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

Report on Stage 2

April 2005

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

Interim Report on Stage 2
April 2005

1 Introduction

The Clinical Effectiveness and Evaluation Unit of the Royal College of Physicians of London has been 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 bladder and/or bowel continence problems in determining whether the development of standards to date reflects consumer opinion and need, and to incorporate their views into the development process.

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. The 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, and eliciting their views and those of their carers.

This report provides the methodological approach and findings of **Stage 2** of the study, conducted in Bournemouth and Camden & Islington. Stage 1 was completed in February 2004 and 1 was concerned with the development of an initial draft questionnaire from a professional and user and carer perspective (see Billings 2004 for full report).

The purpose of stage 2 was to

- test the standard statements further to ascertain their importance to a wider population group of older users;
- determine whether any standard statements needed to be removed, or added through written comments
- detect any differences between sites, ages and self-reported health status.
- determine the characteristics of older people underrepresented in the survey for stage 3.

2 Method

This stage used a descriptive survey design. Ethical approval was given by Camden and Islington LREC and Bournemouth LREC.

2.1 Overview of questionnaire

Development of standard statements for the questionnaire was guided by the standards that had been developed with the UK expert panel group of professionals. Accompanying focus groups of users of continence services and their and carers provided further statements and changes to those put forward by the expert panel to augment meaningfulness.

There were numerous additional features that went into its construction to enhance rigour. For example, scales were used for respondents to rate the standard statements 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 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 seen as important to add a qualitative dimension and include space for respondents to add comments (Robson 1993). This was particularly so for this stage, in order to check that any features of continence services important to respondents were not missing.

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 be 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 seen as important in estimating the extent of problems among the target population and restrictions on life, valuable in starting to inform service priorities. For example, it was considered that 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. See appendix 1 for questionnaire.

2.2 Data collection approach and analysis

Service users were accessed through the continence services database in each of the pilot sites. Staff were asked to select 150 users age 60 years or over at random from their databases. One site sent these handwritten, while the other sent a file containing 161 service users aged 65+. The sample (n=311) was sent the questionnaire with an accompanying information letter (appendix 2) and stamped addressed envelope.

Reminders were not initially planned, but as the response was quite slow, a reminder letter with another copy of the questionnaire was sent approximately a month after the initial mailing. The reminder enhanced the response rate.

Analysis was largely executed using descriptive statistics and cross-comparisons with variables of interest. Due to the small samples, cross comparison was limited. Particular attention was given to written qualitative comments, which were grouped into themes and reported using anonymised quotes. Some comments were amenable to quantification, such as lists of additional symptoms or problems experienced by respondents.

3 Findings

The findings are separated into five sections. Sample characteristics will be followed by users' views about continence service features, which reports degrees of importance attached to standards statements, differences between groups and additional comments. Users' descriptions of their continence problems are given next, followed by an overview of services used by the respondents, and a description of their self-rated general health and impact of continence problems on daily life. Finally, general comments on how their conditions affects them are provided. As there was very little difference in the findings between the sites, they are mostly reported using total numbers responding.

3.1 Sample Characteristics

This section does not present any data on the characteristics of users beyond what was supplied from the questionnaire, which is date of birth, gender and ethnic group.

The overall response rate was 55%, with 15 responses out of the 155 from men (see table). Response rates were slightly lower in the Camden & Islington area (52%) compared to Bournemouth (57%).

Table 1: Response rates from Bournemouth and Camden & Islington

	Bournemouth			**Camden & Islington**		
	Sampled	**Responded**	**Response rate**	**Sampled**	**Responded**	**Response rate**
Female	140	81	58%	108	59	55%
Male	6	4	67%	27	11	41%
Not known	2	0	0%			
Valid sample	148	85	57%	135	70	52%
Died	2			4		
Undelivered	0			22		
Total sampled	150			161		

The number of men responding was very small in the Camden & Islington area (4%), compared to Bournemouth where 20% males appeared in the sample of users. The Camden & Islington area also differed in the relatively large number of undeliverable addresses (22), which reduced the sample size. In both areas a few of the people sent the questionnaire had died.

The distribution of responses by age was quite similar, with the best response rates for users in their 70s (see table 2). There was a poorer response from people age 80 and over in the Bournemouth area compared to Camden &

Islington. The absence of people age 60-64 in the Camden & Islington area should be noted when comparing results for the two areas.

Table 2: Number and characteristics of respondents per site

Characteristics	Bournemouth	Camden & Islington
Total participants	85	70
Age: minimum age	60	65
Age: number (%) age 60-69	9 (13%)	27 (32%)
number (%) age 70-79	34 (49%)	35 (41%)
number (%) age 80-89	25 (36%)	19 (22%)
Gender: number (%) female	81 (93%)	59 (84%)
Ethnic group: number (%) white	82 (89%)	62 (97%)
Health: number (%) good/very good	30 (43%)	49 (58%)

3.2 Users' views about continence service features

Users were asked how important various features of a continence service were to them. They were given the options 'not at all', quite important' and very important'. A large proportion of these features (15 out of 25) were deemed 'very important' by the majority of responders. See chart 1.

3.2.1 Features considered very important

At the top of the list, 78% of service users thought it was very important to deal face-to-face with staff who have been properly trained in continence problems, and 76% felt it was very important to be assessed by someone who is friendly, understanding and reassuring. Other features deemed very important were having good channels of communication between all professionals who deal with the bladder/bowel condition (73% of users said this), to be able to have a full assessment of their problem if they mention it (72%), and being able to fully understand their condition and what the future holds (72%). Two thirds put getting hold of a local expert for advice and/or treatment when they need it as very important.

The other features considered very important by at least 50% of users were:

- to have full health assessments that include questions about continence (63%),
- to be involved in a full discussion about care and treatment face-to-face (63%),
- to have an assessment of treatment in a private room (61%),
- to have warm, clean and separate male and female toilets nearby that can be used without difficulty (59%),
- to get regular understandable updates about bladder/bowel conditions, services and equipment, free of charge (58%),
- to be given a choice of treatments by continence specialists, when possible (57%),
- to have a regular assessment of need, to find out changes in needs and treatments (56%),

3.2.2 Features considered least important

Least important features were questions about the continence problem affecting their sex life (54% said not at all important), and being able to get in touch with other people in similar conditions (50% said not at all important). Interestingly as many as 31% said that being able to choose the gender of the person assessing them was not at all important.

3.2.3 Age differences

As people get older the importance they attach to aspects of the service tends to fall, although this is not the case for two of the questions asked. People aged 80 and above attached greater importance to ‘getting equipment such as pads delivered on time and to where they live’, and ‘being able to choose the gender of the person assessing them’.

3.2.4 Differences between sites

There were also differences in the importance attached to aspects of the service between the two sites. Service users in the Bournemouth area attached greater importance in general to the features the questionnaire asked about and were more likely to rate them as very important, especially having equipment such as pads delivered on time to where they live. These differences are consistent with the differences in age profile. In other words the relatively small differences appear to be due to age rather than geographical area.

3.2.5 Self-rated health status and degrees of importance

Respondents were asked to rate their general health (this is analysed more fully in 3.5). Results were cross-compared with degrees of importance attached to the statements.

Deteriorating general health appeared to be related to the way people rated the importance of aspects of a continence service. People who rated their health ‘poor’ attached greater importance to the following features.
To:

- beable to choose the gender of the person assessing,
- beconsulted about how the service runs and how it should be run in the future,
- beable to get into the building easily, at the clinic,
- have disposable pad facilities in the toilets for men and women,
- have a regular assessment of need, to find out changes in needs and treatments,
- get regular understandable updates about bladder/bowel conditions, services and equipment, free of charge.

3.2.6 Comments

Respondents were asked if there was anything else they would want from a service. This section was important to indicate any additional standard statements. Twenty people commented from Camden & Islington and 28 from Bournemouth (n=48). Comments were grouped into two main categories, namely (i) *professional care* and (ii) *treatment issues*. An indication of numbers commenting is provided with abbreviations B for Bournemouth and C for Camden & Islington. On the whole, the comments tended to enlarge on the standard statements. People often provided examples of personal experiences to show that they were either receiving good quality care, or that an aspect of care was needed due to its absence.

(i) Professional Care

Comments in this category were further sub-divided into dignity, delivery of care, communication and specialist nurse support

Dignity: Some respondents were keen to point out the importance of preserving dignity (B=3, C=1), such as conducting assessments in a sensitive way and not forcing people to disclose information. One respondent wrote

> "*Because the problem of incontinence is a very personal one, great care should be taken to ensure that the patient is not made to feel embarrassed and uncomfortable*" (B164)

Delivery of Care: This was related to the importance of consistency of care (B=3, C=2) and being seen promptly (B=2, C=1).
With respect to consistency, views expressed were largely concerned with issues around assessment and record keeping. One respondent summed up the view:

> *"Seeing the same person each time, rather than a stranger who asks you all the same questions you answered on the first visit" (*B179)

It was clear that respondents felt prompt delivery of service was important and could cause frustration. One carer illustrates this with a personal experience:

> "*I was told….I needed night pads for my husband….but despite many calls from me and faxes from my GP it took over two months to get them*" (C156)

Another respondent wrote:

> *"Being able to see someone without waiting months"* (B213)

Communication: The importance of *"having empathetic care workers*"(B206) was expressed by some (B=1, C=2), including personal contact. Another respondent had experienced difficulties with interagency communication, and highlighted this as important:

> *"Good communication between different sections is vital. I have received no advice about protective wear. It is always trial and error"* (B206)

For two respondents (B=1, C=1), this had an impact on follow-up care where they felt they had been left in the dark. One wrote:

> *"Who is responsible for follow-up? Do I need follow-up and from where?"* (B290)

Specialist Nurse Support: By far the most frequent comments related to the positive support and individualised care respondents had received from their specialist nurse, highlighting the important function this role has to play in maintaining standards (B=4, C=4). It was clear from the comments that for some, the nurses have given prompt, appropriate and reliable advice and support that has helped people cope. These comments give an overview of the general view:

> *"The specialist nurse gave us 100% support and positive action, for as long as was necessary. Gave us reassurance and positive direction at all times…she was the mainstay of my…operation recovery"* (B306)
>
> *"The advisors who are trained nurses are excellent and very understanding"* (C142)
>
> *"I get proper advice through my continence nurse who I see regularly…I don't need anyone else*" (C38)

(ii) Treatment Issues

While single respondents commented upon preferences such as the need for female doctors (B=1) and the importance of having help with exercises (B=1), most comments related to the cost of and access to equipment. For some, participating in the survey was an opportunity to find out for the first time that pads could be free and delivered to their home. The sub-divisions in this category are resource and access issues, local services, and product and treatment information needs.

Resource and Access Issues: The cost of equipment was a heartfelt concern of those respondents able to comment (B=6, C=4). These respondents sum up the experiences:

> *"I am spending a fortune on pads each week, being unable to get to the toilet in time…is it possible to get some help for this, please?"* (B235)
>
> *"I was told by my district nurse that they do not supply sheets when they supply pads. I had to spend nearly £100"* (C39).

Coupled with this, easy access to equipment was important for independence:

> *"My problem mainly is that I am using far more pads and so have to buy from the chemists. It is getting awkward having to get somebody to buy these for me not being able to go myself"* (C152)
>
> *"My continence services are excellent with deliveries being the only problem – they don't happen or are not offered"* (C19)

Local Services: Two respondents (B=1, C=1) stressed the importance of having local community services:

> *"That the continence clinic remains at [centre] is important as this is very convenient for many and access is good"* (C142).

In addition, three respondents felt they had a good local service and were satisfied with their care (B=2, C=1), for example:

"I am so thankful for the care I have received over the years and my ability to live a normal life" (B183).

Product and Treatment Information Needs: In this section, there were a variety of requests such as more books and research to be made available to users (C-1), more information about alternative treatments (C=1), and general concerns about not really knowing what was on offer (C=2), such as this respondent:

> *"Making help available for incontinence advertised discretely would be good. Many people do not know what help is available. I purchased pads and 'put up' with my condition for many years until a district nurse …told me about it"* (C15)

A number of comments were related to difficulties around obtaining free products, or enough products (B=3, C=4), such as these respondents:

> *"I don't get …equipment free of charge. Up until now I have bought my own because I haven't been offered anything. Information on this matter would be appreciated"* (B174).

> *"I have had difficulty in convincing [person] that I should get a larger supply of pads. In the shops I cannot find similar pads so there is anxiety about whether the supply will las.it would help if I knew that I could purchase similar pads"* (C21)

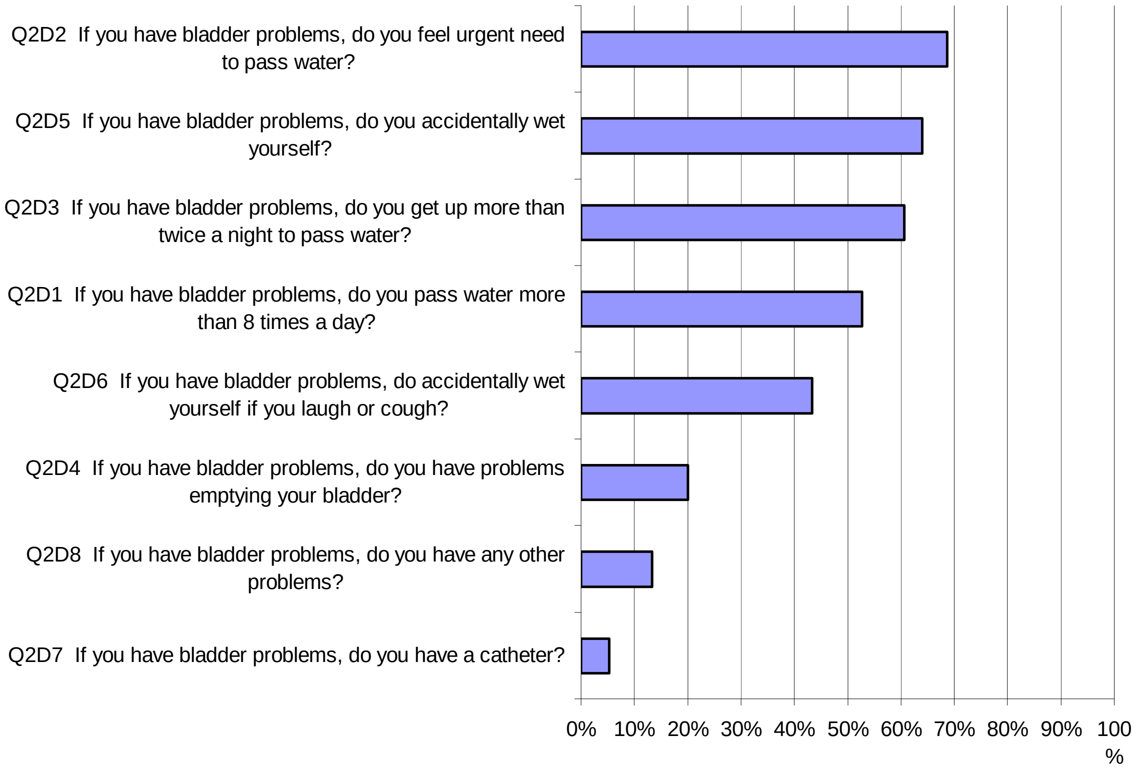
3.3 Users' descriptions of their continence problems

The purpose of this section was to discover the extent of respondent's bladder and/or bowel problems. The frequency of these problems was quite similar between the areas taking part in the study. A total of 91% reported bladder problems, 47% reported bowel problems.

3.3.1 Bladder problems

The questionnaire asked about eight particular bladder problems, and most people replied. Problems most commonly experienced were 'feel urgent need to pass water' (66%), 'accidentally wet themselves' (62%), 'get up more than twice a night to pass water' (59%), 'pass water more than eight times a day' (51%), and 'accidentally wet themselves when they laugh or cough' (42%). Smaller numbers had 'problems emptying their bladder' (19%), had 'other problems' (13%), or had a catheter (5%) (see chart 2).

Chart 2: Percentage of service users with specific bladder problems



3.3.2 Comments about bladder problems

The comments in this section mainly reiterated the problems people were suffering. Other bladder problems that respondents mentioned were amenable to quantification in the table below

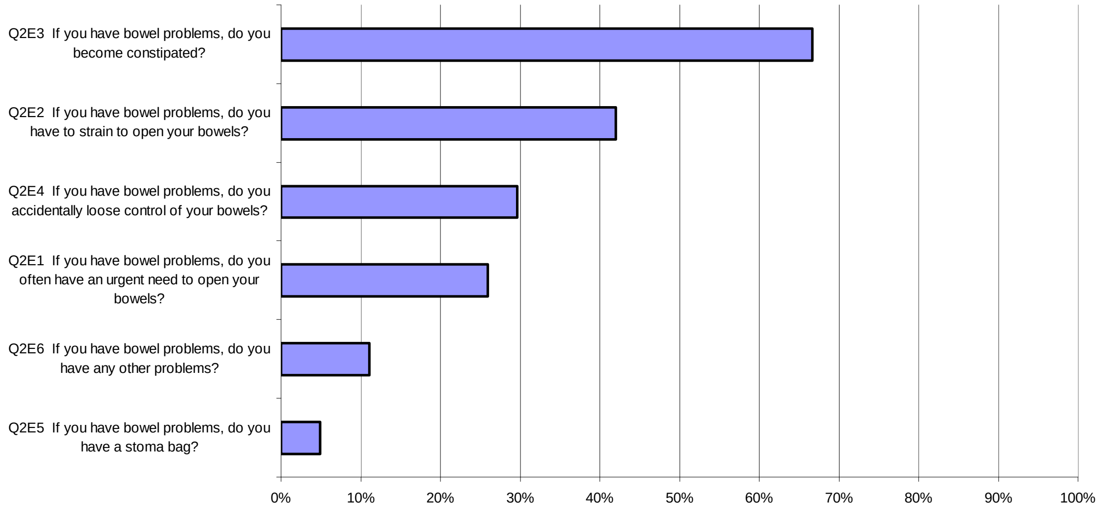
Table 3: Other bladder problems

Bladder problem	Bournemouth	Camden	Total
Urgency on movement (eg exercise, getting up)	4	0	4
General lack of control	2	0	2
Aural stimulation (eg tap turning on)	0	1	1
Permanent urine infection	3	1	4
total	9	2	11

3.3.3 Bowel problems

The questions on bowel problems applied to less than half of the sample. Most common was constipation (67% of those with bowel problems and 35% of all service users). 42% of those with bowel problems complained of having to strain to open their bowels. Among people with bowel problems, 30% report accidentally losing control of the bowels, and 26% having an urgent need to open the bowels.

Chart 3: Percentage of service users with specific bowel problems



3.3.4 Comments about bowel problems

Again, a few comments were added which referred to medication being taken, although not always with the desired effect. One comment was about it taking an hour to clean up after an incident.

3.4 Services used

This section asked respondents to list the services they used to help them with their continence problem. The services of specialist continence nurses were most frequently used (69%), with many also using GP (60%), and hospital consultant (57%). Physiotherapists helped 15% of users, practice nurses 11%, district nurses 9%, with other services bringing up the rear (5%).

The comments did not elaborate on these answers except to say one person had unsuccessfully tried to get access to the services of a herbalist.

A handful of people (7%) in Camden & Islington PCT did not answer these questions indicating that they had not used any services to help their bladder/bowel problem. This may indicate a difficulty with sampling current users or that the services had not helped.

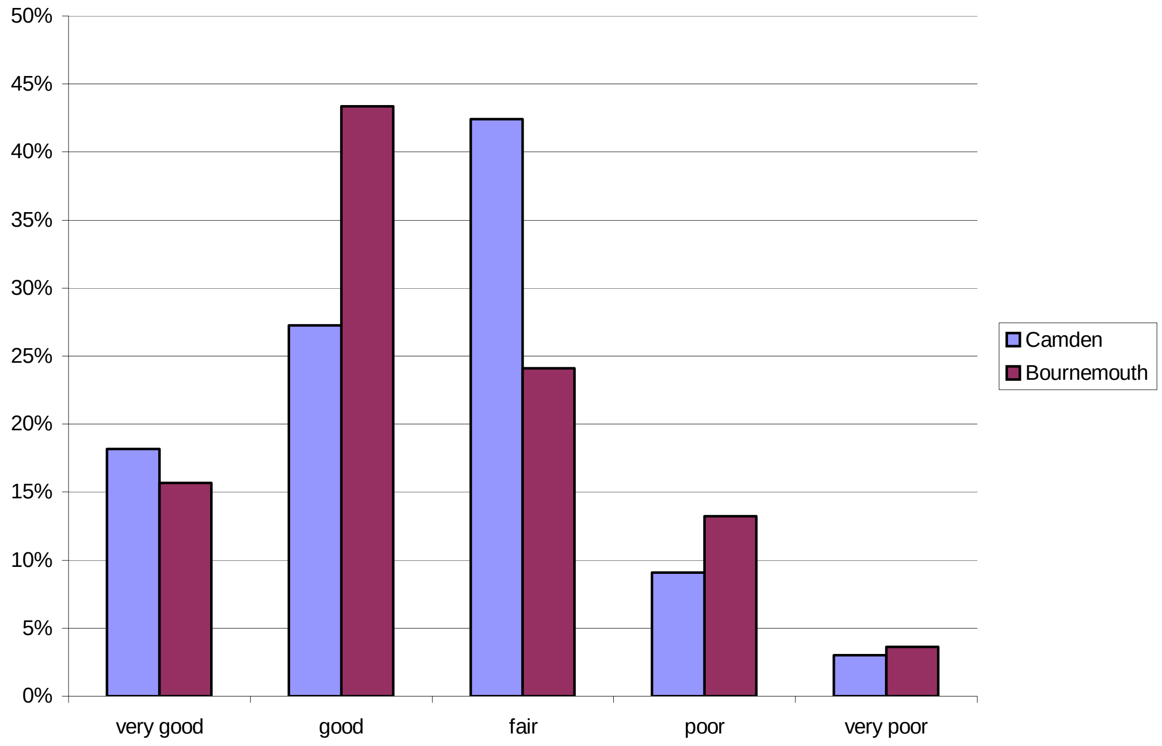
3.5 Self-rated health status and impact of continence problems on daily life

In this section, respondents were asked to rate their health status and indicated the impact their problem had on their lives.

3.5.1 *Self-rated health status*

Just over a half (51%) said their health was good, or very good, 31% said it was fair and 14% said it was poor or very poor (see chart 4). For this age-group, that is the same as found by the Health Survey for England in 2003, suggesting that users of continence services do not suffer poorer health overall than the general population. Respondents in Bournemouth appeared to rate their health better than those in Camden & Islington.

Chart 4: Self-rated health



3.5.2 *Impact on daily life*

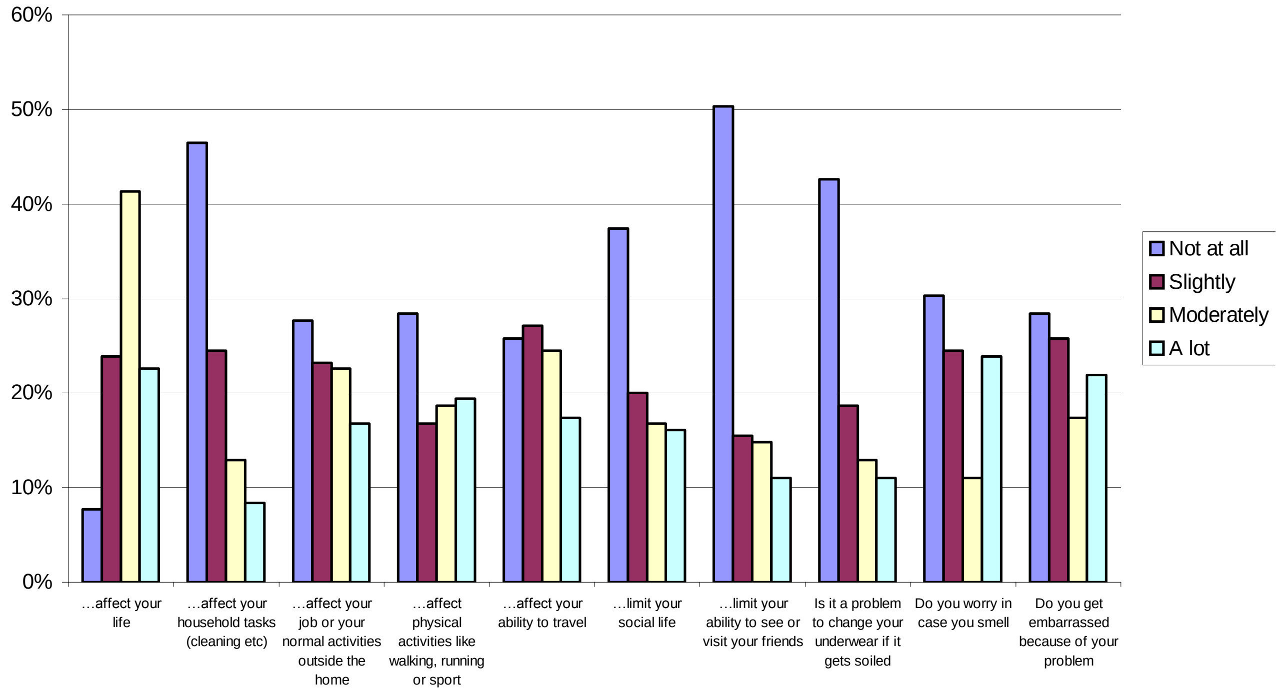
When asked a global question on how much their problem affects aspects of their lives, nearly a quarter (23%) said it affected them a lot. Nearly two thirds (64%) said it affected them at least moderately, leaving nearly a quarter (24%) slightly affected and 8% saying that it did not affect their lives at all.

When asking about the impact on specific aspects of on daily life, the worst was worry about smelling (24% worried a lot) or getting embarrassed (affected 22% of people a lot). The other problems affected between 8-19% of people a lot. See table 4 and chart 5.

Table 4: Impact of bladder/bowel problems on social activities

Impact of bladder/bowel problem				
How much does your problem…	Not at all	Slightly	Moderately	A lot
…affect your life	8%	24%	41%	23%
…affect your household tasks (cleaning etc)	47%	25%	13%	8%
…affect your job or your normal activities outside the home	28%	23%	23%	17%
…affect physical activities like walking, running or sport	28%	17%	19%	19%
…affect your ability to travel	26%	27%	25%	17%
…limit your social life	37%	20%	17%	16%
…limit your ability to see or visit your friends	50%	16%	15%	11%
Is it a problem to change your underwear if it gets soiled	43%	19%	13%	11%
Do you worry in case you smell	30%	25%	11%	24%
Do you get embarrassed because of your problem	28%	26%	17%	22%

Chart 5: Impact of bladder/bowel problem



The following provides a ranking that combines those affected ‘moderately’ with those affected ‘a lot’ (87% of sample) to indicate the percentages reporting a substantial impact on their lives:

affects life	(64%),
affects ability to travel	(42%),
get embarrassed because of problem	(39%)
affects job or normal activities outside the home	(39%),
affects any physical activities like walking, running	(38%),

- worries in case smell	(35%),
- limits social life	(33%),
- limits ability to see or visit friends	(26%),
- a problem having to change underwear if it gets soiled	(24%),
- affects household tasks (cleaning etc)	(21%).

3.5.3 Impact and self-rated health status

Bladder and bowel problems had the greatest impact on people rating their health as ‘poor’. Apart from worry about smell and embarrassment, which was experienced by several respondents in all categories of health, there was a gradient of how much people were affected across levels of health status. Those in good and very good health reported the lowest impact (15% or fewer affected a lot), and a larger proportion of those with fair general health (10-23%) were affected a lot. For those with poor or very poor health around 20-80% were affected or limited a lot in daily life. See table 5 showing percentage affected a lot.

Table 5: Impact of bladder/bowel problems according to self-rated health

	Very good	**Good**	**Fair**	**Poor**	**Very poor**
Q3B affects life a lot	8%	15%	21%	59%	100%
Q3C affects household tasks (cleaning etc) a lot	0%	6%	10%	12%	60%
Q3D affects job or normal activities outside the home a lot	4%	9%	19%	41%	80%
Q3E affects any physical activities like walking, running or sport a lot	8%	15%	19%	41%	60%
Q3F affects ability to travel a lot	0%	7%	23%	41%	60%
Q3G limits social life a lot	4%	9%	19%	35%	60%
Q3H limits ability to see or visit friends a lot	0%	4%	15%	35%	40%
Q3I a problem having to change underwear if it gets soiled a lot	0%	7%	17%	24%	20%
Q3J worries in case smell a lot	28%	17%	23%	29%	40%
Q3K get embarrassed because of problem a lot	20%	29%	19%	29%	60%

3.5.4 Comments

In this final section, respondents were invited to comment on how else their problem affected them. It provided a range of comments relating to health, lifestyle and resource issues. Despite the often debilitating nature of the problems, many respondents gave examples of strategies they have developed enabling them to lead as normal a life as possible. Sub categories in this section are *(i) physical and emotional problems, (ii) getting out and about* and *(iii) coping strategies*.

(i) Physical and Emotional problems

There were a large number of on-going health problems and concerns experienced by respondents, listed in the table below.

Table 6: Physical and emotional problems experienced by respondents

Health problem/concern	Bournemouth	Camden	Total
Weakness	3	1	4
Tiredness	5	2	7
Perineal soreness and rashes	3	4	7
Multipathology (diabetes, arthritis, skeletal problems, stroke, heart disease, wheelchair bound/disabled, had surgery for cancer)	8	9	17
Pain and discomfort	2	1	4
Unable to do exercise	2	2	4
Loss of confidence, embarrassment and despair	6	1	7
Long term nature of the condition	2	2	4
Totals	31	22	53

The situation for some respondents was clearly difficult, given the range of associated discomforts in addition to other conditions that affected health, as this arthritic respondent wrote:

> *"I'm in terrible pain when I get out of bed and am in agony with my back and legs trying to get to the toilet in time. Sometimes I feel as if I don't want to go to bed because of the pain"* (B235)

The emotional side of the problem was also evident, with concerns expressed about the future:

> *"I try to contain my condition but I fear it will deteriorate"* (C100)
>
> *"I worry about the future. Am I going to control this problem as I get older?"* (B238)

(ii) Getting out and about

This section related to worries about practical limitations on social activity. Some respondents were unable to go out or be active because of concern about the location of toilets and suitable places to change pads (B=3, C=1)

> *"Difficulty in planning outings not always knowing the places where to change. This leads to accidents and embarrassment. Unable to go walking or swimming. Therefore not able to exercise to keep fit" (B206)*
>
> *"Not always disabled toilets or cubicles to change pads etc and disposal of them in male toilets a problem"* (C52)

Others were unable to stay over with friends, enjoy themselves on social events or just did not go out (B=3, C=2)

> *"Fear of incontinence does sometimes stop me from doing things"* (B277)
>
> *"I feel I can't go out without worrying if I can get to the toilet. I can't stay anywhere to sleep because it is such a bad problem at night. I am embarrassed if I do wet the bed." (*B309)

(iii) Coping Strategies

Respondents were keen to point out how they coped with their conditions, in the face of sometimes great inconvenience and discomfort. There was a desire to carry on with life, and being prepared as well as taking advantage of the treatment on offer seemed to be key elements. The following table provides a quantification of comments, followed by some quotes.

Table 7: Coping strategies used by respondents

Strategy	Bournemouth	Camden	Total
Making sure you always have the right equipment with you	4	4	8
Knowing where the toilets are	3	2	5
Using medication, diet and exercise	3	4	7
Having free delivery of pads	0	2	2
Adjusting fluid intake	2	1	3
Getting different pads to suit the occasion	2	1	3
Total	14	14	28

> *"I try not to let it rule my life. Check where the toilets are, wherever I am"* (C139)
>
> *"A combination of exercises…, plus the use of decaffeinated tea have been effective in halting the condition and improving it somewhat"* (C154)
>
> *"I occasionally wet the bed when I am asleep. So I use a waterproof sheet to protect the mattress. I take the sheet with me whenever I am going to spend the night away from home"* (B244)

4 Summary of Key Points

The following provides a summary of the main findings:

(i) The overall response rate was 55% (n=155) with slightly more respondents from Bournemouth (n=15). The sample consisted mainly of white older women in their 70's, with more respondents in their 60's from Camden & Islington and more aged over 80 from Bournemouth. Just over half the sample rated their health as 'good' or 'very good', with 14% rating themselves 'poor' or 'very poor'.

(ii) With respect to the standard statements, most of them were seen as 'very important' by the majority of respondents. Features of particular importance related to the characteristics of staff, such as being seen face-to-face by friendly and approachable specialist staff, who enabled respondents to fully understand their condition and possessed good interprofessional communication skills. Least important features related to assessments of respondents' sex lives and being able to choose the gender of the person assessing them

(iii) Some differences existed within the sample. Older people attached greater importance to getting equipment such as pads delivered on time, and being able to choose the gender of their assessor. Respondents in Bournemouth attached greater importance to the statements overall. Those rating their health as 'poor' attached greater importance to gender and assessment, being consulted about the service and being able to get into the building easily.

(iv) Around a third of respondents added comments, which tended to enlarge on the standard statements by allowing them to describe their experiences. No new service features important to respondents were revealed. The most frequent comments related to the prompt, appropriate and reliable care received by specialist nurses, and issues around treatment and pads.

(v) Most of the respondents had bladder problems, the most common were urgency, accidental wetting and frequency at night. Less than 10% had catheters. Less than half had bowel problems, mainly constipation and having to strain to have their bowels opened. With respect to service use, most had contact with specialist nurses, GPs and hospital consultants.

(vi) More than 80% of respondents felt that their condition impacted on their lives either 'moderately' or 'a lot'. The worst worry overall was about smelling or being embarrassed. For those where the impact was greatest, the ability to travel, work and have a social life were adversely affected. Bladder and bowel problems also had the greatest impact on those rating their health as 'poor', with the inability to do household tasks and normal activities predominant.

(vii) Final comments invited members to disclose how else their problem affected them. This revealed a range of physical and emotional problems, with 17 respondents having multipathological conditions. In addition, some were keen to elaborate on coping and adaptation strategies that enabled them to carry on living a normal life.

5 Commentary

The main purpose of this stage of the pilot project was to test further the relevance of the standard statements to a wider population group of older people and to isolate features that should be included or removed from the list. Additionally, the survey sought to isolate any differences between variables in the data, and to determine the sample characteristics for stage 3.

Although the response rate was 55% which could be considered low, it was slightly higher than is usually achieved in general health surveys to this age group (Burnside et al 1998). The fact that the sample was bias towards a certain age group, gender and cultural origin is however a weakness, although it was not possible to ascertain whether the sample was representative of all the users of the two continence services. It does however indicate the direction of the sampling framework for stage 3, in that men, those from ethnic minority groups and older people over 85 should be targeted. In all, there were very few differences in responses between the sites.

It was clear that most statements were important to respondents from both areas. Importance attached to service delivery issues relating to personal qualities of staff (training in specialism, friendliness and communication skills for example) was evident, which is a common finding in surveys across all age groups that seek opinions on aspects of service provision (McDonald & Langford 2000). In this study, this was also supported by the comments, which elaborated on the interpersonal and professional skills of the specialist staff. It must be recognised however that older people have a tendency to be supportive of services upon which they have a degree of dependency (Edwards & Staniszewska 2000). This does apply more to their evaluation of specific services, rather than seeking their general perceptions of abstract features of a service less directly connected to themselves, such as in this study.

It was of interest that, overall, respondents found choosing the gender of their assessor less important, but this was found to be more important among older people and those whose self-reported health status was poor. This finding may be due to the detailed nature of information required as conditions progress or become complicated with multiple co-morbidities. However, we do not know which gender respondents would favour, although a presumption could be made that same-sex assessors would be preferred in this age group.

The clear impact that the condition had on the lives of the respondents came through strongly in the data. This was not only statistically with around 80% being affected to some degree, but supported by the comments detailing significant limitations on everyday activities. It was of interest that the threats of embarrassment and odour were predominant concerns, which in turn resulted in social restrictions. The connections between potential social isolation and mental health are well documented (Callagan & Morrissey 1993), indicating the importance of screening and support in this area, especially those with poorer health status.

Conversely however, the statement concerned with contacting other sufferers for support was seen as least important overall. This may be due to the view that dwelling on one's problems and sharing the experiences of others does not appeal in all cases and can be unproductive (Edwards 2004). This view could in part be supported by the small number of comments made in this study, where respondents were keen to highlight coping mechanisms that permitted life to continue, despite severe inconvenience.

To conclude therefore, this phase of the pilot project takes the development of consumer-based clinical standards one step further. It provided an indication that the statements appear to be generally relevant to the sample group responding, across different age spans over 60 and sites.

6 Recommendations for Stage 3

There are two key recommendations from the findings to take forward into stage 3:

(i) Given that no statements were universally seen as unimportant, and that no new service features were identified, it is recommended that the statements remain the same for the next stage.

(ii) It is recommended that the sample group be purposefully selected with the assistance of staff at the site, targeting older men, ethnic minority groups and more frailer older people over 85. Particularly with the latter two groups, it is recognised that the inclusion of carers must be considered, either as joint interviewees or as main informants depending on the situation.

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Appendix 1: 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.***

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

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

Feel an urgent need to pass water ☐

Get up more than twice a night to pass water ☐

Have problems emptying your bladder ☐

Accidentally wet yourself ☐

Accidentally wet yourself if you laugh or cough ☐

Have a catheter ☐

Any others? Please describe them below. ☐

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

Often have an urgent need to open your bowels ☐

Have to strain to open your bowels ☐

Become constipated ☐

Accidentally loose control of your bowels ☐
If you have ticked this one, is it a) when you pass wind? ☐
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.

	Not at all	**Slightly**	**Moderately**	**A lot**
c) Does your problem affect your household tasks (cleaning etc)?	☐	☐	☐	☐
d) Does your problem affect your job or your normal activities outside the home?	☐	☐	☐	☐

	Not at all	**Slightly**	**Moderately**	**A lot**
e) Does your problem affect any physical activities like walking, running or sport?	☐	☐	☐	☐
f) Does your problem affect your ability to travel?	☐	☐	☐	☐
g) Does your problem limit your social life?	☐	☐	☐	☐
h) Does your problem limit your ability to see or visit friends?	☐	☐	☐	☐
i) Is it a problem having to change your underwear if it gets soiled?	☐	☐	☐	☐
j) Do you worry in case you smell?	☐	☐	☐	☐
k) Do you get embarrassed because of your problem?	☐	☐	☐	☐

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.

Appendix 2

Camden NHS
Primary Care Trust

Health **C**are of **O**lder **P**eople **P**rogramme
Continence **P**roject
Associate Director: Dr Adrian Wagg

Centre for **H**ealth **S**ervice **S**tudies
University of **K**ent at **C**anterbury
Research Fellow: Jenny Billings

Camden and **I**slington **C**ontinence **S**ervices
Senior Specialist Nurse

Dear

I would like to invite you to take part in a research study about continence. The title of this research is:

A study to involve older continence service users in the development of standards of care in continence services

Before you decide, it is important that you understand what the research is about and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you want to.

What is the research study about?
The staff who run the continence service want to make sure that they give the highest standards of care and treatment. They are developing a list of things that they feel are important to ensure the best care, but need your help in making sure that they have included everything that is important to you (and your carer if you have one).

If I want to take part, what do I have to do?
All you have to do is to fill out the questionnaire and return it to the researcher at the University of Kent within the next week in the envelope provided. There are four sections to the questionnaire and I would be grateful if you could complete all the sections. The first section has some statements in it about continence services and will help us get an idea of what you feel is important about a service. The

other three sections ask questions about your continence problem and your life. This information will give us a picture of you and help us to develop the service around the needs of the people who use us.

I would be particularly interested in any comments you may have about the continence service, so feel free to use the spaces provided. Please get someone to help you if you have difficulty.

I would like to reassure you that any information collected about you through the questionnaire will be anonymous and not be seen by staff who care for you

Do I have to take part?
It is entirely up to you whether or not to take part, but if you do not want to take part, this will not affect your care in any way. If you decide to take part but change your mind, you are free to do so, and this will also not affect your care.

If there is anything that is not clear or you would like some more information that will help you to fill in the questionnaire, please contact the researcher on the project, Jenny Billings, on this number 01227 823876.

Thank you for your help

Yours sincerely

Senior Specialist Nurse