, where I often wet myself. I think it is something genetic as my mum had issues (that she never talked about) and some of my children have had their own issues.

“It took me decades before I sought help. Initially, I just restricted the fluid I drank but I now know that wasn’t a good option. I’d had three children by the time I went to see my GP. I was 40 and pregnancy made everything even worse. After I’d had my first child, I was in hospital and needed help to go to the toilet. The nurse asked if I had any issues and I said no. I wasn’t ready to admit it.

“I couldn’t go on as I was anymore. I went to the GP and she referred me to a specialist and told me that I would need surgery as it was so severe – something I dreaded. The consultant was lovely and helpful. He said I had a hyperactive bladder and stress incontinence and that an operation wasn’t appropriate, which was a massive relief.

“When I moved to York, I saw a women’s physiotherapist. She was excellent and looked at how to stimulate and then strengthen my muscles, which does help. Lockdown triggered a number of issues, and I was struggling. The physio was there for me to talk to, she really listened, took a holistic approach and made a real difference.

“The consultant tried me on Botox, which was experimental at the time. It was transformational, but I didn’t continue as I think it may have reduced some of my sensitivity and sensation.

“I have been back to my GP and hospital to look at further tests to see if there was anything they can do. The consultant was very good and the nurse excellent. They were very empathetic.

Case study: Jamie

“Eight months ago, I started having problems with my bum. It was bleeding and I was in a lot of pain. Initially I hoped it would go away. But it got worse.”

“I went to my GP. They did a prostate check and blood tests. I felt I wasn’t being taken seriously and had to use certain trigger phrases to get something to happen. I was given some ointments, which did help a bit initially, but they didn’t solve the problem.

“It all got a lot worse, and I was in chronic pain when sitting and even worse when driving with severe bleeding. I contacted my GP once every week or fortnight but was told I could only have an appointment in three weeks unless it was an emergency. For me, it was an emergency as I was in so much pain with a lot of bleeding. I wanted an appointment to see a specialist but was told it would be 12 months to see someone and 18 months for a colonoscopy as it wasn’t cancer.

“I was astonished and knew I couldn’t wait that long so started looking at the costs of going private. In the meantime, I spoke to the specialist’s secretary who said ‘I don’t know why you’re worried as they don’t think it’s cancer’. I was shocked at this response and raised it with PALS (Patient Advice and Liaison Service).

“As a result, I had a colonoscopy appointment three weeks later and saw the consultant. He diagnosed an anal fissure and prescribed fibre supplements. He also recommended a follow-up appointment with my GP.

“The consultant gave me a letter which he also sent to my GP. It said I would need fibre supplements in the medium to long term. When I went to get a repeat prescription via my GP I was told I would have to buy the supplements myself. I had to challenge my GP and show them the consultant’s letter before they agreed to a repeat prescription.

“Everything has been a battle.

“Things are now manageable, and it was a relief to have the appointment and colonoscopy to know what was wrong and that it wasn’t something more serious. But if I hadn’t contacted PALS I would still be waiting and in total it probably would have been two years until I had the colonoscopy.

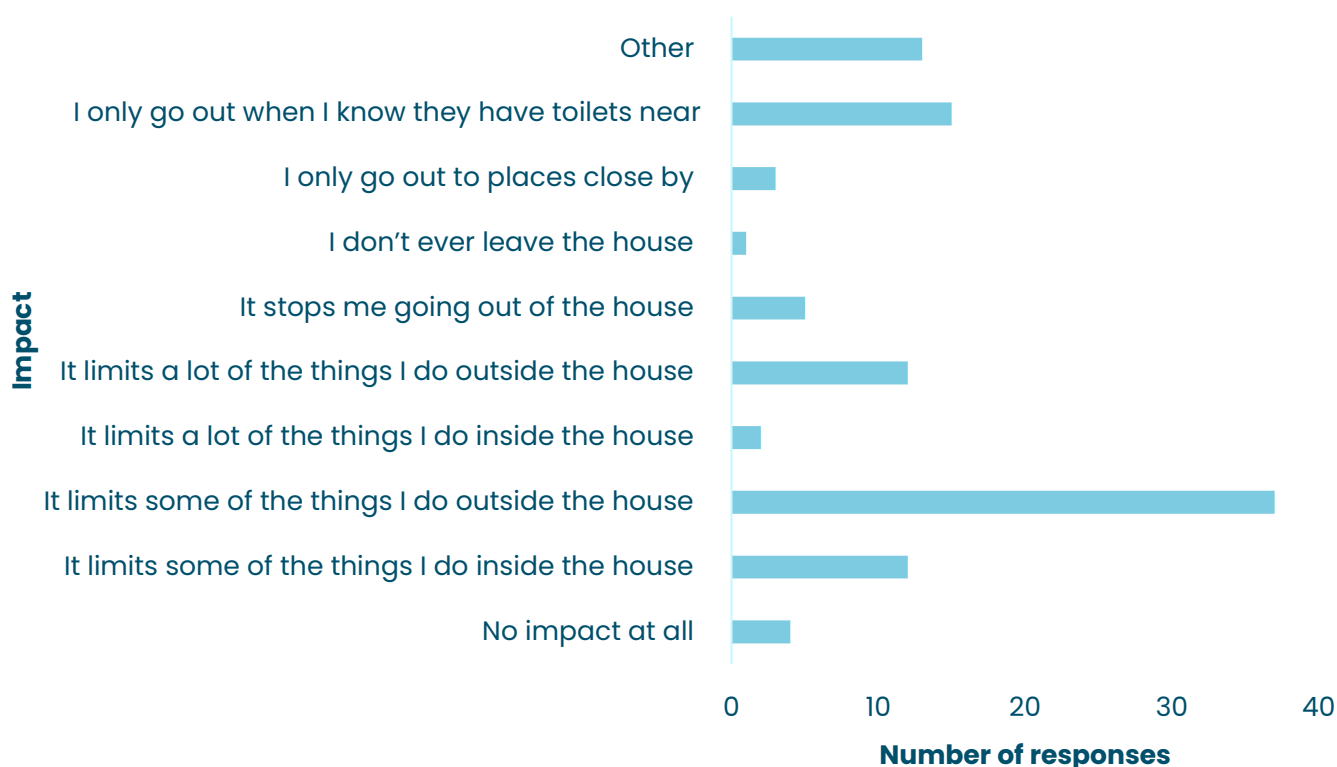
“I am very worried about people who don’t kick up a fuss and will be waiting in awful pain for up to two years.”

The impact of continence

Issues with continence can significantly affect a person's life and can have knock on effects for their family. This can include having to plan every trip to ensure you have everything you need in case of accidents and knowing where all the nearest toilets are. This can mean that some people do not go out very much, or at all.

Continence issues can be very isolating and due to the stigma, people can find it hard to explain the issues to friends or family and be seen as anti-social or not wanting to join in and find themselves losing contact with others. We asked people who experienced continence issues about the impact on their lives and there is some impact for almost everyone. People shared the impact for them, including a common plea for more public toilets and for these to be open all year round. People living in coastal areas said that public toilets are only open during the tourist season, so they cannot go out during the colder months.

Impact of continence problems



“Having continence issues is a nightmare. You always must take a lot with you, including continence products, a full set of clean clothes etc. and know where the toilets are just in case.”

“It's expensive and tiring. It's embarrassing and limiting. Anything to make it less so would be welcome. And we need more public loos.”

“More public toilets everywhere. I'm constantly planning my route /activities depending on amenities.”

“It is completely life limiting - I can only leave the house for 90 minutes if I dehydrate myself for 12+ hours or wear a nappy.”

“For many years it spoilt family holidays, get-togethers and it wasn't very nice for my husband or kids to witness my episodes of worry.”

“Very damaging to friendships and social life. Lots of activities I can't do such as large gigs, I frequently need to cancel or change plans so friends tend to get fed up and drift off.”



Conclusion

Our research and engagement has highlighted the impact that continence has on people and the need for bladder and bowel health and issues with wee and poo to be talked about, information to be more available and barriers to be broken down.

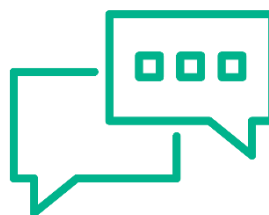
Whilst our findings are limited by the number of people we heard from, they provide a snapshot of the many challenges faced by people who live with continence issues on a daily basis.

Problems with bladder and bowel affect people of all ages, backgrounds, and lifestyles. Continence can be part of an existing long-term condition, or a standalone condition and it significantly impacts the quality of people's lives. However, with effective treatment, information, and support, this doesn't have to be the case.

We hope that this report will help to start continence conversations across North Yorkshire. We also hope that our findings will support the excellent work that specialist services and healthcare professionals are already providing and will highlight the need for more support and for training and information to be available at a much earlier stage, for example in GP practices and in the community, such as supermarkets and libraries.

Thank you again to the organisations and volunteers who were part of this project. Thanks also to those who shared and circulated the survey and to everyone who responded to our questions, including healthcare professionals and continence specialists for sharing their experiences and ideas.

This report would not have been possible without you.



Our thanks to:



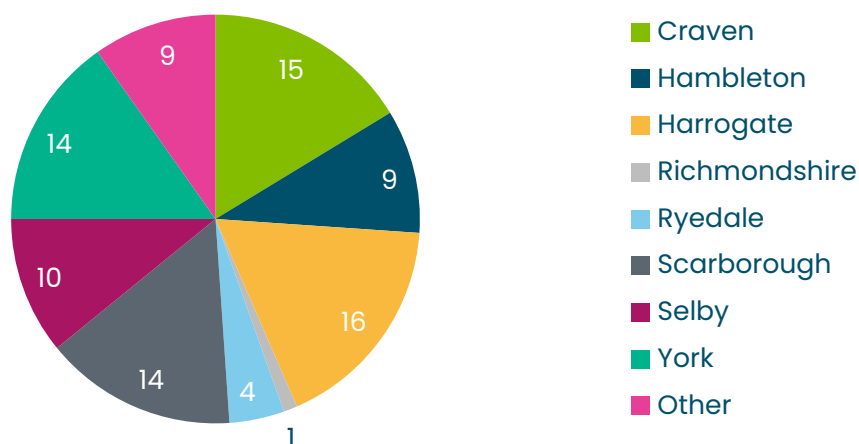
Tadcaster Volunteer Community Support Association

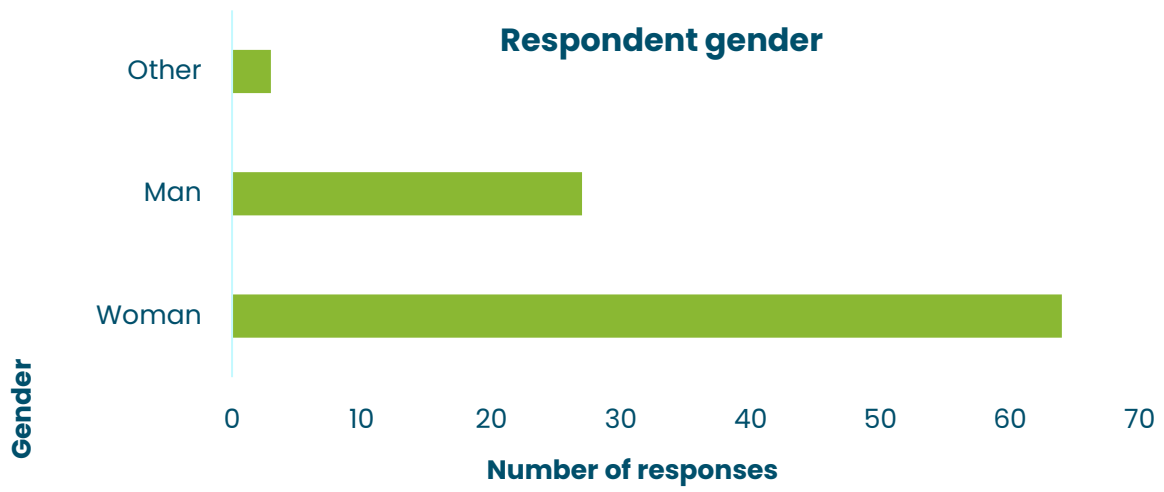
Appendix

Demographic breakdown of survey respondents

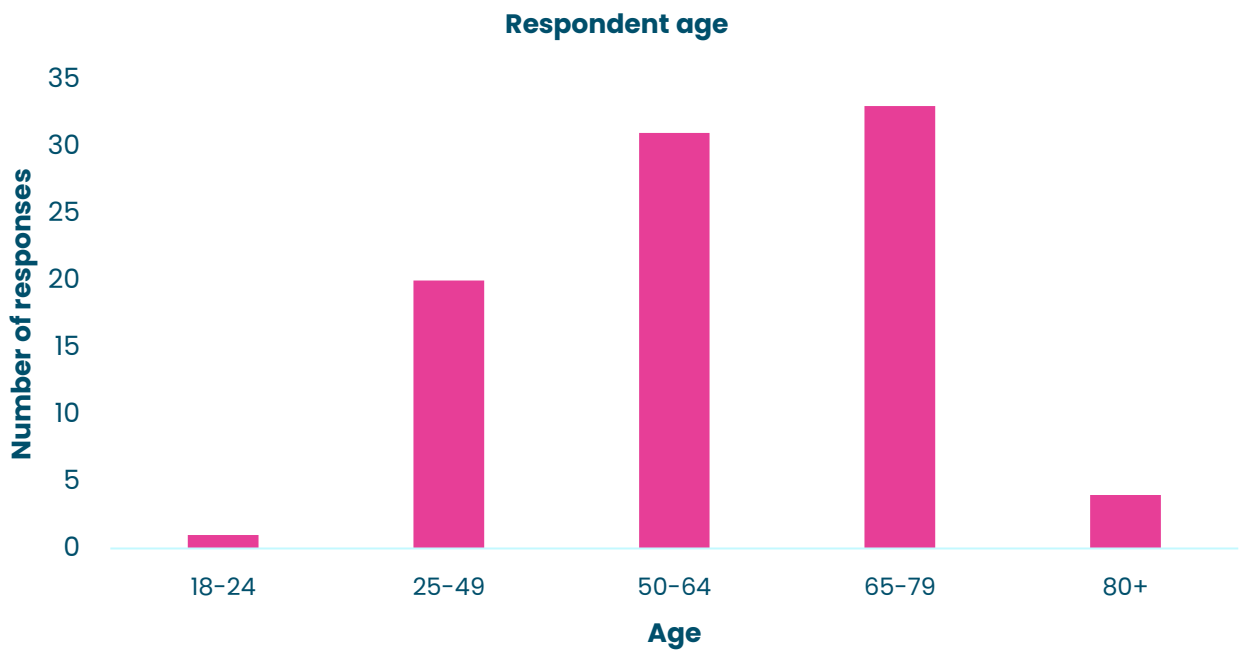
Ninety-five people responded to our surveys from across North Yorkshire:

Where respondents live





Most were women and there was a good mix of respondent ages:





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