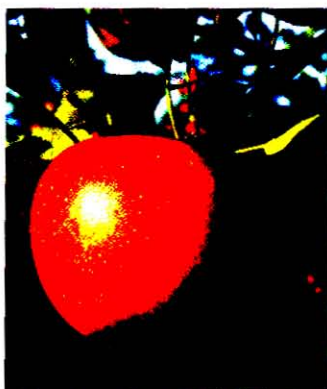


# Involving Older Users of Continence Services in Developing Standards of Care: A Pilot Study

Report on Stage 1

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## Involving Older Users of Continence Services in Developing Standards of Care: A Pilot Study

The Clinical Effectiveness and Evaluation Unit of the Royal College of Physicians of London is in the process of identifying quality outcome indicators for continence services, using national expert panel groups of professionals.

Given the importance currently placed on user involvement in service development (DoH 2001), there is a need to involve users with continence problems in determining whether current standards reflect consumer opinion and need, and to incorporate their views into future developments.

This report provides an account of the method and findings of the first stage of this three stage project that involves users.

### 1.0 Aims and objectives

The overall purpose of this pilot study is to involve, identify and incorporate the views of older continence service users in the development of standards of care in continence services.

### 2.0 Methodology

The pilot study has three stages:

- Stage 1: develop a questionnaire with the assistance of service users
- Stage 2: undertake a pilot survey in two contrasting areas
- Stage 3: identify older groups not represented in the pilot survey, such as the frail elderly, to elicit their views and those of their carers

This report provides the methodological approach and findings of Stage 1 of the study, which was undertaken in two phases. Phase 1 was concerned with the development of an initial draft questionnaire from expert panel views of standards in continence care. Phase 2 sought the views of service users regarding their perceptions of good standards. This information was then incorporated into the initial questionnaire. The following gives an account of the methods and outcome of this stage.

### 3.0 Developing the questionnaire: Expert Panel Views

Development of standard statements for the questionnaire was initially guided by the standards that had been developed with the UK expert panel group.

There were numerous features that went into its development to enhance rigour. For example, scales were used for respondents to rate the standard statements according to their self-perceived importance. Rating used in this way was seen as helpful in reflecting a measure of value in relation to service provision and standard inclusion, and also determine service priorities in the wider study (Bowling 1997). To support this method further, previous research by Burnside et al 1998 on instrumentation development for older people strongly recommends the avoidance of multi-field response selections with positive and negative statements (such as five scale likert configurations) in favour of familiar terms (such as degrees of importance) and narrow fields of selection as this avoids confusion and entry mistakes. Given that some carers may act as intermediaries in gaining responses, this design also reduces measurement inconsistency (Walker and Dewar 2001).

The questionnaire construction also adhered to other general recommendations such as adequate font size, limited use of memory recall items as this causes anxiety (Dellefield and McDougall 1996), and restrictions on length to avoid fatigue in order to enhance validity and reliability (Burns and Grove 1997). As with most questionnaire construction, it was important to add a qualitative dimension and include space for respondents to add comments (Robson 1993).

The questionnaire was also designed to elicit demographic information such as age, gender, ethnic group, service use and type of bladder or bowel problems. A quality of life section was also included, using the validated King's Health Questionnaire (Kelleher 1997). This has been specifically designed to highlight restrictions on daily activities and social interaction in relation to continence issues. These additional areas were important in estimating the extent of problems among the target population and restrictions on life, valuable in starting to inform service priorities. For example, degrees of importance placed on certain aspects of service standards could be cross-referenced with the respondent's profile to potentially assist with population targeting.

#### 4.0 Including the Older User's Perspective in the Standard statements

Two focus groups took place with continence service users between December 2003 and January 2004 in Bournemouth and Camden and Islington. The purpose of this exercise was to obtain users' views of what constituted good standards of care in continence services, and to include these views in the development of a questionnaire that will survey a wider selection of service users. In addition to the focus groups, two individual interviews took place at Camden and Islington with users who were unable to attend the focus group meeting but wanted to express their views.

The aim of this phase was to identify quality issues that were important for inclusion in the standards, expressed by participants independently of the expert panel view. In addition, at the end of the discussion, participants were asked to comment on the standard statements developed in phase 1, and to reflect on whether they paralleled their views. This was to ensure specificity and applicability of the statements to personal experiences.

#### 5.0 Sample characteristics

Service users aged 60 and over were invited to take part. They were recruited via staff at the continence services, who distributed 20 information sheets and consent forms at each site (n=40). Carers of more dependent users were also encouraged to participate, given the importance of including their views in standards setting. The following table indicates the number and characteristics of participants per site, highlighting the greater diversity of age and ethnic background in Camden and Islington, and the inclusion of carers in the Bournemouth group. Most participants were female.

Characteristics	Bournemouth	Camden and Islington
Total participants	7 (2 carers)	7
Age	5 aged between 60-69 2 aged between 50-59	2 aged 80-89 2 aged 70-79 2 aged 60-69 1 aged 50-59
Gender	3 males, 4 females	7 females
Ethnic group	All 'white'	4 'white' 1 'Indian' 1 'Pakistani' 1 'Black Caribbean'

## 6.0 Data Collection: Focus groups

The use of focus groups is well documented in health and social care research (Morgan 1997), as a means of probing issues and exploring experiences from the participant's perspective. Qualitative research of this nature is particularly suited to groups of older people, and can be encouraged through the use of prompts and scenarios to express a more personal or alternative view (Burnside et al 1998). This was an important consideration, necessary to guard against the tendency for older people to concur with the service perspective (Hudson 1992).

The interview schedule used is in appendix 1 and this was loosely followed with the use of prompts. Each focus group was taped and transcribed, and subjected to content analysis (Flick 1998). In addition, notes were written on the flip charts as participants were speaking, in order to provide a visual reinforcement of points made and gain consensus views about suggested standards. For the telephone interviews, notes were made as participants spoke and repeated back to the respondent at the end of the interview to ensure completeness of data collection.

## 7.0 Findings

The data that resulted from the independent discussions of the participants is reported in sections 8.0 to 10.0. Extracts from the dialogues are used to provide justification for keeping, changing and adding new standard statements to the questionnaire. This section will firstly give a rationale for those statements that were supported intact, and those that were changed or added to so that they reflected the discussions (8.0); secondly it will provide justification for the new standard statements (9.0). Inclusions are highlighted in blue italics.

As stated, participants were asked to review the standard statements on the questionnaire constructed in phase 1 the end of the sessions. This was to see if the expert panel's ideas of what constituted good standards of care matched those of the participants. A summary of their views is provided (10.0). The full altered questionnaire is attached as appendix 2.

Participants were able to articulate standards of care by being encouraged to describe their experiences, and in doing so, come to an agreement about the sorts of standards they should expect. The supporting anonymised quotes therefore reflect these experiences, and the new statements were generated by the participants themselves.

8.0 Standard statements fully supported or changed to include user perspectives

**Statement (a)**

Getting hold of a local expert for advice and/or treatment when I need it.

This statement was overwhelmingly supported and appreciated by both groups as this dialogue between a patient and his carer illustrates:

“if I need someone, [name] will pop in a couple of times, you can't fault that”

“Yes, it puts my mind at rest” (carer) 1:8

Again, the importance of this statement was highlighted by this respondent, who seemed to have difficulties in accessing specialists at the point of need, with detrimental effects:

“I've had a lot of problems with my catheter... the ward staff showed me how to catheterise myself,,well I felt terrible because I didn't know where to put it or anything...when I went home I kept getting urine infections. Months later they sent a continence nurse who said to me 'Good lord, ...you've got the wrong catheter' Well it was all ok after that” 1:5

**Statements (b) and (s)**

(b) Dealing *face-to-face* with staff that have been properly trained in continence problems

(s) Being involved in a full discussion about care and treatment *face-to-face*

There were two elements to these statements. Firstly, with reference to statement (b), the importance of having properly trained staff was clear:

“[name]'s an expert and has been dealing with people....she's got the experience.....and comes down to our level when anything has to be explained...there's a lot of humour in it as well...she's never embarrassed about how she describes anything, you know, and it should always be like that” 1:9

Secondly, the importance of having someone who the participants could talk face-to-face with was also evident, and the value of a home visit was also articulated:

“you can't travel with a catheter easily, things are going wrong and you want someone who would pop in and just have a look at you...and give you some reassurance...you

want a trained nurse to actually come and see you, face-to-face, like” 1:9/10

“I do think that speaking to people, face-to-face is a practice that, I think is the most important thing because you can then ask the questions, you know. I think that really is the answer” 2:16

### Statement (e)

Having *full* health assessments that *include* questions in them about continence

Participants who were carers felt that all health assessments should be ‘holistic’ and include questions about the family, and not necessarily be focused on the continence problem. This was generally agreed.

“Well, she asks about, well everything about my wife, but she also asks about the family and how I’m coping. It’s not just your basic continence problems” 1:9 (carer)

### Statement (g)

Being assessed by someone who is friendly, *understanding and reassuring*

The characteristics of the person assessing the participants were also clearly expressed by both groups

“what you need is reassurance, someone to put your mind at rest and who understands what you are going through” 1:13

“the nurses....are always pleasant, you know. Always very pleasant and charming...they are understanding...and they listen. Well, it is important..yes.” 2:1/2

### Statement (m)

Having warm, clean *and separate male and female* toilets nearby that can be used without difficulty

Some respondents felt very strongly about having separate toilets:

“I don’t like to share toilets and I am amazed that in a health place like here, it is one toilet for men and women. Everywhere you go, you have separate toilets, don’t you.”  
2:10

Others who were less mobile and in wheelchairs were also keen to point out the shortcomings of access to the current provision, especially reducing the potential to be independent. One carer explains:

“It’s the same with toilets, if I’m not with her, she can’t do it...if the door opened inwards, that’s fine, but how do you get out?” 1:6 (carer)

### Statement (q)

Being able to choose from a full range of *good quality, reliable and properly fitting pads, knickers and other products* irrespective of cost

This statement provoked the most comment and consensus among the participants. In general, people were dissatisfied with the basic provision which was seen as ill-fitting and of poor quality. The debate highlighted the need for a standard around the supply of reliable products:

“they are only looking at it from the money point of view and in the end it’s going to cost them more...what we need is good quality stuff..” 1:1

“If I don’t have the right equipment, well, I leak and I don’t feel confident, I don’t go out.” 1:2

“These elastic knickers, they’ve just got two threads across – that doesn’t really hold the pad...one end of it slips down your leg and the other ends up God knows where! A lot of them are useless.” 1:8

There also seemed to be inconsistency between participants at the same service regarding the type of products received, and the frequency with which they received them, as this dialogue about knickers demonstrates:

Mrs. X: “Do you get the knickers?”

Mrs. Y: “I don’t get them every time”

Mrs. X: “I get them on occasions”

Mrs. Z: “I have never been able to get them” 2:23



One participant preferred to pay in order to get the choice and quality she needed:

"I pay for mine at Boots you know, I know that you can get them free....there's a better choice...they've got odour control...they also have various sizes...the free ones should be like that." 2:11

### Statement (y)

Being *consulted about* how the service runs and how it should run in the future

With the move to involve users much more in the evaluation and planning of services, it was interesting to hear that consultation appeared to be the involvement method of choice by the respondents:

"I'm not sure that I really want to be involved in things to do with my incontinence, I wouldn't know what to say....but I would like to be asked about changes before they happen" 1:13

"...they changed the kinds of pads they gave us a few months ago....and the thing is they are useless, they leak, so why weren't we consulted before they changed them?" 1: 1

### Statement (v)

Getting *regular updates* about bladder and bowel conditions, *services and equipment* free of charge in a form I can understand

There did appear to be a mismatch between what was available and when it was needed in terms of information, so the importance of giving up-to-date information regularly about a range of issues was expressed by participants as a way forward:

"there's nobody to tell you what's available when you come out of hospital" 1:4

"you could bring out a monthly newsletter about the latest products that will tell you everything you want to know" 1:8 (carer)

"there are plenty of booklets...they are all the same...quite easy to understand but it doesn't really help" 2:14

## 9.0 New standard statement

### **Statement (c)**

*At the clinic, being able to get into the building easily (eg having ramps or lifts)*

Participants who had mobility problems were keen to point out the problems with accessing buildings (as with the toilets), highlighting the need for standards around this issue:

“there is no point having a door that you have to pull to get in the building – you can’t get through it. You need automatic doors with sensors on them.” 1:6 (carer of participant in a wheelchair)

“..ideally it need to be all on one level, but if not then you need proper working lifts or ramps” 2:6

### **Statement (d)**

*Having comfortable and warm waiting areas in the clinic*

Although waiting times for appointments were not raised as an issue for participants at both sites, there was recognition for the need for warmth and comfort while waiting:

“A warm waiting area is a must, you haven’t got one here, sit in the cold” 1:7

“This place is always warm and comfortable. It’s quite spacious too, and you can get a drink. It would be awful to wait in the cold.” 2:11

### **Statement (i)**

*Having a regular assessment of need (eg 6 monthly or yearly) to find out changes in needs and treatments*

There seemed to be some inconsistency between the participants about frequency of assessments that resulted in some feeling that they were ‘drifting along’ in the system in an unsatisfactory way. This dialogue illustrates the importance of regular assessments or contact with the service:

Mrs..A: “I think we should have regular updates, because I’ve been here 13 years and my care hasn’t really changed...I get

whatever they supply...my pads are not suitable, I've got a leakage now"

Mrs. B: "I have an assessment every six months"

Mrs. A: "Well I'm just a lost cause! I'm just one of those that plod along..." 1:7

"she does actually examine you and so, when you see her she gives you the next appointment three months ahead. That works well for me" 2:9

"I can't remember the last time I had an assessment to be honest" 2:12

In addition, some participants did not seem to have any future care plans and reassurances that care would continue, highlighting the need for planned follow-up appointments:

"when I had my assessment, the nurses, they were very, very professional and I hope it will continue like that and that I see them regularly" 1:7

### **Statement (l)**

*Whenever possible, being given a choice of treatments by continence specialists*

Being given choice seemed to feature in the dialogues at both sites, important again for maintaining a sense of independence:

"my nurse always gives you a choice of things to do, even if they are little things, it makes me feel like I can choose....and I think that's important" 1:9

"I would like, in a way..to choose. I would like that they have different sizes of pads." 2:4

### **Statement (n)**

*Having disposable pad facilities in the toilets for men and women*

There appeared to be a clear difficulty with respect to disposing of used continence pads, especially for the men. Whilst there were facilities for women such as nappy disposal bins in some areas,

there was rarely a facility for men. In the absence of a disabled toilet that sometimes provided proper bins, this caused quite a problem:

“there’s never any place where you can get rid of pads in men’s toilets and it’s a problem” 1:7

“...in the disabled toilets you don’t automatically have disposal units pads. There should be a yellow bin for proper disposal.” 1:6

“there must be bins about in toilets that you can use if you want to” 2:11

### **Statement (p)**

*Having good channels of communication between all professionals who deal with my bladder/bowel condition*

Those participants who had undergone surgery seemed to have had the most difficulty with ‘seamless’ specialist care, especially on discharge. This often had quite distressing consequences, highlighting the need for efficient communication at this point:

“then they sent us home...someone came to visit, she was struggling, she was a midwife...she didn’t know what to do about my leaking catheter...we never saw her again...we thought we’d been abandoned, actually.” 1:1

This carer describes the relief when the continence nurse became involved:

“the District nurse said he needed pads, I had no idea what pads to buy...I went from one shop to the other...I was totally unsupported and confused... and eventually we got the specialist nurse and [name] was brilliant. Shame it didn’t happen earlier.” 1:3 (carer)

### **Statement (r)**

*Having equipment such as pads delivered on time to where I live*

Participants were keen to point out the importance of home delivery of equipment as these contrasting experiences demonstrate:

"I have quite a good service.. I have a supra-pubic catheter, so if I need them I just ring them up and the next day there are here. Everyone should have this kind of service": 1:2

"I phoned the person up and said 'Where are my pads?' 'Oh' they said 'Our supplier hasn't supplied' .....and I said 'What am I going to do? I've got four pads left.' 'Well I'll send you two emergency packs'. I mean they sent us some pads...and they were crap!" 1:10

### **Statement (t)**

*Being able to fully understand my condition and what the future holds for me*

It was clear that some participants did not fully understand what was happening to them, or how their condition came about. In addition, the need for some sort of prognosis was articulated in order to better plan for the future:

"there's a lot of literature going around, particularly for the women....but you're too embarrassed to talk about it and so don't really understand it....and when is the problem going to stop, or will it ever go away? These are the things that you really want to know – what the future holds." 1:16

"[name] didn't tell me why it was that the muscle is now so weak, I just assumed it was old age" 2:13

This lack of knowledge seemed to lead to confusion for some:

"I was really left in the dark for ages....I was always under the impression that incontinence meant that you didn't know you were going, but I know what I am doing...I didn't know what the word 'incontinence' meant" 2:15

"I mean a few years ago...people say it could be the amount of children that you have had, I have only had one....my mother had twelve children and there was nothing wrong with her bladder!" 2:16

Others who appeared to be more fully informed however were able to express the benefits, as this participant illustrates:

"...so when I had mine [operation] they showed you where the bladder, you know, the muscles were and it had sort of dropped, that was where they cut, where it was weakened.

Then again, I learned about and understood what was happening and what would happen later, which was good.”  
2:17

## 10.0 Participants' views of the Expert Panel's standards

In general, the statements developed in phase 1 were supported by groups at both sites as being reflective of participants' opinions. The following statements however were specifically commented on or discussed.

### **Statement (j)**

Being asked if I have any difficulties with my sex life because of my problem

Overall participants felt uncomfortable about this subject and embarrassed about discussing it at the focus groups. While one group felt slightly offended at the prospect of being asked about matters of a sexual nature...

“..it's not necessary to ask about sex, that's personal information!” 2:22

another participant highlighted the need for a better professional approach through his experience:

“questions about sex? Well I remember this houseman concentrated on 'dysfunction' what ever that means in real life, and there was one about erections. It was all a bit vague”  
1:15

### **Statement (u)**

Having a personal care plan made with an expert that is regularly reviewed

This statement appeared to be met with some bemusement by one group:

“what's a care plan?”  
“where's mine?” 1:15

In general, the groups lacked understanding about the nature of care plans and what they were for.

### **Statement (w)**

Being able to contact other people with similar conditions for support

Groups seemed to be divided regarding the usefulness of support groups, as demonstrated by these quotes.

“They are either ever so helpful or they can be a pain in the backside!” 1:13

“You don’t always want to discuss you continence issues with everyone” 1:14

Most however agreed that they do have a place in facilitating recuperation and sharing a problem:

“It’s nice to know there are so many people with similar problems” 1:14

“...you get things in perspective, you realise you’re not going to get better overnight” 1:14

“ the support group here is excellent, I learned a lot from coming here and they put your mind at rest.” 2:20

## 11.0 Commentary

These initial findings highlight some interesting themes that provide insight into factors that constitute best practice through the experiences of a small population of users at two sites.

It was clear that a large number of participants were complimentary about the service they received, and that impediments to care appeared to rest on quick access at the point of need, sometimes due to communication problems between services.

It was of interest that perceptions largely matched those of the expert panel views, although the user contributions tended to furnish the original statements with more detail. This included greater description of the nature of the equipment required and the attributes of the professionals. The new statements generated by users appeared to be based on either negative or positive experiences. Particularly poignant was the statement about understanding the bladder or bowel condition and future prospects, where many of the participants seemed to be confused.

While some participants had regular contact with the service, a further recurrent issue that cut across the statements was the feeling that some participants were left 'in limbo' with no apparent future care planning or provision for continuous assessment. The need for a standard in this area to avoid enduring unpleasant symptoms was evident.

The dialogue that was provoked as a result of seeing the expert standard statements was also of interest, especially the difficulty discussing the issue of assessment of sexual function and the lack of understanding of care plans. Despite this, the statements were not removed at this early point in the development of the standards.

This stage of the project has therefore been useful in commencing the process of user involvement, but it will be important to test the standard statements further in order to gain the perceptions of a wider and more diverse consumer population group.



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## 13.0 Appendix 1

### **Focus Group Schedule**

Imagine you have been asked to help develop a new service for people who have continence problems. What kinds of things do you think are important to include?

***Prompts to help respondents:***

About the building and surroundings?

About the people who will run it?

About the appointment times?

About the assessment and consultation?

About the information you are given about your condition?

About the supplies?

Is there anything else?

## 14.0 Appendix 2 **Continence Services Questionnaire**

This questionnaire has three sections to it. The first section is about getting some idea of what you feel is important about the care and treatment of bladder or bowel problems. In the second and third sections, we want to find out a bit more about you and your problem. Each section involves simply ticking boxes or writing something in a space.

Section 1: About the service...

***In this first section there is a list of statements that are all to do with caring for people with bladder and bowel problems. Please tick one box for each statement that best describes how important each one is to you personally.***

	<b>not at all</b>	<b>quite important</b>	<b>very important</b>
a) Getting hold of a local expert for advice and/or treatment when I need it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Dealing <i>face-to-face</i> with staff that have been properly trained in continence problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) <i>At the clinic, being able to get into the building easily (eg having ramps or lifts)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) <i>Having comfortable and warm waiting areas in the clinic</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Having <i>full</i> health assessments that <i>include</i> questions in them about continence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Being able to choose the gender of the person who is assessing me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Being assessed by someone who is friendly, <i>understanding and reassuring</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Being able to have a full assessment of my problem if I mention it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) <i>Having a regular assessment of need (eg 6 monthly or yearly) to find out changes in needs and treatments</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Being asked if I have any difficulties with my sex life because of my problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	<b>not at all</b>	<b>quite important</b>	<b>very important</b>
k) Having an assessment or treatment in a private room	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) <i>Whenever possible, being given a choice of treatments by continence specialists</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) Having warm, clean <i>and separate male and female</i> toilets nearby that can be used without difficulty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) <i>Having disposable pad facilities in the toilets for men and women</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) Having a service that can easily link me to specialists or other services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) <i>Having good channels of communication between all professionals who deal with my bladder/bowel condition</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) Being able to choose from a full range of <i>good quality, reliable and properly fitting pads, knickers and other</i> products irrespective of cost	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) <i>Having equipment such as pads delivered on time to where I live</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s) Being involved in a full discussion about care and treatment <i>face-to-face</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t) <i>Being able to fully understand my condition and what the future holds for me</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u) Having a personal care plan made with an expert that is regularly reviewed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v) Getting <i>regular updates</i> about bladder and bowel conditions, <i>services and equipment</i> free of charge in a form I can understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
w) Being able to contact other people with similar conditions for support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x) Being asked my views about standards	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- y) Being *consulted about* how the service runs and how it should run in the future

Is there anything else that you think is important to you about the care and treatment you get from a service? Please write about it in the space below.

## Section 2: About you.....

**In this section, we would like to find out some things about you. This includes your approximate age, your ethnic group and the type of condition you have.**

- a) Please tick the box which is nearest to your age

- 50 – 59   
60 – 69   
70 - 79   
80 - 89   
90 and over

- b) Are you male  female

- c) Please tick the box that best describes the ethnic group to which you belong

White

- |                    |                          |                     |
|--------------------|--------------------------|---------------------|
| Black Caribbean    | <input type="checkbox"/> |                     |
| Black African      | <input type="checkbox"/> |                     |
| Black - other      | <input type="checkbox"/> |                     |
| Indian             | <input type="checkbox"/> |                     |
| Pakistani          | <input type="checkbox"/> |                     |
| Bangladeshi        | <input type="checkbox"/> |                     |
| Chinese            | <input type="checkbox"/> |                     |
| Other ethnic group | <input type="checkbox"/> | Please specify..... |

Now we would like to know a bit more about your bladder or bowel problem. Please tick the box or boxes that best describe them:

**d) *If you have bladder problems, do you.....***

- |   |                          |
|---|--------------------------|
| Pass water more than about 8 times a day        | <input type="checkbox"/> |
| Feel an urgent need to pass water               | <input type="checkbox"/> |
| Get up more than twice a night to pass water    | <input type="checkbox"/> |
| Have problems emptying your bladder             | <input type="checkbox"/> |
| Accidentally wet yourself                       | <input type="checkbox"/> |
| Accidentally wet yourself if you laugh or cough | <input type="checkbox"/> |
| Have a catheter                                 | <input type="checkbox"/> |
| Any others? Please describe them below.         | <input type="checkbox"/> |

**e) *If you have bowel problems, do you.....***

- |   |                          |
|---|--------------------------|
| Often have an urgent need to open your bowels             | <input type="checkbox"/> |
| Have to strain to open your bowels                        | <input type="checkbox"/> |
| Become constipated  | <input type="checkbox"/> |
| Accidentally loose control of your bowels                 | <input type="checkbox"/> |
| If you have ticked this one, is it a) when you pass wind? | <input type="checkbox"/> |

- b) liquid?
- c) solid?
- Have a stoma bag
- Any others? Please describe them below.

f) Which services have you used to help you with any bladder or bowel problem?  
(Please tick all the ones that apply to you)

- GP
- Practice nurse
- District Nurse
- Specialist continence nurse
- Physiotherapist
- Occupational therapist
- Hospital consultant

Any other? Please specify

### Section 3: About your life.....

The next questions ask how you about how your bladder or bowel problem affects your life

a) How would you describe your health at present?

- Very good
- Good
- Fair
- Poor
- Very poor

b) How much do you think your problem affects your life?

Not at all   
Slightly   
Moderately   
A lot

Below are some daily activities that can be affected by bladder or bowel problems. How much do they affect you? Please try to answer every question by ticking the box that applies to you.

	<b>Not at all</b>	<b>Slightly</b>	<b>Moderately</b>	<b>A lot</b>
c) Does your problem affect your household tasks (cleaning etc)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Does your problem affect your job or your normal activities outside the home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Does your problem affect any physical activities like walking, running or sport?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Does your problem affect your ability to travel?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Does your problem limit your social life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Does your problem limit your ability to see or visit friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Is it a problem having to change your underwear if it gets soiled?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Do you worry in case you smell?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) Do you get embarrassed because of your problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Is there anything else you would like to add about how your problem affects you? Please use the space below.



Thank you for completing this questionnaire. Now please return it to us in the stamped addressed envelope.