NHS
Northern Lincolnshire and Goole
NHS Foundation Trust

healthwatch
North Lincolnshire

CONTINENCE REPORT

Date: January 2024

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Disclaimer

Please note: This report is based upon feedback provided to Healthwatch North Lincolnshire from members of the public and professionals. The findings are based upon
individuals' perceptions, which are not verified for factual accuracy.

Quotes in the report are written as received, to ensure opinions are kept in context, as such there may be grammatical errors within quotes.

1 Introduction

1.1 What is Healthwatch North Lincolnshire?

We are the independent champion for people who use health and social care services. We exist to make sure that people are at the heart of care. We listen to what people like about services and what could be improved. We share their views with those with the power to make change happen. We also help people find the information they need about services in their area.

We have the power to make sure that people's voices are heard by the government and those running services. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them. Our sole purpose is to help make care better for people.

In summary Healthwatch is here to:

- Help people find out about local care
- Listen to what people think of services
- Help improve the quality of services by letting those running services and the government know what people want from care
- Encourage people running services to involve people in changes to care

2 Background

2.1 Why this subject?

During 2020 and 2021 talks began between Healthwatch and Northern Lincolnshire and Goole NHS Foundation Trust (NLaG) about undertaking a co-production piece of work around the Bladder and Bowel Service (also mentioned within the report as the Continence Service), with the aim of

finding out what patients want from the service and where improvements could be made. Healthwatch had also received some negative feedback from members of the public about the service including the Carer's Advisory Partnership (now Carer's In Partnership).

At the same time talks also occurred between NLaG and North Lincolnshire's Clinical Commission Group (CCG) about extra resourcing for the department. The previous service had two members of staff: a Band 7 (whole time equivalent (WTE)) and a Band 4. Information provided by NLaG showed that before changes were made the service had a caseload of 2077, with 266 new patients on the waiting list. The longest waiting time was 54 weeks. (Information provided by NLaG).

Once extra funding became available the service could fund more staff. Staffing now consists of a band 7 (WTE), Band 6 (WTE), Band 4 (22.5 hours) and a Band 5 (45 hours). When examining the service six months on NLaG had noted a reduction in the caseload to 1922. (Information provided by NLaG).

Other changes that NLaG made to the department included:

- Reviewing the triage waiting list throughout the day
- Setting care plans for all patients
- Reducing care home waiting times to 2-4 weeks
- Increasing clinic capacity
- Working on caseload management
- Carrying out pad weighing
- Taking continence assessments from the District Nurses
- Providing annual reassessments
- Carrying out training for Care homes
- Developing patient information leaflets

(Information provided by NLaG)

Other changes that are planned for this department, include the following:

- Staff to complete children's continence training
- Developing a 1st time male catheterisation pathway.
- Developing a children's continence assessment template
- Improving the transition process from children's continence to adults' continence
- To make pathway developments in Stoma care and colorectal services
- To carry out a Catheter Formulary Review
- To undertake team development

(Information provided by NLaG)

Healthwatch North Lincolnshire has created surveys, with the help of staff at NLaG, to find out public and professional opinions on the Bladder and Bowel Service.

2.2 Methodology

Two surveys were created, one for members of the public to complete and one for professionals. Continence nurses were consulted on the questions and on the 9th January 2023 continence nurses at NLAG started to hand deliver public surveys to their patients during home visits. Healthwatch Freepost envelopes were also provided to patients so that they could post back their completed surveys; this ensured people could remain anonymous if they did not wish the continence nurses to know who had made the comments. Wherever possible surveys were also handed out during regular engagement sessions at Scunthorpe General Hospital and at the Ironstone Centre. Healthwatch North Lincolnshire also gave out 50 hard copies to Brigg Carers Support Centre.

In addition, we (Healthwatch North Lincolnshire) created online copies of both the surveys so that we were able to share these out electronically, for anyone wishing to complete the surveys online. We then shared links to the surveys on our social media pages and via email to Healthwatch North Lincolnshire's 462 contacts.

Finally, we also contacted local care homes, home care providers, schools, and other organisations, which we believed may be able to help distribute the survey. This included: St Luke's school, St Hugh's School, Demeter House School, The Parent Involvement and Participation Forum and The Learning Disabilities Partnership.

2.3 Limitations of the study

Despite our attempts at promoting the survey and the work staff at NLaG did in distributing the survey, we captured only nineteen responses. Although the feedback has provided some insight a larger response rate would have been preferable. We have, however, examined the results and the key findings are provided in this report.

2.4 Local services/pathway

The Northern Lincolnshire and Goole NHS Foundation Trust's (NLaG's) Bladder and Bowel Service is available to help those who face urinary and faecal continence problems. The service covers children from the age of 5 and adults. They carry out assessments and can help patients by treating and managing their condition. If required, the service can prescribe containment products (NLaG, 2023[1]).

[1] https://www.nlg.nhs.uk/services/bladder-and-bowel-service/

Assessment clinics take place at different locations across North Lincolnshire with home assessments being available for those who are unable to attend the clinics including those who are housebound (Ibid[1]).

The service understands the impact that incontinence can have on adults, including:

- Low self esteem
- Anxiety and Depression
- Loss of independence

2.5 The national picture

Continence is a large subject nationally and the NHS spends thousands of pounds every year on caring for individuals who suffer from incontinence and providing them with the products they need. It is estimated that in the UK almost 14 million adults, young people and children have a bladder issue. (NHS England, 2018, p6[2]).

According to NHS England's Excellence in Continence Care: Practical guidance for commissioners, and leaders in health and social care, 61% of men are estimated to experience a lower urinary tract symptom, and 34% of women have urinary incontinence problems. It is also reported that 900,000 children and young people have a bladder and bowel issue and that 1 in 10 people suffer from faecal incontinence (Ibid[2]).

The report also highlights that, one in three people in residential homes have urinary and faecal incontinence and in nursing homes this rises to two in three residents (Ibid[2]**Error! Bookmark not defined.**).

[2] https://www.england.nhs.uk/wp-content/uploads/2018/07/excellence-in-continence-care.pdf

The Urology Foundation article named 'Hundreds and Thousands Suffer in Silence' highlights the opinions of a urology surgeon "…*Ms Greenwell (*Urology surgeon at University College Hospital, London) *says that although there are an estimated six million people who suffer from incontinence in the UK, it could be double this figure as many more are undiagnosed due to an unwillingness to see their doctor about symptoms...*" (The Urology Foundation[3])

The Cost-Effective Commissioning for Continence Care Report 2011 is a guide to commissioning continence services. It was felt that a truly effective continence service could only be delivered through a proper integrated approach, and it explained that monetary savings could be achieved by decreasing:

- *"Unnecessary catheterisations and associated urinary tract infections (UTI)"*
- *"Pressure ulcers linked to poor continence care"*
- *"Acute hospitalisations for UTI, urinary retention renal failure and faecal impaction"*
- *"Care home admissions precipitated by incontinence"*
- *"The use of continence products through low-cost interventions such as bladder retraining, pelvic floor muscle training and appropriate use of medications for incontinence."*

(APPG, 2011, p5[4])

When looking at the commissioning cycle the report highlights the significance of involving service users in the development of continence services (Ibid, p9[4]) it also mentions the importance of local knowledge around demographics. North Lincolnshire's JSNA states that "…By 2035 it is

[3] https://www.theurologyfoundation.org/news/277-hundreds-of-thousands-suffer-in-silence#:~:text=This%20is%20desperately%20sad%20because,see%20their%20doctor%20about%20symptoms

[4] http://www.appgcontinence.org.uk/wp-content/uploads/2020/02/CommissioningGuideWEB.pdf

estimated that 10% men and 20% women aged 85+ will have high dependency needs, ie needs help everyday with using the toilet, or has problems with continence, transferring from bed or chair, feeding, and putting on socks and shoes.." (NLH&WB, 2018, p46[5]).

2.6 The local picture

Figures from NLaG suggest that the number of people who suffer from continence issues in North Lincolnshire is around 42,425. However, the true figure is unknown due to the amount of people in the local area who may not have come forward to highlight the issues they are facing. (Information provided by NLaG).

In the 2019 Care Quality Commission Report some issues were highlighted for Community Services. For the Continence service the report specifically highlighted waiting times and stated that the trust 'must ensure that patients receive timely assessment and treatment and put measures in place to address the long waits in the continence service (CQC, 2019, p14[6]). The report states that long waits for patients was also highlighted at their previous inspection. The findings of the inspections were a catalyst for the improvement of NLaG's community services.

3. Key Findings:

To find out whether opinions differed between service users and professionals we asked people to state whether they were completing the survey: for themselves, for someone else or as a professional that works with patients with

[5] https://m.northlincs.gov.uk/public/nldo/resources/well%20evidence%20base%20(JSNA)%202018.pdf

[6] https://api.cqc.org.uk/public/v1/reports/b4451e94-7a1b-45e6-ae4a-1b9c648d09d2?20221125114744

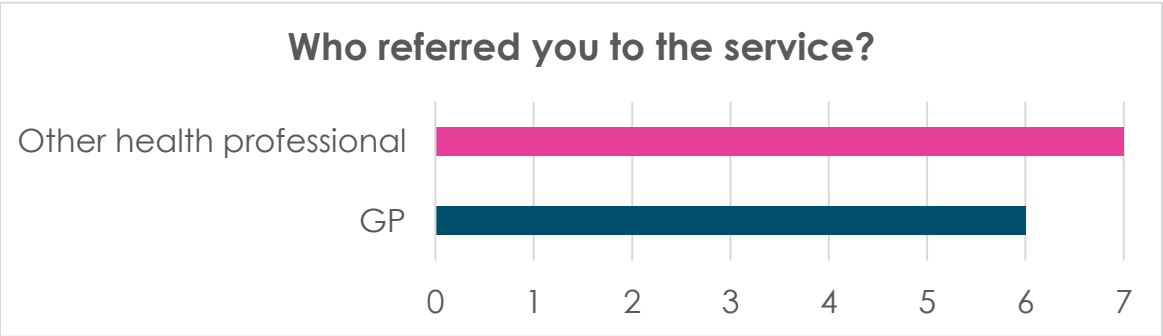
incontinence. We received feedback from all groups, with similar numbers representing each group.

Responses from the public and professional surveys have been analysed and highlighted over the following pages.

Responses from the Public Survey

The Referral Process

The results revealed a near equal split over who referred people to the service, whether it was the GP or another health care professional. People that were not referred by their GP came through the following routes: the Community



Matron, Urology Spinal Unit (Sheffield), Rehabilitation Unit, Carers Support and their local school.

How long ago was your referral made?

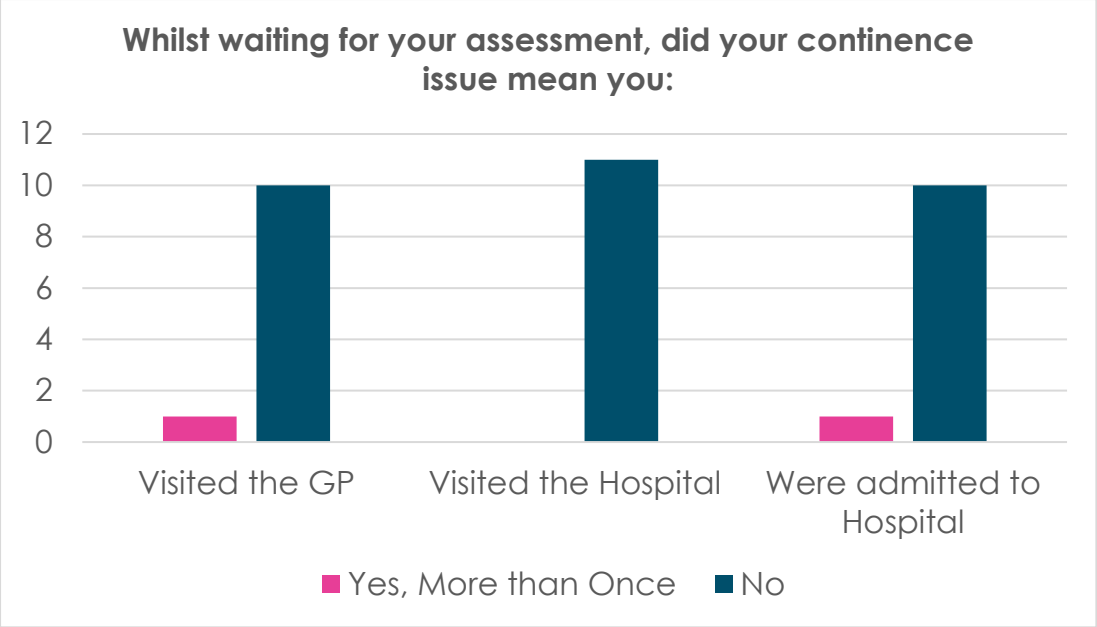
Four service user's referrals were made within the last six months and nine service user referrals were made over six months ago.

The Assessment Process

Twelve service users had had their initial assessment, and one was still waiting. The person who was still waiting for their assessment said that they had been waiting between one and three months. They also mentioned that whilst waiting they had had to visit the hospital and been admitted, they also said that they had to visit their GP more than once. This person did say, however, that they had been given advice or information, around diet and exercise, which could help improve their condition and that they had been able to follow this.

Of the 12 people who had already had an assessment five stated that they had waited between one and three months from referral, four had waited less than one month and one had waited between three and six months. Two people did not reply.

One person who was waiting for an assessment stated that they needed to visit their GP and were admitted to hospital.



Three out of the 12 service users who had had an assessment felt that there had been no impact on them whilst waiting for their assessment.

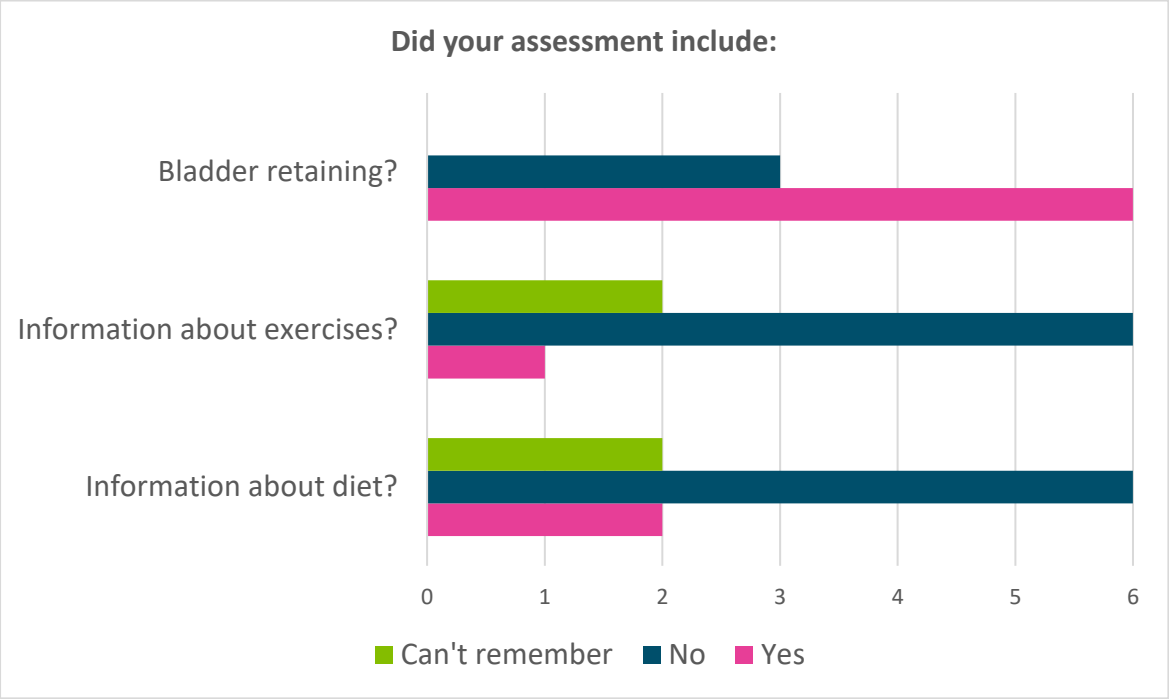
- ***"A short wait and coped with problem."***
- ***"None"***
- ***"None- got seen very quickly."***

Six service users, however, highlighted a detrimental impact including issues obtaining the correct containment products and the costs associated with buying the products. People also mentioned having to wait for additional care/support.

- ***~~"Additional Care."~~***
- ***~~"Getting the right people involved with my needs Right Catheters and incontinence service needs."~~***
- ***"Very costly buying incontinence aids from supermarkets lack of dignity knowing if I was using right products."***
- ***"Feeling uncomfortable and embarrassed without the correct support and pads."***

- *"Difficulty in finding suitable/adequately sized continence products. Financially difficult in terms of paying for continence products which were expensive and largely unfit for purpose."*
- *"I was referred many years ago as I have MS. After following the advice of the continence nurse I am then discharged. Then I have to get another referral as my condition worsens."*

To find out how informative service user's assessments were, we asked those who had had an assessment whether they had received information on diet, exercise, and bladder retention.

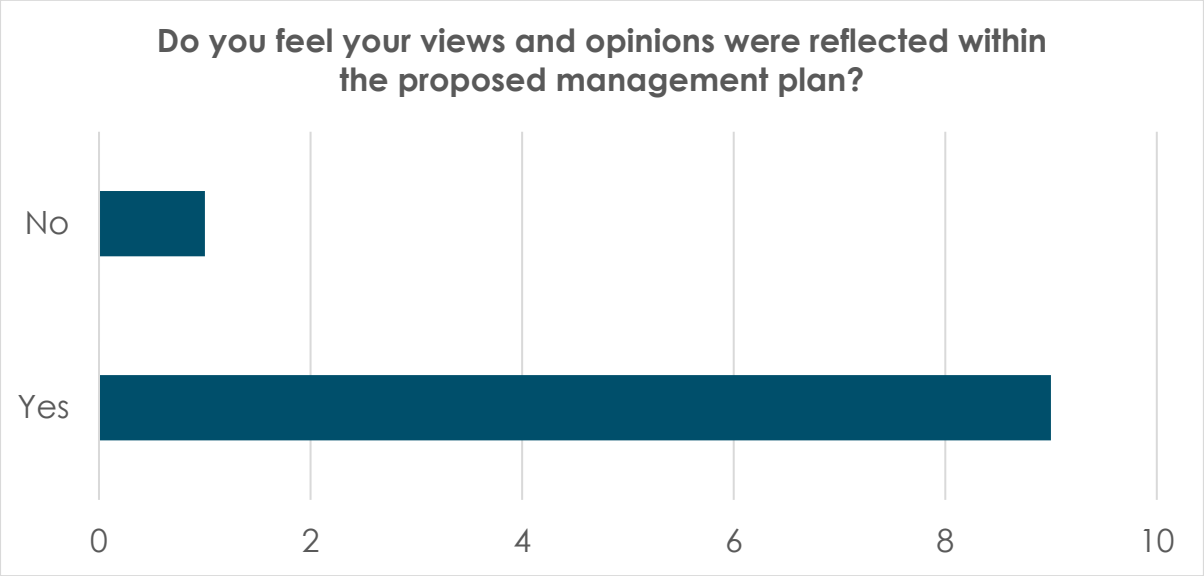


Six respondents said that they had received information on Bladder Retention. Whilst only one person remembers receiving information about exercises and only two remembered being given information about diet.

The Management Plan

Nine respondents, who had had an assessment, felt able to discuss their views and opinions in relation to the proposed management plan during their assessment.

Nine people also felt that their views and opinions were reflected within the proposed management plan.



However, we found that most people (seven) had not had exercises or treatment to regain continence included within their management plans.

One person mentioned the inclusion of treatment within their management plan, another stated that exercises were included. Only one person said both were included.

Review of the Management Plan

We received a mixed response when we asked how often management plans were reviewed. Four people said that their plan had not been reviewed.

The two people who gave other as their answer provided the following comments:

- **"One review has been completed over the course of almost ten years, when the continence service changed supplier."**
- **"If I ask for a new referral."**

We then asked who completed the review. The vast majority (10) were completed by a Continence Nurse, one by the GP and one person did not know.

We asked those who said that they had had a review how long it took. Two people said 30 minutes, one said minutes, one said 30-40minutes and another said an hour. One final person said that they took different amounts of time depending on the subject, ongoing issues or conversation that was being had.

People mentioned that the following information was discussed with them at the review:

- **"Size and absorbency requirements of continence products"**

- **"Medications to be taken/trialled. Other hospital appointments that may have an effect on patients and effect his plan, keeping bladder and bowel diary to map changes and progress."**
- **"Records of bowel and bladder condition, improved by continence nurse and filled in by me."**
- **"Diet, how to use pads, fluid intake, bowel movements and what products are available."**
- **"All things regarding Incontinence, product usage, how things have been going."**
- **"Catheter infection control bowel management."**
- **"I received samples which was useful."**

We then asked what opportunity people had to share their views and opinions within the review process. The following answers were received:

- **"Little to none"**
- **"All the time, very open and honour conversations that take place"**
- **"full opportunity to explain my condition and concerns and to discuss recommendations and reasons for same."**
- **"Included in review"**
- **"Fully Discussed"**
- **"All needs are assessed"**

The following suggestions were given as to how the review process could be improved:

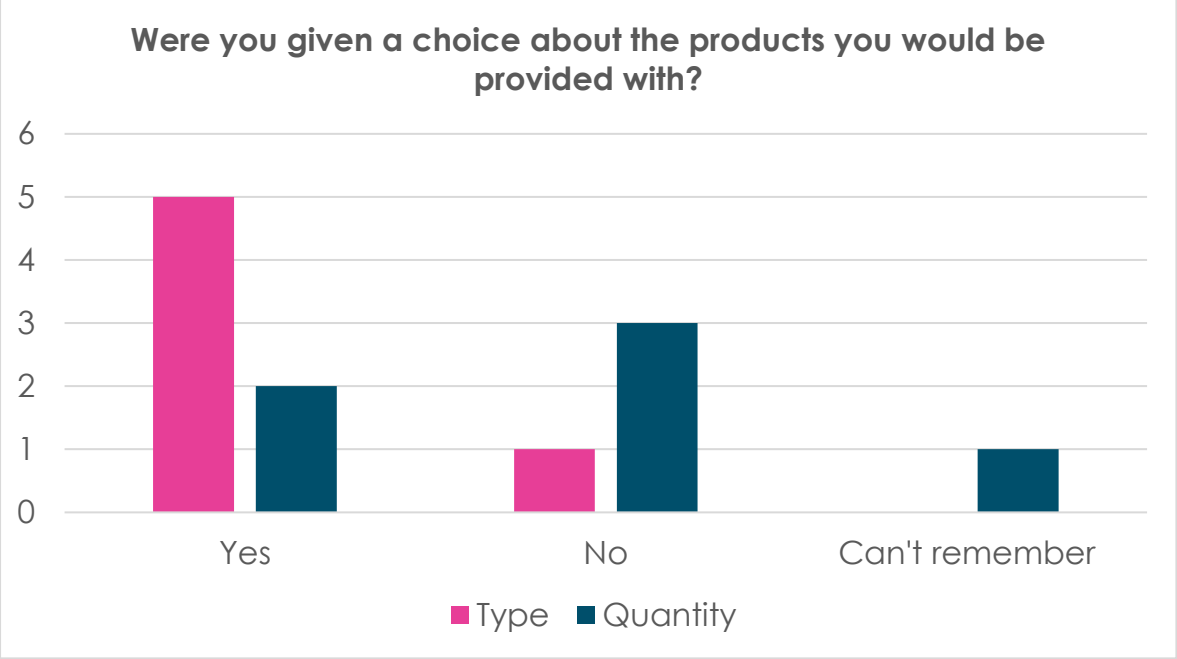
- **"The review is impersonal and perfunctory, serving only to ascertain the number/size and absorbency requirements of the client. Input from the continence team is minimal, information is minimal, further signposting has been non-existent. The service is merely a point of contact concerning potential order issues as opposed to a supportive and informative service that helps to manage the many issues surrounding incontinence."**

- **"With our current nurse- none, she is brilliant, so don't want to replace her."**
- **"None, I am extremely satisfied with the whole progress."**
- **"N/A"**
- **"Review Excellent"**
- **"There is no formal system of review of my incontinence. It is crisis management really."**

Containment Products

Of those who had had an assessment, seven stated that they required containment products and of those five stated that they had been given information about the containment products that might be suitable for them.

Of the seven people who required containment products, five stated that they were given a choice about the type of products they were provided with and two were given a choice around quantity.



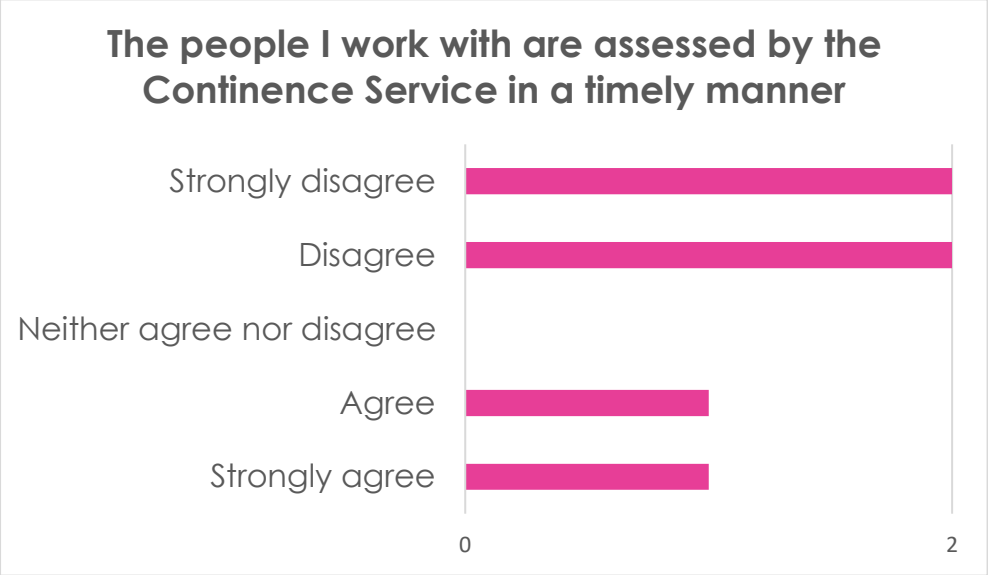
Three people stated that they received their containment products within a week, three waited longer than a week and one received them immediately.

Responses from the Professional Survey

We asked professionals about where they worked. The majority (5) stated that they worked in residential care, with one person saying that they worked for the Stroke Association.

Assessment Process

Professionals were asked whether they agreed that people were assessed in a timely manner. Most people disagreed.

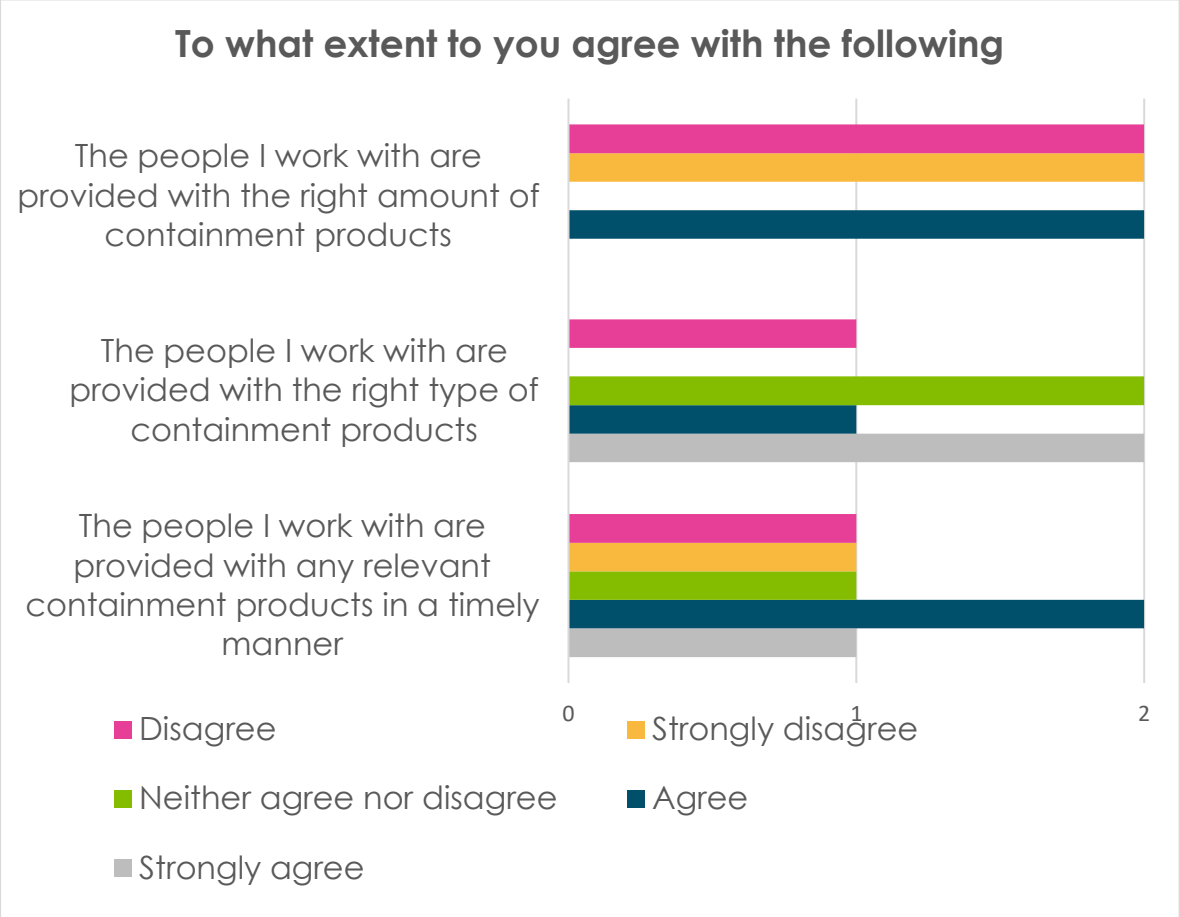


Containment Products

Professionals were asked to what extent they agreed with a series of statements. The next chart highlights the result and shows that professionals had different opinions as to whether the people they worked with were provided with the right amount of containment products with four either disagreeing or strongly disagreeing and two agreeing.

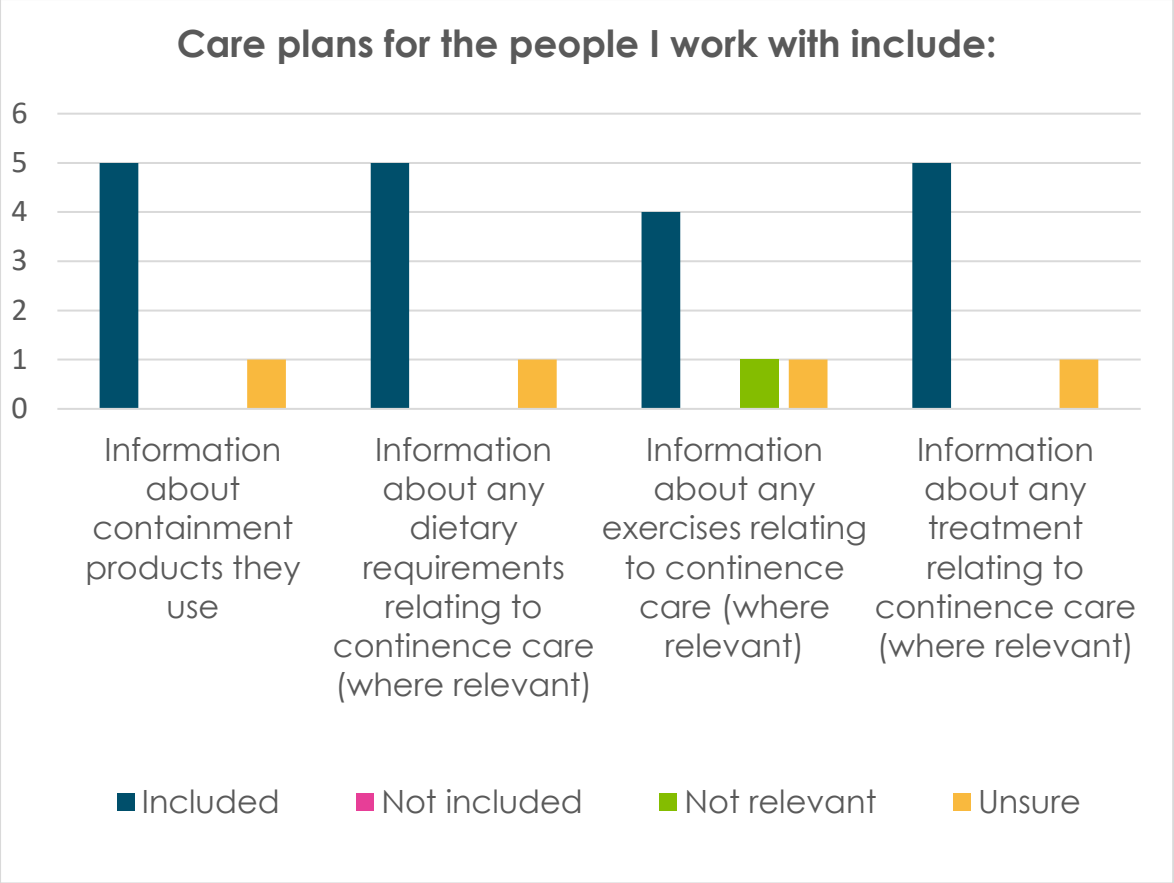
Three people felt that those they worked with were provided with the right type of containment products, two neither agreed nor disagreed and one disagreed.

In addition, three professionals agreed or strongly agreed that the people they worked with were provided with relevant containment products in a timely manner. One person neither agreed nor disagreed and two disagreed to some extent.



Care Plans

Overall, professionals stated that care plans contained information about containment products, dietary requirements, exercises and treatment relating to continence care.



Two respondents who worked in residential care settings explained that they had an involvement in care planning.

- **"Care plans are written by myself or the Deputy Manager"**
- **"I develop, review and update the care plans in the home"**

All professionals working in residential care stated that they had received training on the appropriate use, of a range, of containment products, hygiene and reducing the risk of infection whilst using containment products.

Overall opinions about continence care

All residential care staff felt either very or fairly confident with continence care. Only one professional stated that they were not confident.

On average professionals rated the service 52 out of 100 with 100 being excellent and 0 being poor.

Four comments were made about the service. They included:

- **"I feel that the people we support do not get the adequate amount of products, often having to purchase additional continence products form their own money which leave them with very little to spend on their personal or recreational items"**
- **"New management of the continence service appears to be improving the service, at last we may have a continence service to be proud of. The way it used to be under [name omitted]."**
- **"Obviously there were a lot of difficulties throughout Covid for all healthcare providers, but since then the continence service have been extremely efficient."**
- **"There is a long waiting list and patients do not seem to be supported as they should be with something which is deeply embarrassing and limits lifestyle"**

We asked professionals to tell us about a time when they received excellent customer care form the Bladder and Bowel Service.

- **"Every time we are in touch with [name omitted]."**
- **"After Covid when they had to catch up on a lot of referrals."**

We then asked about what made that experience excellent. The following replies were received:

- **"The updated approach and comprehensive service [name omitted] is delivering."**
- **"They were able to spend the time at the house with the individual residents to discuss their continence care."**

Two professionals gave their suggestions for improvement to the service:

- **"I believe the number of products that each individual receive[s] should be reviewed and especially now the extra absorbent "pull up" option has been removed from distribution as some of our individuals are heavily incontinent within 2-3 hours or urine and unfortunately the liner and netted pants are not absorbent nor robust enough to support those who are incontinent of faeces."**
- **"More staff"**

4. Conclusion

The findings highlight variations in the length of time service users waited for assessment and the impact long waits had. In addition, most professionals stated that those they worked with were not assessed in a timely manner.

The public survey revealed that Information given during assessments could be improved and that management plans often didn't include information about exercises or treatment to help regain continence. Professionals, on the other hand, felt that individual care plans did contain relevant information.

Overall service users felt involved with their management plans with most being able to discuss their views, during assessment. The public survey showed that most management plan reviews were carried out by continence nurses but the frequency of these differed from person to person.

Most service users who had had an assessment needed containment products and had been given information about the products that might be suitable for them. However, only two people felt that they had been given choices around quantity. Similarly, four out of six professionals felt that the people they worked with were not provided with the right amount of containment products.

Service users and those responding on their behalf indicated that the time people waited for their continence products after being assessed ranged from straight away to more than a week.

Finally, all professionals working in residential care felt confident with continence care and had received relevant training.

5 Recommendations

Moving forward we would recommend that the Bladder and Bowel Service:

1. Look to reduce waiting times further for those waiting for initial assessments. Alternative approaches could be trailed, such as virtual assessments, for patients who have the technology to accommodate this, where they do not then face to face assessments should continue.
2. Provide more information to those waiting for their initial assessment, especially around types of containment products and the costs of products. When relevant, people should also be signposted to where they can get more support. Both the additional information and signposting could be done by staff undertaking a phone call to those waiting for an initial assessment, once referred.
3. Should provide information to all service users, during their assessments on bladder retention and whether diet and exercise may help them.
4. Ensure all Management plans contain information about exercises or treatment to help regain continence.
5. Ensure service users are fully consulted about the quantity of containment product they will need.
6. Ensure the timely delivery of containment products to service users.

6 Acknowledgements

We would like to thank NLaG staff for their work on the project, especially: The Head of Nursing for Communities and Therapies, The General Manager for Family Services, Community and Therapies and the Continence Nurse Specialist who provided background information to Healthwatch to help establish context for the project. We would also like to thank all staff who helped to distribute the survey.

Finally, we would also like to thank everyone who took part in the surveys and provided us with information for the project.

7 References

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Healthwatch North Lincolnshire
Suite 36
Normanby Gateway,
Lysaghts Way, Scunthorpe, DN15 9YG
Tel 01724 844986
enquiries@healthwatchnorthlincolnshire.co.uk
www.healthwatchnorthlincolnshire.co.uk

2nd January 2024

Rachel Greenbeck

Head of Nursing

Community and Therapies

Northern Lincolnshire and Goole NHS Foundation Trust

Global House

Ridgeway

Scunthorpe

North Lincolnshire

DN15 1BS

Dear Ms Greenbeck,

Formal report with recommendations submission under the Local Government and Public Involvement in Health Act 2007 (part 14) as amended by the Health and Social Care Act 2012 (Part 5)

I am writing to formally submit the enclosed Healthwatch report **'Continence Report'.** for your consideration. In particular, I wish to refer you to the recommendations on page 22. I would ask that the Northern Lincolnshire and Goole NHS Foundation Trust respond to the following recommendations:

- Look to reduce waiting times further for those waiting for initial assessments. Alternative approaches could be trailed, such as virtual assessments, for patients who have the technology to accommodate this, where they do not then face to face assessments should continue.

- Provide more information to those waiting for their initial assessment, especially around types of containment products and the costs of products. When relevant, people should also be signposted to where they can get more support. Both the additional information and signposting could be done by staff undertaking a phone call to those waiting for an initial assessment, once referred.
- Should provide information to all service users, during their assessments on bladder retention and whether diet and exercise may help them.
- Ensure all Management plans contain information about exercises or treatment to help regain continence.
- Ensure service users are fully consulted about the quantity of containment product they will need.
- Ensure the timely delivery of containment products to service users.

As you will be aware, it is a legal requirement that within 20 working days from receipt of the report you:

- Acknowledge receipt
- Provide an explanation of any action you intend to take in respect of any recommendations, or an explanation of why you intend to take no action.

If you would like to discuss any aspect of the report before you respond please contact me.

Yours sincerely,

Jennifer Allen

Manager, Healthwatch North Lincolnshire

Confidential Note:

The information contained in the letter is strictly private and confidential to the person

to whom it is addressed and must not be divulged without consent of the writer.

10th May 2024

Rachel Greenbeck

Community and Therapies

Global House

Ridgeway

Scunthorpe

North Lincolnshire

Enquiries To: Rachel Greenbeck

E-Mail: Rachel.greenbeck@nhs.net

Our Reference: RG/JA Healthwatch Continence

Jennifer Allen

Manager- Healthwatch North Lincolnshire

Suite 36

Normanby Gateway,

Lysaghts Way

Scunthorpe

North Lincolnshire

DN15 9YG

Dear Ms Allen

I write further to the Healthwatch Report on Continence services provided by Northern Lincolnshire and Goole NHS Foundation Trust in North Lincolnshire in which you outline the key findings of a survey undertaken in January 2023 and make 6 recommendations. I note the limitations of the study and that only 19 responses were received and therefore the results may not be reflective of the overall views of the patients on the caseload at that time and their families/carers.

Please find below the current position in relation to the recommendations and any further actions we intend to take to improve the service provided by our Bladder and Bowel Team.

Recommendation 1

Look to reduce waiting times further for those waiting for initial assessments. Alternative approaches could be trailed, such as virtual assessments, for patients who have the technology to accommodate this, where they do not then face to face assessments should continue.

Response: Waiting times have significantly reduced to what they were a year ago when the surveys were completed. Clinic waiting time is approximately 6 weeks. Home visit waiting time is approximately 4 weeks. Trial without catheters waiting time is approximately 2-3 weeks. There is a possibility that virtual appointments could be trialled, however as assessments include pelvic floor assessments and bladder scans this may lead to further delays as patients would still need to be seen to complete these as part of the assessment process. Bladder and bowel diaries which are reviewed as part of the assessment would also need to be electronic.

Recommendation 2

Provide more information to those waiting for their initial assessment, especially around types of containment products and the costs of products. When relevant, people should also be signposted to where they can get more support. Both the additional information and signposting could be done by staff undertaking a phone call to those waiting for an initial assessment, once referred.

Response: Information and self-help tips are sent out with all appointment letters. Links to the Bladder and bowel website and other sites will also be added to the appointment letters. We do not give information initially on product guidance as it can increase patient's expectations that they will automatically receive pads when they attend clinic. The use of containment products is the final management option with the focus initially on managing continence issues with other approaches. Information on Water Sure will also added to self help tips, this would enable patients to look to see if they can receive discount on their water bills.

Recommendation 3

Should provide information to all service users, during their assessments on bladder retention and whether diet and exercise may help them.

Response: All patients are sent the appropriate information leaflets following their assessments, this includes diet and exercise, bladder retraining etc.

Recommendation 4

Ensure all Management plans contain information about exercises or treatment to help regain continence.

Response: All patients seen in clinic receive a follow up letter with a detail plan of care and what they need to do before their next appointment.

Recommendation 5

Ensure service users are fully consulted about the quantity of containment product they will need.

Response: All patients who require products for containment of urine have a pad weigh and are advised how to use the products appropriately and how many they will be provided per day. They are also advised on when to change a pad and how to fit a pad correctly. We also discuss trouble shooting and how to prevent the pad leaking. A home delivery service information leaflet is also provided and explains how to generate their next delivery. Patients who require products for faecal incontinence are also advised on how many products they will be prescribed a day.

Recommendation 6

Ensure the timely delivery of containment products to service users.

Response: The timely delivery of containment products is the responsibility of the home delivery company which is not provided by the Trust, this is often where the delays can occur. Patients who are given samples of containment products to try are advised to re-contact the Bladder and Bowel once samples have been tried, only then will a prescription be generated. If patients fail to call back this can cause delays in patients receiving a delivery, this is discussed with the patient at the appointment.

Yours sincerely

Rachel Greenbeck

Head of Nursing

Community and Therapies