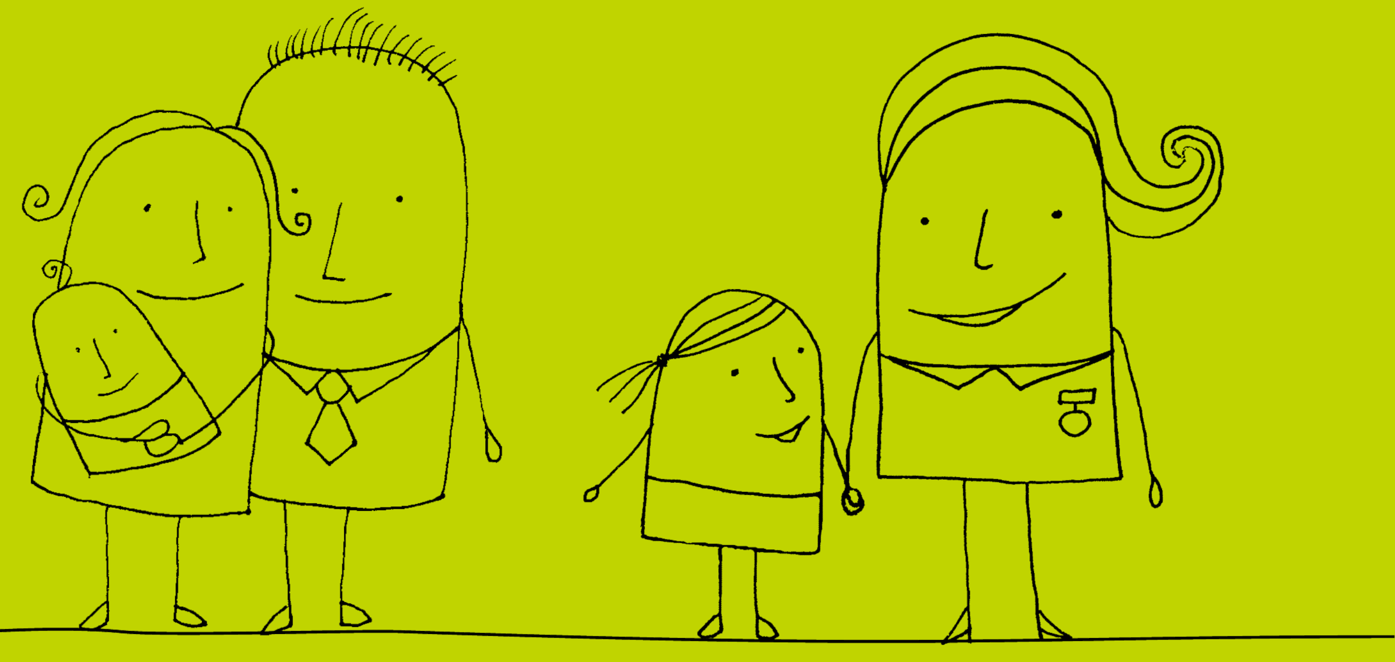
Patient and Client Council
Your voice in health and social care

Accessibility and Quality of Continence Services in Northern Ireland

May 2020



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1.0 Introduction

1.1 What are 'continence issues'?

Continence issues affect people's ability to control their bladder and/or bowel movements. Common bladder problems include urgently needing to pass urine, bladder leakage, bed-wetting or difficulty emptying the bladder. Common bowel problems may include faecal leakage, constipation and difficulty emptying the bowel[1].

There are many common causes of continence issues such as:

- Urinary tract infections – common and usually bacterial;
- Constipation – straining during bowel movements can weaken the pelvic floor muscles or a full bowel can press against the bladder causing the urgent need to urinate or having to pass urine more frequently;
- Surgery – on the lower abdomen can result in the bladder tilting, leading to continence issues;
- Pregnancy and childbirth – due to pressure on the bladder or hormone-related changes in the lining of the bladder or urethra;
- Excess weight – causes pressure on the bladder.
- Neurological conditions – conditions like Parkinson's disease or Multiple Sclerosis affect the brain and spinal cord and can cause incontinence;
- Prostatitis – an inflammation of the prostate gland;
- Benign Prostatic Hyperplasia – An enlarged prostate gland[2,6,7].

How are continence issues treated?

In Northern Ireland, each of the five Health and Social Care Trusts has its own Continence Service. These Continence Services initially either provide or quality assure the assessment of a person's continence issues. Where necessary, they then provide ongoing individualised treatment and management for people who have bladder or bowel problems, so that symptoms are alleviated and, where possible continence is attained[3, 4].

These treatment and management options may include:

- Lifestyle changes – such as losing weight or dietary changes;
- Pelvic floor exercises;
- Bladder training – where patients learn ways to wait longer between needing to urinate and passing urine;
- Bowel management;
- Continence products – such as absorbent pads and catheters;
- Medication;
- Surgery[5,6,7].

How prevalent are continence issues?

It is estimated that around 14 million people in the UK have a bladder problem and around 6.5 million have a bowel problem[1]. Applying these proportions to Northern Ireland, there are approximately 500,000 people living with bladder control problems and 225,000 people with bowel control problems. Many will also suffer from both forms of continence impairment[8].

Men, women and children can all be affected by continence issues. However, it is not a topic that is openly discussed because people often feel uncomfortable discussing their symptoms and problems given the personal nature of the issue. As a result, many 'suffer in silence' or wait a long time before discussing their continence issues with a healthcare professional. It is widely accepted that continence issues are significantly under-reported; some estimates suggest that as little as 20% of those effected go on to seek treatment[2].

What are the impacts of continence issues?

Continence issues can impact greatly on all areas of an individual's life, from self-esteem and wellbeing to quality of life[1]. A person's independence, their ability to work and sleep, and emotional wellbeing can all be impacted. Furthermore, continence issues can lead to social isolation[9].

Why explore Continence Services in Northern Ireland?

The Patient and Client Council's Client Support Service has received a number of complaints from service users reporting poor experience of continence care, typically as part of wider complaints around domiciliary care.

Continence issues are also a priority for the Public Health Agency (PHA), as evidenced by:

- The vaginal mesh initiative, the inquiry resulting from the problems with that intervention; and
- An initiative currently being undertaken to scope the staffing, activity and caseload of Continence Services in Northern Ireland.

As discussed above, incontinence is widely recognised as a 'hidden issue', which is both more prevalent and more debilitating than would be expected. For example, the increasing incidence of cancer and higher survival rates have resulted in a growing number of people – in Northern Ireland and elsewhere – suffering from long-term continence issues as a result of radiotherapy and surgical intervention[10].

Furthermore, based on anecdotal evidence from clients of the PCC Client Support Service, continence issues can be a significant contributing factor to social isolation. This is especially the case where people's anxiety about their continence deters or prevents them from getting out, socialising and going about their 'normal' life.

Based on this evidence, there was a clear rationale to undertake research to improve understanding of continence issues in Northern Ireland. It was decided that the initial focus should be on seeking the views of those accessing or working in Continence Service clinics. The aims were to assess accessibility and effectiveness, explore patient experience and identify areas for improvement .

2.0 What we did

The Patient and Client Council (PCC) 2019/20 Business plan includes the following objective:

Goal 1 - Representing the Interests of People

1.1 Access and Quality of Continence Services

The Patient and Client Council will carry out a two year project to seek and report on the views of current users of adult continence support services in the community. Report findings will be shared with service delivery organisations.

(a) Review and summarise existing evidence on Continence Services, including demand, prevalence and what makes Continence Services effective.
(b) Review existing work scoping current provision of community-based Continence Services in Northern Ireland.
(c) Invite people suffering from continence issues and their carers to discuss their use, experience and opinions of Continence Services and explore areas for improved access or effectiveness.
(d) Invite people involved in delivering and managing Continence Services to discuss barriers and enablers to service delivery, best practice and areas for improvement.

Bring together outputs from (a) to (d) to draw evidence-based conclusions and make practical recommendations for increasing, sustaining and/or improving Continence Services in Northern Ireland.

2.1 Overview of our approach

2.1.1 Interviews with service users

Engagement and planning

At the beginning of this project, we attended a meeting of the PHA's Continence Service Regional Steering Group in order to understand their work and to explain to them the plans for our project. In addition, we invited people from this group to sit on our Project Steering Group.

A Project Steering Group for our project was established, consisting of Patient and Client Council staff, service users and Continence Service staff. This group would meet throughout the project, and advise and help the PCC in planning the project, developing research tools and supporting the recruitment of service users and Continence Service staff to participate. Membership of the Steering Group can be found in **Appendix 1.**

Research design

A key role of the Project Steering Group was to inform our research approach. Initially, we had planned to undertake telephone interviews with people with continence issues but, after discussion within the Steering Group, it was decided that we should:

- Carry out face-to-face interviews (because it was felt this would enable a better rapport and generate richer data than phone interviews);
- Focus exclusively on Continence Service users; and
- Recruit participants through the Continence Service community clinics.

It was decided that we should undertake qualitative research for the service user fieldwork, and that participants should take part in semi-structured interviews immediately after their Continence Service clinic appointment. This was in order to document their experiences and opinions of continence issues and Continence Services, and to explore areas for improvement.

Development of research tools

A topic guide for service user interviews was developed with input and feedback from the Steering Group, including two current users of Continence Services. The full topic guide can be found in **Appendix 2.** We also sought advice on ethics from the Office for Research Ethics Committees Northern Ireland, and were advised that the study did not require formal ethical approval.

Recruitment

Participants were recruited at Continence Service clinics, with the help of Continence Nurses. Some of these clinics were delivered on hospital sites and others were based in the community. A full breakdown of the interview sites can be found in **Table 5**. Prior to their appointments, nurses provided service users with information about the project and what would be involved. They encouraged those attending the clinic to take part in a 30-45 minute interview following their appointment. In the South Eastern Trust, participants were not interviewed on the day of their clinic appointments and went to Bangor Community Hospital to be interviewed.

Prior to visiting each clinic, a separate room was pre-booked in the hospital where interviews were to be conducted. The PCC interviewers assigned for each day of fieldwork reflected the number and gender of potential participants on that day.

When interviewing at the clinic was not possible, service users were given the options either to:

- Take part in a telephone interview, where the Continence Nurse sought their prior consent to share their details; or to
- Arrange an interview by contacting the PCC team directly, using details provided by the Continence Nurse at their clinic appointment.

Telephone interviews were carried out in the Southern Trust (because there was no room available to interview service users after their appointments) and in the Northern Trust (where it did not suit some services users to be interviewed on the day of their appointment.) In addition, an article was published on the PCC Membership Scheme newsletter, promoting the project and inviting Members with continence issues to get in touch for interview.

Fieldwork

Between July and October 2019 interviews were conducted at venues across Northern Ireland's five Health and Social Care Trusts or by telephone.

Verbal consent was gained from participants to audio record their interviews for transcribing purposes, assuring them that they would not be identifiable in the recording or report. If the participant did not consent to being recorded then the interviewer took notes.

Interviews were carried out by PCC staff. The exception was in the South Eastern Trust, where participants were interviewed by a service user from the Project Steering Group, who had attended the Continence Service in the Belfast Trust and had a background in research. Participants were asked a set of questions focussing on the key issues relating to people's experiences of continence issues of the Continence Service (See **Appendix 2**). All participants were asked the same questions, but interviewers probed and asked additional questions where appropriate.

Sample

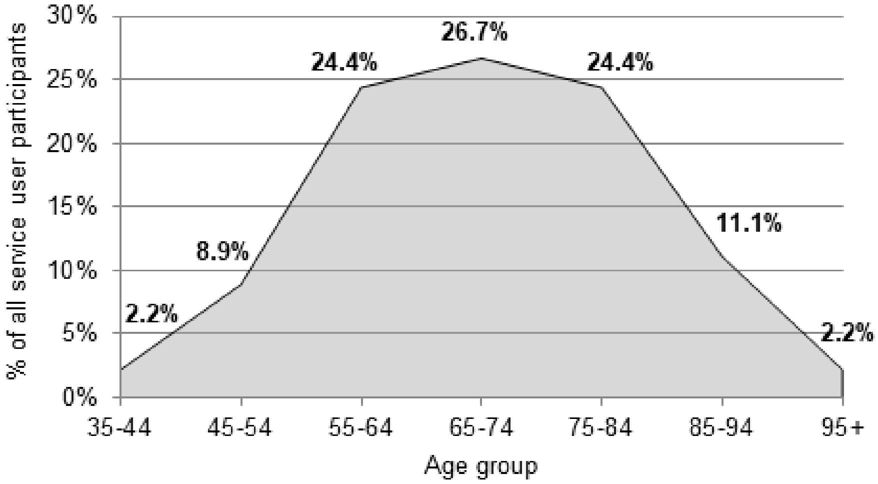
A total of 45 people were interviewed. A breakdown of the demographics of participating service users can be found below. **Table 1** gives an overview of the interview sample by Trust area and gender.

Table 1: Table 1: Service user participants by Trust area and gender

Trust Area	Male		Female		Total	
	Number	% within Trust	Number	% within Trust	Number	% of total interviewed
BHSCT	4	40.0%	6	60.0%	10	22.2%
WHSCT	5	50.0%	5	50.0%	10	22.2%
SEHSCT	-	0.0%	7	100.0%	7	15.6%
SHSCT	6	75.0%	2	25.0%	8	17.8%
NHSCT	2	20.0%	8	80.0%	10	22.2%
Total	**17**	**37.8%**	**28**	**62.2%**	**45**	**100.0%**

Figure 1 provides a breakdown of our sample by age group.

Figure 1: Service user participants by age



When interviewed, the participants outlined what kinds of continence issues they were living with:

Table 2: Service user participants by type(s) of continence issues

Type of continence issues	Number	%
Bladder	34	75.6%
Bowel	0	0.0%
Both	11	24.4%
Total	**45**	**100.0%**

We also asked people how long they had been attending the Continence Service clinics. For some participants, it was their first appointment but others had been attending for several years:

Table 3: Service user participants by duration of Continence Service use

Duration	Number	%
1st appointment	4	11.4%
2-5 appointments	16	45.7%
6-9 appointments	2	5.7%
More than 10 appointments	13	37.1%
Total	**35**	**100.0%**

Table 4 provides a breakdown of when and where interviews were conducted.

Table 4: Overview of interviews by venue and date

Trust	Venue	Date(s)
Belfast	Arches Wellbeing & Treatment Centre	12th - 14th August 2019
Western	South West Acute Hospital, Enniskillen Omagh Hospital and Primary Care Complex	6th September 2019 10th September 2019
South Eastern	Bangor Community Hospital	9th September 2019
Northern	Coleraine Health Centre Whiteabbey Hospital Telephone Interviews	1st October 2019 1st - 3rd October 2019 2nd October 2019
Southern	Telephone Interviews	8th August -11th October 2019

Table 5 shows the breakdown of different interview methods used.

Table 5: Service user participants by interview methods

Interview Method	Number	%
Face-to-face	36	73.3%
Phone	12	26.7%
Total	**45**	**100.0%**

Data Analysis

After all interviews had been transcribled, the responses were analysed and recurring and key themes were identified. Section **3.0 'What People Told Us'** provides an outline of the views and experiences of service users under each of the key themes. Quotes which characterise people's experiences of continence issues and Continence Services have also been included.

2.1.2 Staff survey

Research design

Through our Project Steering Group, it was decided that Continence Service staff should be included in the fieldwork. This was to gather their views on their roles and to discuss the barriers and enablers to service delivery, best practice and areas for improvement. The Project Steering Group decided that this should be carried out using an online survey.

Development of research tools

A survey questionnaire for Continence Service staff was drafted and shared with the Project Steering Group to review and revise. The final survey questionnaire can be found in **Appendix 3**.

Recruitment

The survey was set up in an online survey platform (Snap Survey) and a link generated. We asked the Continence Nurse Leads in each Trust to complete the survey, and to circulate the online survey link to their Service staff and to other healthcare professionals with a remit to manage/improve continence issues. We sent out reminder emails each week for the two weeks the survey was live.

Fieldwork

A total of 28 people participated in September/October 2019, with job roles such as Continence Lead Nurses, Continence Nurses and Physiotherapists.

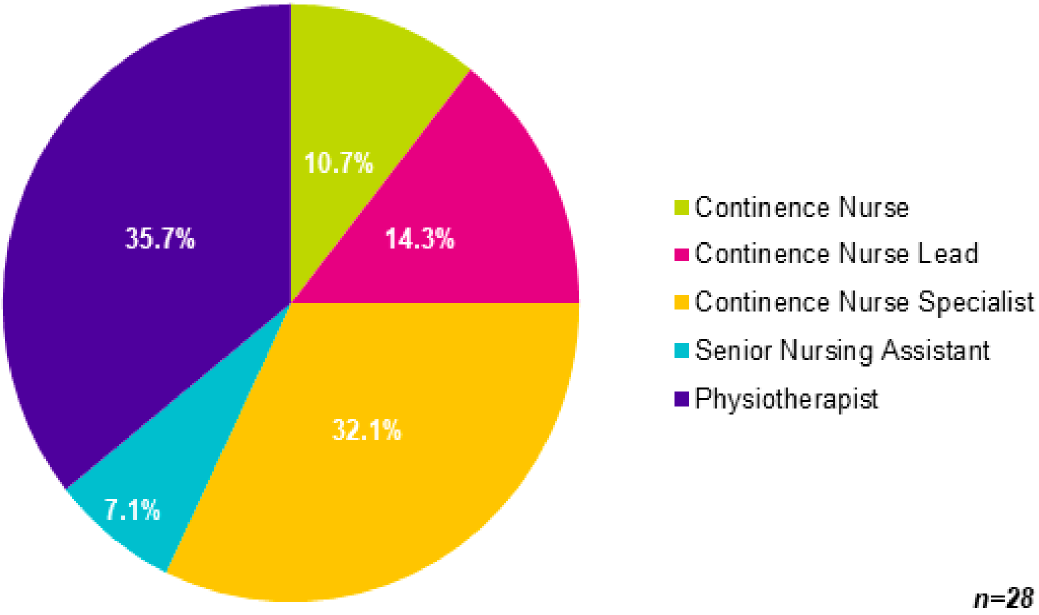
Analysis

Once the online survey closed, quantitative analysis of the categorical response data was conducted, with qualitative analysis of the free text responses. Section **4.0 'Continence Service Staff Feedback'**, provides an outline of the staff's views and experiences of working in the service and improvements that could be made.

Sample

The staff survey was completed by eighteen members of Continence Service staff and ten physiotherapists[i] . The breakdown of staff who responded can be found in **Figure 2.**

Figure 2: Responses to staff survey by job role



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[i] Physiotherapists are not direct members of Continence Service staff but work intensively with certain Continence Service users.

Calculating response rates per profession is difficult due to a lack of information on the total number of staff working in each job role across Northern Ireland. However, a draft scoping report stated that there were 39.4 whole-time equivalent (WTE) staff members working directly within Northern Ireland's continence services in March 2019. Based on this, the eighteen non-physiotherapist respondents indicate a response rate of 46.1% (18/39)[ii].

2.2 Limitations

We were reliant on interviewing people who attended the clinics. Sometimes we interviewed fewer people than we had anticipated, due to people cancelling their appointments or not attending the clinic that day.

Being interviewed in the clinic immediately after appointments, people may not have felt comfortable enough to be fully open and honest in their responses. In one Trust, Continence Service staff were allowed to select participants and organise interviews separate to clinics. These circumstances could arguably have created a positive bias in responses.

Our service user sample did not include people with continence issues who were unable to attend clinic appointments, nursing home residents or people living with continence issues who do not access Continence Services. As such, our sample cannot be considered representative of people living with continence issues. However, we can aim to address these unrepresented groups as we undertake further work in the second phase of this project.

It is difficult to assess the representativeness of our samples due to lack of knowledge on how many people have continence issues, use Continence Services or work in Continence Services in NI.
With regards to the Staff Survey, we did not have the opportunity to pilot the survey due to time constraints. In addition, there was a very small pool of potential respondents, with 28 respondents, ten of whom were Physiotherapists.

The decision to include Physiotherapists was made within the Project Steering Group. It may be argued that the findings are not a reliable reflection of Continence Service staff views due to the inclusion of Physiotherapists. However, comparative analysis showed few notable differences between the response data for the Physiotherapists and the direct Continence Service staff and, where there were major differences, we have highlighted them in our reporting.

[ii] The scoping report only specifies the WTE count and not the actual staff headcount so this calculation should only be taken as an estimate.

3.0 What service users told us

The 45 service users we spoke to described the impact of their continence issues on their lives and shared their experience of the treatment and support they received from Continence Services. They also discussed their continence-related treatment and care outside the Continence Services. The following sections detail these experiences and opinions.

3.1 Services accessed

3.1.1 Timing of first contact with services

Most people said that they waited a long time between first experiencing continence issues and doing something about them. Many people said that it took them a long time to see someone about their continence issues because they were embarrassed or because they initially tried to manage it themselves.

> ***"It was at least 12-15 months when it first happened, so it was. I was kind of embarrassed about asking anybody"***
>
> *Male Service User, 35-44, Western Trust*
>
> ***"I would say it was about three or four years I waited with my bladder, and I decided to go because it just got really, really bad … You just sort of put up with things and then I thought, 'No, I really need to go'"***
>
> *Female Service User, 65-74, Northern Trust*
>
> ***"I was waiting for two, three years, and in the end I said I can't go on unless I [go] cause I'm getting older and it's not getting any better so I better do something now about it"***
>
> *Female Service User, 55-64, South Eastern Trust*
>
> ***"I really didn't think it was a very big thing at the time …I honestly thought it was only a small thing that would go away but no"***
>
> *Male Service User, 75-84, Southern Trust*

Some people said that they did not wait long before they went to see someone about their continence issues. However, in most cases this group had sought help due to very severe symptoms of discomfort and pain. Indeed, some said they first went to A&E to see someone about their continence issues.

> ***"I had to go as an emergency then in the middle of the night"***
>
> *Male Service User, 55-64, Southern Trust*
>
> ***"I went straight to A&E because the waterworks just stopped and I was in quite a lot of pain after a short period of that"***
>
> *Male Service User, 85-94, Southern Trust*

3.1.2 Referral process

55.6% (n=45) of participants were referred to the Continence Service by their GP who was their first point of contact. In most cases, GPs knew to refer them onto the Continence Service; this was not the case for all participants.

35.6% (n=45) were referred by a consultant. In most of these cases, it was through a Gynaecologist, or a Neurologist. In a few cases, a nurse within the Neurology service referred the participant.

One person said they were referred to the Continence Service through their physiotherapist and another through their social worker. Two people had self-referred to the Continence Service.

> ***"He [my husband] was referred to the Continence Service and that was when I found out that it existed, and then I thought, 'Right could I use this service too?'"***
>
> *Female Service User, 75-84, Belfast Trust*

Most people said that in their opinion they did not wait a long time from when they were first referred to when they got their first appointment. Some of these may have been urgent referrals to the service.

> ***"I would say about six months … I actually thought it was quite quick to be honest. I was happy enough"***
>
> *Female Service User, 55-64, Northern Trust*
>
> ***"I didn't have long to wait because I remember saying 'Gosh, that was quick'. I didn't have long to wait at all"***
>
> *Female Service User, 75-84, Southern Trust*
>
> ***"It was basically seamless. It just moved straight to the other"***
>
> *Male Service User, 55-64, Southern Trust*

3.2 Perceptions and impact of continence issues

3.2.1 Anxiety

When asked how their continence issues made them feel, some participants talked about how difficult it had made their lives. 69.2% said that it impacted on their day-to-day life and 30.8% (n=39) said it did not have any impact. Participants said they were "embarrassed" about their continence issues, or that they had left them feeling "anxious". Some spoke of how they were always concerned about proximity to a toilet.

> ***"If I'm going anywhere I have to plan it like a military operation because I have to know that at a certain time I'll be close to a toilet"***
>
> *Female Service User, 65-74, Northern Trust*
>
> ***"I find sometimes when we're driving home, the urgency to go is incredible. I just wonder will I always make it"***
>
> *Female Service User, 65-74, Northern Trust*
>
> ***"I didn't really leave the house much at all, you know, I was just very cautious, you know"***
>
> *Male Service User, 65-74, Northern Trust*
>
> ***"I kept looking for a toilet every half an hour. It was dreadful"***
>
> *Female Service User, 64-74, South Eastern Trust*

A few people said that they were reluctant to let other people know they had continence issues. One person spoke of feeling anxious about having an odour due to his continence issues.

> ***"People can smell, and they'd keep their distance in church too … cause they can smell it"***
>
> *Male Service User, 45-54, Western Trust*

3.2.2 Limited choices and loss of control

When asked how their continence issues affected their lives, people spoke about the issues "interfering with" and controlling their life. It limited what "you want to do and you can't do", and where they could and could not go. This included limiting people's ability to socialise.

> ***"It just makes me feel miserable. No matter where I'm going, I have to have, you know, [bring] a change of leggings with me, and underwear and that, and I always make sure I've lots of pads and wipes. It's constant like, urine just runs out of me constantly; I have no control over it whatsoever"***
>
> *Female Service User, 65-74, Northern Trust*
>
> ***"It's harder going to places other than where you live … If I were to go on holiday … I would have to arrange somewhere I could go if there was a blockage"***
>
> *Male Service User, 75-84, Southern Trust*
>
> ***"There is no social life; there isn't any so there isn't"***
>
> *Male Service User, 55-64, Belfast Trust*
>
> ***"Going away socially, I don't like going away anymore. You know, just in case I have an accident"***
>
> *Female Service User, 55-64, Western Trust*

3.2.3 Emotional/mental health impact

Some participants spoke of how their continence issues had affected them emotionally. One person described it as "very, very depressing". Two other participants said that they had suicidal feelings when they first experienced continence issues.

> ***"I did isolate myself altogether like at the very, very start now, I was about to – it's hard to talk about like … suicide"***
>
> *Male Service User, 35-44, Western Trust*
>
> ***"Just before Christmas I-I was suicidal with the excruciating pain I was getting"***
>
> *Male Service User, 75-84, Belfast Trust*
>
> ***"It's ruined my life … I rather be in a wheelchair and have my bowels and bladder intact"***
>
> *Female Service User, 45-54, Western Trust*

3.2.4 Impact on work life

A few people spoke about being unable to work due to problems such as urinary tract infections (UTIs) and kidney infections. In some cases, this meant having to give up their jobs or retire early.

"It's the UTIs that you get as a consequence of and they are very debilitating, and eh it leaves you dreadful … when you get [a UTI] I just can't work"

Male Service User, 55-64, Southern Trust

"I had to sell my business. I had it for twenty years"

Female Service User, 55-64, South Eastern Trust

"With kidney infections and all, I had time off work through sickness"

Male Service User, 55-64, Southern Trust

3.2.5 Acceptance of continence issues

When asked if they felt continence issues were a natural part of getting older, those who responded were divided in their opinion. 56.3% said that they did see it as part of getting older, but 43.8% (n=16) said they did not. Participants listed numerous causes of continence issues unrelated to age, such as having a condition like Multiple Sclerosis or as a consequence of childbirth, a hysterectomy or an injury.

"I keep telling myself … it's part of getting older; you just have to come to terms with it"

Female Service User, 55-64, South Eastern Trust

"No, I think maybe at one time I did think [it was a natural part of growing older], but I don't know"

Female Service User, 65-74, Northern Trust

3.2.6 Impact on sexual relationships

A few people spoke of the pressures and difficulties that their continence issues had caused their sexual relationships, and one person attributed the breakdown of their marriage to their continence issues.

"I suppose it did. I suppose cause I felt that my bladder was sort of shifting and moving and it didn't really help"

Female Service User, 45-54, South Eastern Trust

"This illness killed my relationship with her… I couldn't perform and I lost that relationship"

Male Service User, 75-84, Belfast Trust

3.3 Continence Service experience

3.3.1 Treatments and interventions received

When asked what treatment and support they received, participants listed a range of interventions, such as continence pads, catheters, medication and lifestyle changes. Of those interviewed, the most common intervention they were receiving was continence pads. People told us of how it helped them feel more confident about leaving the house.

> ***"They really do the trick and it's good to have them"***
>
> *Female Service User, 75-84, Northern Trust*
>
> ***"I do have a certain amount of leakage, where the water isn't collected in the catheter and it runs down my leg. So it's useful to wear pads as well as protection"***
>
> *Male Service User, 75-84, Southern Trust*

Many people also used catheters to help with their continence issues. They attended the clinics to get these changed and to get advice and information on how to use them.

> ***"I use intermittent catheters … I come here usually about once a year just to check that I'm coping and everything is how it should be. But I'm always told that I can contact them at any time should I get into trouble"***
>
> *Female Service User, 55-64, Western Trust*

Some people mentioned that they had taken medication they were prescribed to help deal with their continence issues, while others mentioned that they had undergone surgery. A few said that they had attended a Physiotherapist to help them and several of the lifestyle changes made by service users involved physiotherapy. These included doing exercises (e.g. pelvic floor exercises), but also reducing their fluid intake and making changes to their diet.

> ***"More or less just trying to drink more water and less tea"***
>
> *Female Service User, 75-84, Northern Trust*

3.3.2 Fit with service user needs

Most participants said that the Continence Service fitted around their needs. They spoke of how the Service was dependable and available to them in times of need. This seemed to be of great importance and benefit to several participants.

> ***"With everything that happened over the whole thing, and all being looked after and looked into … [The Continence Service] was the one constant. This was the one thing at that time that I could count on. And (nurse's name) was just a god send"***
>
> *Female Service User, 45-54, South Eastern Trust*

> ***"Well they're there if you need them … I've got [the nurse's] number and I know if I do need them, if something goes wrong I can just phone her up"***
>
> *Female Service User, 45-54, Western Trust*

> ***"It fits absolutely perfect. If I have a query or anything, you can lift the phone and talk to them. If I need anything done, I've got the number I can ring and they'll take me in as an emergency"***
>
> *Male Service User, 55-64, Southern Trust*

Most people said that they found the clinics easy to access, either by car or by public transport. One person mentioned that the clinic site was very accessible with regards to wheelchair access.

> ***"It's in a hospital so it's all wheel chair friendly. And the doors and everything there is absolutely fine because it's set up for patients who would be in wheelchairs and stuff so it's absolutely fantastic in that way"***
>
> *Male Service User, 55-64, Southern Trust*

However, a few participants said that parking was a problem at the clinic sites. In addition, a few said that public transport was not very frequent or took a long route to get to the hospital.

Most people found that the services had "good flexibility" with regards to appointment times. Participants said that the times they were given suited them. In some cases, participants told us that the Continence Nurses had made sure to give them an appointment time that suited them.

> ***"They were able to make [the appointment times] convenient for me. Both times I've been able to access the service [in an emergency] within 24 hours of giving contact"***
>
> *Male Service User, 55-64, Southern Trust*

> ***"The times are great … [The nurse] actually books my appointment when I am with her and she'll check with me. You know, 'Does the morning suit you or is the afternoon better for you?'"***
>
> *Female Service User, 55-64, South Eastern Trust*

> ***"A couple of times they've given me an appointment too early ... and I couldn't make that time. So they rearranged that time a wee bit later"***
>
> *Male Service User, 65-74, Southern Trust*

3.3.3 Staff continuity

Participants were asked if they saw the same nurse on each visit. 64.1% of those interviewed said that they did, with 35.9% (n=39) saying they did not. In the latter group, most said that this did not bother them and that they would not have expected to see the same nurse each visit, given the capacity of the services.

> ***"I don't think it's possible really but it is nice to have the same contact as much as you can"***
>
> *Male Service User, 55-64, Southern Trust*

> ***"They're busy people and you just be glad to get the appointment and get on with it"***
>
> *Female Service User, 55-64, Western Trust*

> ***"I don't really mind to be honest with you … I know there's nothing they can do so I don't get annoyed about it. It's just one of those things"***
>
> *Female Service User, 75-84, Southern Trust*

However, most participants said that it would be ideal to see the same nurse at each visit and it was important because the nurse knew their experiences and background and a trusting relationship had been established. This was especially important to them due to their continence issues being a very personal condition. A few people mentioned that it was hard to explain their situation and continence background when they saw a different nurse.

> ***"I just think it's a personal matter and you get used to one face and she gets to know you as well"***
>
> *Female Service User, 55-64, Northern Trust*

> ***"I think it's very important because you get a rapport with her"***
>
> *Female Service User, 75-84, Northern Trust*

> ***"I find it very hard you know, if I see somebody different person all the time ... I don't really want to have to go through everything like the mental health background and all that"***
>
> *Male Service User, 65-74, Northern Trust*

3.3.4 Person-centred approach

A number of people told us that they felt they received tailored, holistic care within the Continence Service. They spoke about how they felt the Continence Nurses took time to listen to their concerns and to equip them with suitable products and provide them with information.

"The service here … I have always found it well tailored to my needs. I always thought I was getting a very personal thing to me. It wasn't just like a blanket approach to this problem"

Female Service User, 55-64, South Eastern Trust

"I felt you know cause, [nurse's name] wanted to know everything to do with my disease and how it all affected me so she could help me work out how to look after this issue with my bladder and bowel, with the whole picture in mind"

Female Service User, 45-54, South Eastern Trust

"They have been excellent in terms of providing me information and getting me equipment that works with my lifestyle and work… She was extremely competent in what she was doing – explained everything, listened to what I had to say and took it on board"

Male Service User, 55-64, Southern Trust

3.3.5 Overall experience of care

Most participants had a positive overall experience with the Continence Service nurses. They spoke of the nurses' skill, how comfortable they made them feel and how they had helped improve their health and wellbeing since coming into contact with them.

"It's quite an ordeal really – having a catheter changed. But it's done very professionally and in a caring way. It isn't something I look forward but I know that I'm confident in the treatment that I receive"

Male Service User, 75-84, Southern Trust

"I'm more than happy to say, you can't get no better than them girls and my heart goes to them. I can't speak highly enough of them"

Male Service User, 35-44, Western Trust

Furthermore, many participants told us that the Continence Nurses were flexible and specifically that they were able to phone and speak to the Continence Nurses if they needed more advice and information. A few mentioned that nurses were available to help them out of hours if they had an emergency.

"I know that now if I had a problem I would lift the phone… I feel that I could lift the phone and phone her and say 'Look, what do I do here?'"

Female Service User, 55-64, South Eastern Trust

"I could ring them up and say 'Look I'm very… bad today – I don't want to travel', and like they're more than accommodating, 'Ok what time would suit you?'"

Male Service User, 35-44, Western Trust

"[The nurse] explained that there are other nurses that can come out to my home if for whatever reason a catheter breaks or blocks up they will then come out to my home at the weekend or on the holidays and replace it for me. I've got that back-up service there as well as that so I'm absolutely delighted with it"

Male Service User, 55-64, Southern Trust

3.3.6 Suggested improvements

As described, the majority of participants were very satisfied with their Continence Service and did not feel that any changes were necessary. However, some had suggestions on how the service could be improved, including seeing the same nurse at each appointment.

"I think the one thing I would change would be that maybe the one nurse would do the clinic here for these patients ... that would be the ideal"

Female Service User, 55-64, Belfast Trust

"If one were able to go to the same nurse … but that can't always be arranged"

Male Service User, 75-84, Southern Trust

A few people wished that they had had more information or better communication about the Service and the different types of treatments available to them, prior to starting new treatments or interventions. They said they would have felt more at ease and comfortable with accessing the Service had they gotten this knowledge beforehand.

"I would say in my circumstances if I had more information about what was going to happen to me as soon as I was told, 'Right, you're going to be using catheters possibly for the rest of your life' and be left with that and not even see catheters, not even know that there are different catheters"

Female Service User, 55-64, South Eastern Trust

"It would have been easier to make the choice [to use catheters] sooner if somebody had just shown me the products, how it worked. So, you know, it's not that frightening"

Female Service User, 45-54, Western Trust

Some participants said that there should be greater awareness of Continence Services among the general public so that people would know that they exist and could access them.

> ***"Well they could advertise it a bit more … Because there's still a lot of people who don't know it exists"***
>
> *Female Service User, 75-84, Belfast Trust*
>
> ***"There's so many women who don't talk about this issue and I think that it's vital that people are aware of the services out there and eh the good work that they do … Make it more accessible to other people who don't know about it and could benefit from it, cause it's such a brilliant service"***
>
> *Female Service User, 45-54, South Eastern Trust*

3.4 Outcomes from accessing the service

3.4.1 Changes to health and wellbeing

Since accessing the Continence Service, most participants (77.4%) said that their health and wellbeing had improved, while 22.6% (n=31) said they had not noticed an improvement. Many said that it had enabled them to feel more confident about leaving the house and *"much more in control"*, with some specifically describing how their quality of life had improved.

> ***"Before maybe I was finding I had to go to the bathroom every hour and half and now I'm finding that I can maybe hold for four or five hours at the minute"***
>
> *Female Service User, 55-64, Northern Trust*
>
> ***"It definitely has improved it … I've no hesitation now in being out and about"***
>
> *Female Service User, 75-84, Belfast Trust*
>
> ***"[It's] made me more confident in going out, … I had reached a point where I was really very reluctant to leave home because I was worried because of the overflow"***
>
> *Female Service User, 55-64, South Eastern Trust*

A few people also mentioned that accessing the Service had also improved their mental health, as they felt that they were getting support from the Service and help to cope with the emotional impact of their continence issues.

"It was more or less giving me a lot of depression too … That's improved from getting my catheter in and getting the service from the Continence Service"

Male Service User, 55-64, Southern Trust

"It has helped my wellbeing and my mind the most, because at least now there's somebody in my corner like. I've somebody to stand behind me right, and there's routes to go down. Cause at the start I didn't know where to go or what to do"

Male Service User, 35-44, Western Trust

3.4.2 Effectiveness of treatments and interventions

With regards to treatments they received, most participants said that they had helped them (91.7% n=24). They spoke of how they were educated about how to manage their continence issues effectively.

"They gave me a full range of different types of catheter … We tried with the bag, without a bag, we tried silicone, we tried long, short. They were really very good. I couldn't rate them high enough"

Female Service User, 55-64, South Eastern Trust

"Yeah it has got better. It's helped me to control [my bladder] … I'm not kind of worrying as much"

Male Service User, 35-44, Western Trust

3.5 Continence pad experience

With regards to continence pad services, most participants said that they were satisfied. When asked if they received enough continence pads, most said they did. Most people also said that they had received enough information on how to use their continence pads. Everyone who received pads through the Continence Service got them free of charge.

[Before coming to the Clinics] "I've been paying for them for years up until now. I have spent an absolute fortune! So that has been great now, getting those sorted"

Female Service User, 65-74, Northern Trust

However, some people did say they purchased extra pads as they had run out of them between appointments or deliveries. In a few cases, people said they bought their own pads as they did not feel that the continence pads they received through the Continence Service were suitable.

"I think it works out that they allow you 3 or 4 pads per day, but that is nowhere near the amount I would need"

Female Service User, 65-74, Northern Trust

"The ones you buy … you can't see …The ones you get here [from the clinic] are really thick, and they just, you know, they are not comfortable and they are not suitable"

Female Service User, 45-54, Western Trust

There were some suggestions on how to improve the continence pad service. Some participants had issues with the continence pad delivery service (though this service is not provided by the Continence Service itself). They mentioned that they felt embarrassed to have them delivered to their house as they did not like their neighbours seeing the pads or knowing about their continence issues. A few people explained that they would prefer to pick theirs up themselves from the service when they needed them.

"They're not very private and they drop them off at the door"

Female Service User, 65-74, Western Trust

"I get them delivered … but I would like to know when they are coming with them so that I'm there to receive them. Cos I don't want them being left with neighbours … A simple phone call does the trick and is very appreciated"

Female Service User, 75-84, Northern Trust

"I'd need to make sure that I was in when the thing was going to be delivered … I'm not always in, you know. I wouldn't want it to be left outside"

Male Service User, 75-84, Southern Trust

3.6 Continence care and support beyond the service

69.6% (n=23) of participants agreed that other medical staff (i.e. outside of the Continence Services) were aware of, or knowledgeable about continence issues and services.

"My GP would be pretty good … They have been so good in giving me advice and directing me to the right people"

Male Service User, 55-64, Southern Trust

"[When waiting for an operation] the people [staff] in the hospital certainly did understand it. The nurses and all couldn't have been better"

Male Service User, 85-94, Southern Trust

But 30.4% (n=23) participants did say they felt other medical staff were lacking in continence awareness and knowledge. In addition, some felt they did not get enough support and information from the other medical staff who were their first point of contact. Instead they got this information from the Continence Service.

> ***"All that information [on managing catheters] came from the continence nursing team, not from the doctors"***
>
> *Male Service User, 55-64, Southern Trust*
>
> ***"The GP was unaware of continence products when I went to see her. She couldn't help me, at all cause she didn't know"***
>
> *Female, Service User, 45-54, Western Trust*

Indeed, one person said that, had their GP referred them to the Continence Service when they first experienced continence issues, they could have gotten help a lot earlier.

> ***"It could have been quicker … You know, cause three years is a long time to be buying pads all the time"***
>
> *Female Service User, 85-94, Belfast Trust*

Likewise, some participants told us about their negative experiences in hospitals, often to do with poor communication. This included being discharged with a catheter but being given little information on how to use it.

> ***"I've had lots of up and downs with this journey … When I got out of hospital…I was just informed that I would be using catheters and was allowed to leave hospital. Now it said on my discharge that I was explained [about catheter], no I wasn't. So I had no explanation on how I had to deal with this situation"***
>
> *Female Service User, 55-64, South Eastern Trust*
>
> ***"I got a catheter while I was in hospital that time and then the catheter got blocked and I had to go back in and I was in hospital for five weeks"***
>
> *Male Service User, 85-94 Southern Trust*

When asked if they thought that the different people who help with their continence issues worked well together; most felt that there was good coordination across staff and services.

"They always look up where I was and am I still getting the treatment for this before they would say 'Right, we can give you treatment for this'. You know like they do correspond with each other"

Male Service User, 35-44, Western Trust

"They seem to do it very well. There has to be … that consistency and … [where] everybody knows what everybody else is talking about – on the same page… and I think that was the case"

Female Service User, 45-54, South Eastern Trust

Some felt that medical staff outside the Continence Service did not listen to them when they spoke about their continence issues – because it was "not their department". Nonetheless, most participants did feel listened to.

"People do listen. I can't think of a time when I've had somebody who hasn't taken notice of what I've said"

Male Service User, 55-64, Southern Trust

"Well it was the physio that referred me and put it into motion, she was the first one … she was the help"

Female Service User, 65-74, Northern Trust

"My GP's one of the best GPs I've ever had … She gives me the time … she's done more for me than um anybody else has done in a long time so I can't complain"

Female Service User, 45-54, Western Trust

4.0 What service staff told us

4.1 Work wellbeing and job confidence

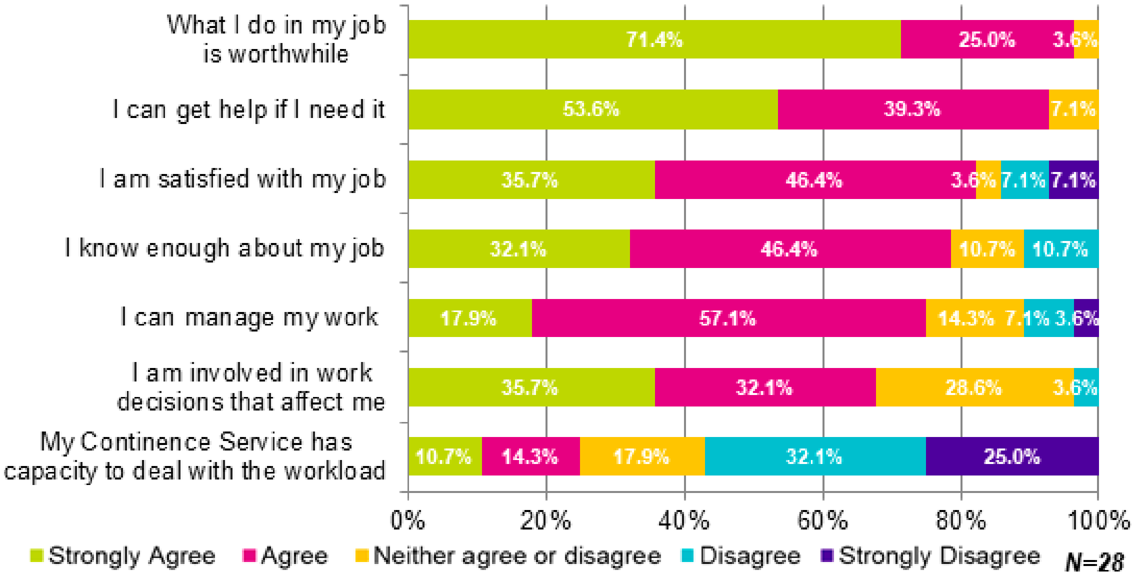


Figure 3: Service staff levels of work wellbeing and job confidence

There was high satisfaction with regards to job roles within the Continence Service. 82.1% (n=28) agreed or strongly agreed that they were satisfied with their job and 96.4% (n=28) agreed or strongly agreed that their job was worthwhile. Most felt knowledgeable about their job, with 78.6% (n=28) in agreement. Many respondents, 75.0%; (n=28) could manage their workload and, 92.9% (n=28) felt they could get help when the needed it.

When asked whether they were involved in work decisions that affect them, most agreed to some extent 67.9% (n=28) but 28.6% (n=28) said they neither agreed nor disagreed. Around a quarter agreed and 57.1% (n=28) disagreed when asked if their Continence Service had capacity to deal with the workload. One person summarised that:

> ***"[There's] great job satisfaction but often not enough capacity to deal with the demands and referrals"***
>
> *Physiotherapist*

Among the Continence Nurse Leads, one agreed that their service had the capacity to deal with the workload; the other three disagreed. Their free text comments reinforced this view of Service staff feeling satisfied and supported in their roles, but being less positive about perceived understaffing and heavy workload.

"Sometimes I feel it is difficult to manage the workload due to the existing balance between clinical and management role. The service is currently understaffed due to staff having retired / on leave / unfilled posts which can impact on workload and waiting lists"

Continence Nurse Lead

"I love my job and am passionate about it. However, I am unsure if my managers really understand my role or value our contributions"

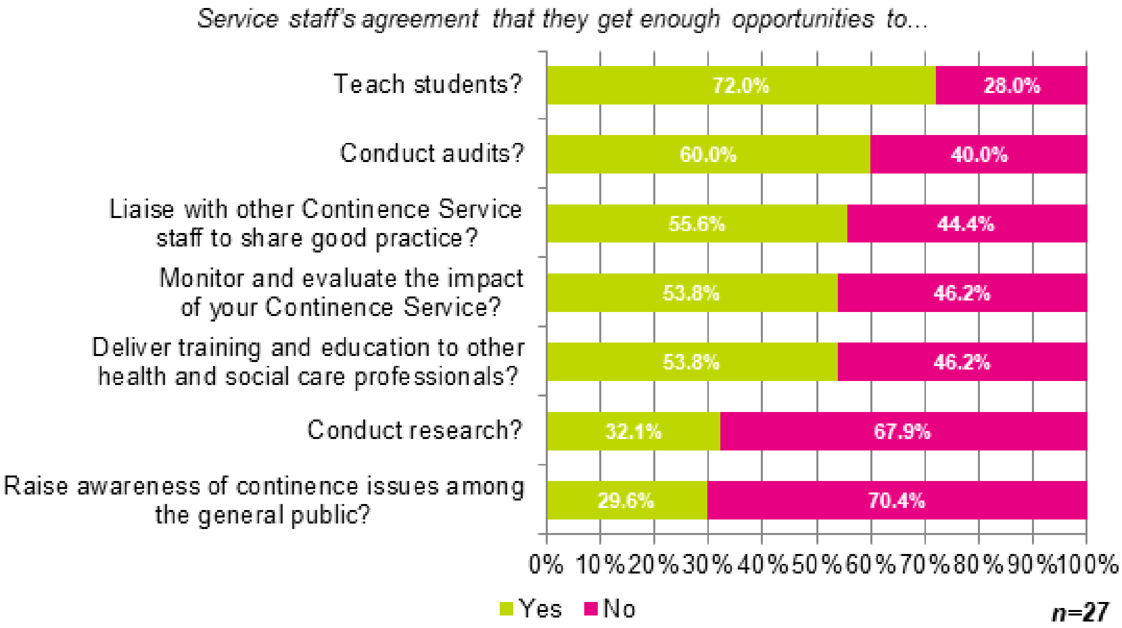
Continence Nurse Lead

"I feel very supported by my line manager. However it can be frustrating when the daily workload is heavy and my colleagues feel overwhelmed by the volume of work and the travel time involved"

Continence Nurse Lead

4.2 Opportunities for Supporting Professional Activities

Figure 4: Service staff perceptions of SPA opportunities



70.4% (n=27) of respondents did not get enough opportunities to raise awareness of continence issues among the general public. 72.0% (n=25) said that they got enough opportunities to teach students. With regards to delivering training and education to other health and social care professionals, there was a mixed response, with 53.8% saying 'Yes' and 46.2% saying 'No' (n=26). The same proportion (53.8%; n=26) felt that they had enough opportunities to monitor and evaluate the impact of their Continence Service. 32.1% (n=25) said that they got enough opportunities to conduct research:

“I feel due [to the] work load I am unable to look into new research spend time on improving things within the service and attend study days etc. I feel we are always firefighting with in the service and never get enough breathing space to grow our service”

Continence Nurse

With regards to conducting audits, 60.0% (n=25) felt that they got enough opportunities.

We are allowed time in clinic to undertake the work on audits which is really good”

Physiotherapist

55.6% (n=27) felt that they had enough opportunities to liaise with other Continence Service staff to share good practice.

“Liaising with other Continence Service staff needs to be improved so we can all learn from each other and share experiences and knowledge”

Continence Nurse Specialist

“Due to the limited number of staff in the team to cover clinics, domiciliary calls, emergency call outs, covering all aspects of the role can be challenging”

Continence Nurse Lead

Overall, respondents perceived a lack of opportunities to share knowledge and good practice in continence care across the Trusts. They felt that there was a general lack of capacity for the non-patient facing aspects of the role.

82.1% (n=28) felt that there was room for development within their role, with some aspiring to better resource and expand the non-patient-facing, outreach elements of the services.

“[There’s a] great scope for a bigger role in health promotion, to all clients, particularly the maternity population”

Physiotherapist

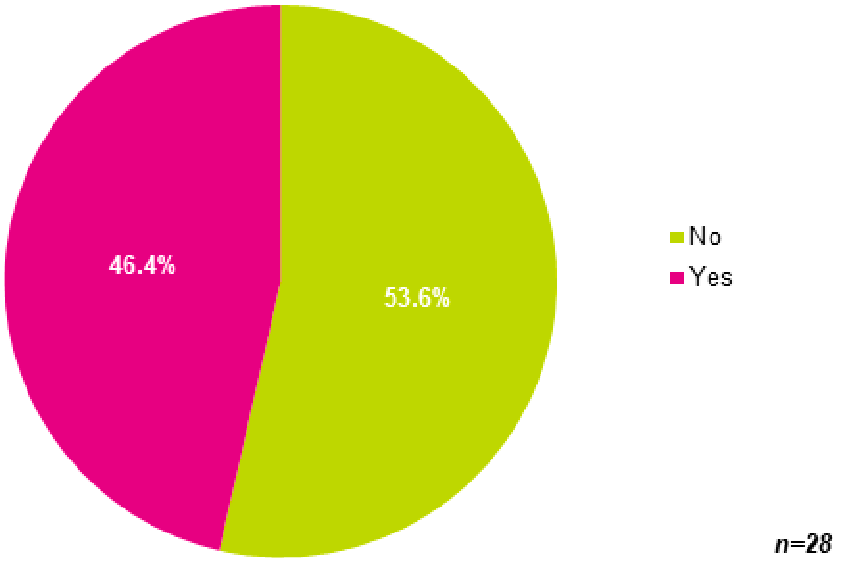
“There is so much to learn in this field and a lot of potential to develop services for patients, if funding, accommodation and staffing were expanded”

Continence Nurse

4.3 Opportunities for Continuing Professional Development

We asked respondents what training they had received that they had found to be beneficial for their career development, their Continence Service and their service users. Respondents listed a range of training they had undertaken, including a course in Prolapse and Bowel irrigation.

Figure 5: Lack of opportunities to attend potentially useful training



When asked whether there were any non-mandatory training courses they would like to undertake but had not had the chance to do so, the response was split, with 46.4% saying 'Yes' and 53.6% saying 'No' (n=28). Importantly, there were no significant differences in responses to this question from Physiotherapists and direct members of Continence Service staff. Respondents said that they would like to attend courses such as urology and bowel management, and courses offered by Northern Irish universities.

4.4 Perceived purpose of Continence Services

When asked what they thought the core purpose of the Continence Service was, eighteen (n=26) said that it was to educate, empower and equip service users to manage their symptoms, as well as to improve patients' quality of life.

> ***"Helping patients to improve and manage their continence needs as independently as possible [and] trying to improve their quality of life"***
>
> *Continence Nurse*
>
> ***"The main purpose of The Continence Service is to provide holistic treatment and management of bladder and bowel dysfunction with empathy and compassion. To provide a service so that service users feel empowered to be involved in their care"***
>
> *Continence Nurse Lead*

"Improve [the] quality of life for patients, improve self-management strategies. Target service to meet needs of increasingly complex and elderly population in the future"

Continence Nurse Lead

Three respondents (n=26) said that the main purpose of their service was, where possible, to alleviate or cure service users of their continence issues.

"The purpose of the Continence Service is to where at all possible alleviate incontinence or bladder or bowel dysfunction, and to provide education to promote best practice"

Continence Nurse Lead

"I hope to help cure my patient's incontinence or at least help improve it and help them manage it better"

Continence Nurse Specialist

Nine respondents (n=26) said that the Continence Service was there to educate service users and encourage good practice in managing their continence issues. However, these responses were largely from Physiotherapists, with three out of eighteen direct Continence Service staff seeing education as part of their remit.

"I feel our purpose and aim is to educate and empower our patients so that their symptoms improve along with their quality of life"

Physiotherapist

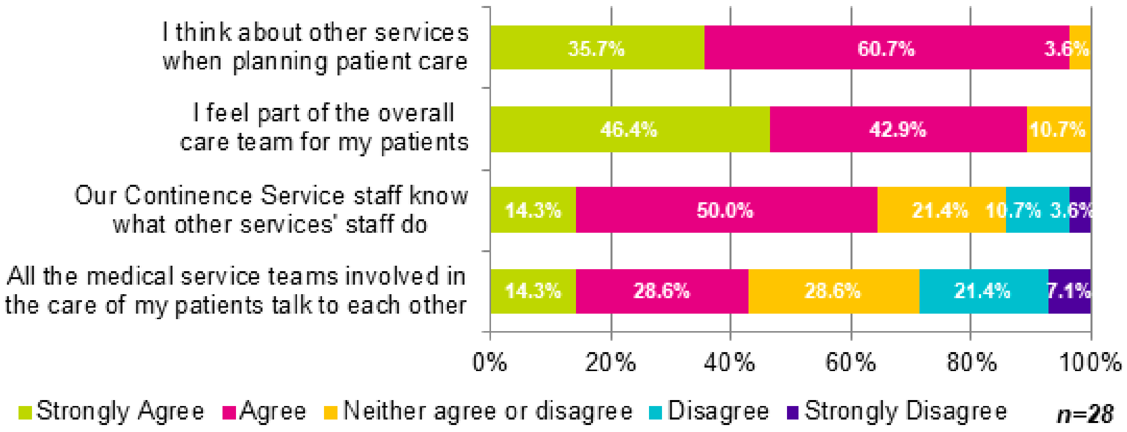
"To assess, treat and educate people with regards to continence problems"

Continence Nurse

4.5 Coordination and integration of care across services

Almost all respondents (96.4%) either agreed or strongly agreed with the statement 'I think about other services when planning patient care' (n=28). Similarly, 89.3% agreed that they felt part of the overall care team for their patients (n=28).

Figure 6: Service staff perceptions of care coordination and integration



64.3% (n=28) either agreed or strongly agreed that the Continence Service staff in their team knew what other services' staff do. When asked whether all the medical service teams involved in the care of their patients talk to each other, 42.9% agreed but 28.6% disagreed (n=28). Among Continence Nurse Leads, opinion was split, with two saying 'Yes' and two saying 'No'.

Staff were asked how integrated they felt their Continence Service was with any other services their patients used. Respondents said there was a strong awareness and knowledge of the other services being used by their patients, but communication between these services was not as good as it should be.

> ***"We work very closely with colleagues in Urology, Gynae, and Physiotherapy department. We use NIECR (Northern Ireland Electronic Care Record) everyday which is extremely beneficial to staff and service users. We don't always receive referrals from hospital when a patient is discharged with a urinary catheter"***
>
> *Continence Nurse Lead*

> ***"We have strong connections with Physio, Urology and District Nursing. Not all GP surgeries are aware of our service despite our trying to get our voice heard"***
>
> *Continence Nurse*

4.6 Service evaluation efforts

75.0% (n=28) of respondents said that they made efforts to consult service users about their experiences of the Continence Service. Service users' opinions were typically gathered through questionnaires and feedback forms.

> ***"We currently have a questionnaire which service users can complete at clinic, take home and complete with a postal and email address"***
>
> *Continence Nurse Lead*

Likewise, when asked if they made efforts to involve service users in decisions about how their Continence Service operates and how it could be improved, half of respondents said 'Yes' (n=28). Again, they said they used feedback forms, but some also ran focus groups.

> ***"We encourage patients / clients to avail of 'we value your view' leaflets and ask them at each face to face contact if they have any issues / ways to improve the service"***
>
> *Continence Nurse Lead*
>
> ***"The Continence Service have a user support group which meets every 2-3 months. All past and present service users are invited to come along"***
>
> *Continence Nurse Lead*

4.7 Suggested steps to improve Continence Services

In terms of what respondents would like their Continence Service to look like in the future, most said that they would like to see more funding and more staff for the service.

> ***"An expansion of the service to help meet the changing needs of our patients"***
>
> *Continence Nurse Specialist*
>
> ***"More investment, more staff, more recognition for the excellent work we do"***
>
> *Continence Nurse Lead*
>
> ***"Better interdisciplinary working, better communication/liaison between services including Trust Continence teams"***
>
> *Continence Nurse Lead*
>
> ***"More staff to be able to get through the workload"***
>
> *Senior Nursing Assistant*

They also wished for better integration and communication across Continence Service teams and with other services caring for the patients. Furthermore, staff wanted more advertising and promotion of the service. They hoped that, with better exposure, they could promote the service – and good continence care generally – to a wider audience.

> ***"More promotion of continence issues and prevention with younger service users / school age mums and school nurses and younger ladies such as post-natal. I would love links with our midwives to promote good continence care in these fields"***
>
> *Continence Nurse Lead*

"More knowledge about what we do as a service for patients and health care professionals"

Continence Nurse

In addition, staff spoke about expanding the Services' remit and activities. This included having a wider choice of appointment times to work around the lives of their patients, as well as specific developments in what the services deliver.

"Development in areas of pelvic pain, mesh clinics, pessary clinics and perineal clinics"

Physiotherapist

"More choice of clinic times, e.g. evenings and weekends. Reduction in waiting time for clinics and domiciliary visits"

Continence Nurse Lead

When asked what they would change about the service to help provide the best possible care to Continence Service users, respondents provided a range of responses. By far the most common suggested change was the addition of more trained staff, and provision of the funding required to support this. Respondents anticipated that increased staffing would reduce waiting times and lead to earlier intervention and patients being seen and treated before their health deteriorated.

"More staff to increase clinics and reduce waiting times. And improvements to hospital waiting times for patient for whom our service is not enough"

Continence Nurse Specialist

There was also a desire to see an increased capacity for "preventative work" and education to make sure that people were being seen when their continence issues began and not having to wait a long time to see someone.

"To be available in a reasonable time frame for patients - early intervention to minimise morbidity"

Physiotherapist

"More preventative work going out into community"

Physiotherapist

5.0 Conclusions

This study has generated rich insights, using mixed methods research to explore various aspects of Northern Ireland's Continence Services from different perspectives. Despite this diversity in approaches and participants, several clear recurring themes have emerged. These are summarised below.

5.1 Service user interviews

Based on what service users said during interviews, it can be concluded that:

A. Continence issues can have a **severe and debilitating impact on people's lives**. Two thirds of participants said that continence issues affected their day-to-day lives. These impacts were:

- *Practical* – limiting people's choices and activities, including work;
- *Emotional* – causing anxiety, depression and, in a small but notable number of cases, having very serious impacts on mental health. These problems were linked to the stress of continence issues but also to ongoing pain.

B. Many **people are reluctant to seek help** with continence issues, often waiting until their condition gets so bad that they are unable to manage it themselves.

C. People have **overwhelmingly positive experiences of Continence Services** and of the staff that provide them. Staff were described as flexible and person-centred, and sensitive in carrying out procedures that are often unpleasant. A recurring finding was that Continence Nurses are very responsive in times of need. Many respondents recounted phoning their Service when things went wrong and getting care and support that was prompt and went above and beyond.

D. The main suggestions for improving Continence Services were:

- *Improving continuity in staff*, i.e. avoid seeing different nurses at each clinic appointment about what are very personal issues;
- *Improving continence pad services*, specifically the quality and quantity of products and the sensitivity in how they are delivered.

E. There is **apparent divergence between services across Trusts** in terms of:

- *Profile of service users* – based on the profiles of clinic groups as well as actual participants, some Trusts' Continence Services see almost exclusively females, some largely male and some balanced. Based on this, there may be substantial sections of the population who are not accessing or benefiting from the Services in some Trusts;
- *What the Services deliver for them* – some Trusts' Continence Services seem to focus mainly on managing continence pads and catheters, while others prioritised keeping patients off continence pads.

Based on our experience of conducting the service user fieldwork at clinic sites:

F. There seem to be **high numbers of 'Did Not Attends' and cancellations**, perhaps due to the requirement to come for pad reviews, which some patients see as unnecessary.

5.2 Service staff survey

Based on data collected for the staff survey, it can be concluded that:

G. Staff feel **satisfied and supported** in their jobs but are **less positive about perceived understaffing and heavy workload.**

H. Staff **feel like they have too little time and opportunity to address the aspects of their jobs beyond direct patient-facing appointments** (e.g. awareness raising/promotion, teaching, training, research/audit/evaluation, sharing good practice).

I. Staff have **quite strong awareness and knowledge of the other services** being used by their patients. However, they are much **less positive about communication between these services and between Continence Services.**

J. The main suggestions from service staff for changing Continence Services were:
- **More funding and more trained staff**, in the hope that this will improve waiting times, support earlier intervention and release capacity for non-clinical work;
- **Better integration and communication across Continence Service teams;**
- **More advertising** (of how the Services can help people) and **more promotion** (of how the Services have helped people);
- **Development and expansion of the services' remit and activities** (e.g. pelvic pain, mesh clinics, pessary clinics and perineal clinics).

6.0 Recommendations

Drawing on our findings and conclusions, we recommend eight areas for action; these are presented below (R1-R9). Each is linked to the conclusion(s) (A-J) upon which it is based and with relevant considerations and contextual factors noted.

A. Continence issues can have a severe and debilitating impact on people's lives

B. People are reluctant to seek help

I. Staff are less positive about communication between the services used by their patients

Continence Services, Trusts and other HSC organisations should make efforts to:

R1. Raise awareness of Continence Services and promote the positive impact that they can have on people's lives (with the general public and other HSC staff)

R2. Raise awareness of continence issues and care (among other HSC staff)

Considerations: May lead to a challenging increase in demand for Continence Services.

D. Some service users suggested that improving continuity in Service staff would be a positive change

Continence Service staff and managers should:

R4. Consider options to enable patients to see the same nurse at each continence clinic appointment, e.g. 'key worker' model

Considerations: May or may not be feasible with current staffing/capacity of Continence Services.

D. Service users highlighted issues with the quality, quantity and delivery of continence products

Continence Service staff and managers should:

R5. Consider a separate review of continence pad services - including checks on pad reviews during clinics - to get a reliable picture of service user satisfaction

E. There is apparent divergence between services across Trusts in service user profile and interventions delivered

Continence Service managers and regional HSC organisations should:

R6. Agree and support a regional service model for continence care, based on existing clinical standards and guidelines and covering a 'full life path'

Considerations: Supports the proposal in the PHA's Scoping Paper of Continence Services. Model must be developed in partnership with service users and their carers.

F. There seem to be high numbers of DNAs and cancellations

Continence Services should:

R7. Identify - through consultation with service users - the reasons for high DNA/cancellation rates

G. Service staff perceive understaffing and heavy workload

H. Service staff see little opportunity to address non patient-facing ascpects of their roles

Continence Service managers and regional HSC organisations should:

R8. Consider increasing Continence Service funding and staff levels

Considerations: This is a longer term proposal, subject to evaluating current practice, capacity and demand, i.e. outcomes of R1, R3, R6 and/or R7.

J. Service staff suggested that better integration and communication across Continence Service teams would be a positive change

Continence Services should:

R9. Re-establish a regular forum – 'Community of Practice' – for Continence Service staff to meet and share good practice, solve problems and ensure regional consistency in service delivery

7.0 Next steps

The findings and recommendations from this study will be communicated to relevant stakeholders (including the Regional Steering Group).

The PCC will carry out further research into Continence Services in Northern Ireland during 2020/21. As well as the recommendations set out above, the report demonstrates that there is merit in identifying how GPs and other medical staff beyond the Continence Service respond to patients presenting with bladder and/or bowel incontinence before being referred to the Continence Service. Such findings are mirrored in extant research in this area, particularly with GPs. Thus further research in Phase 2 is required to:

- Identify how GPs and other medical staff respond to patients presenting with bladder and/or bowel continence issues, specifically their attitudes, knowledge and practice;
- Explore the factors that influence such responses;
- Makes recommendations to improve patient experience and maximise resources; and
- Develop an Integrated Care Pathway for bladder and bowel continence issues for such patients in Northern Ireland.

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Appendix 1 – Steering Group Membership

- Colm Burns – Research Manager, Patient and Client Council
- Laura O'Neill – Research Officer, Patient and Client Council
- Sandra Aitcheson – Assistant Director of Nursing
- Caroline Graham - Nurse Consultant, Director of Nursing
- Mark Ryan - Assistant Service Manager, Community Health Nursing, Belfast Health and Social Care Trust
- Bronagh Wells – Community Continence Nurse Lead, Belfast Health and Social Care Trust
- Jackie Granleese – Continence Service User
- Michael Bailey – Continence Service User

Appendix 2 – Topic Guide

Section	Question	Time (indicative)
Introduction/Respondent Details	Gather demographic information such as; Gender, Age and Trust location. Trust location may be apparent if conducted in clinics.	5 min
Continence Background	What type(s) of continence issues do you have? *Prompts:* ➤ *Bladder (stress, urge, overflow)* ➤ *Bowel* ➤ *Mixed incontinence(both bladder and bowel)* How many appointments have you had at the clinic so far? What treatment/support are you currently receiving for this? *Prompts:* ➤ *Pads?* ➤ *Physio?* ➤ *Lifestyle Changes?* ➤ *Medication?* *If interviewee uses pads ask about experience here;* *-Do you feel your pads are suitable?* How long after you first experienced continence issues did you do something about them? ➤ *Why?* Who referred you for continence services? ➤ *Was this referral process easy or difficult?* What was the time period between your referral and your first appointment with the continence services? ➤ *How did you feel about this?*	
Perceptions of Continence	Tell me how your continence issues make you feel? *Prompts:* ➤ *Does it affect your day to day life?* ➤ *Social life?* ➤ *Work life?* ➤ *Family relationships?* ➤ *Do you feel it's seen as a natural part of getting older?*	
Continence Service Experience	How well does the service fit around your needs? *Prompts:* ➤ *How accessible is the Clinic for you?* ➤ *How convenient are Clinic times for you?*	

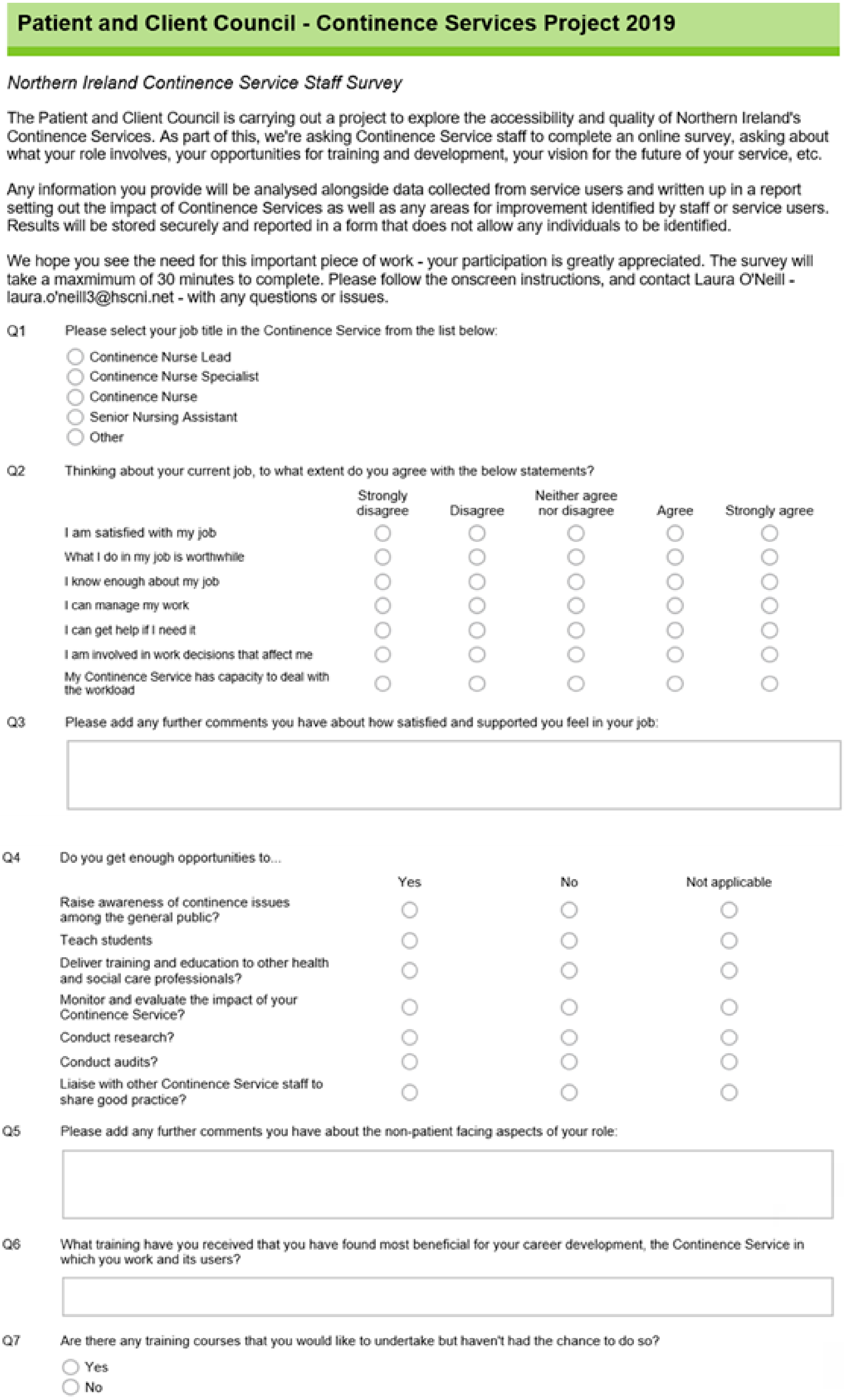
	➢ *Do you see the same nurse on each visit? Would you say this is important to you?* What would you change, if anything and how do you think this would make things better?	
Outcomes from accessing the service	Has the continence service made any change to your health or wellbeing since accessing the continence services? *Prompts:* ➢ *Has your continence issues improved?* ➢ *Physical health improved?* ➢ *Mental health improved?* ➢ *Social life?* ➢ Family relationships? Have you found the treatments you've received so far helpful? *Prompts:* ➢ *If not, why not?* Have you found the support you've received so far helpful? *Prompts:* ➢ *If not, why not?*	
Continence Pad Experience	If you use continence products, do you receive enough continence pads to cope with your continence issues? Are you always able to get them free of charge? Have you been given the information and support you need to use them properly? Describe any improvements you would like to see to the continence pad service you receive?	
Continence Care and Support beyond the service	Apart from the continence services, do you feel that other medical staff, such as hospital doctors/nurses and GPs are knowledgeable about/aware of continence issues/services? *Prompts:* ➢ *Do you feel listened to by them when you talk about continence issues?* ➢ *Do the different people who help with your continence issues work well together?* Are you currently living with another health condition apart from your continence issues? *Prompts:*	

Conclusion	Is there anything else you'd like to add that we haven't talked about today? Thank them for their time and close	

Note:

- Officers should capture the demographics of the participant (in particular gender and age or age group [16-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, 85+], and any other information that might add value to the quotes and information we record.

Appendix 3 – Staff Survey



Patient and Client Council - Continence Services Project 2019

Northern Ireland Continence Service Staff Survey

The Patient and Client Council is carrying out a project to explore the accessibility and quality of Northern Ireland's Continence Services. As part of this, we're asking Continence Service staff to complete an online survey, asking about what your role involves, your opportunities for training and development, your vision for the future of your service, etc.

Any information you provide will be analysed alongside data collected from service users and written up in a report setting out the impact of Continence Services as well as any areas for improvement identified by staff or service users. Results will be stored securely and reported in a form that does not allow any individuals to be identified.

We hope you see the need for this important piece of work - your participation is greatly appreciated. The survey will take a maxmimum of 30 minutes to complete. Please follow the onscreen instructions, and contact Laura O'Neill - laura.o'neill3@hscni.net - with any questions or issues.

Q1 Please select your job title in the Continence Service from the list below:

○ Continence Nurse Lead
○ Continence Nurse Specialist
○ Continence Nurse
○ Senior Nursing Assistant
○ Other

Q2 Thinking about your current job, to what extent do you agree with the below statements?

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I am satisfied with my job	○	○	○	○	○
What I do in my job is worthwhile	○	○	○	○	○
I know enough about my job	○	○	○	○	○
I can manage my work	○	○	○	○	○
I can get help if I need it	○	○	○	○	○
I am involved in work decisions that affect me	○	○	○	○	○
My Continence Service has capacity to deal with the workload	○	○	○	○	○

Q3 Please add any further comments you have about how satisfied and supported you feel in your job:

Q4 Do you get enough opportunities to...

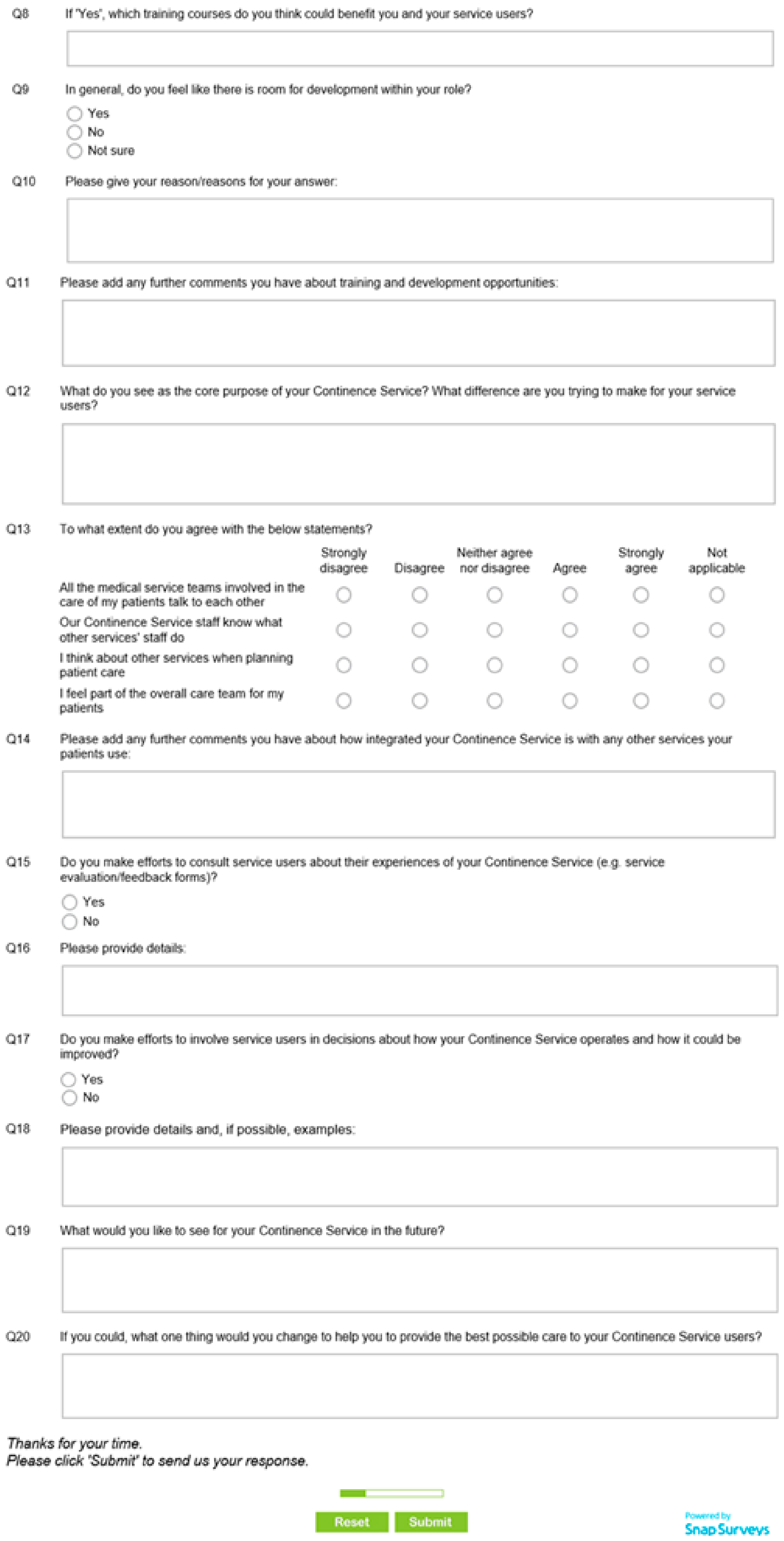
	Yes	No	Not applicable
Raise awareness of continence issues among the general public?	○	○	○
Teach students	○	○	○
Deliver training and education to other health and social care professionals?	○	○	○
Monitor and evaluate the impact of your Continence Service?	○	○	○
Conduct research?	○	○	○
Conduct audits?	○	○	○
Liaise with other Continence Service staff to share good practice?	○	○	○

Q5 Please add any further comments you have about the non-patient facing aspects of your role:

Q6 What training have you received that you have found most beneficial for your career development, the Continence Service in which you work and its users?

Q7 Are there any training courses that you would like to undertake but haven't had the chance to do so?

○ Yes
○ No



Q8 If 'Yes', which training courses do you think could benefit you and your service users?

Q9 In general, do you feel like there is room for development within your role?

○ Yes
○ No
○ Not sure

Q10 Please give your reason/reasons for your answer:

Q11 Please add any further comments you have about training and development opportunities:

Q12 What do you see as the core purpose of your Continence Service? What difference are you trying to make for your service users?

Q13 To what extent do you agree with the below statements?

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Not applicable
All the medical service teams involved in the care of my patients talk to each other	○	○	○	○	○	○
Our Continence Service staff know what other services' staff do	○	○	○	○	○	○
I think about other services when planning patient care	○	○	○	○	○	○
I feel part of the overall care team for my patients	○	○	○	○	○	○

Q14 Please add any further comments you have about how integrated your Continence Service is with any other services your patients use:

Q15 Do you make efforts to consult service users about their experiences of your Continence Service (e.g. service evaluation/feedback forms)?

○ Yes
○ No

Q16 Please provide details:

Q17 Do you make efforts to involve service users in decisions about how your Continence Service operates and how it could be improved?

○ Yes
○ No

Q18 Please provide details and, if possible, examples:

Q19 What would you like to see for your Continence Service in the future?

Q20 If you could, what one thing would you change to help you to provide the best possible care to your Continence Service users?

Thanks for your time.
Please click 'Submit' to send us your response.

Remember you can contact us by

Telephone
0800 917 0222

Email
info.pcc@hscni.net

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