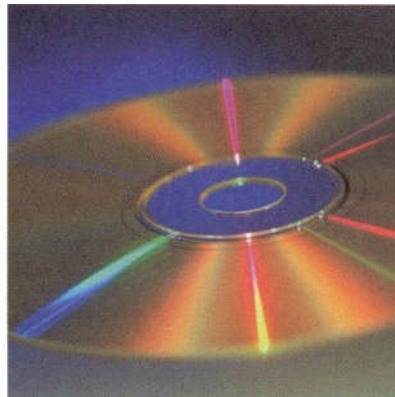


**Involving Older Users of
Continence Services in
Developing Standards of
Care: A Pilot Study**

Final Report on Stage 3



**Jenny Billings, Research Fellow
Patrick Brown, Research Assistant**

**Centre for Health Services Studies
University of Kent**

April 2006

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

Executive Summary, April 2006

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Introduction

The Clinical Effectiveness and Evaluation Unit of the Royal College of Physicians of London has sought to clarify a range of factors useful in indicating quality in the provision of continence services with a view to national audit. Whilst this process began by using various panels of national experts, it has been seen as important to involve the opinions, views and experiences of the users of continence services (DoH 2001).

With this aim, a three-stage project was enacted to involve, identify and incorporate the views of older service users in the development of standards of care. In stage 1, a questionnaire was developed with the assistance of users that set out a range of standards of care in continence services, blending user and professional views. It also contained a section that elicited health status, quality of life and continence problems. In stage 2, this questionnaire was piloted with 150 continence service users in two contrasting areas to measure degrees of importance attached to the standards statements and to determine their inclusiveness about how care should be delivered.

The report describes the third stage project which sought to identify the views of older service users not represented in the pilot survey with the aim of ascertaining completeness of standard statements. These were women over 85, men over 65, and frailer older people and their carers. The research took place in two sites; Camden and Islington PCT and Canterbury and Coastal PCT.

Method

The descriptive survey design used in the pilot survey was reapplied here as the basis of semi-structured interviews where further qualitative comments were elicited and recorded by the interviewer. The aim was to target a total of 80 older people, 40 in each site. The quantitative survey responses were analysed through descriptive statistics and the qualitative responses were themed through content analysis.

Summary of Key Findings

- Given our target of 80, the response rate was 58% (n=46). However, 599 people had to be contacted to achieve this. There were slightly more respondents from Camden and Islington - 54% (n=25) of the sample. The characteristics of the sample varied markedly between the

two areas. Female users made up 52% (n=11) of the sample in Canterbury and Coastal yet only 4% (n=1) for Camden and Islington; 26% (n=12) overall. 40% of the London-based sample were from different ethnic groups (n=11), and 5% (n=2) for the Canterbury and Coastal sample. The average age of the sample was 83 years (91 for women and 80 for men), indicating the project was successful in capturing the views of the very old.

- With respect to self-rated health, just over half the sample (54%) rated their health as 'good' or 'very good', with 26% rating themselves 'poor' or 'very poor'. 74% of the respondents were frail (dependent on others for care due to functional impairment). 19 participants took part in the study with the assistance of their carers.
- 16 of the 25 standard statements were seen as 'very important' by at least half the respondents. Features of particular importance related to privacy, communication between different agencies involved in the provision of continence services, and being assessed by a caring professional. Least important features for respondents related to being asked about their sex lives and being able to choose the gender of the person assessing them.
- Within the sample, older users were less likely to be interested in being asked how services could be improved in the future and if continence problems affected their sex lives. Older users were less likely to see aspects of provision as very important, though this difference was small. There were also subtle differences between the two sites. Those in Camden were less likely overall to rate standards as 'very important', whilst those in Canterbury seemed much more concerned about access than their London-based counterparts. This importance attached to access was also more common amongst frail users.
- More than half of the respondents felt that their condition impacted on their lives either 'moderately' or 'a lot'. Those rating their health as 'poor' were affected most. The biggest impact was on travel and worrying about smelling.
- A rich body of qualitative responses arose from the interviews. Comments made about the standards tended to focus around service experiences regarding access to expert advice and to pads. The importance of always seeing the same expert was also frequently stated. Maintaining dignity was a key feature, both from a user and carer perspective, and professional care was seen to be intrinsic to this. Other comments underlined the emotional and physical impact on those affected by continence problems and the complex nature of co-existing conditions. Key themes emerging included carer experiences, complex nature of problems, dignity, emotional problems, getting out and about and coping strategies.

Commentary

This study has provided some hitherto unrecorded insight into what service factors are important to this group and has interestingly revealed perspectives into both the complexity and simplicity of continence service provision. Complexity was revealed in the multi-pathological problems faced by the older, frailer respondents and their carers, and simplicity was evident in that providing the appropriate number of comfortable, absorbent pads is what most of these users see as the ultimate benchmark of a quality continence service.

Although the statements resonated with clients and reflected their experiences of service use, it must be recognised that respondents' experiences and day-to-day management of their conditions emphasised the relatively narrow service orientation of clinical standards. To this end, the user perspective is restricted to the boundaries of what is clinical and can be relatively easily measured.

The qualitative responses were an important aspect of the project. A predominant theme to emerge was that of maintaining dignity. The maintenance of dignity seemed paramount but easily eroded by a number of quite specific agents. This included the attitude, conduct and assessment skills of their professional contact, lack of gender-specific amenities, and ill-fitting pads. All of these factors were in turn connected to self-esteem, confidence and control, articulated not only by the users themselves, but witnessed by their carers.

The shortcomings must however be acknowledged. The very low response rate is a weakness of the study and impacts on the spread of opinions. Though perhaps predictable given the physical and mental frailty of many of those being contacted, further testing of the instrument would be needed. The method did though provide a more complete picture of the experiences of those who did respond, and included the views of carers.

Recommendations

- (i) Supplementary standard statements based on dealing with emotional issues should be developed and added to the tool; the following could be considered:
 - Having support to help reduce my anxieties and fears about my continence problem
 - Providing me with strategies that help me to cope with the condition
 - Being able to maintain my dignity and self esteem
- (ii) The complexity of users experiences should be acknowledged by further informative inquiry, so that quality care can be seen as provision which actually seeks to tackle such problems rather than merely satisfying a list of criteria. An exploration of the meaning of dignity and how it can more specifically be maintained in the

continence care setting would be a particular area for further research. Focusing on outcome rather than simply the inputs of the service may offer a more complete picture of quality.

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

Report on Stage 3 April 2006

1 Introduction

The Clinical Effectiveness and Evaluation Unit of the Royal College of Physicians of London has sought to clarify a range of factors useful in indicating quality in the provision of continence services with a view to national audit. Whilst this process began by using various panels of national experts, it has been seen as important to involve the opinions, views and experiences of the users of continence services (DoH 2001). Accordingly, it was crucial that these service users, with bladder and/or bowel continence problems, be targeted to help determine whether the indicators put forward by the expert panels are valid and adequate in seeking to define *quality* with respect to continence services.

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 groups of older patients not represented in the pilot survey and elicit their views and those of their carers.

This report provides the methodological approach and findings of **Stage 3** of the study, conducted in Canterbury & Coastal and Camden & Islington PCTs.

Stage 1 was completed in February 2004 and was concerned with the development of an initial draft questionnaire from a professional and user and carer perspective (see Billings 2004).

Stage 2, completed in April 2005, sought to test the standard statements further, to ascertain their importance for a wider population group of older users. A qualitative component asking for written comments sought to determine whether any standard statements needed to be removed or added. Stage 2 also looked to detect any differences between sites (the same two as in stage 1), ages and self-reported health status (see Billings et al 2005).

Stage 3, the final stage of the project, is concerned with incorporating the views of those groups under-represented in stages 1 and 2. This again used two contrasting areas: Camden & Islington and Canterbury & Coastal PCTs. The completion of this third and final stage completes the basis on which a wider national study may be undertaken.

2 Method

This stage, as with stage 2, used a descriptive survey design (see overview below), however there was a critical methodological difference in that rather than this being a postal questionnaire, an interviewer used the survey to conduct an interview. Burnside et al (1998) suggest that methods of choice for involving older people, and especially frail older people, should include those that entail some form of personal interaction, to ensure that questions are fully understood and to allow time for the exchange of ideas and thoughts.

This stage of the research study involved a change of site. Access to Camden and Islington PCT remained the same; however Bournemouth PCT was replaced with Canterbury and Coastal PCT, which has a similar demographic and geographic profile. Ethical approval was given by Camden and Islington LREC and by East Kent LREC for Canterbury & Coastal PCT.

2.1 Overview of questionnaire

The descriptive survey design that formed the basis of the interviews and was undergoing its second stage of piloting, had been developed in stage 1 of this project. This development process had initially been informed by the advice given by expert panels, but predominantly acted to modify and add to these original standard statements after a series of focus groups of users of continence services and their carers. This augmentation of meaningfulness (Billings 2005: 2) was then captured in a questionnaire.

Various issues such as measurement scaling (Burnside et al 1998) and consistency (Walker and Dewar 2001) were taken into account in order to enhance the accuracy of the responses by an older sample group and enable the measurement of value (Bowling 1997) through the standard statements of service provision. Equally, font size and limited demands on memory capacity were seen as important in minimizing anxiety (Dellefield and McDougall 1996), whilst deliberative encouragement of qualitative comments was vital at this pilot-stage in order to illuminate areas neglected by the standard statements. Section 3, looking at quality of life and is based on the validated King's Health Questionnaire (Kelleher 1997), has been constructed to capture the restrictions on daily life that continence problems may cause.

A number of demographic questions such as age, gender and ethnicity were asked to highlight where gaps might be occurring in the piloting process.

This framing of the questionnaire was applied in stage 2 (n=155) and given that no statements were universally seen as unimportant, and that no new service features were identified, the statements remained the same for this next stage (see appendix 1 for questionnaire).

2.2 Sample and Access

The aim was to target a sample of 40 older people and/or their carers in each site (n=80) with the assistance of staff at the continence services, using existing user databases and local knowledge of patients. Criteria for inclusion in both areas were those under-represented in stage 2:

- Frailer older people aged 85 and over. This refers to those people with functional impairment who are dependent upon others for personal care and for the purposes of this research, are living at home.
- Older men aged 65 and over living at home

With respect to definitions and measurement of frailty, with increasing life expectancy this has become a subject of much debate and its complexity has been revealed (Fisher 2005). This research has opted for a more loose interpretation focusing simply on levels of dependence and mobility, as suggested by Gill et al (2006).

The sample size was determined through discussion with local staff who have awareness of their patient group and are able to estimate numbers who fulfil the study criteria. The sample of 40 was stratified into two groups. It was anticipated that 10-15 frailer older people and/or their carers would be recruited (these will be largely women) and 25-30 older men. The involvement of carers was important to give insight into the views of users who have difficulty participating, or to include comments in a joint interview situation if assistance was required, if this was desired by the user.

Service users were accessed through the continence services database in each of the two PCTs. The approach was slightly different in each site according to the different ethical approval requirements and professional resource issues at each site. In the case of Camden and Islington, continence team staff assisted researchers by selecting users from their database who fulfilled the above criteria. This sample was then sent a pack containing an information letter (appendix 2), consent form (appendix 3) and a stamped addressed envelope. If the potential recruits wanted to take part, they were asked to return a signed consent form and provide contact details, whereupon the researcher would contact them directly to arrange an interview.

In Canterbury and Coastal PCT, the service users were contacted by continence team staff by telephone, to establish whether they wanted to take part or not. Those agreeing were then sent a pack containing the same information, consent form and SAE. This approach was subsequently deemed too time consuming for staff; as an alternative, a further sample of information/consent packs (n=65) were posted by the continence service staff.

2.3 Data collection approach and analysis

If the recipients of the packs completed and returned the consent form agreeing to take part, they were then contacted by telephone to arrange a suitable time for the interview to take place. The consent form gave the user the choice to be interviewed either face to face or by telephone. Providing older people with a choice of data collection methods, such as telephone interviews enabled people preferring less intrusive methods to take part (Robson 2002).

The survey schedule was followed in the same order with each respondent, with the various closed-questions being asked each time. The respondents were however given asked more open-ended questions at the end of each section to help elicit more expansive responses to their broader opinions and

experiences of both continence problems and services. This enabled the respondent to highlight issues of care and experience beyond those covered by the survey. Such comments, made in response to the open-ended questions, and indeed throughout the interview, were recorded verbatim by the interviewer and read back to the respondent to ensure accuracy (Flick 1998).

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.

3 Findings

The findings of this stage of the project are described below under the following headings:

- Sample characteristics
- Users' views about continence service features
- Users' descriptions of their continence problems
- Services used by the respondents
- Self-rated general health and impact of continence problems on daily life.
- Users comments on impact of continence on quality of life

3.1 Sample Characteristics

From a target sample of 80, 46 interviews were achieved giving a response rate of 58%. However, as indicated in Table 1, a total of 599 older people and/or their carers had to be contacted to achieve this, 492 in Camden and Islington PCT and 107 from Canterbury and Coastal PCT, of which only 7.7% actually took part.

Table 1: Responses from Canterbury & Coastal and Camden & Islington

	Canterbury & Coastal			Camden & Islington		
	Sampled	Responded	Response rate (total contacts)	Sampled	Responded	Response rate (total contacts)
Female		11		120	1	0.8%
Male		10		361	24	6.6%
Valid sample	107	21	19.6%	481	25	5.2%
Died	0			10		
Undelivered	0			1		
Total contacted	107			492		

NB total numbers of males and females contacted in Canterbury and Coastal not recorded

As a percentage of total contacts, numbers in the Camden & Islington area were much lower (5.2%) compared to Canterbury & Coastal (19.6%). This was perhaps influenced by a large section of the latter sample having been contacted by telephone by the continence team. However, the study was successful in recruiting more men (n=34) especially in Camden and Islington PCT, thus giving the overall study greater balance.

It was of concern that there was some sampling of people who had died, and this information was fed back to the continence team in Camden and Islington. There was no problem with either deaths or undelivered packs in Canterbury & Coastal as the users had been contacted by telephone immediately before being sent the consent packs.

Issues surrounding low response rate

The sample information is striking by its very low response rate and we were unable to achieve our target sample of 80. Inevitably, by its very nature, it is hard to explain the reasons for non-response, though from the experiences of the Canterbury & Coastal continence team who telephoned users, along with comments made by some of the users who seemed reticent to respond, certain tentative reasons can be put forward.

It was noted by the continence team that a significant number of those telephoned suffered from some sort of dementia and were therefore unable to understand the requests to take part in the research or became confused by this. Others were so hard of hearing as to make it impossible to get across the relevant information. It is feasible to suggest therefore that some of those in Camden & Islington who received the information directly through the post might have suffered similar problems. Even amongst those who did respond, there appeared to be certain confusion around the information provided. For example several did not understand what was meant by 'carer', making reference to a consultant or GP. Issues around capacity might also concern writing ability; a number of the responses were very hard to read and a few of those replying were apologetic and seemingly embarrassed by their handwriting. It is quite possible that there were others (without carers) who could not manage to adequately fill out their personal details.

Amongst those replying saying they did not want to take part were some who felt they were contacted too frequently by people asking their opinion and did not want to go through '*yet another*' questionnaire. There were also certain individuals who agreed to take part but seemed to think their opinion was not valid or of interest due to their age and therefore seemed reticent. Finally it is likely that there were many individuals who felt embarrassed to talk about their problems. This should be remembered when approaching the findings below; that especially with such a low response rate, it is likely that those most at ease with their incontinence and discussing it were more likely to respond.

Distribution

The distribution of responses by age was quite similar between the two areas, with the most common responders being users in their 80s (see table 2). There was a poorer response from people aged 90 and over in the Camden & Islington area compared to Canterbury & Coastal.

The absence of people age 65-69 in the Camden & Islington area should be noted when comparing results for the two areas. The mean age of respondents was 83, (91 for women and 80 for men). The average ages per site were similar – Canterbury and Coastal = 84, Camden and Islington = 83. The composition was somewhat different regarding gender. For the Canterbury cohort, the age range for men was 67-85 (mean=76) and for women 86-101 (mean=91) apart from one outlier, aged 78. In London, the range of the men was slightly wider at 71-94 (mean=82) and there was only one female respondent, aged 99.

As might be expected, the Canterbury and Coastal sample was ethnically much more homogenous with only one user not describing themselves as white British, being white Irish. In London, 10 (40%) respondents were not

white British, one being white Irish, two Black Caribbean and seven other white backgrounds, from various parts of Europe. One of these latter group of users could not speak English and their carer answered on their behalf.

As already mentioned in the methods section, the definition of frailty used was a user who is 'dependent on others for care due to functional impairment'. This was not asked directly, but rather ascertained during the interview. Practically speaking, the definition referred to people who, at the bare minimum, could not get out and about by themselves and so relied on someone to take them out. Often the dependence was greater than this and involved help in household matters, particularly changing of sheets, getting dressed along with more cognitive tasks such as remembering to take one's tablets. The proportion of frail users was roughly similar between sites, with approximately three quarters of respondents in both areas (Canterbury and Coastal = 76%, Camden and Islington = 72%) being held as frail.

Table 2: Number and characteristics of respondents per site

Characteristics	Canterbury& Coastal	Camden & Islington
Total participants	21	25
Age: minimum age	Men 65+. Women 85+	Men 65+. Women 85+
Age: number (%) age 65-69	2 (10%)	0 (0%)
number (%) age 70-79	6 (29%)	7 (28%)
number (%) age 80-89	8 (38%)	14 (56%)
number (%) age 90 +	5 (24%)	4 (16%)
Average age (range)	84 (67-101)	83
Average age of men (range)	76 (67-85)	82 (71-94)
Average age of women (range)	90 (78-101)**	99 (***)
Gender: number (%) female	11 (52%)	1 (4%)
Ethnic group: number (%) white: British	20 (95%)	15 (60%)
Health*: number (%) good/very good	11 (52%)	14 (56%)
Frailty: number (%) limited mobility	16 (76%)	18 (72%)
Number (%) of carers answering on user's behalf	4 (19%) (3 on behalf of women)	7 (28%) (all 7 on behalf of men)
Number (%) where carer answered alongside user	5 (24%) (3 alongside women)	3 (12%) (1 alongside a woman)

*Self-rated

**All but one were over 85

***Only one woman respondent

Due to such frailty, it was necessary in a number of cases for service users to consent to their carers answering on their behalf, or at least alongside them. Hence 11 of the 46 (4 in Canterbury, 7 in Camden) or 24% had carers answer on their behalf, with 8 (5 in Canterbury, 3 in Camden) or 17% answering with the help of the carer. From this latter niche, it became clear that the views and responses varied between that of the service user and the carer, especially in section 3 about how much continence affects one's life. Usually the user was likely to suggest a smaller impact at first than the carer. The response recorded by the interviewer was the final answer given by the user. Though only visible in a small number of cases, this tension ought to be noted when assessing responses. See also section 3.5.4 (i).

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 (17 out of 25) were deemed 'very important' by the majority of responders. See chart 1 for responses. It should be noted that it would be unusual for some of these aspects, for example being assessed in a private room, not to be seen as important, though they nonetheless offer a conception of essential basic standards.

3.2.1 Features considered very important

91% of service users thought it was very important to have an assessment in a private room. 'Having good channels of communication between all professionals who deal with my bladder/bowel condition' was also agreed to be imperative, as was 'being assessed by someone who is friendly, understanding and reassuring' (both 87%).

Other features deemed very important by over two thirds of respondents were:

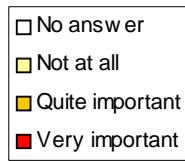
- Being able to have a full assessment of my problem if I mention it (85%)
- Having a service that can easily link me to specialists or other services (83%)
- Having equipment such as pads delivered on time to where I live (83%)
- Being able to choose from a full range of good quality, reliable, and properly fitting pads, knickers and other products irrespective of cost (83%)
- Getting regular updates about bladder and bowel conditions, services and equipment free of charge in a form I can understand (76%)
- Being able to fully understand my condition and what the future holds for me (74%)
- Whenever possible, being given a choice of treatments by continence specialists¹ (74%)
- Getting hold of a local expert for advice and or treatment when I need it (67%)
- Being involved in a full discussion about care and treatment face-to-face (67%)

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

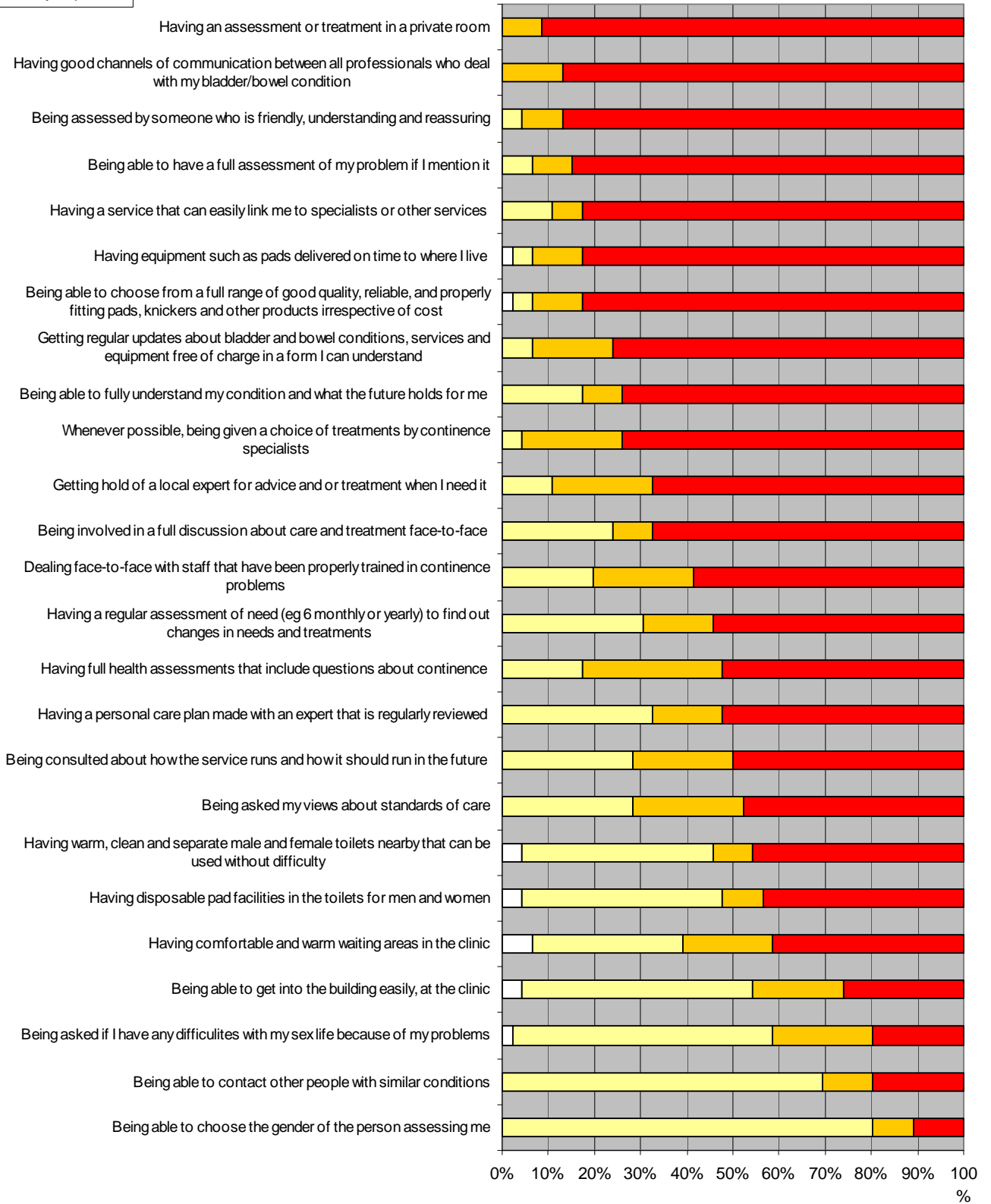
- Dealing face-to-face with continence staff (59%)
- Having a regular assessment of need (eg 6 monthly or yearly) (53%)
- Having full health assessments that include questions about continence (52%)
- Having a personal care plan made with an expert that is regularly reviewed (52%)
- Being consulted about how the service runs and how it should run in the future (50%)

¹ This was usually interpreted as a choice of pads, which was the only form of 'treatment' received by the vast majority of the users interviewed.

Chart 1: Most important aspects of services



Most important aspects of services (ranked by very important)



3.2.2 Features considered least important

The least important features were questions regarding choosing ‘the gender of person assessing me’ (80%), ‘being able to contact other people with similar conditions’ (70%), ‘being asked if I have any difficulties with my sex life because of my problems’ (57%) and ‘at the clinic, being able to get into the building easily’ (50%).

To clarify the nature of the responses to the latter two questions, being asked about one’s sex life tended to be seen as unimportant by the majority who explained that “*I have no sex life, so it wouldn’t be useful*” (C&I 41) or “*sex doesn’t interest us at our age*” (C&I 12). Conversely, those who were still sexually active held it as very important (20%) and suggested “*this aspect is not made enough of*” (C&C 04).

That only a quarter of users saw access as a very important issue might be explained in that those who were very frail (75%) were usually visited at home, whilst those who were more mobile did not see access as an issue.

3.2.3 Age differences

In general there were highly similar responses between those under 85 and those 85 and over. The tendency noted in stage 2 for the younger in the cohort to be more likely to see aspects of service provision as very important was perceptible, but not markedly so. There were two questions where differences in responses arose. The younger users were more likely to want to be asked about how provision could be improved in the future (64% saw this as very important compared with 33% for those 85 and over). They were also more likely to see it as important to be asked about their sex lives and how continence affected these (24% as opposed to 14%).

3.2.4 Differences between sites

There were also subtle differences in the importance attached to aspects of the service between the two sites. As with stage 2, service users in the Camden and Islington area attached lesser importance in general to the features the questionnaire asked about and were less likely to rate them as very important. The stage 2 report noted that these differences are generally consistent with the differences in age profile, in other words the relatively small differences could be due to age rather than geographical area. However, those living in Canterbury seemed much more concerned with access at the clinic than was the case in London, a contrast not noteworthy when comparing age.

3.2.6 Differences associated with frailty

The differences in degrees of importance attached to access at the clinic are more likely to be linked to frailty. Those who were frail (dependent on others for care due to functional impairment) were much more likely to see access as a very important aspect of service provision. In addition, they held the gender of the expert to be important, and were less likely to hold as important either warm/clean toilets or being asked about their sex life.

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.

In general, there was little evidence that deteriorating general health was related to the way people rated the importance of aspects of a continence service. However, there were five aspects where there was a noticeable difference in attitudes. People who rated their health 'poor' or 'very poor' attached greater importance to the following features:

- Being consulted about how the service runs and how it should be run in the future,
- Being able to get into the building easily, at the clinic,
- Being involved in a full discussion about care and treatment face-to-face.

Those describing their general health as 'good' or 'very good' attached greater importance to the following features.

- Being able to choose from a full range of continence pads
- Getting regular updates about bladder and bowel conditions, service and equipment

3.2.6 Comments

That the questionnaire was conducted as an interview facilitated the collection of many qualitative responses to the service-orientated questions of section 1. Such comments were partly in response to the final question, which explicitly asked for feedback on other issues relating to service provision, but equally were in response to many of the preceding questions, with respondents offering insights into their own experiences and opinions of care.

These comments about service provision were similar to those expressed in the stage 2 report and hence were grouped under similar headings – (i) [professional care](#) and (ii) [treatment issues](#). Within these, sub-sections have been defined to bring together certain predominating themes. C&C denotes respondents from the Canterbury and Coastal sample; C&I refers to Camden and Islington.

(i) Professional Care

Within this section, comments were separated further into three areas, namely [dignity, delivery and continuity of care](#), [communication between agencies](#) and [specialist nurse support](#).

Dignity: Dignity was a recurring issue, with a few suggesting because of age and life experience it did not pose a problem - "*when you've had babies you don't mind*" (C&C 26), though most agreeing that professional care should reflect that continence "*is a very sensitive issue*" (C&I 43).

Experiences of care in this regard were mixed. There were some contrasting views of experiences with district nurses. Some felt that:

*“district nurses are a bit insensitive in asking frank questions” (C&C 06)
“the district nurses are not very professional or confidential - they left messages on my answer-phone concerning my condition...” (C&I 31).*

Others noted more positively that:

“the [continence] nurses are excellent at putting you at your ease” (C&C29).

Delivery and continuity of care: Expertise and continuity were apparently crucial to the delivery of quality care:

“The issues I’m interested in are knowing what’s available and getting hold of nurses and that they are on top of the job” (C&C 34).

As seemed to be the case with dignity, the way care was delivered also varied to a certain degree on whether one saw a continence nurse or a district nurse, with the former apparently offering more satisfactory care:

“I have a lack of confidence in district nurses. Some seem rather bored...and I get told different things by different people” (C&I 31)

“The District Nurses don’t care about general state, like soiled sheets. They just check he’s medically ok and then head off (C&I 33).

“With district nurses you hold your breath...you don’t know if they will show up...you don’t get a name. [It would be nice to have] ...someone who knows what they are talking about. [I have had] very practical, good advice on sterileness [sic] etcetera. Some of the district nurses have very poor English, it is very hard to understand...very bad” (C&I 43).

“We are happy we have [continence nurse’s name] on hand to approach should we have any problems” (C&C 07).

As with this last comment, the ability to contact a particular, familiar individual, along with accessing all services at one phone number, was held as very important by many:

“It would be handy to have one number you could call for everything. Also it would be good to have the same person or if the record system meant they knew where you were in terms of problems. At the least, it would be nice to be able to put a face to a voice on the telephone” (C&I 31).

Communication between agencies: The desire that all continence agencies should be accessible from one number seemed to stem from a frustration of ringing around various numbers and not getting very far:

“One [TENA or the continence team] will play the other off.[With TENA] you’re lucky if you get through...you can’t get hold of them” (C&C 37).

“there are all these different bodies, we don't know who knows what!”
(C&C 36)

“Internal communication, one point of contact, that's the most important thing.. The irritation... I found, when initially UCH suggested wearing pads at night, nothing much happened, there was a lack of liaising between district nurses and continence services” (C&I 31).

This lack of co-ordination between primary services was reflected in links with more acute care:

“After prostate operations someone should be going to see the patient to follow up to see if they are ok. They wait for you to complain rather than follow up. I don't go unless I'm really bad” (C&C 08).

“In hospital they don't take any notice of incontinence problems” (C&C 27)

Though this was not always the case:

“If he hadn't been in hospital I don't think he would have got such effective pads” (C&C 36).

Specialist nurse support: Issues here tended to develop points already present in the standard statements, with competence and availability being paramount. Though whilst some were very happy with care provided through district nurses – *“the district nurses are pretty good”* (C&C 34) – many of the comments seem to challenge an assumption within the standard statements that these professionals were indeed experts...

“I was amazed at the district nurses, how little they knew...they are excellent women, very caring and efficient, but their knowledge is very shallow indeed.” (C&C 37)

“some of [the district nurses] look like they don't know what they're doing” (C&I 43)

“Specific knowledge is useful...district nurses don't know that much”
(C&I 21).

Whilst not everyone wants to contact an expert in an emergency, there was a general notion that quickly accessible advice was useful, especially at first. Yet such immediacy was often found wanting...

“These nurses are very good, but when you phone up you can't get hold of the nurses, it is at times when you need advice very frustrating”
(C&I 16)

“My experience is the ability to contact the relevant nurses is not always immediately there...When I've wanted some advice, I've got

through to answer phone which hasn't been followed up, its very bad'
(C&C 29)

The need for home visits was also underlined, either due to lack of mobility or the need to accurately assess the situation:

"They don't come and see what the situation really is" (C&C 25)

"When [the continence team] rang, my mum [who has Alzheimer's] told them she wasn't incontinent when in fact she is" (C&C 46)

There were also a number of users who had never seen any expert or felt neglected:

"I've never been visited by anyone to do with continence" (C&I 33)

"They don't check on you. If you want something you have to chase them" (C&C 35)

(ii) Treatment issues

Comments were subdivided into *resource quality/access issues*, *local service*, and *product and treatment information needs*.

Resource quality/access issues: For the majority of users, the role of continence services was chiefly the provision of pads. Accordingly much of the users comments were in relation to pads, particularly in their utility and comfort as well as the quantity supplied.

Attitudes towards the pads were mixed:

"I want to tell them how useless these bloody [pads] are...we need better designed pads" (C&I 21)

"I think it is pretty good actually. There are so many different pads for different situations" (C&I 17)

"They are very good these pads. I can't believe how much they hold. I don't think I'd be able to do anything or go anywhere without them except sit on the potty all day" (C&C 02)

"The previous pads were better [than TENA], these ones don't last as long" (C&C 07)

Many, especially male users, found the pads insufficient or not fitting correctly:

"The equipment is not designed with men in mind, they can't supply them as they're too expensive. The pads leak as they are the wrong shape for men... Women's shaped pads slip" (C&C 06).

"I have asked for change of model, size or shape of pad. The new supplier [TENA] don't make them wide enough" (C&C 34)

“She finds [the pads] very uncomfortable and the tightness around the crotch. The [most absorbent type of] pads are often overflowing in the morning” (C&C 37)

Issues to do with comfort also had negative consequences of a dermatological nature:

“...tell them the pads rub a bit. Today I discovered one side is bleeding because of the rubbing” (C&I 38)

“[The pads are] not very comfortable... they rub, it hurts my skin...my skin is like paper due to steroids so the pads really irritate me” (C&C 26)

Access to pads was another common issue of discussion, with many complaining of an apparent rationing, whilst conversely even more described an over-supply:

“The pads don’t last, there aren’t enough” (C&C 25)

“The district nurses ring every two months and there is a pressure to stop using the pads, as though they would rather not give them to us because of the cost” (C&C 36)

One carer (C&C 37) even had the impression that the only reason the continence service rang was to see if the user had died so they could stop supplying pads. Others had far too many pads:

“I always have too many pads” (C&I 30)

“The pads came, and they came and they came and they didn’t stop!” (C&C 43)

In addition to pads, the provision of sheets was also at issue. Several carers and users noted the inconvenience and cost of washing that accompanies continence problems. Whilst two (C&I=1, C&C =1) noted that they were being supplied with plastic sheets, at least four others (C&I=2, C&C=2) said these would be invaluable:

“Sheets are very important, the current ones are useless...not had any for a while” (C&C 24)

“I would like plastic or waterproof sheets” (C&I 12)

Local services: Other local service provision was discussed in terms of clinical waste disposal. With several users across both areas noting they had problems disposing hygienically of pads:

“Disposing of pads is a bit difficult. I wrap them up in newspaper and put them in the dustbins. I would like to know about clinical waste” (C&C 01)

In Canterbury at least, such a service is available, though apparently this is not widely advertised:

“I use the clinical waste disposal service from Canterbury City Council (C&C 34)

Waste disposal concerns included other issues as well:

“Disposing of colostomy bags very difficult when away from home” (C&C 34)

“[The quantity and lack of biodegradability] is a problem mentally for me. I am very aware of the environment and I hate it” (C&I 39)

Product and treatment information needs: As well as being well informed of what products (mainly pads) were available, other concerns included:

“I think you should be told if certain products you're used to using are going to stop being supplied cos it can have quite a big impact” (C&C 34)

With regards to products not supplied such as water-proof car-set covers:

“I had to do a lot of ringing around and the prices are much cheaper by mail order than from disability shops. A list of useful numbers or contacts would be helpful” (C&C 36)

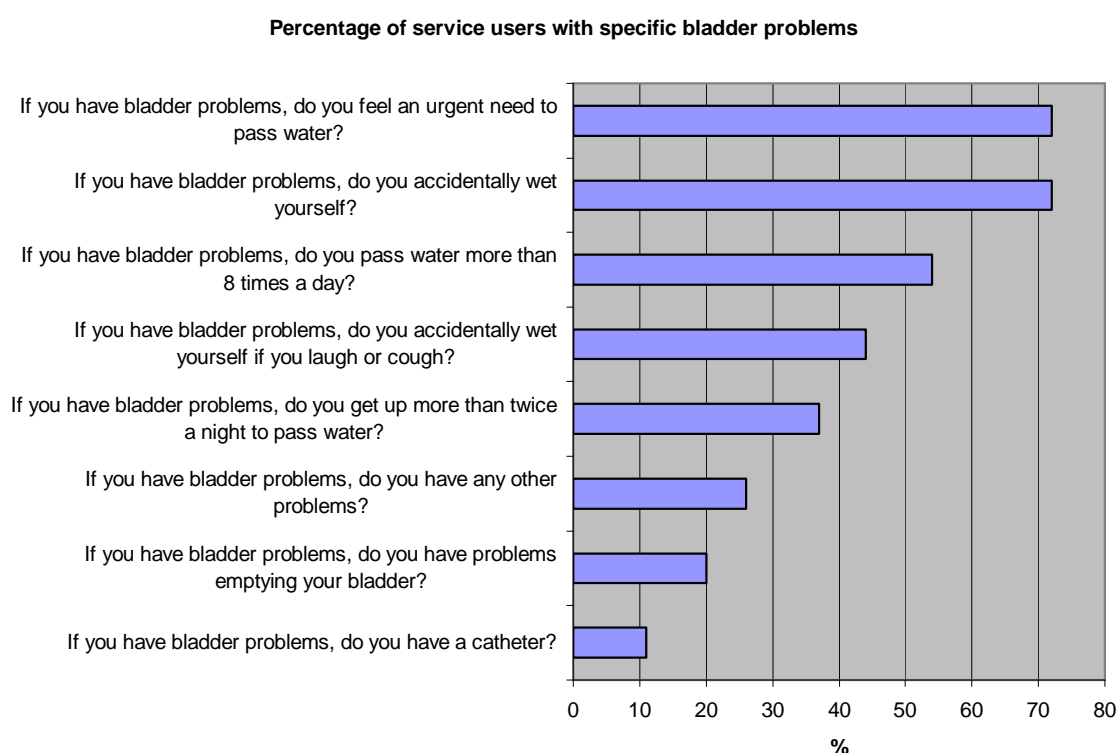
3.3 Users' descriptions of their continence problems

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. 100% of those interviewed described having bladder problems whilst 63% reported bowel problems as well.

3.3.1 Bladder problems

The questionnaire asked questions on seven specific bladder problems, also allowing for other problems to be mentioned. Problems most commonly experienced were related to urgency (72%), accidental wetting (72%), frequency (54%), stress incontinence (44%) and nocturia (37%) (see chart 2).

Chart 2: Percentage of users with specific bladder problems



3.3.2 Comments about bladder problems

The comments in this section mainly expanded upon the list of problems mentioned above. Other bladder problems that respondents mentioned were amenable to quantification in the table below. Whilst some of these may appear to be unrelated to specific bladder dysfunction (particularly the last two), these were included due to their being seen as 'bladder problems' by the respondents. It is important to recognise such perceptions of incontinence as well as to highlight the complexity of the problem and the way it is compounded by issues surrounding mental and physical capacity that are more common to the age-range of the cohort (see table 3 overleaf).

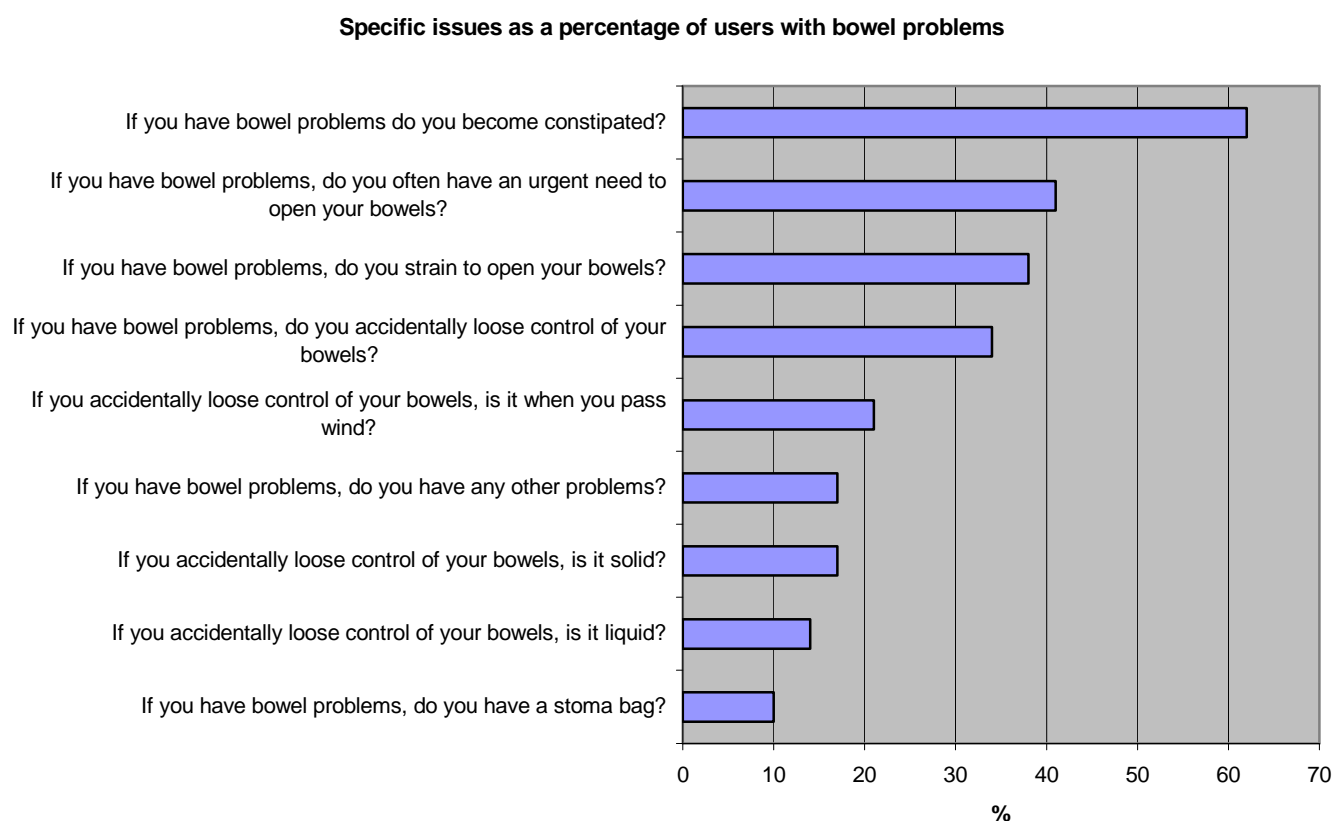
3.3.3 Bowel problems

The questions about bowel problems applied to almost two thirds of the sample (63%). Most common was constipation (62% of those with bowel problems and 39% of all service users). 41% of those with bowel problems complained of having an urgent need to open the bowels and 38% of having to strain. Other issues affecting people with bowel problems included many who reported accidentally losing control of the bowels (34%), two thirds of these (21% of those with bowel problems) said that this was linked to passing wind. (See chart 3 overleaf).

Table 3: Other bladder problems

Bladder problem	Canterbury	Camden	Total
Constant leakage	2	4	6
Night-time bed-wetting	2	2	4
Sneezing inducing incontinence	2	1	3
Skin rash/irritation from urine/pads		3	3
Sleep disruption due to incontinence	2		2
Irregular flow	1	1	2
Problem worsens due to lack of sleep	1		1
Problem worsens due to depression		1	1
Seepage from super-pubic catheter	1		1
Loss of bladder control after activity	1		1
Loss of bladder control from standing up		1	1
Urine contains blood		1	1
Problems increased by use of diuretic		1	1
Lack of sensation around bladder		1	1
Alzheimer's impairs awareness of bladder		1	1
Catheter induced bladder infections		1	1
Cystitis/infections		1	1
Problems cleaning up after one-self due to disability	1		1
Physical injuries from getting up in the night and falling over		1	1
Total	13	20	33

Chart 3: Specific issues as a percentage of users with bowel problems



3.3.4 Comments about bowel problems

There were fewer comments about other problems than was the case with bladder continence, 10 in total. Again, much of this surrounded the influence of other conditions, such as more developed Alzheimer's (n=3) which meant the users lacked the capacity to realise they were to need to go to the toilet and hence - "...there is no pattern, we just clean him as we find him. He goes whenever" (C&I 39).

Others (n=2) lacked the physical capacity either to access toilets or to clear up sufficiently afterwards, one of these was linked to Parkinson's - "*It was a big problem when I was weaker. Getting changed is hard too, and varies due to the Parkinson's*" (C&C 36).

Two carers noted their partners had constant leakage all the time, one due to an operation - "*His anus was operated on and since then there is a permanent flow*" (C&I 17).

Another user dealt with such a problem via a loop colostomy bag but needed pads to deal with seepage. A number of comments were made in relation to medication such as *Senokot* or *Movicol* to combat constipation.

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 (67%), with many also using GP (56%). Almost half (46%) were in contact with a district nurse with regards to continence and many, mainly post-cancer, saw a hospital consultant (39%).

9% had spoken to a practice nurse, 4% to a physiotherapist whilst one person (2%) had been helped by an occupational therapist.

Several users (15%) had been seen by another type of service. One each had seen their 'paid carer', a Parkinson's nurse, an expert from a continence charity, a stoma nurse, a Camden carers' support nurse and a post-burglary support nurse employed by Islington PCT.

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.

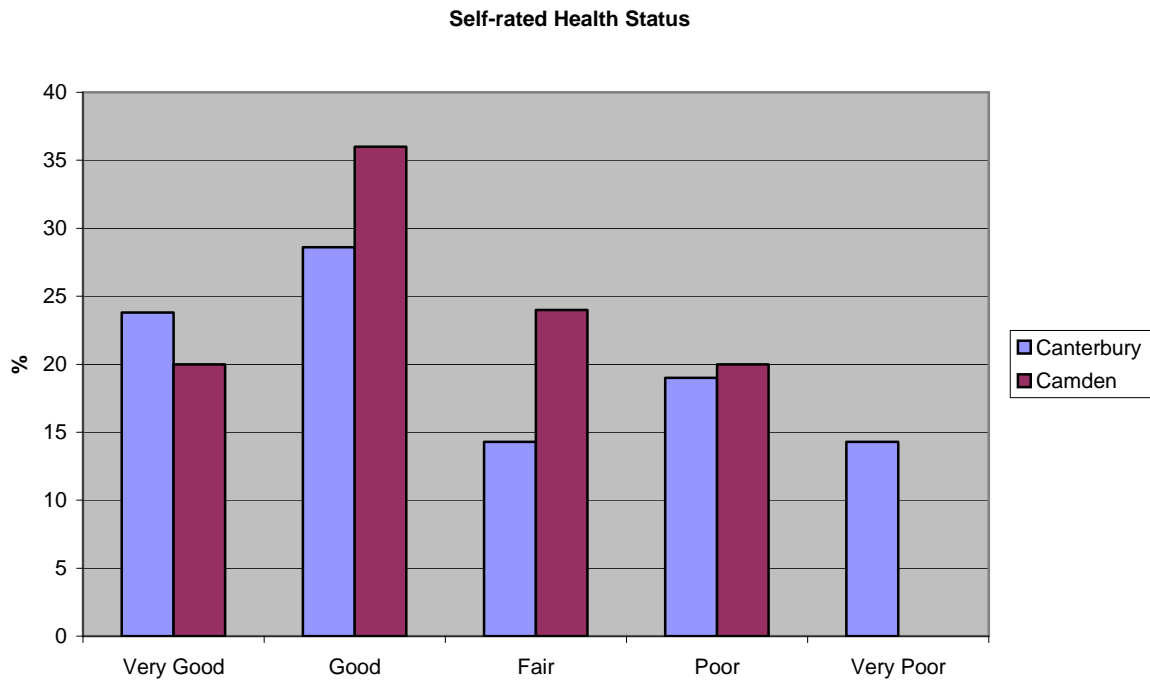
3.5.1 Self-rated health status

Just over a half (54%) said their health was good, or very good, 20% said it was fair and 26% 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 Camden & Islington appeared to rate their health better than those in Canterbury, with nobody in the former area describing their health as very poor. As is always the case with self-rated health, it is important to acknowledge that general demeanour

and feelings on the day can have an impact. Hence a wheelchair-bound lady aged over one hundred with both impaired vision and hearing described her health as “...good considering”, whilst a carer pointed out – “...it depends on what time of day you’re asking me, whether I’m frazzled or not...” (C&C 46).

A handful of respondents asked if this question was referring to physical or mental health, which suggests there is a case for differentiation in future studies.

Chart 4: Self-rated Health Status



3.5.2 Impact on daily life

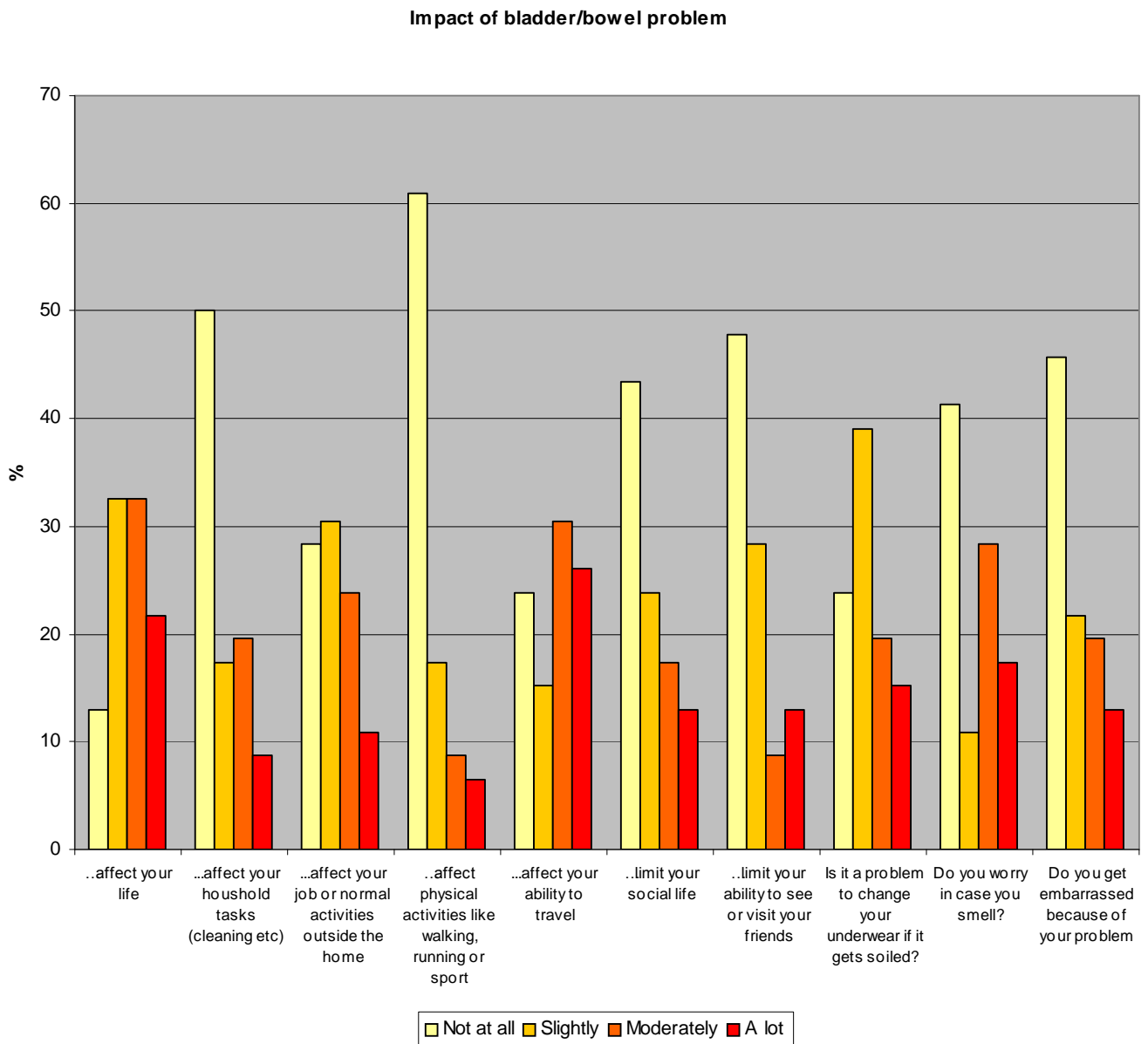
When asked a broad-ranging question about how much their problem affected aspects of their lives, nearly a quarter (22%) said it affected them a lot. Just over half (55%) said it affected them at least moderately, leaving a third (33%) slightly affected and 13% saying that it did not affect their lives at all. Whilst these figures suggest a lesser impact on life in comparison to stage 2 of the research, it would be unwise to link this to lower expectations of life quality held by the older cohort of stage 3. When splitting stage 3 respondents between those 85 and over and those younger, the older group report a slightly heightened impact on life (57% a lot or moderately) with 14% noting no impact at all.

When asking about the impact on specific aspects of on daily life, the worst was a limiting of ability to travel (26% were affected a lot) or worrying about smell (17% worried a lot). The other problems affected between 7-15% of people a lot (see table 4 and chart 5).

Table 4: Impact of bladder/bowel problems on daily life

Impact of bladder/bowel problem				
How much does your problem...	Not at all	Slightly	Moderately	A lot
...affect your life	13%	33%	33%	22%
...affect your household tasks (cleaning etc)	50%	17%	20%	9%
...affect your job or your normal activities outside the home	28%	30%	24%	11%
...affect physical activities like walking, running or sport	61%	17%	9%	7%
...affect your ability to travel	24%	15%	30%	26%
...limit your social life	44%	24%	17%	13%
...limit your ability to see or visit your friends	48%	28%	9%	13%
Is it a problem to change your underwear if it gets soiled	24%	39%	20%	15%
Do you worry in case you smell	41%	11%	28%	17%
Do you get embarrassed because of your problem	46%	22%	20%	13%

Chart 5: Impact of bladder/bowel problems on daily life



Many respondents were not affected at all with respect to physical activity (61%) or household tasks (50%). Often this was because respondents were too frail to indulge in such activities regardless of continence problems. Similarly, when asked how much continence problems limited their social life, many replied – “*Very few of my friends are still alive - I don't go out a great deal*” or “*you don't have a social life at my age*” (C&I 16). Hence when ability to take part in activities is diminished anyway, continence is described as being less effectual.

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

- affects ability to travel (56%),
- affects life (55%),
- worries in case smell (45%),
- affects job or normal activities outside the home (35%),
- a problem having to change underwear if it gets soiled (35%),
- get embarrassed because of problem (33%),
- limits social life (30%),
- affects household tasks (cleaning etc) (29%),
- limits ability to see or visit friends (22%),
- affects any physical activities like walking, running (16%).

3.5.3 Impact and self-rated health status

Although numbers are small, some interesting features emerge that parallel stage 2 findings. Apart from impact on physical exercise which affected very few, regardless of category; those in very good health reported the lowest impact (10% or fewer affected a lot) whereas those with poor or very poor health around 11-66% 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	10%	13%	0%	55%	67%
Q3C affects household tasks (cleaning etc) a lot	0%	13%	0%	11%	33%
Q3D affects job or normal activities outside the home a lot	0%	13%	0%	22%	33%
Q3E affects any physical activities like walking, running or sport a lot	0%	0%	0%	33%	0%
Q3F affects ability to travel a lot	0%	33%	0%	55%	67%
Q3G limits social life a lot	0%	0%	0%	44%	67%
Q3H limits ability to see or visit friends a lot	0%	7%	0%	33%	67%
Q3I a problem having to change underwear if it gets soiled a lot	0%	13%	11%	33%	33%
Q3J worries in case smell a lot	10%	20%	11%	22%	33%
Q3K get embarrassed because of problem a lot	0%	13%	11%	11%	67%

3.5.4 Comments

In this final section, respondents were invited to comment on how else their problem affected them. It provided a wide range of comments looking at health, lifestyle and resource issues. It gave the opportunity for respondents to elaborate on their experiences and as with the stage 2 report, many respondents gave examples of strategies they have developed that helped them to lead as normal a life as possible.

Sub categories in this section are *(i) carer experiences, (ii) complex nature of problems, (iii) dignity, (iv) emotional problems, (v) getting out and about and (vi) coping strategies.*

(i) Carer experiences

Comments made by carers with specific regard to their own role covered a wide range of topics but three key themes seemed to emerge. The first theme illustrates the difficulties to do with a loss of dignity in having to be cared for, as these quotes demonstrate:

“It was a real humiliation at first. Oh, terribly embarrassed at the beginning - we almost fell out about it. She was so angry and upset; really angry and upset” (C&C 03)

“She found it hard at first when I had to start changing her but now she just takes it in her stride” (C&I 10)

“He has Parkinson’s so he can’t clean up after himself. He is faecally [sic] incontinent and has problems getting to the toilet in time. He would fall over getting up at night but now the pads are better so he doesn’t have to get up so much. Accidents help him realise his condition. At first he would say ‘I want to throw myself under a bus’. He was very independent so it was hard for him to accept help... He says ‘They have to bear me’... He feels depressed about it - he says ‘what is the purpose of my life from now on?’” (C&I 17)

Secondly, there appeared to be a contrast between different levels of awareness of the continence problem between the user and the carer:

“He doesn’t have a sense of smell but he gets upset when told about it” (C&I 17)

“My dad doesn’t like to admit he’s wet himself... He has a bad sense of smell but it bothers me...he doesn’t notice” (C&I 21)

This also related to information needs:

“It can be very frightening for elderly people to know its getting worse... As a carer, I would want to know - the carer should be kept in the picture” (C&C 37)

“I would like some advice on changing pads. I always end up tearing them... I would like 30 minutes being shown how to change her” (C&I 10).

Thirdly, the effort and strains of caring came through strongly, as did the restrictions on the carer's own sense of independence:

"I worry about my own health as I have to look after my wife...I can't leave her on her own you see" (C&C 25)

"It used to affect me a lot more when we went out, he would open his bowels and then we had to go home straight away" (C&I 39)

"If I go out then I have to leave notes all over the house to remind her to go to the loo [due to Alzheimer's]" (C&C 46)

"I joined a carers' group but James doesn't like me being away too long" (C&I 33)

(ii) Complex nature of problems

Many of the users' problems were made more complex by other issues surrounding physical mobility and mental capacity. These co-existing conditions often accentuated the difficulties associated with incontinence. It should be noted too that in describing their problems, often there was no distinction made between specific continence and other issues, but rather they seemed to be perceived as one large and complex problem:

"Medicine for cancer causes constipation and diarrhoea... As you get older you can't concentrate and you don't think about such things" (C&I 16)

"The main issue is clearing up after going to the loo... It is exhausting just getting to there, and I can't get there quick enough [due to bronchitis, asthma, obesity etc]. I get impatient with myself" (C&C 05)

"I had radiotherapy after prostate cancer...twice. Since then my sex life has been greatly curtailed" (C&C 04)

(iii) Dignity

The multi-pathology noted above often led to a lesser ability to cope with continence problems and correspondingly dignity is adversely affected. Examples of this are listed below along with more general comments as to how dignity is compromised by continence problems, wearing pads and other issues:

These comments relate to odour; concerns about this have been a recurrent theme throughout this project:

"I feel so embarrassed cos I know I'm getting all wet. I really worry about being smelly. I try to keep as clean as possible but you can't help it sometimes. It affects my confidence quite bit. I get very nervous about what might happen" (C&C 23)

"Wetting the bed upset me more than anything, being a smelly old woman" (C&C 27)

"I was embarrassed at first, since then all dignity goes out the window... I'm terribly afraid of attractive nurses... I'm conscious of [the smell]. There was a case recently where the bus driver threw someone of the bus... I'm afraid of being a dirty old man" (C&I 416)

For some, this troubled their partners more:

"It affects my wife who is embarrassed about the pads so it affects her more than me" (C&C 11)

Some respondents were also keen to keep pads hidden and had a fear of discovery:

"The only thing is I hope folks don't know I'm wearing [the pads]" (C&C 26)

"I don't like anyone seeing them...the nappies. The worst thing is when I have to undress in front of people, at the osteopath, having sex, at the gym..." (C&I 18)

Describing pads as 'nappies' like this last respondent was a frequent occurrence, which seemed to add to the loss of dignity for some respondents and infantilise their situation. This respondent makes a suggestion to overcome the problem:

"It would be nice if they designed the pads to look a bit more like underwear, with a floral print or something... rather than now they look like nappies!" (C&I 10).

Whilst issues linked to continence itself may be hard to rectify, other issues also impacted on dignity...

"Having to trek around with bags full of wet pads...he almost didn't want to go anywhere because of it. I had to take a suitcase full of pads and I had to get special clearance for extra-luggage" (C&C 36)

"The waiting facilities at K&C are pathetic. It is really just a little bay out of a corridor...and one feels absolutely depressing...awful" (C&C 29)

(iv) Emotional problems

Linked into this loss of dignity were a number of more general comments made in regard to user's emotional state, experienced as a consequence of the physical condition. It was clear that considerable frustrations were experienced by some respondents and witnessed by their carers, creating anxiety and stress:

"He gets very frustrated, angry and upset about being so helpless" (C&C 40)

"There are times when I don't feel I can carry on much longer. After mishaps when you have to change everything...they don't come and find out what the needs are" (C&C 25)

"I really live from month to month hoping that nothing bad happens"
(C&C 28)

"A cough or sneeze is fatal... It's terrible" (C&C 26)

There was also frustration at the limiting affect continence has on quality of life:

"This is getting me down. Especially as I can be up 8 times a night. Of course the next day you feel absolutely gone... It irritates as I can't stop it and it seems that no one else can" (C&C 35)

(v) Acceptance and stoicism

For many respondents, the frustrations and difficulties of continence problems were accepted and linked to a certain inevitability of old age. There was a fair degree of stoicism in their attitudes towards their conditions:

"I just accept it as part of old age. Different services are immaterial"
(C&C 09)

"You just deal with it and accept it at 90 years old" (C&C 03)

"One gets used to it" (C&C 29)

This was often linked to wearing pads, and sought comfort in sharing experiences with others in the same situation:

"It's a pest having to wear pads, but there you go, I've got used to it"
(C&I 18)

"I've got used to the mental embarrassment of wearing pads. Certainly with one's contemporaries it is not a problem. It is better now than it was, as there is much more openness about these things. I've got used to it, one gets used to anything" (C&C 29)

Others suffering from multi-pathology were less frustrated as they were able to put the continence problem in a comparative perspective:

"Its just a bit of a nuisance... I took it philosophically, I was happy they caught my cancer before it spread outside the bladder so I think it is a very small price to pay" (C&I 20)

"Compared with the overall picture it isn't that significant... I'm lucky to be alive" (C&I 16)

(vi) Getting out and about

Difficulties travelling and enjoying a social life were very clear in this stage of the project, and have been a feature throughout the study. Comments pointed to the impact of continence on personal freedom and independence, highlighting fear and tension once more:

"It's a damn nuisance. I can't go shopping...unless I run in and out like a yo-yo, I wouldn't wish it on anyone" (C&I 41)

"We can't go out much at all now. And my wife can't go either...we can't go to the theatre" (C&C 35)

"It's terrible, if we go out to a restaurant for a meal you have to make sure there is a loo which can take the wheel chair" (C&C 25)

Preparation for journeys are paramount:

"I'm scared, I always take a spare pad and pants everywhere I go" (C&C 27)

"I can't go anywhere unless I know exactly where I am going and what the facilities are" (C&C 35)

"It takes for hours after I get up until I'm ok...can't go out for long. I always like to know where there's a toilet" (C&C 26)

(vi) Coping strategies

As much as continence can have a significant impact on users, most talked about coping strategies to minimise this effect. The theme of 'planning' and being prepared is taken up here once more:

"I just always have pads in my handbag" (C&C 02)

"It's not too bad, you just have to plan by taking supplies and it can be difficult when disposing of things" (C&C 34)

"I have to be very careful about how I prepare to go out. Make sure there is a toilet near by to be on the safe side. Sometimes just stumbling going down a curb brings it on" (C&C 23)

"Sometimes, you think "why didn't I think of that 3 years ago?"... you learn a new routine... you organise the bedroom... there is quite a lot of routine attached to it" (C&C 34)

4 Summary of Key Points

The following provides a summary of the main findings:

- (i) Given our target of 80, the response rate was (n=46) 58%. However, 599 people had to be contacted to achieve this, of which only 7.7% actually took part. There were slightly more respondents from Camden and Islington (n=25), 54% of the sample. The characteristics of the sample varied markedly between the two areas. Female users made up 52% (n=11) of the sample in Canterbury and Coastal yet only 4% (n=1) for Camden and Islington; 26% (n=12) overall. 40% of the London-based sample were not of 'white: British' ethnicity (n=11), this figure was only 5% (n=2) for the Canterbury and Coastal sample. The two areas were much more similar in regards to self-rated health and frailty. Just over half the sample (54%) rated their health as 'good' or 'very good', with 26% rating themselves 'poor' or 'very poor'. 74% of the respondents were frail (dependent on others for care due to functional impairment). 4 (19%) of the Canterbury sample consented for a carer to answer on their behalf, 5 (24%) took part in the interview alongside their carer. For Camden and Islington, 7 (28%) had carers answer for them whilst 3 (12%) answered with the carer.
- (ii) With respect to the standard statements, the majority (16 of 25) were seen as 'very important' by at least half the respondents. Features of particular importance related to privacy, communication between different agencies involved in the provision of continence services, and being assessed by a caring professional. Least important features for respondents related to being asked about their sex lives and being able to choose the gender of the person assessing them.
- (iii) Some differences existed within the sample. Older users were less likely to be interested in being asked how services could be improved in the future and if continence problems affected their sex lives. Overall, the older users were less likely to see aspects of provision as very important, though this difference was small. There were also subtle differences between the two sites. Those in Camden were less likely overall to rate standards as 'very important', whilst those in Canterbury seemed much more concerned about access than their London-based counterparts. This importance attached to access was also more common amongst frail users.
- (iv) Comments made about the standards tended to focus around service experiences regarding access to expert advice and to pads. The importance of always seeing the same expert was also frequently stated. Maintaining dignity was a key feature, both from a user and carer perspective, and professional care was seen to be intrinsic to this.

- (v) All of the respondents had bladder problems, the most common of which were urgency, accidental wetting and frequency during the day. Other bladder problems included constant leakage and skin irritation from urine soaked pads. Almost two thirds also had bowel problems, mainly linked to constipation or urgency. With respect to service use, most had contact with specialist nurses, GPs, District Nurses and hospital consultants.
- (vi) More than half of the respondents felt that their condition impacted on their lives either 'moderately' or 'a lot'. The biggest impact was on travel and worrying about smelling. Bladder and bowel problems also had the greatest impact on those rating their health as 'poor', with the inability to travel and socialise predominant.
- (vii) A rich body of qualitative responses arose from this final section on impact. These underlined the emotional and physical impact on those affected by continence problems and the complex nature of multi-pathologies. Key themes emerging included carer experiences, complex nature of problems, dignity, emotional problems, getting out and about and coping strategies.

5 Comparison with stage 2

Stage 2 was, quantitatively speaking, clearly a larger-scale project (n=155 as opposed to 46) and therefore, particularly due to the small numbers involved in stage 3, direct comparisons and statistically significant conclusions cannot be made. However, a number of tentative conjectures can be offered, based both on the qualitative difference in sample as well as the more interactive methodological approach.

5.1 Differences based on sample

Although the sampling for stage 3 deliberately included more men and frail, elderly adults, the majority of the findings acted to reaffirm many of the findings of stage 2, particularly in regard to the standard statements.

Whilst 15 of the 25 statements were held as very important by at least half of the stage 2 respondents, the users interviewed in stage 3 saw 17 in this light. Peculiarly, younger members of the sample were more likely to see aspects of service provision as 'very important'. Stage 3 respondents, frailer and older overall, were more likely to describe standard statements as 'very important'; 12 statements were held to be 'very important' by at least two thirds stage 3 respondents compared with 5 statements in stage 2. Generally, the same statements were prioritised in both studies, though the notion of privacy seemed more important to the stage 3 cohort.

The aspects held as least important by service users were highly similar for both stages. Yet it ought to be noted that older/frailer users were more likely to see access to the site as an important issue, although many of the frailest assumed they would be visited at home. Equally, whilst the overall number of respondents in this predominantly (74%) male sample saw it as unimportant to be asked about continence problems affecting their sex lives, those that did see it as very important were younger men.

Overall, bladder problems affected the older, frailer and predominantly male respondents of stage 3 only slightly more. The proportionalities of certain problems were again similar, though with the frailer/older group less likely to get up at night (probably due to lack of mobility) and more likely to be troubled by going during the day, or by accidentally wetting themselves.

Of those affected by bowel problems, there were no notable differences between respondents in the two stages apart from those in stage 3 being more likely to urgently need to open their bowels.

Though the respondents in stage 3 were older and frailer, they were more likely to rate their health as very good, though also slightly more likely to see their health as very poor. They also reported themselves as being less affected by continence in their daily lives, physical activity, often because they had less active lives regardless of continence. They did see travel as being more affected by continence than those surveyed in stage 2, were more likely to worry about smell but less likely to be embarrassed, perhaps as they saw it as unavoidable at their age.

5.2 Differences based on method

That interviews rather than a postal-survey formed the basis of the methodological approach of stage 3 meant that a great deal more qualitative material was gathered. That this was done in an interactive setting allowed the elucidation of a range of issues which stage 2 was not equipped to open up.

Although one of the PCT continence services remained the same, there seems to be a certain degree of variation in views aired between the two stages, with stage 3 eliciting many more negative views regarding the standards of care, particularly in respect to Camden and Islington. It is possible to infer that it is the opportunity to speak with an interviewer face-to-face that encourages a more open, perhaps more honest, account of users' opinions of the services.

Moreover, whilst stage 2 showed patients expressing a key interest in the provision of pads, the findings of stage 3 highlight much more clearly that for the large majority of respondents, the provision of pads *is* the continence service. A certain number had not been visited at all by any specialist yet as long as they received pads of good quality, in appropriate quantity, were very satisfied. The response highlighted the complexity of what makes a good pad, such as absorbency, lack of skin irritation, non-nappy-like appearance and fit. This latter quality was found lacking by many of the male respondents, who felt that pads were not designed with their anatomy in mind.

Finally, the accounts given in regards to life quality shed much light on the physical, mental and emotional struggle which those with continence problems and their carers face. These were suggested to an extent in stage 2 but came across all the more forcefully in stage 3, again perhaps due to respondents opening up more fully to a person than when simply filling out a questionnaire form. Though differences may also be linked to the characteristics of an older, frailer sample and the complexities of the problems they face. In the small number of cases where service user and carer were interviewed together, a variance in response between the two was clearly perceptible, with the user often acknowledging less of an impact than the carer. This methodological issue of objectivity is hard to rule out but nonetheless should be noted, albeit based on a few examples.

6 Commentary

The main purpose of this stage of the project was to include those groups under-represented in previous stages, namely older men and frailer older women and/or their carers, in the development of standards of care for continence services. This section will critically review the extent to which this was achieved and the contribution this stage has made to the development of standards. It will also reflect on the project as a whole, and comment on the degree to which such an approach can assist with developing clinical standards.

It could be argued that the strongest features of this stage were the targeting of an albeit small but neglected and difficult to access group, and that they were approached in a more qualitative fashion through face-to-face interviews. This stage gave the opportunity for the voice of the carers to be heard, and while numbers were not sufficient for a separate analysis of their quantitative replies to be made visible, comments were valuable in revealing their perspectives. It is clear that the standard statements relate equally to their situations. Findings of a study undertaken by Cassells and Watts (2003) concerning the impact of incontinence on caregivers connect to our research, and elaborate further on the physical and emotional difficulties they have to absorb.

The shortcomings must however be acknowledged. The very low response rate is a weakness of the study, though perhaps predictable given the physical and mental frailty of many of those being contacted. The method did though provide a more complete picture of the experiences of those who did respond, but this picture is still far from accurate. While the carer involvement was an important inclusion, it became clear during certain interviews with both carer and service user present, that opinions of service provision and problems faced varied. This did not however constitute a major part of the data, but must be recognised. In addition, while the comments were plentiful, they were recorded by hand, not taped and transcribed, and this could have reduced accuracy and completeness. Despite this, there were deliberate strategies put in place to minimise inaccuracies through checking, such as reading comments back to respondents (Flick 1998). It must be noted that the slower pace at which older people interact facilitated the recording of verbal data by hand.

Despite this, this study has provided some hitherto unrecorded insight into what quality means for this group and has interestingly revealed contradictory perspectives into both the complexity and simplicity of continence service provision. Elaborating on this further, complexity was revealed in that the multi-pathological problems faced by the older, frailer respondents and their carers suggest that it is not only continence service provision that has an impact on the experience of continence, but a wide range of primary and more acute care providers. This includes non-NHS agencies such as clinical waste disposal by local councils. Simplicity was evident in that providing the appropriate number of comfortable, absorbent pads is what most of these users see as the ultimate benchmark of a quality continence service.

It was clear that, overall, the statements resonated with clients and reflected their experiences of service use. The fact that users were able to provide qualification of them through powerful illustrations signifies their validity in this respect. Although there was some variation in degrees of importance attached to the statements and differences associated with health status and impact of condition, overall their continued inclusion in future testing is warranted. This rationale is supported by the accompanying comments. Variations in responses are not noteworthy at this stage, given the relatively small samples. Previous research on continence sufferers supports the inclusion of the types of issues developed in this pilot study (Bowling 1995; Brown et al 1998; Cassells & Watt 2003).

It must be recognised however that the elaborations made by respondents through their comments emphasised the relatively narrow service orientation of clinical standards, particularly in relation to the emphasis on physical, medical and environmental factors. To this end, the user perspective is restricted to the boundaries of what is clinical and can be relatively easily measured. Such is the impact of continence however, sufferers will inform on much wider quality of life issues when encouraged to do so (Ashworth and Hagan 1993; Brown et al 1998).

It is important to be aware of other issues that cause severe restrictions on people's quality of life, but less easy to address them directly in clinical standards. For example, issues relating to socialising were emphasised, but not straightforward to craft into service delivery outcomes. This issue raises the not unfamiliar difficulty of how to include the consumer view and associated wider quality of life issues into service monitoring. The methodological approach of this stage of the project puts the issue of measuring quality in sharp focus. The argument that quality should not or cannot be measured because "what matters is never measurable and what is measurable rarely matters" (Kennedy 2004:162) is of little use to agencies trying to ensure better provision for service users.

While practitioners recognise these issues as important to patients, they find it difficult to include them into standards of care or quality programmes designed to measure efficiency and equity of service (Clayton et al 1998). It could be argued however that clinical standards are pivotal to improving quality of life and not detached from them; access to expert and regular assessment, correct treatment regimes and the supply of appropriate high quality products all contribute towards this end point.

One way forward is to ensure the consumer view is integrated into the audit cycle, as this will go some way to eliciting the degree to which standards are able to address these issues. This was captured to some extent in our study; respondents qualified the importance they attached to getting delivery of properly fitting pads, for example, by relaying their frustrations when this did not happen. Interestingly, past studies have related similar problems of equipment supply that still seem to be problematic today (eg. McKeever 1990).

Continuing on this theme, the study overall has demonstrated well the repercussions of not having a set of standards to adhere to, and underlines

the importance of these to the users. Of particular concern for example were the comments linked to the importance of expertise among staff, and a number of the respondents had experienced less than expert care. Cheater (1991) discovered over a decade ago that there were severe deficiencies in nurses' educational preparation and knowledge about continence; our study hints that this may be an on-going problem. However, the issue of local resources and specialism is relevant here, as in both of our study sites professionals were working against a backdrop of political change and uncertainty, coupled with severe staff shortages. This not only had an impact on recruitment but may also have had some influence over the kinds of interactions experienced by the users. It was clear that where specialist continence help was available and accessible, it was invaluable.

This aside, there are further noteworthy features that surfaced in stage 2 and were strengthened during the more exploratory dialogue in stage 3. Firstly, the emergence of dignity as a strong concept was of interest, but perhaps not unsurprising given the context of continence. The maintenance of dignity seemed paramount but easily eroded by a number of quite specific agents. This included the attitude, conduct and assessment skills of their professional contact, lack of gender-specific amenities, and ill-fitting pads. All of these factors were in turn connected to self-esteem, confidence and control, articulated not only by the users themselves, but witnessed by their carers.

While commentators analysing dignity remark on similar links to these broader characteristics (Mairis 1994; Walsh and Kowanko 2002), it remains a vague, ambiguous and highly abstract concept (Griffin-Heslin 2005). Consequently, maintaining dignity has become difficult to translate into explicit patient-centred practice interventions, especially in older people's care (Jacelon et al 2004). It could be argued that our study has started to reveal some specific features that connect to maintaining dignity in continence care.

Added to this, respondents provided us with a range of useful tried and tested coping strategies that contributed towards maintaining dignity in everyday situations. As an aside, this also gave some insight into the resilient nature of continence sufferers, acting as a contrast with those who seemed more fatalistic and powerless about their conditions. These areas are worthy of further exploratory research.

To conclude, the aim of the study was to include users in the development of standards of continence care and to this end this has been achieved. It is important to reflect now on the inclusiveness of the statements, and what additions need to be made. Given the largely physical emphasis of the standards, it is at least worth considering that more be developed that focus on supporting users emotionally. Issues related to anxiety, fear, as well as dignity and self-esteem are well worth considering. Importantly, providing information about coping strategies could be an important supportive feature of standards of care for users and carers.

7 Recommendations

- (iii) Supplementary standard statements based on dealing with emotional issues should be developed; the following could be considered:
 - Having support to help reduce my anxieties and fears about my continence problem
 - Providing me with strategies that help me to cope with the condition
 - Being able to maintain my dignity and self esteem

- (iv) The complexity of users experiences should be acknowledged by further informative inquiry, so that quality care can be seen as provision which actually seeks to tackle such problems rather than merely satisfying a list of criteria. An exploration of the meaning of dignity and how it can more specifically be maintained in the continence care setting would be a particular area for further research. Focusing on outcome rather than simply the inputs of the service may offer a more complete picture of quality.

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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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Dealing face-to-face with staff that have been properly trained in continence problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) At the clinic, being able to get into the building easily (eg having ramps or lifts)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Having comfortable and warm waiting areas in the clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Having full health assessments that include 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, understanding and reassuring	<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) Having a regular assessment of need (eg 6 monthly or yearly) to find out changes in needs and treatments	<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"/>
k) Having an assessment or treatment in a private room	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	not at all	quite important	very important
l) Whenever possible, being given a choice of treatments by continence specialists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) Having warm, clean and separate male and female toilets nearby that can be used without difficulty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) Having disposable pad facilities in the toilets for men and women	<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) Having good channels of communication between all professionals who deal with my bladder/bowel condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) Being able to choose from a full range of good quality, reliable and properly fitting pads, knickers and other products irrespective of cost	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) Having equipment such as pads delivered on time to where I live	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s) Being involved in a full discussion about care and treatment face-to-face	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t) Being able to fully understand my condition and what the future holds for me	<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 regular updates about bladder and bowel conditions, services and equipment 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 of care	<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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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 | <input type="checkbox"/> |
| 60 – 69 | <input type="checkbox"/> |
| 70 - 79 | <input type="checkbox"/> |
| 80 - 89 | <input type="checkbox"/> |
| 90 and over | <input type="checkbox"/> |

- b) Are you male female

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

White

- British
Irish
Any other white background

Black or Black British

- Caribbean
African
Any other Black background

Mixed

- White and Black Caribbean
White and Black African
White and Asian
.....
Any other mixed background

Chinese or other ethnic group

- Chinese
Any other

Asian or Asian British

- Indian
Pakistani
Bangladeshi
Any other Asian background

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

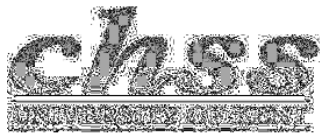
Below are some daily activities that can be affected by bladder or bowel problems. How much do they affect you? Please try to answer every question by ticking the box that applies to you.

	Not at all	Slightly	Moderately	A lot
c) Does your problem affect your household tasks (cleaning etc)?	<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

Appendix 2: Continence Services Questionnaire



Camden 
Primary Care Trust

Health Care of Older People Programme
Continence Project
Associate Director: Dr Adrian Wagg

Camden and Islington Continence Services
Senior Specialist Nurse: Maxine Hammond

Centre for Health Service Studies
University of Kent at Canterbury
Research Assistant: Patrick Brown

Dear _____,

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

I would like to invite you to take part in the above research study about continence. 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 standards to ensure the best quality of care, but need your help in making sure that they have included everything that is important to you. I am a researcher from the University of Kent and I want to find out what you feel is important about the care, support and treatment you receive from the continence service. Also, I would like to know more about the type of information you get, the surroundings where treatment is given, and the team who support you. Finally, I would like you to tell me a bit about how continence affects your quality of life. Your views are very important to me.

If I want to take part, what do I have to do?

The continence team have selected your name because they thought you might be interested in helping us with this research. If you would like to take part, please sign the consent form attached

and return it to me in the pre-paid envelope. You will need to provide your contact details, and decide whether you would like to be interviewed face-to-face either at home, in another place, or by telephone. When I receive your consent form, I will contact you and arrange a convenient time and place for the interview. If you choose a telephone interview, I will send you a copy of the questions beforehand.

I will record the information by hand using a form like a questionnaire and will also make a note on this form of any other things that are discussed about continence services in the interview. This will be destroyed when the project has ended. The interview will last between 30 to 45 minutes. If you incur any expense as a result of taking part in this project, this will be reimbursed. If you prefer, your carer can be approached to take part in the study on your behalf. This will mean that details about your use of the continence services and your quality of life will be discussed with me. I will need your permission to do this.

I would like to reassure you that any information collected about you will be strictly confidential, and no one will be able to identify you from your replies. If there are any questions that you do not want to answer, you can choose not to answer them.

Do I have to take part?

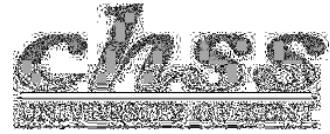
It is entirely up to you whether or not to take part, but if you do not want to take part, this will not affect your care in any way. If you decide to take part but change your mind, you are free to withdraw at any time, and this will also not affect your care.

If you would like some more information about the study or there is anything that is not clear, please do not hesitate to contact me, Patrick Brown, on 01227 823878.

Yours sincerely

Patrick Brown, Researcher

Appendix 3: Consent Form



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

Please initial the boxes on the right, write your name in capitals and sign over the page. Please include your address and telephone number so we can contact you. Thank you.

1. I confirm that I have read and understand the information letter about the research and have had the chance to ask questions

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and that my health care will not be affected

3. I agree to take part in the project

4. I give my permission for my GP to be informed about my taking part in the project

5. Are you taking part in any other projects?

Yes No

If you are, please write the name of the project below

5. I would prefer a face-to-face interview
or a telephone interview

If the carer is being interviewed, service user to initial the following:

6. I am happy for my carer to discuss details about myself with the researcher

.....
(Name of Person – please print) (Signature)

Address.....
.....
.....

Telephone Number.....

Now please return this form in the stamped addressed envelope. Thanks you