



# National audit of continence care (NACC)

## Capturing patients' experience of NHS continence services

### Pilot phase evaluation report

July 2012

Commissioned by:



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**Report approved by members of the National Audit of Continence Care (see appendix 2).**

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## Foreword

The National Audit of Continence Care (NACC) has been reporting on continence care (bladder and bowels) in the UK since 2005 with subsequent audits taking place in 2006 and 2010. These audits have been measuring practice against NICE clinical guidelines and have regularly showed that there is a real need for improvements in continence care for people with bladder and bowel problems, particularly in those aged 65+. The most recent audit in 2010 showed persistent deficits in quality of care, in particular the assessment, diagnosis and communication with patients.

Following the 2010 NACC, we worked with a group of continence service users to translate audit data into a report that would be understandable and useful to members of the public. Significantly the group felt the public report should signpost people with continence problems to the standards of care that should be provided and so the emergent report was called *'Keeping control: What you should expect from your NHS bladder and bowel services'*<sup>2</sup>. It was clear to both this user group and the National Audit of Continence Care (NACC) Steering Group that a patient experience questionnaire should compliment this work to map the continence care patients are actually receiving, and, for the first time, give them a voice within the national audit.

A questionnaire was designed titled, *'A questionnaire to ask about your experience of the continence (bladder and bowel) service (see appendix 6)*, with input from the continence service user group and piloted it, and this report presents the findings. This work complimented the NACC 2012 pilot which tested a shortened web-based audit tool, the full report *'Pilot audit evaluation report'*<sup>3</sup> has been made available to our funders Health Quality Improvement Partnership (HQIP) and the Department of Health.

At the start of November 2011 NHS continence services were asked to volunteer to participate in this questionnaire pilot. Seventeen volunteered to participate in this phase of work to assess the questions and methodology. Staff working in continence services were asked to give a questionnaire to 10 patients who had accessed the service. Ninety-nine (58%) of the 170 questionnaires we sent out were returned via a prepaid self addressed envelope (SAE). One question prompted patients for comments and thoughts about any other areas of care we should be asking about, and we received a high number of illuminating free text comments (reproduced in this report).

This pilot suggests that both continence providers and users are keen to engage with a patient experience questionnaire, and that this pilot version elicited meaningful and varied responses. The received questionnaires were all fully complete apart from one demonstrating patients were able to answer the questions.

Further development of this patient experience work is recommended, expanding the user-provider collaboration with a view to evolving into a national audit. Broader sampling methods (both paper and online questionnaires), revision of content will be required. A method of providing participating continence services with their results would need to be developed and a way to follow up how these services take action to make positive changes.

## Executive summary

The first round of the National Audit of Continence Care (NACC) was undertaken in 2004 and focused on clinical and organisational elements of the services. Successive audit of 2006 and 2010 demonstrated service improvements but, overall the picture remained of inconsistent continence care across the nation. The 2010 national audit looked at care delivery to patients, but did not capture patient's views of this care and services as per recent National Institute for Health and Clinical Excellence (NICE) guidance on patient experience (NICE CG 138). Work was undertaken with a user group to produce a public friendly version of the 2010 NACC report, and the ensuing publication (*Keeping control: What you should expect from your NHS bladder and bowel services*<sup>2</sup>) aimed to inform patients of what standards of care they should expect to receive and what to do if this was not apparent. The logical next step had to be a patient questionnaire finding out what care people are actually receiving, and how they perceive that care.

Obtaining the experiences of continence service users requires direct patient enquiry into the process of assessment, information provision, treatment planning and follow up. The content of the questionnaire was developed by the NACC steering group with much input from the continence user group. This user group was important in providing feedback on the questions the steering group had come up with. The group was also sent the final draft version of the questionnaire in the post and they were asked to send back any further comments that we could use for further development.

The questions covered existing clinical guideline (CG) evidence for good quality bladder and bowel care (NICE CG 40, NICE CG49, NICE CG 97), privacy and dignity issues, patient communications and follow up (see **appendix 6** for questionnaire). Some questions were derived from the Royal College of Physicians (RCP) Older people's experiences of falls prevention services<sup>1</sup> questionnaire. The questionnaire covered topics in the new recently piloted NACC audit, Continence pilot audit evaluation report<sup>3</sup>, and the NACC 2010 public friendly report<sup>2</sup>.

There is no preceding national work in this area of practice, so this pilot was essential to test feasibility and acceptability of a patient experience questionnaire, based on current evidence in bladder and bowel continence care. This report evaluates how well the questionnaires process worked, the responses given by users, and lessons learnt for the future. We provided space in this questionnaire for patients to give feedback on the questions we used, including their thoughts on what other questions they would like to see included (see pages 24-28). This report with the full results will be made available to HQIP, Department of Health, stakeholders, and the participating continence services.

## Summary of findings

### *Patient sample*

For the purpose of this pilot, volunteer continence services distributed the 10 questionnaires we provided to them to patients who had been through their continence (bladder and bowel) services. The way we would choose the patient sample to participate in a full national patient experience audit will be much more inclusive (see next steps). A total of 99 questionnaires were returned to us and the majority (84%) of responders were female, and most (66%) were aged between 55-84 years.

### *Results*

The actual results from this pilot questionnaire are of interest, especially regarding how well informed patients feel during their treatment process and how well the continence care pathway works for them. Open questions with space for free text responses provided helpful insight to the issues patients face. Too much significance should not be placed on this questionnaire due to the low numbers and sampling methodology.

### *Feasibility – questionnaire distribution*

When continence services registered to participate in the pilot we provided them with the 10 questionnaires required. These were then be passed on to the patients to complete and returned to the RCP in a self-addressed envelope. Through this method, we received back 99 out the potential 170 questionnaires distributed (58%)

### *Feasibility – data collection*

All responses received were from patients who were handed the paper surveys by the continence service. These responses then had to be checked and each was manually inputted into an excel spreadsheet. Although this is probably a more time consuming approach than alternatives, the paper version of the questionnaire worked very well.

### *Feasibility – acceptance by users*

Response rate was reasonable at 58%, and comparable to the '*Older people's experiences of therapeutic exercise as part of a falls prevention service report*'<sup>1</sup> audit. Most were fully completed, and the number of free text comments (reproduced below) demonstrated that users were keen to comment both favourably and unfavourably on their experiences.

### *Feasibility – acceptance by continence service providers*

Continence service provider feedback was obtained through telephone conversations and following email requests to the locally identified individual involved in the day to day provision of continence care. Comments related to the questionnaire, the process and idea behind a patient experience questionnaire. Most feedback was provided by continence nurse specialists. Almost all commented on the possible usefulness of the questionnaire and believed that this could be a useful resource. Some also commented on the fact that they currently have no system of receiving patient feedback, and that this could serve that purpose. Otherwise, the feedback received was in relation to how several of the questions should be worded.

### *Pilot questionnaire results*

Overall the majority of patients were positive about the experience and treatment they receive from attending their continence service. There are however comments that point towards certain failings and a little dissatisfaction. As previously mentioned the small scale of this pilot means we cannot extrapolate too much meaning from these results but it gives a snapshot of patient's experience of NHS continence care.

- Ninety two percent of patients were referred to the continence service by a healthcare provider, and only 6% were by self-referral.
- Most patients understood why they were referred and 88% felt they were seen soon enough to be helped. These figures seem very positive, but the picture is less impressive when taking into consideration some comments left in the free text section. Results show 8% of patients said that it took a great deal of time to be referred or seen by a doctor, there was qualitative feedback to back this figure. One patient saying that they had to 'battle' to be referred.
- Ninety four percent (93 out of 99 patients) felt that they received a thorough health examination, had possible causes and treatment options explained to them, were given the opportunity to ask questions, and asked about how their bladder and bowel problem affects them.
- Slightly fewer (89%) felt they were involved in deciding what actions should be taken after they were seen by the continence service, with some frustration expressed in the comment section about phone calls not being returned.
- Patients were on the whole pleased with the help they received to manage their problem and felt that they were treated with dignity. There were however some examples given of patients not being well treated.

- In terms of joining up care for patients, there was some indication that this was lacking. Thirty-two percent did not know if information on their treatment had been passed on to their GPs, and 60% said they had not been given any information about support groups.
- Comments from patients regarding what else should be asked in the questionnaire included:
  - Does your GP seem sufficiently concerned about your condition?
  - What other problems do you have that make your condition more difficult to manage e.g. sight and mobility problems?
  - Are you able to get adequate supply of items that you need?
  - Were you and your carer given practical advice about how to cope with difficulties?

## Recommendations

Targeting patients through NACC participating continence service providers was most expedient for this pilot, but for future audit we would want to look at broader sampling methods including online access and wider distribution of paper versions. We would also like to target the large number of NHS patients who receive first level bladder and bowel care i.e. delivered by GPs, district nurses, hospital ward staff on generic medical or surgical wards, care home nurses etc., rather than by dedicated continence services.

The next steps are dependent on funding but would be to refine the questionnaire content using the feedback from patients and staff plus extended user involvement (e.g. individuals with Multiple Sclerosis, Parkinson's, or Stroke).

The questionnaire could be adapted to include experience of patients who have received continence care outside formal services (e.g from GPs, or other hospital specialists). It might be possible to expand the privacy and dignity section as provider audits have shown that this is a very difficult area to audit from case notes. Another alternative could be to test the feasibility of expanding the scope of the audit to reach many more people, including those who have yet to (or are having difficulty) accessing continence service, and those confined to home or in residential care.

The method, scope and patient sampling would need further work, but the outcome would be a revised questionnaire allowing patients to describe their experiences in relation to bladder and bowel problems that can cause much suffering and loss of confidence.

Work with continence services also needs to be taken forward to decide on the best method to feedback questionnaire results to them so that they can be used to inform the delivery of services. As this was a pilot results were not fed back to participants.

Another potential area of work is identifying how to assist participants to act on the results to make changes to their services.

## Key objectives

- To design and then test a patient experience questionnaire.
- To test the feasibility of carrying out a paper-based patient questionnaire to assess experiences of patients receiving continence care via bladder and bowel services.
- To obtain patient feedback via a questionnaire about their experiences of NHS run continence services.
- To obtain feedback from users and NHS providers participating in this pilot on the usefulness of this questionnaire (content and format).
- To assess the feasibility of the methodology
- To summarise the pilot findings in an evaluation report with a view to informing future continence audit work.

## Methods

### Development of questionnaires

The questionnaires came as a result of work being carried out during the discussions of the continence booklet *'Keeping control – what you should expect from your NHS bladder and bowel service'*<sup>2</sup>

The original content of the questionnaire was developed through many discussions between the experts in the NACC steering group. The questions that were decided upon were then showed to a continence user group and they were asked for their views and opinions. We met with the user group on 3 separate occasions allowing them to feedback on the questions. The group was also sent the final draft version of the questionnaire in the post and they were asked to send back any further comments.

### Recruitment of pilot continence services

We invited previous participants (primary care, acute hospitals, and mental health services) of the NACC audit to take part in testing the patient experience questionnaire via the NACC monthly newsletter. As organisations contacted us, we provided them further information, and those who agreed to take part were sent a letter detailing what they needed to do, a cover letter for patients, a patient information sheet and 10 questionnaires with their NACC organisation code on them. They were also provided with a letter to pass onto their Clinical Audit / Clinical Governance Department to ensure that the project followed appropriate information governance requirements for the trust.

A total of 17 NHS continence service users agreed to take part, with a potential total number of 170 questionnaires being sent out to patients. The original timeline for recruiting volunteer continence services, and for them to distribute questionnaires to patients was short (from October 2011 to January 2012); the original final date of January 2012 was extended to take into account the busy Christmas period and some late returns, and to give continence services more time to send questionnaires out to their patients, and for those patients to return the questionnaires to the RCP.

### Patient sample

From November 2011 volunteer continence services were sent the information and questionnaires to be distributed to patients. Those continence services that registered later were sent their paperwork once they confirmed participation.

Participating continence services were asked to identify up to 10 patients who had attended their local continence service (bladder and bowel service). Patients had to be aged 18 or over and able to complete the questionnaire or be able to provide answers to the questions with a carer or relative writing their answers down for them.

Potential patients were to be approached by a locally identified individual involved in day to day provision of continence care. The participant pack included an invitation letter template to be printed on the local NHS Trust headed paper (see appendix 3,4); a patient information sheet (see appendix 5), the questionnaire which could be posted or handed out to patients, and a pre-paid reply envelope. Patients were advised that someone (e.g. a carer) could help them complete the questionnaire if required.

Any questions regarding the project were answered either by the locally identified individual involved in day to day provision of continence care or a member of the project team (contact details were on the information sheet).

## Data collection and entry

Patients completed the questionnaire and returned it anonymously to the RCP project team via a pre-paid envelope. As each questionnaire was received it was allocated a number and the data entered into an Excel spread sheet.

The original deadline to return the questionnaires was 22 January 2012, and then extended to 19 February, but questionnaires were accepted until the data were sent to our statistician for analysis and cleaning on 9 May 2012.

### *Patient questionnaires*

A total of 99 questionnaires were returned to the RCP.

**Table 1: Response rate (Estimated)**

<b>Overall</b>	58%	(99/170)
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This response rate was similar to the RCP Falls patient questionnaire audit, '*Older people's experiences of therapeutic exercise as part of a falls prevention service*'<sup>1</sup>, and was reasonably good for a pilot.

## Information governance

The National Research Ethics Service (NRES) confirmed that an ethical review by an NHS Research Committee was not required for this pilot project.

Patients were identified and contacted directly by participating sites. The RCP had no contact details for the patients. Questionnaires were returned by the patient directly to the RCP, these were anonymous and no patient identifiable information was collected. The patient covering letter and information sheet clearly stated that the patient did not have to take part and their treatment would not be affected by their participation. Patient consent was obtained by the patient completing and returning the questionnaire.

A letter was provided for clinical governance and/or audit departments after the locally identified individual involved in day to day provision of continence care were identified to ensure that the paper work used fulfilled their patient and public involvement requirements.

## Participating staff feedback

This feedback was obtained from participating continence services through telephone conversations and email. They were asked to comment on the questionnaires, the process and concept behind a patient experience questionnaire. Continence services participating were positive on the process

Clinical nurse specialist:

- Questionnaire is a very useful tool as we do not have any patient feedback forms in our service. 'The only comments that I have would be:
  - Q4 – the wording 'check up' – I am not sure that this would be best to use – maybe 'first appointment' or something similar.
  - Maybe include a question to ask if lifestyle issues were discussed e.g. diet, fluids etc
  - Include a question to see if discussed about environmental factors e.g. access to toilet, carers, equipment (commodes etc).'

Clinical nurse specialist:

- 'I think the questionnaires were well worded.'

Continence staff nurse

- 'I think the questionnaire overall is excellent and hopefully will obtain some useful information.'
- 'However question 5 asking about the thorough health examination could be misconstrued, as patients may think along the lines of a full check up like what they receive from the GP, rather than a holistic approach to their continence.'

Continence nurse specialist:

- 'I think the only things I would add to the questionnaire would be questions on where the clinic was held i.e. community, GP surgery, Hospital.'
- 'And question on who did they see e.g. doctor, community nurse, specialist nurse, physio etc.'

Clinical nurse specialist:

- 'Question No. 7 seems to leave it quite open, or should it explain, the appointment, consultation, making the appointment, letters?'
- 'Question No.10, can you move or get rid of products so that is it not the first thing that is read in the question, may be more promotion, exercises, lifestyle changes'
- 'Question No.11, Is "mostly always" the right way to put it? maybe "most of the time", sounds better?'
- 'I think this could be a very useful tool to use'

Bladder and Bowel specialist nurse:

- 'In question 3 they have missed the word bowel out of Bladder and Bowel service. Otherwise it seems very similar to patient satisfaction survey and note audit that I have been involved in. It will be good to see the final article.'

Continence nurse specialist:

- 'The patient questionnaire does not differentiate whether the continence service is community or outpatients. I feel this should really be identified as to where they were seen and who by as an outpatient service can differ from community services.'

## Questionnaire methodology

This pilot showed that the Patient sampling method needs to be more robust for a full national patient experience questionnaire. We feel it is important to use a paper version alongside an online form, as much of our target audience (such as older people or those with long-term conditions) will have difficulty in accessing and completing online version.

Our next step would be to design a scannable paper form. Through the Medical workforce unit at the RCP we can get assistance with designing the form and posting it out to. Once the forms are returned they can be scanned and results can be downloaded to Excel, Access or SPSS. A member of the continence project team can be trained to conduct the scanning using the facilities in Medical workforce unit. Charges are £25 hour set up (and if required analysis). Set up time depends on your form's complexity but can range from 3 hours to a few days.

To complement the questionnaire we could also use other methods to obtain patient experience information such as telephone interviews, focus groups etc. While this may help to get an even fuller picture, it would be time consuming and could prove expensive.

This work and carrying out the pilot has led us to conclude that we should use both online and paper form giving patients the option of using either thus increasing response rates. The paper form and letter with instructions sent to patients would provide them with a web address for them to go to where they can complete the questionnaire online. The patient would be provided with a unique code that they must enter before starting the questionnaire. This code would link them to the site that provided them with the questionnaire. Those that find going online difficult will be able to complete exactly the same questionnaire but on paper and return it to us in the freepost envelope. This paper version would already contain a unique code which identifies the continence service, hospital site or trust. This enables us to feedback site results. Further work will need to be undertaken to determine the level of this feedback with the main objective for patients not to be identifiable whilst providing feedback useful to improve services.

## Results of the patient questionnaire

These are the full and anonymised patient questionnaire results from all participating sites. Where participants were given the opportunity to comment, those comments deemed by the National Audit of Continence Care Steering Group to be relevant are used and sometimes summarised. The percentages for the responses within tables have been rounded up or down so their total will not always equal 100.

The project team received 99 questionnaires back from users from an assumed total of 170 sent out by participating continence services. The results presented below are based on these 99 questionnaires.

**Table 2: Gender**

Possible options	% (Number)
Female	84% (83)
Male	15% (15)
Response missing	1% (1)

**Table 3: Age group**

Possible options	% (Number)
34 years or less	3% (3)
35–44 years	7% (7)
45–54 years	14% (14)
55–64 years	21% (21)
65–74 years	25% (25)
75–84 years	20% (20)
85–94 years	8% (8)
95 years or greater	0% (0)
Response missing	1% (1)

The questionnaires had age groups so patients were less identifiable. We did not ask actual age. Most questionnaires returned were from patients aged 55–84 year. More women than men returned questionnaires, but as we do not know the gender of those sent questionnaires, we cannot comment on the significance of this.

**Table 4: Q1 Do you know who referred you to the Continence Service (bladder and bowel service)?**

Possible options	% (Number)
Yes	96% (95)
No	3% (3)
Response missing	1% (1)

**Table 5: Q1a Who referred you to the Continence Service (bladder and bowel service)? (Only tick one box). Applicable if Q1=YES (n=95)**

Possible options	% (Number)
GP	55% (52)
Hospital doctor	19% (18)
Physiotherapist (Physio)	1% (1)
Occupational therapist (OT)	0% (0)
Nurse	18% (17)
Self	6% (6)
Social Worker or Warden	0% (0)
Other*	1% (1)
Don't know	0% (0)
Response missing / whole question left blank	0% (0)

\*Urology department

**Table 6: Q2 Do you understand why you were referred to the Continence Service (bladder and bowel service)?**

Possible options	% (Number)
Yes	92% (91)
No	0% (0)
I referred myself	5% (5)
Response missing	3% (3)

Comments made:

*'I was on a catheter after a stroke and needed to attend a trial without catheter (TWOC) and loose the catheter'*

**Table 7: Q3 Do you feel that the Continence Service (bladder and bowel service) saw you soon enough to be able to help you?**

Possible options	% (Number)
Yes	88% (87)
No	8% (8)
Don't know	2% (2)
Response missing	2% (2)

**Q3a – If you answered NO to question 3, can you explain why it was not soon enough for you?**

Participants were asked to comment in question 3a if they had responded 'no' to question 3. Comments were given by 7 of the 8 patients. These ranged from lack of knowledge about treatment options, communication delays and progressing treatment which resulted in delay referring to the service.

**Lack of knowledge about treatment options**

*'I battled for nearly 3 years before I was referred to the continence service. My doctor told me I would have to learn to live with it. This was the bowel, I also had bladder incontinence. I credit "name" as my life saver if I had been referred to this dept. by my doctor it would have saved me from clinical depression. I just felt nobody wanted to know'*

*'I had asked my GP 3 times over 2 years! Eventually he referred me and I was contacted.'*

**Communication delays:**

*'A lot of time was taken being referred from a central call centre to the specialist nurse.'*

*'The continence dept. gave me first available appointment, but no information had been passed on to them about me. If my wife hadn't phoned we would still be waiting for an appointment.'*

**Treatment progression causing delays:**

*'The doctor/specialist made an unsuccessful operation. I refused to go back to him at his request, I had lost trust. However the dr suggested a dribble stop which I had to buy and claim on the hospital approx. oct/nov 2010. Once I went to the continence service I received good service.'*

*'My problems started in 2002. I was referred in 2011 after major surgery and sphincter repair and other investigations.'*

*'Doctor advised further tests before going to incontinence service but I ended up in hospital before results received. They then referred me but I had the problems for a few months before.'*

**Table 8: Q4 Were you asked about your symptoms?**

Possible options	% (Number)
Yes	98% (97)
No	1% (1)
Don't know	0% (0)
Response missing	1% (1)

**Table 9: Q5 Did you feel that you received a thorough health examination when you attended the Continence Service (bladder and bowel service)?**

Possible options	% (Number)
Yes	94% (93)
No	2% (2)
Don't know	3% (3)
Response missing	1% (1)

**Q5a – If you answered No to question 5 please can you tell us why you feel that you did not receive a thorough health examination?**

The two comments were: *'No health examination received'* and *'No thorough talking about symptoms. No examination except urine test.'*

This question might need to be reviewed with a user group to check patients understanding of the meaning of thorough health examination.

**Table 10: Q6a Were the possible causes of your continence (bladder and bowel) problem explained to you?**

Possible options	% (Number)
Yes	93% (92)
No	3% (3)
Don't know	2% (2)
Response missing	2% (2)

**Table 11: Q6b Were the treatment options for your continence (bladder and bowel) problem explained to you?**

Possible options	% (Number)
Yes	95% (94)
No	1% (1)
Don't know	2% (2)
Response missing	2% (2)

**Table 12: Q6c Were you or your relative or carer able to ask questions about the causes and/or the treatment of your continence (bladder and bowel) problem?**

Possible options	% (Number)
Yes	93% (92)
No	1% (1)
Don't know	3% (3)
Response missing	3% (3)

**Table 13: Q7 Did you feel satisfied that good communication took place?**

Possible options	% (Number)
Yes, fully satisfied	93% (92)
Partially satisfied	2% (2)
Not very satisfied	1% (1)
No, not at all satisfied	2% (2)
Response missing	2% (2)

**Q7a – If you were not fully satisfied with the communication that took place can you tell us why?**

3 out of the 5 comments received gave the following reasons:

*'Failure by doctors to return telephone messages from patient seeking advice and help on the effectiveness of medication prescribed. Inordinate delays between appointments when doctors are incommunicado.'*

*'I didn't like the way the lady I saw said there is nothing we can do. I don't want to see her again.'*

*'I had to confirm I was doing the correct exercises after which after I got further explanation then I was then satisfied.'*

Some other comments praised the service and explaining why they were satisfied: *'I was explained fully about being incontinent. I felt at ease without being embarrassed.'*

**Table 14: Q8 Were you asked about how your continence (bladder and bowel) problem affects you?**

Possible options	% (Number)
Yes	92% (91)
No	3% (3)
Don't know	2% (2)
Response missing	3% (3)

**Table 15: Q9 Were you asked about how you manage/cope with your continence (bladder and bowel) problem?**

Possible options	% (Number)
Yes	94% (93)
No	3% (3)
Don't know	1% (1)
Response missing	2% (2)

**Table 16: Q10 Did you feel you were involved in deciding what actions should be taken after you were seen by the Continence Service (bladder and bowel service)**

Possible options	% (Number)
Yes	89% (88)
No	6% (6)
Don't know	3% (3)
Response missing	2% (2)

**Q10a – If you answered Yes to question 10, can you tell us what decisions you were involved in?**

There were over 60 comments explaining what decisions they were involved in. The comments ranged from all decisions to those about specific areas of care and treatment. Examples are provided under each group heading as follows:

**Involved in everything (n=12) 8 mentioned involved in all**

*'The treatment options were .... With me'*

*'Choice in medications options, choice in pads and follow up appointments.'*

*'What medication, possible outcomes, next steps.'*

*'We made a plan of action together which so far has been successful.'*

**Treatment and care options (n=42)**

**Lifestyle changes (n=3)**

*'Drink more throughout each day. Switch to decaf tea.'*

*'Taking tablets earlier with less water. Drinking green tea instead of ordinary tea.'*

**Exercises (n=8)**

*'Not to opt for surgery but try exercises first.'*

*'Number of pelvic floor exercises and how to do them properly.'*

*'Doing pelvic exercises and holding on to the bladder rather than keep going to the loo.'*

**Medication (n=10)**

*'I agreed to take medication as recommended to aid the control of my bladder. I agreed to record bowel function.'*

*'Review of medicines.'*

**Pads (n=3)**

*'Whether I wanted pads. Did I want drugs initially?'*

**Catheters and other devices (n=14)**

*'I was given a wide choice of CIC catheters to choose from - excellent service of care.'*

*'Staff listened to me. I was frightened to go out; if I did I have to know there was a toilet nearby. I was so frightened of an accident, it was suggested I try an anal plug, which gave me back my life.'*

*'Discussion was made relating to which type of catheter to go for. I chose the normal catheter not the self install type.'*

#### **Operative procedure (n=4)**

*'Operation on a prolapsed bladder due to bowel pressing.'*

*'Whether to go to physio or have an op.'*

#### **Information provision and communication (n=4)**

*'I was not given any continence products. But was given leaflets and advice on how to manage my continence. I also received a follow up phone call at home.'*

*'I received literature and products to help relieve bladder retention. Different products were explained and showed to me before use.'*

*'I was very impressed by the professionalism of the continence nurse - she discussed the wide range of incontinence products with me and gave her recommendations for me. She encouraged me to a series of muscle exercises - which have proved very helpful.'*

#### **Referrals (n=4)**

*'I was referred to a urologist and supplied with pads to help cope. Also I am able to contact the continence service for advice and support anytime.'*

*'Referred to attend hospital for 'more advanced' exercises which was a waste of time. No real help offered so went back to clinic and the person who was very helpful.'*

#### **Other (n=2)**

*'My original faecal incontinence was due to a constipation blockage and use of. My GP prescribed a heavy dose with disastrous affects. Urinary incontinence was due to bladder falling forwards and my GP could not fit a pessary because I was too small.'*

*'Because I have a permanent infection in my bladder it was discussed along with the bladder problems.'*

**Table 17: Q11 Did you feel you were always treated with dignity?**

Possible options	% (Number)
Yes, always	94% (93)
Mostly always	3% (3)
Sometimes	1% (1)
No, not at all	0% (0)
Response missing	2% (2)

**Q11a – If you felt you were not always treated with dignity, can you tell us why?**

There were three comments received. These ranged from commenting on inpatient care to making suggestions to deal with low staff numbers:

*'Whilst in hospital after major surgery I was treated dreadfully and a formal complaint was made. Also during investigations and explanatory appointments I feel that because the teams deal with these issues on a daily basis they seem to lack empathy.'*

*'The urology department at my hospital is under heavy pressure. At times the nursing staff seemed overwhelmed. They were not well organised to deal with this. For example I was left alone in a treatment room for one hour while the nurse was attending to other patients. It would surely be better to treat one patient at a time.'*

**Table 18: Q12 Was the information about your attendance at the Continence Service (bladder and bowel service) provided to your GP?**

Possible options	% (Number)
Yes, I know the information was provided to my GP	63% (62)
No, I know the information was not provided to my GP	4% (4)
I don't know if the information was provided to my GP	32% (32)
Response missing	1% (1)

This question might need further explanation to state that information could be a letter from the clinic.

However in Table 16, 6 % (n=6) feel that were not involved in deciding what actions were to be taken after attending the continence/bladder and bowel service. This result could be influenced by a lack of information provided such as a copy of the clinic letter.

**Table 19: Q13 Do you feel your treatment was reviewed regularly to meet your needs?**

Possible options	% (Number)
Yes	87% (86)
No	2% (2)
Don't know	8% (8)
Response missing	3% (3)

In the pilot organisational and clinical audit, 76% (91/119) primary care and 57% (134/236) acute services had organised follow-up in patient's treatment plan. However, only 57% (107/188) primary care and 25% (107/424) acute services could find evidence that a copy of the treatment plan was given to patients.

This may explain why questions have been suggested, around follow up and interventions, to add to this questionnaire.

**Table 20: Q14 Was information given to you about any local user support groups?**

Possible options	% (Number)
Yes	19% (19)
No	60% (59)
Don't know	16% (16)
Response missing	5% (5)

This low response to this question might be attributed to the fact that in the pilot organisational audit only 31% (4/13) of primary care and 19% (5/26) of acute service have a user group for their continence service. So this question might need to be reworded or explained.

**Table 21: Q15 How easy did you find travelling to appointments with your local Continence Service (bladder and bowel service)?**

Possible options	% (Number)
Easy	56% (55)
Fairly easy	23% (23)
Not very easy	11% (11)
Difficult	2% (2)
Did not need to travel	6% (6)
Response missing	2% (2)

Some people commented on the difficulty in parking and one suggested that the clinic opening times could be extended to include some evening clinics.

This next section of the questionnaire was related to the patients overall experience of the continence service.

**Table 22: Q16 Can you tell us about your overall experience of using your local Continence Service (bladder and bowel service) by ticking one statement that sums up your views?**

Possible options	% (Number)
Useful for me	93% (92)
Quite useful for me but could do better	5% (5)
Not useful for me	0% (0)
Response missing	2% (2)

**Q16a – If you answered ‘Quite useful for me but could do better’ or ‘Not useful for me’ to question 16, please can you explain why?**

Comments (from 4 of the 5):

*‘Everything offered was very useful but not a lot helped. So was signed off for 2 or 3 years and then asked to be referred back.’*

*‘I have treatment follow up appointment but unsure what the treatment will be and how long it will take.’*

*‘Nothing solved after quite a time.’*

*‘Arrived on time at appointment but was kept waiting for 40 minutes. Staff could have been more helpful.’*

The questionnaire then provided space for patients to provide any further comments relating to the questionnaire and the service itself.

**Table 23: Is there anything that you feel should be asked in this questionnaire about your care / treatment that has been missed out?**

Possible options	% (Number)
Yes	18% (18)
No	77% (76)
Response missing	5% (5)

**If you answered ‘Yes’ can you tell us what else should be included in this questionnaire?**

Comments about further topics to be added were grouped under the following headings:

**Communication and relationships (n=7) 2 comments praised level of communication**

*‘Doctors and nurses should talk to me about my continence problem.’*

*'Was your advisor easy to talk to? My advisor is excellent and easy to chat with. I gather a lot of people do not come forward with information often because they are too shy or embarrassed.'*

*'I found that this difficult problem was dealt with great sensitivity and understanding. Before the meeting I was very apprehensive but left feeling very reassured. I would not hesitate to consult the team again if I needed further help and advice.'*

*'How the patients relationship to the provider proved to be. In my case it was fully professional, but I was able to connect, and made me fully at ease, with, what for me is a very trying condition, which has been part of my life for years.'*

*'Does your GP seem to be sufficiently concerned about your condition /problems?'*

### **Presence of other conditions/circumstances (n=3)**

*'Disability and wheelchair users'*

*'What other problems do you have which make your condition more difficult to manage? E.g. sight problems and mobility'*

*'I feel there should be space for me to put my circumstances.'*

### **Promotion of service and access (n=5)**

*'Too early to say but first visit was excellent. The service needs to promote itself better, particularly its ability to deal sensitively about these issues. Explain that there will be a pelvic exam and what will be involved before appointment. Would be excellent if you could self-refer, rather than needing to go via GP'*

*'I am grateful to be supplied with appropriate padding supplies from TENA. I am very grateful for the helpfulness and kindness of the nurse practitioner who looked after me and continues to be available at need.'*

*'No, I am very pleased with all the help I have been given so far and I know that help will be on-going to try to solve the problem.'*

*'Would you recommend this service to other people experiencing similar problems?'*

*'Has the use of this service assisted in improving quality of life?'*

### **Treatments offered and level of success (n=3)**

*'List of treatments and how useful each one was'*

*'Are you able to get adequate supplies of items needed easily?'*

*'A question about examination should be included.'*

### **Information provision and help (n=4)**

*'Was a bit confused regarding the hospital I was asked to visit. Was sent to one place and then told I should be going somewhere else.'*

*'Were you (and your carer) given practical advice about how to cope with difficulties?'*

*'I was using more than one pad a day, I asked for assistance but was told I would not qualify. So I have had to pay out for Tena for men. I don't know what would have happened if I had not bought pads myself.'*

*'Explain that there will be a pelvic exam and what will be involved before appointment.'*

#### **Follow up (n=4)**

*'If I had a follow up appointment after any specific period of time'*

*'It would be nice to be asked what future offers of help are happening. In my case waiting for a particular piece of equipment to come to the hospital.'*

*'Follow up, structured exercise program, my understanding of successful results i.e. when my problem may be cured'*

*'Why is it that when an emergency catheter is fitted there is no follow up. District nurses should have changed bag but dint. Now taking antibiotics in the hope my kidneys are not damaged.'*

#### **Do you have any other comments that could help improve the Continence Service (bladder and bowel service)?**

Comments were grouped into the following headings:

##### **Raise awareness with GPs and the public about continence services (n=4)**

*'I think the whole subject should be made more public and more advertising about continence and the number of people it affects. Many people feel isolated and alone because they have continence problems. Why does the benefits system not cover urinary incontinence as a disability? This is so unfair.'*

*'GP's need to be better informed about the value of this service'*

*'I feel doctors should be made aware of the importance of this service to the patients. If my doctor had referred me instead of putting me on anti-depressants. There should be a poster up in surgeries because it is embarrassing to talk about. You can ask to attend these clinics. This is an excellent dept. I know I can call them and they will help. Without this dept. I dread to think what my life would have been like.'*

*'I think that there should be product available on hospital wards & gp surgeries so that people can see what is available to help with incontinence.'*

##### **Received good service (n=13) 5 stated excellent, very good or good service**

*'I received excellent care/treatment. Treated with dignity and care.'*

*'I couldn't have wished for a more lady like & dignified approach to my problem. The hospital should get a medal for being able to explain such a delicate subject'*

*'The nurse has helped me a great deal and I feel much healthier in mind and more confident'*

*I felt embarrassed attending this clinic but the professional and caring treatment I received put me at ease.'*

*I was very happy with the nurse. She instructed me to do pelvic exercises each day and my condition has much improved.'*

*'I have excellent care they are only a phone call away if I need them. I don't know how I would get on without them.'*

*'The specialist nurse who treated me was good and through her instructions I did improve somewhat, but still had to use a pad a day!'*

*Thank you, excellent service and really helpful.'*

#### **Access to clinics (n=5)**

*'Perhaps the option of a late clinic - up to 6pm, as I have to take annual leave to attend appointments.'*

*'I needed to cancel appointment; there was a delay of quite a few weeks until I could get another. I appreciate a lot of people need to use this service and it is a very good service but I could have improved quicker if I didn't wait so long between the appointments.'*

*'Wish it were nearer'*

*'Parking at service was appalling.'*

*'travelling to the facility was easy, but arriving/parking was very difficult'*

#### **Information provision n=3)**

*'I am the type who questions and the consultant picked up that I had some background knowledge. I feel that some information might not have been given if I hadn't asked. But I am very grateful to the unit for sorting out my problems.'*

*'More information or support groups or helpline to discuss issues out of hours. Information on alternative methods for bladder/bowel incontinence.'*

*'Things could be explained better. I now know that I will have to be catheterised for the rest of my life. Don't like it at all.'*

#### **Other (n=3)**

*'Providing pads as £5 a week is a lot out of pensioners allowance'*

*'Have more specialist trained nurses available'*

*'Being able to shower the lower parts before putting clothes on after urodynamic investigations.'*

#### **If you have a helper, carer or a relative do they have any comments that could help improve the Continence Service (bladder and bowel service)?**

Comments:

*'All GP's should have more information about the availability of these clinics. It confuses alphabetical listing to refer to 'continence' and 'incontinence' clinics.'*

*'When a patient is referred to the continence clinic a full investigation of medical history and medication should be undertaken. If the first diagnosis doesn't work - details and facts gradually are uncovered.'*

*I am completing this with my gran but she has advised she has treatment but is unsure of what exercise program. She could do with a regular exercise program that involves diagrams, instructions or even classes.'*

*'Advice sent in writing because it is a lot to take in while at the appointment.'*

## Appendix 1

### References

1. Royal College of Physicians. *Older people's experiences of therapeutic exercise as part of a falls prevention service*. London: RCP: 2010
2. Royal College of Physicians. *Keeping control – what you should expect from your NHS bladder and bowel service*. London: RCP: 2011
3. Royal College of Physicians. *Pilot audit evaluation report'* London: RCP 2012

## Appendix 2

### National Audit of Continence Care Steering Group

Title	Forename	Surname	Representing
Dr	Danielle	Harari	Clinical Effectiveness and Evaluation Unit, Royal College of Physicians (Associate director and chair)& British Geriatric Society
Dr	Kevin	Stewart	Clinical Effectiveness and Evaluation Unit, Royal College of Physicians (Director)
Mrs	Janet	Husk	Clinical Effectiveness and Evaluation Unit, Royal College of Physicians (Programme manager)
Mr	Jose	Lourtie	Clinical Effectiveness and Evaluation Unit, Royal College of Physicians (Project coordinator)
Ms	Rhona	Buckingham	Clinical Effectiveness and Evaluation Unit, Royal College of Physicians (CEEU Manager)
Dr	Adrian	Wagg	Professor of Healthy Ageing, University of Alberta, Edmonton
Dr	Karen	Ward	British Society of Urogynaecology
Dr	Imran	Rafi	Royal College of General Practitioners
Mrs	Gaye	Kyle	Association for Continence Advice / Bowel care expertise
Ms	Amanda	Cheesley	Royal College of Nursing
Mr	Stephen	Miles	Royal College of Nursing
Dr	Doreen	McClurg	Physiotherapist – ACPWH
Ms	Debbie	Yarde	Chair – Association of Continence Advice
Ms	Ginny	Storey	Head of Care Governance & Regulation – Anchor Care Homes
Ms	Julie	Vickerman	PromoCon & Disabled Living Manchester
Ms	Mandy	Wells	Head of Bladder & Bowel Devon
Mr	Phil	Assassa	Bladder and Bowel Foundation
Dr	Ronald	Fernandes	MS Society
Dr	Margit	Physant	Age UK
Ms	Lavinia	Fernandes	Parkinson's UK
Mr	Ian	Ireland	Director, IAI consultancy – Care Home Sector

## Appendix 3

### Patient invitation letter

For printing on local NHS trust headed paper. All items in <> to be added by staff

Dear <Patient name>

**Re: People's experiences of their local continence service (bladder and bowel service).**

We would like to invite you to take part in helping us test a questionnaire as part of a national patient involvement project which aims to improve the availability and quality of continence services (bladder and bowel service) that people in the NHS receive. We want to check that the questions we are asking are the right ones and your views are very important because you recently attended your local continence service.

People suffering with incontinence can often be too embarrassed to come forward and seek help for it. It is not an easy subject to discuss with your doctor or nurse. So it is important that you receive the best treatment and care which meet your needs when you attend these services. We are therefore inviting you to complete a questionnaire about your experience of your local continence service. Please be assured that your feedback will be entirely anonymous so it cannot in any way be identified as coming from you. We hope that this will encourage people to be entirely open about the care they have received.

The project is being run jointly by <Add your trust name or service here> and the Royal College of Physicians (London). Your local service has signed up to this project because they are keen to receive feedback on the continence care that they provide. You as a patient will not be in any way identified when we give local services the results of this questionnaire.

The project has been funded by the Healthcare Quality Improvement Partnership (HQIP), which is a government funded body whose role is to commission projects to assess the quality of services provided by the National Health Service (NHS).

Please read through the attached information. If you do wish to take part, please complete the enclosed questionnaire and return it in the pre paid envelope or using the FREEPOST address to the Royal College of Physicians.

If you need more information about the project please contact <Add your lead name and contact number here> or the project co-ordinator at the Royal College of Physicians on 020 3075 1619.

If you do not wish to take part, you do not need to do anything and we will not contact you again. It will not affect your treatment in any way if you decide not to take part.

We do hope that you will take part in this project and complete the enclosed questionnaire as your views and experiences are important to inform future services.

Yours sincerely,

## Appendix 4

### Participant information sheet

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On behalf of the Royal College of Physicians we would like to invite you to take part in completing a questionnaire. Before you make a decision to take part, it is important that you understand why the project is being carried out, by whom and what your participation will involve. Please take time to read the following information carefully and discuss it with others (family, friends) if you wish before making a decision. If anything is not clear, or if you would like more information, we would be happy to discuss this with you. Please contact a member of the project team on 020 3075 1619.

#### **Purpose of the project**

The purpose of the project is to test a questionnaire about your experiences of your local continence service (bladder and bowel services). We are very interested in hearing about your experiences and getting your feedback.

#### **1. Why have I been chosen?**

Your views and first-hand experience of the continence service will help to develop services and information for patients. To get balanced feedback, we need to obtain the comments and opinions of a cross section of people who have used continence services.

#### **2. Do I have to take part?**

Absolutely not! Your involvement is entirely voluntary and you may withdraw at any time. We would like to assure you that the standard of care you receive will not be affected at any time if you participate or choose to withdraw.

#### **3. What happens next if I agree to take part?**

If you decide to take part in the project, you should read and keep this information sheet before completing the questionnaire. Once completed, the questionnaire should be posted to us in the pre-paid envelope or sent to FREEPOST (55), Royal College of Physicians, 11 St Andrews Place, London NW1 4LE

Each questionnaire has a code which shows us the geographical area it was sent or given out from, but you will not be identified as no personal information is asked for in the questionnaire.

**4. What will happen to the results of the project?**

We are currently testing this questionnaire; we will use your feedback to decide whether we should roll out this project into a full nationwide audit of patient experience.

**5. Who has approved the project?**

The project has been approved by the Healthcare Quality Improvement Partnership (HQIP) which is a government funded body whose role is to ensure the quality of services provided by the NHS.

**6. Contact for further information**

The project lead within your hospital will give you his/her name and their contact number when he/she sends you the invitation letter about the questionnaire. If you would like any further information about this project please contact Jose Lourtie, the project co-ordinator on 020 3075 1619 or email [jose.lourtie@rcplondon.ac.uk](mailto:jose.lourtie@rcplondon.ac.uk).

**Thank-you for taking the time to read and consider this information**

## Appendix 5

### Staff information sheet

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#### **National Audit of Continence Care – Patient Experience Questionnaire (Pilot)**

##### **Project background**

This project aims to test a questionnaire exploring patient's experiences of the local continence service (bladder and bowel service). This work builds upon the programme of the national audit of continence care currently being conducted by the Clinical Effectiveness and Evaluation Unit (CEEU) of the Royal College of Physicians (RCP), London. The first phase of the national audit undertaken in 2004 focused on clinical and organisational elements of the services, this was followed with further audits in 2006 and most recently in 2010. This data has covered patient related activities, but did not capture patient's views of these services. Obtaining the experiences of service users requires a patient centred enquiry into the process of assessment, information provision and to treatment planning which can then be used to inform future provision of services.

##### **Methodology**

The National Audit of Continence Care steering group, which is comprised of experts in the continence field, nurses and other professionals, has worked to produce a patient experience questionnaire.

In order to obtain patients' experiences, questionnaires will be sent or given out by appropriate healthcare professionals to people who have recently attended their local continence service (bladder and bowel service). Data from these questionnaires will be analysed by the CEEU.

We have provided you with a letter to pass onto your Clinical Audit / Clinical Governance Department to ensure that the project follows appropriate information governance requirements for your Trust.

The National Information Governance Board (NIGB) has been contacted and the process of individual Trusts identifying their patients, sending or giving out questionnaires with the project information is acceptable. Patients consent to take part by completing and returning the questionnaire. Due to ethical constraints, the Royal College of

Physicians can not recruit patients directly as this has to be performed by a member of NHS staff involved in patient care or organisation of care. However, once patients have been identified and have been given or sent the questionnaire the analysis and reporting will be undertaken by RCP project staff. Potential participants must be approached by an individual (identified locally) involved in the day to day provision of continence care. Questionnaires should be sent or given out to people who have recently attended the continence service (bladder and bowel service). Patients must be aged 18 or over and able to complete the questionnaire or be able to provide answers to the questions with a carer or relative writing their answers down for them. Patients who have been discharged more than 12 weeks should not be sent questionnaires because they might not be able to recall the details.

The patient questionnaire does not take long to complete. The majority of answers are tick boxes but we do ask for comments.

## **What happens next?**

### **Once you or your trust has signed up**

- You will identify up to **10 patients** (recent users of the continence (bladder and bowel) services)
- A member of the RCP project **staff will** email you the template invite letter
- A member of the RCP project staff will **send you in the post** 10 questionnaires with your site code in the footer, 10 patient information sheets and 10 pre-paid reply envelopes
- You will need to identify who will send or hand out the invite letters along with the questionnaire, patient information sheet and the reply envelope
- You will need to print the invite letters on your headed paper to send or give to patients along with the questionnaire, patient information sheet and the reply envelope
- If you are requested by RCP project staff to identify more patients please do not photocopy the questionnaires because we would like to log how many are sent out to get an accurate picture of response rates
- We (the RCP project staff) will update you on the progress

### **The participants**

Questionnaires will be sent or given out by an appropriate person within the Trust to people that have recently been through the continence (bladder and bowel) service. Participants must be aged 18 or over. Participants need to be able to complete the questionnaire. It can be completed by a carer or a family member but it should be the patient's views that are expressed in the replies. The potential participants will be invited by letter from the local service provider (you) and given an information sheet and the questionnaires providing more detail about the project and a pre paid return envelope. Any questions regarding the project should be answered by the member of staff in charge of recruitment or a member of the project team (contact details provided on the information sheet).

### **Safety and Confidentiality**

Data collected will be anonymised and participants can withdraw their participation at any stage of the project with no consequence to them or their care.

### **Reports and outputs**

We will produce a summary report and evaluation on the patient involvement project pilot to our commissioners, Healthcare Quality Improvement Partnership (HQIP). As this is a pilot it is unlikely that number of returned questionnaires will be high enough to produce individual reports for each continence service, however we will make a summary of the results available to participants. The summary results will need to be used with care as this would be based on a small sample.

**Any further questions:** Jose Lourtie, Tel: 020 3075 1619

Email: [jose.lourtie@rcplondon.ac.uk](mailto:jose.lourtie@rcplondon.ac.uk)

## Appendix 6

### Patient questionnaire

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#### **A questionnaire to ask about your experience of the continence service (Bladder & Bowel Service)**

**Please return the completed questionnaire by the date: 19 February 2012**

This is a **questionnaire** from the Clinical Effectiveness Unit at the Royal College of Physicians and it will not take long to complete. For most of the questions you just need to tick the box. The last page is for any additional comments you may have. Take your time to read the questions and reply to each question by ticking a box in the column on the left, or by writing your comments. There are no right or wrong answers.

Please do not worry if you cannot remember. Just tick the box which says “don’t know” next to that question. This is important so that we know that you have not missed the question accidentally.

If the questionnaire is difficult to read, it is OK for someone else to read it and to write your answers in for you **but it is your views that are important.**

Your participation is voluntary and your answers will be treated in confidence. The staff who provide your local Continence Service (bladder and bowel service) won’t see your individual answers.

#### ***This section contains questions about referral to the Continence Service***

**1. Do you know who referred you to the Continence Service (bladder and bowel service)?**

- Yes → go to question 1a
- No → go to question 2

**1a. Who referred you to the Continence Service (bladder and bowel service)? (Only tick one box)**

- General Practitioner (GP)
- Hospital Doctor
- Physiotherapist (Physio)
- Occupational therapist (OT)
- Nurse
- Self
- Social Worker or Warden
- Other, please write here if known?
- Don’t know

- 2. Do you understand why you were referred to the Continence Service (bladder and bowel service)?**
- I referred myself
  - Yes
  - No
- 3. Do you feel that the Continence Service (bladder and service) saw you soon enough to be able to help you?**
- Yes → go to question 4
  - No → go to question 3a
  - Don't know → go to question 4
- 3a. If you answered No to question 3, can you explain why it was not soon enough for you?**

*This section is about the check up (assessment) and follow up*

- 4. Were you asked about your symptoms?**
- Yes
  - No
  - Don't know
- 5. Did you feel that you received a thorough health examination when you attended the Continence Service (bladder and bowel service)?**
- Yes → go to question 6a
  - No → go to question 5a
  - Don't know → go to question 6a
- 5a. If you answered No to question 5 please can you tell us why you feel that you did not receive a thorough health examination?**

**6a. Were the possible causes of your continence (bladder and bowel) problem explained to you?**

- Yes
- No
- Don't know

**6b. Were the treatment options for your continence (bladder and bowel) problem explained to you?**

- Yes
- No
- Don't know

**6c. Were you or your relative or carer able to ask questions about the causes and/or the treatment of your continence (bladder and bowel) problem?**

- Yes
- No
- Don't know

**7. Did you feel satisfied that good communication took place?**

- Yes, fully satisfied → go to question 8
- Partially satisfied → go to question 7a
- Not very satisfied → go to question 7a
- No, not at all satisfied → go to question 7a

**7a. If you were not fully satisfied with the communication that took place can you tell us why?**

**8. Were you asked about how your continence (bladder and bowel) problem affects you?**

- Yes
- No
- Don't know

- 9. Were you asked about how you manage/cope with your continence (bladder and bowel) problem?**
- Yes
  - No
  - Don't know
- 10. Did you feel you were involved in deciding what actions should be taken after you were seen by the Continence Service (bladder and bowel service)?**  
*(For example, you may have been offered continence products, further tests or a review of your medicines)*
- Yes → go to question 10a
  - No → go to question 11
  - Don't know → go to question 11
- 10a. If you answered Yes to question 10, can you tell us what decisions you were involved in?**
- 11. Did you feel that you were always treated with dignity?**
- Yes, always → go to question 12
  - Mostly always → go to question 11a
  - Sometimes → go to question 11a
  - No, not at all → go to question 11a
- 11a. If you felt you were not always treated with dignity, can you tell us why?**
- 12. Was the information about your attendance at the Continence Service (bladder and bowel service) provided to your GP?**
- Yes, I know the information was provided to my GP
  - No, I know the information was not provided to my GP
  - I don't know if the information was provided to my GP

**13. Do you feel your treatment was reviewed regularly to meet your needs?**

- Yes
- No
- Don't know

**14. Was information given to you about any local user support groups?**

- Yes
- No
- Don't know

**15. How easy did you find travelling to appointments with your local Continence Service (bladder and bowel service)?**

- Easy
- Fairly easy
- Not very easy
- Difficult
- Did not need to travel

***This section is about your overall experience of the Continence Service***

**16. Can you tell us about your overall experience of using your local Continence Service (bladder and bowel service) by ticking one statement that sums up your views?**

- Useful for me → go to the section 'about you'
- Quite useful for me but could be better → go to question 16a
- Not useful for me → go to question 16a

**16a. If you answered 'Quite useful for me but could be better' or 'Not useful for me' to question 16, please can you explain why?**

***This section is about you***

**Are you?**

- Female
- Male

**What is your age?**

- 34 years or less
- 35 to 44 years
- 45 to 54 years
- 55 to 64 years
- 65 to 74 years
- 75 to 84 years
- 85 to 94 years
- 95 years or greater

**Is there anything that you feel should be asked in this questionnaire about your care / treatment that has been missed out?**

- Yes
- No

**If you answered 'Yes' can you tell us what else should be included in this questionnaire below:**

*Comments section*

**Do you have any other comments that could help improve the Continence Service (bladder and bowel service)?**

**If you have a helper, carer or a relative do they have any comments that could help improve the Continence Service (bladder and bowel service)?**

If you have more comments please continue on a separate sheet and return it with your questionnaire.

**Please return the completed questionnaire by the date: 19 February 2012  
in the self addressed envelope provided Or FREEPOST (55), Royal College of Physicians,  
11 St Andrews Place, London NW1 4LE**

**Thank-you for completing the questionnaire**