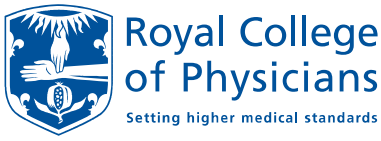
Privacy and Dignity in Continence Care Project

Phase 2 Report

November 2009



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1: Introduction

This report provides an account of the methods and findings of Phase 2 of the Privacy and Dignity in Continence Care for Older People study funded by the Royal College of Physicians and the British Geriatrics Society.

The overall objectives of this two year project were to:

- Identify and validate person-centred attributes of dignity in relation to continence;
- Develop reflective guidelines for dignified care;
- Produce recommendations for best practice.

There are three phases to this project. This second phase was preceded by work, contained in the Phase 1 report in which attributes of dignified bladder and bowel care were developed using a literature search supported by interviews with older people in nursing home and hospital settings (Billings et al 2008).

Phase 2 was in two stages, and sought to develop and refine person-centred attributes of dignity in continence care through observation and validation processes in nursing home and hospital settings.
Ethical approval for this study was obtained from the London Multi-centre Research Ethics Committee. This phase adopted quantitative and qualitative approaches, using a non-participant observation method and interviews. The two stages were:

Stage 1. To develop and pilot a detailed structured observation schedule for measuring the quality of care, using the attributes identified in phase 1.

Stage 2. To validate the observed attributes using a semi-structured interview approach with participants.

Originally this phase of the study was to undertake observation and to develop a quantifiable rating scale to assess dignity in continence care. However, direct observation proved unfeasible, and was therefore changed to a post event qualitative validation approach with participants. The nature of these challenges and rationale for the methodological change is described in this report.
Chapter 2 describes phase 1 and chapter 3 describes phase 2. Both chapters describe the plan of investigation, the findings and the critical review. Chapter 4 summarises the strengths and weaknesses of phase 2 and describes how the results will used in phase 3.

The next stage of this project is to develop guidelines for reflective practice, implement them and evaluate them using a validation process with continence and dignity experts.

2: Stage 1: Developing and piloting the observation schedule

2.1 Rationale for Approach

Previous qualitative studies on dignity in older populations have tended to use focus groups and individual interviews combined with literature reviews (Berg et al, 2006; Franklin et al, 2006; Calnan et al, 2005; Jacelon et al, 2004; Woolhead et al, 2004; Leino et al, 2003; Pope and Mays, 2000). Multi-method studies also have the potential to provide a more complete picture of the research topic under investigation, especially when this topic area is convoluted (Robson, 2002). Given the difficulties regarding specificity in determining the nature of dignified care, a more quantitative approach via observation was initially planned for this phase. This was in order to reveal the complex nature of the interaction between caregiver and patient in the practice setting when delivering dignified care and to augment data drawn from interviews in phase 1. The development of the observation method was in accordance with research guidelines and previous studies (Sommer and Sommer, 2002; Pope and Mays, 2000; Bowling, 1997; Clark and Bowling, 1990; Smith; 1981).

There are few reports of studies using observational methods to investigate the quality of life in care settings for older people. It was initially hoped that this phase would contribute to the literature.

2.2 Location

The study was conducted in London and East Kent. Each location included a, and nursing home and a health care for older people ward. These were selected because as Clark and Bowling, (1990) state, institutions are ideal settings within which non-participant observation can take place in an unobtrusive manner.

2.3 Sample

The purposive sample (n=10) included people aged 65 years and over, either resident in a nursing home or an inpatient on a hospital ward. Criteria for selection included people that had been identified as having either urinary and/or faecal incontinence, who required assistance with toileting or required pads or catheter care to maintain their continence.
As in the phase 1 interview sample, efforts were made to ensure that the sample selection included a gender mix and a balanced representation of urinary and bowel issues. The three instruments used to select participants were:

- A questionnaire completed with the help of a researcher, or the staff directly responsible for their care, recording information about bladder/bowel conditions and quality of life (appendix 1).
- The Barthel Index (appendix 2) which measures functional and physical ability was completed with the help of a researcher, or the staff directly responsible for their care. The Barthel Index was included as it gave an indication of the range of abilities that needed to be included within the study. The higher the score the more "independent" the person.
- The Abbreviated Mental Test Score (AMTS) completed with the help of a researcher, or the staff directly responsible for their care as this provided an indication of the cognitive abilities of participants (appendix 3).

The following table (Table 1) provides information on recruitment and functional and cognitive assessments of the participants.

Table 1: Participants

	Approached	Transferred before consent/ events	Refusal	Withdrawn	Study Participants
Setting					
London Nursing Home	7	1	2	0	**4**
London Hospital	5	1	1	0	**3**
East Kent Nursing Home*	6	0	2	1	**3**
East Kent Hospital	9	1	6	2	**0**
Demographics					
Male	8	0	3	0	**4**
Female	19	3	8	3	**6**
Mean Age** (min-max)	80.8 (68-97)	85.3 (70-97)	78 (73-83)	90 (90-90)	**79.1 (68-89)**
Ethnic group: White	25	3	11	3	**8**
Ethnic group: Black	2	0	0	0	**2**
Mean AMTS Score+ (min-max)	-	7 (5-10)	-	7 (6-8)	**6.3 (2.5-9)**
Mean Barthel Score++ (min-max)	-	13.5 (7-20)	-	16 (16-16)	**6.7 (2-13)**
TOTAL	***27***	***3***	***11***	***3***	***10***

*1 participant withdrew before observation was completed
**age unknown for 11 (9 who refused and 2 who were withdrawn).
+AMTS score unknown for one person who was withdrawn.
++Barthel score unknown for one participant, and two who were transferred and withdrawn.

The recruitment of individuals proved to be difficult. In the acute hospital setting there was a high level of acutely ill admissions and few fulfilling the inclusion criteria, as well as constant movement of patients. In the nursing homes, many participants were unsuitable due to impaired cognition. The sample of ten resulted from a total of 27 potential participants selected by staff. People either refused to take part, withdrew (if offering a reason, usually due to not wanting to be observed), or were unsuitable (e.g. low AMTS, confused, not understanding research involvement). Some suitable individuals were also transferred out of the care setting (e.g. discharged, transferred to another hospital, or from a nursing home into hospital) before consent or before the start of observation if they had consented.

2.4 Recruitment and Access

In NHS sites and nursing homes, prior to observation, researchers explained to staff what the period of observation would consist of and were given an information sheet on the project (appendix 4). Staff were in involved in inviting patients with continence problems whether they wanted to take part in the project. Prospective participants were then given an information sheet on the project (appendix 5) and a consent form (appendix 6) which included permission to provide their details to the researchers if they agreed. Participants were then contacted by the researcher and were provided with further details of the observation schedule and consent was sought. A rolling system of recruitment was necessary due to the rapid turnover of patient especially in the acute hospitals. Participants who consented to being observed were selected from those who had been identified as having either urinary and/or faecal

incontinence, requiring assistance with toileting or requiring pads or catheter care to maintain their continence. Also study participants had to cognitively and linguistically be able to give consent.

2.5 Development and piloting of observational schedule

The development and piloting of the observation schedule took place in tandem. Themes emerging from the literature and interviews were used to construct preliminary observation criteria. The steering group and researchers were involved in reaching consensus on what constituted good practice to further inform this process. General principles were adhered to; the pilot phase sought to determine whether each observation item was sufficiently detailed and defined, that the schedule was exhaustive (covering all possibilities), and that it was easy to record (Robson, 2002).

2.5.1 Determining the content and structure

There were various stages to content and structural development. In the first instance, attributes of dignity ascertained through phase 1 were extracted and developed into specific observable criteria. In addition to recording behavioural observations, organisational and environmental aspects were also recorded. The existing literature on observation tools was considered in the design and the observation schedule was reviewed by experts in the field of continence care from the multidisciplinary steering group. The schedule was developed into four sections: 1. Environmental Factors, 2. Organisational Factors, 3. Participant Information, 4. Event (appendix 7).

(i) Environmental factors

This section describes the environmental context of the care setting in which observation took place. It was developed from an existing environment audit for toilets (British Geriatrics Society, 2006) and from participant's views on accessibility from phase 1. This part of the schedule focused on communal toilet cubicles, assessing their accessibility and existence of facilities within the cubicle and whether they were in easy reach. In addition to communal toilets the space/environment around beds in wards and in residents' rooms was noted and the privacy including the presence of curtains and/or screens.

The environment at night was also described, e.g. noise levels and lighting. One assessment was completed in each setting. The geography of the area (e.g. ward or nursing home floor) was mapped including the number and location of communal toilets in relation to other communal areas, patients' beds and residents' rooms. Behavioural mapping studies have shown that the environment has a strong impact on the well being of the older population in institutionalised care (De Wit et al, 2005; De Weerdt et al, 2000 & 2001; Lincoln et al, 1989; Tinson, 1989; Keith and Cowell, 1987; Fairbanks, 1977).

(ii) Organisational Factors

This section was completed for each period of observation to capture organisational factors that could have an impact on dignity. It included:

- Number of patients/residents
- Numbers of staff and type or grade of staff on duty
- Toileting or checking regimes
- Staff handover times.

This latter aspect was recorded as it had been noted in phase 1 that staff response time to requests for toileting assistance was slower at handover times.

(iii) Participant Information

This section was completed once for every participant being observed and included:

- Demographic information
- Description of the continence problem
- Description of mobility

Any other information or preferences that might affect the way they were cared for as an individual was noted.

(iv) Event

This section of the schedule was used to the record the systematic observation of each toileting and continence care event. Categories for systematic observation should only include items of behaviour that occur naturally in a situation and can be observed and recorded (Sommer and Sommer, 2002). The variables of interest were extracted from phase 1 findings. These were indicators vocalised by participants and connected to a dignified event which were also observable and could be recorded. These variables were plotted within a chronological sequence in the schedule and took the following format:

a. Initial recorded variables were related to the situation: where the patient was located, what they were doing, what was happening in the ward/home, whether the event was initiated by the participant or staff member, staff manner, the care required.
b. Observations during the event related to the process of how participants were taken/put on the toilet/commode; such as privacy during care being carried out (e.g. toilet doors closed, curtains drawn, being kept covered up), and whether the care was done gently and discreetly.
c. Recordings at the end of the event captured how the participant was being kept clean and dry and how they were then left and settled when the toileting/care event had finished.
d. The length of the event, (by noting the start and end time), and the time it took to respond to the request for the toilet were also recorded.

The verbal and non-verbal communication throughout each event were also recorded. Observation is an ideal method for studying non-verbal behaviours (Sommer and Sommer, 2002). The recording of body language was decided upon following the interviews and pilot studies. Eye contact, gestures, use of hands, body posturing, and spatial behaviour were part of the criteria examined. The observer captured positive and negative verbal communication used by staff during the care event, as well as tone of voice, to examine the nature and type of language used when staff talked to patient/residents during events and how they described continence issues.

Systematic observation employs a scoring system and prearranged categories that are applied consistently. In order to do this after completing the schedule, the observer gave the event an overall rating of 1 to 5, 1 describing most dignified to 5 most undignified. The consistency of this rating and the distribution of answers in each observed event within and between different observers were analysed. The basis for how to use the rating scale and for individual observers to make a judgement was an on-going process of development and discussion.

The following criteria (Table 2) were developed for assessing how to rate events:

Table 2: Observation criteria

Most dignified	1	Person centred (e.g. communication exchange, personal care is good, privacy is satisfactory)
	2	Personal care given, privacy is satisfactory
	3	Functional and efficient i.e. 'gets the job gone' (lacking warmth/communication with patient/resident).
	4	Functional and inefficient
Least dignified	5	Not satisfactory at any level

2.5.2 Field notes

The purpose of the development and piloting stage was to ensure a reliable and valid account of what constituted observable dignity criteria in continence care. Formal approaches to observation impose a large amount of structure and direction on what is observed and recorded and this can be at the loss of complexity which often is symptomatic of these settings (Robson, 2002). As an adjunct to this quantification, it was therefore important to record field notes of observers' impressions of the context of care (Bowling, 1997; Pope and Mays, 2000). Observers manually recorded a separate journal of observations that were not quantifiable including feelings and impressions they had about the research and situations they encountered (Bowling, 1997; Pope and Mays, 2000). This also guarded against recall bias. These field notes served to provide case studies highlighting the complexity of dignity and its application to practice, described in the findings section.

2.5.3 Validating the observations with participants

It was also important to test the validity of the emerging observation schedule and verify it with the patient experience. A lesser qualitative element was also blended into this approach; this involved some patient validation of observable events. Attributes of dignity in continence care isolated through observation were checked with the patient experience where possible in order to identify the goodness of fit between criteria that were observed to be dignified and those that were actually experienced. The purpose of this was to provide a more complete and valid picture of what constituted dignity to take forward into phase 3. The number of patient validations actually completed was few due to the frailty of the sample group, and the difficulty participants had in connecting to the details within the schedule. The validation 'checks' therefore became a broad embellishment of dignity and continence themes within the schedule, which provided further saturation and credibility to the qualitative data in phase 1.

2.5.4 Role of researcher

A large proportion of analyses in previous studies on dignity have stipulated that the manner in which health care personnel treat and engage older populations can impact on dignity. The actions of health care personnel are perceived to affect the sense of dignity in older people by both staff and patients (Jacelon, 2002; Jacelon et al, 2004; Chochinov et al, 2007; Kovach, 1995; Moody, 1998; Lothian and Philp, 2001). In observational studies, the role of the researcher is an important consideration in terms of how his/her presence influences recordable behaviour. This is particularly relevant when dealing with sensitive subjects such as incontinence.

Here, the researchers were mindful of the attitude and manner in which they interacted with the participant and how this could potentially affect dignity. The act of the researcher observing continence events could arguably be intrinsic to creating a loss of dignity, and this did become an area of concern. There are a number of guidelines that were used during the research process. For example, Wainwright (1994) suggests that researchers should treat the observed situation with dignity themselves and maintain an appropriate distance. In addition, he recommends that observation be done by keeping a neutral expression and demeanour, being careful about body language, avoiding eye contact and generally adopting a serious manner focused strictly on the research at hand.

2.6 Data Collection and Analysis

Evidence from the literature regarding time periods that achieve adequacy in observation for the development and piloting of a schedule was sparse. Advice was therefore sought from academics working in this field, coupled with the exhaustive strategies outlined in the previous section.

The initial plan was to have two observation periods interrupted by 2 periods of analysis, development, review and consolidation, thereby giving a total development time span of approximately 7 weeks. In the event, only one observation period was possible.

For the observation period, the observation schedules were used in one hospital and two nursing homes and data collection took place over a period of six consecutive days in time spans of four hours. On the first day, observations were recorded over two interrupted four hourly spans; the first span was discarded to account for observer effects. The technique of discarding the first four hours of observational research was necessary to allow for the reactive effect of the observer to wear off, and to encourage observer habituation which happens quickly if the observers appear as unobtrusive as possible (Bowling, 1997). In general four consecutive hours is the maximum a researcher can observe without ‘observer drift’ or fatigue (Robson, 2002).

Observation took place across all shifts of the day, and on both weekdays and at weekends and used two researchers on the first day to check for inter-observer variations. No observations took place at the second hospital as nobody was willing to take part. At the sites that did take part it was not possible to recruit the target number of five participants, so observations went ahead with a total of ten people: three in a hospital rehabilitation ward, four people in one of the nursing homes and three in the other. More people initially agreed, but subsequently withdrew their consent.

A toileting event was defined as any care relating to toileting. This included going or being taken to the toilet, having catheter care, and checking or changing a pad. Events could be initiated by staff, relatives or visitors or by the research participant. It seemed important to include checking as it can involve communication and negotiation between staff and participants, however if this occurred at night when participants were not woken and no care was given, there was very little to record and analyse.

Researchers expected to observe toileting only when caregivers and staff were present, and to withdraw when caregivers withdrew to give patients and residents privacy. Small toilet cubicles sometimes meant there was insufficient space to go in and observe, and on these occasions researchers remained outside within earshot. There were two occasions when a participant asked the researcher to leave.

It was not always possible for the researcher to observe care from start to finish. Researchers asked for staff to alert them when care was to be given, and when this did not happen part or all of an episode was missed. Some of the care staff, especially in nursing homes, expressed strongly-held views that the observation was an intrusion on privacy and dignity and that part of their role was to protect residents. This was an understandable attitude and accounts for some gaps in what could be observed, and is elaborated upon later.

2.7 Findings of the Observational Analysis

2.7.1 Observation Schedule Analysis

Fifty six toileting events were recorded, demonstrating that the observation schedules could be used in the field, although the speed and brief duration of much of the continence care meant that the schedule was completed immediately after (rather than during) toileting and checking events. The data were entered into SPSS and viewed through frequency tables and cross-tabulations.

There was some variation between observers. Inter-observer differences were checked at the beginning of observation in a new site and were not significant, but different use was made of the overall dignity score, especially the 'most dignified' rating. Observers made additional free-text notes and comments on the schedule to give a fuller picture or explanation of what they had seen.

Some results were as one might expect, such as slightly lower dignity rating when the nursing home or ward was busy, and at bed-time or at night. There were also counter-intuitive associations. For example, dignity ratings were not simply linked to whether toileting events were patient or staff-initiated, if toileting/changing/washing was done gently this was not necessarily dignified; similarly privacy did not necessarily mean dignity.

There was much less association than had been expected between the measures recorded and the overall dignity rating, in other words variables taken one at a time are rarely correlated with dignity. For some variables the number of events observed was too small to show definite patterns, especially for parts of the schedule which were not used or applicable.

The results showed that judgements of appropriateness or quality of care take several factors into account, so the answer to individual or specific prompts on the observation schedule will often be insufficient to make these judgements with certainty. For example, for the patient who was not offered a choice of toilet or commode as there was no choice, this did not necessarily lead to a low dignity rating; or the patient who was addressed by name and given full information by the caregiver as to what was to be done, but whose care was purely functional and not done with any warmth, so a low dignity rating was recorded, even though all the boxes on the schedule had been ticked.

Findings from the first week of observation were examined, with the intention of revising the schedules. However, while it was possible to observe and record details about toileting care, there was no clear or identifiable set of circumstances

associated with a high dignity rating. It was also difficult to make any meaningful connections with the data collected on environmental, organisational and participant information factors as it was insufficient. Therefore it was decided not to revise the schedules and repeat the observations for a second week.

2.7.2 Analysis of Field Notes

The field notes that researchers collected about their observations were useful and detailed, and provided some interesting examples of the dilemmas faced when trying to quantify something as complex and variable as a dignified continence episode. The following are two examples of anonymised scenarios of continence events with researcher's comments and overall rating (1= most dignified; 5=least dignified).

Meeting Mary

Mary Ellis is an 80 year old woman. She was undergoing rehabilitation following surgery. Mary was completely orientated in time and place. She was very independent but being a new amputee and wheelchair dependent, she needed help with transferring and toileting. She was not incontinent but has reduced mobility, which particularly at night resulted in 'accidents'.

Day 2: 03.06.08. Shift 10.00-14.00. Episode 4

13.05-13.35 *It was after dinner, Mary was desperate to go to the toilet and unable to get a nurse. The toilet in the dayroom was out of action as they were fitting a new sink. The ward was short staffed as one of the nurses was off sick and the nurses who were there were had to move furniture around. Mary was sitting in the wheelchair in her own clothes. Mary wished to use the toilet but was told by a carer that she would have to use the commode by the bed. The carer had this conversation with her across the dayroom and could be heard by everyone in there. Care was efficient rather than gentle. The carer spoke to me over Mary, saying that Mary was naughty as she would not use the banana board to transfer onto the commode. The carer brought the commode to the bedside, closed the curtains and told Mary to manoeuvre herself onto it. Mary chose to pull her dress right up. Mary wiped her own bottom but was not offered hand-washing facilitates. All equipment was removed and Mary started to propel herself back to the dayroom to get her blanket which goes on her lap and covers her stump. She was eventually brought back by the pharmacist. The curtains were closed around the bed and Mary was allowed to transfer and adjust her own clothing.*

Dignity rating 4: *There was failure to protect Mary's privacy and dignity. The carer was abrupt and also spoke loudly and indiscreetly at times. She told Mary that she had to use the commode as all the toilets were being fixed, she could have done this in private at the beginning but did not tell her until the end. I asked Mary what dignity meant to her. She said respect and self-respect. I asked her about dignity in hospital and she said it did not exist, you left your dignity at the door when you came into hospital. She had never bared her body to anyone except her husband but in hospital the most important thing was to get better. She had got used to men washing her. She said that illness meant that you lost your dignity as a hospital was a public place. She didn't mind because she wanted to get better.*

Meeting Peter
Peter, a patient in hospital, was a very cheerful, chatty man. He suffered from a neurological condition which meant he could not walk and had lost the use of his hands and arms so could not hold a urine bottle. He needed to transfer with the aid of two people and the use of a standing hoist.

Day 3: 04.06.08. Shift 21.30-02.00. Episode 3
This was initiated by the night staff before they settled Peter for the night. He was lying in bed in a hospital gown, chatting to others. He was wearing a pad which was visible and there was an unpleasant smell. He did not appear to be wet but the smell seemed to be one of stale sweat. There was one female carer who had a friendly approach. She gave minimal information about what she was going to do but was discreet and gentle. She put the bed at the right position and height for him. Peter used a bottle in the bed which the carer left in place and came back for. No attempt was made to cover him up when the bottle was in place. He wasn't washed or wiped and he could not do this for himself. His pad had been dirty and he smelt sweaty. The pad was changed the area was left tidy and he was made comfortable. The HCA took great care to do up the back of his gown as his shoulders get cold. She also pulled his covers right up the way he likes them. She appeared to know his individual needs well. She said to him, 'you wet the bed last night'. Peter replied, 'It's not something I do of my own volition, in fact it depresses me'. She said, 'I hope you won't do it tonight'.

Dignity rating 3*: *(perhaps on reflection it should have been 4 but there were some redeeming features).
Some of the communication was good, smiley and warm. However, Peter appeared to be upset about having wet the bed the night before and the nurse was not reassuring about this but appeared to be rather judgemental. Since Peter can control his bladder but needs help, he appeared to find the experience of wetting the bed distressing. He was not clean and was not washed but used the bottle and his pad was changed. While the nurse providing the care was formal, she did appear to know and respond to his individual needs.

It could be concluded that the variables for observation on the schedule (appendix 7) would not have been enough to be able to ascertain the exact nature of the lack of dignity experienced by the participants in these continence events. This is important when considering the limitations that a quantifiable dignity tool would have for revealing important practice issues and ultimately helping caregivers to improve practice.

2.8 Challenges and revisions to the plan of investigation

The observations stage of the project resulted in a number of challenges that required some revisions to this phase of the study. The following provides an account of these challenges and how the remaining stage of phase 2 was adapted to accommodate them. An amendment to the project was approved by the London MREC.

2.8.1 Relationships with Staff
Acquiring adequate sampling was a difficult process due to the general frailty of the population group under study in both nursing home and hospital settings. There were

however additional recruitment factors concerning the reception and attitude of staff towards the project and research team. The engagement of staff was crucial to data collection, not only in identifying potential participants and assisting with screening questionnaires, but also in alerting researchers to observable continence events. While this worked well in some areas, in others, staff seemed to find the project problematic and were suspicious of its intentions. Given the nature of the subject matter with its potential for intrusion, coupled with the desire to act in the patients' best interests, this was understandable. Researchers had the impression that staff wanted to protect potential and actual participants and covertly or more overtly did not appear happy to co-operate. This manifested itself as not informing researchers when an event with a consented participant was about to take place, closing doors to make access difficult, and blocking views.

The information exchange pathways developed with staff to ensure understanding of the project (i.e. a combination of face-to-face discussion and written sheets at shift handovers, and reminders) did not always work. This was due to a number of reasons such as handover times not corresponding to observation periods, lack of time and nurses arriving for duty at different times, all of which resulted in some staff not being fully informed of the project. Unfortunately this sometimes contributed to uneasy relationships between staff and the research team.

2.8.2 Reliability and validity issues with the observation schedule

One of the greatest difficulties in observational studies is ensuring the reliability of the observations. As dignity is a complex and abstract concept, it is vital when measuring attributes of dignity that researchers agree on what actually constitutes dignity. This proved to be a particularly difficult aspect of the study and reflected on the accuracy and overall validity of trying to determine a measure of dignity via a ratings scale.

It became apparent that attempting to apply a rating to an event was variable and complicated. During observation it became increasingly clear that dignity differed during events and between people, in addition it encompassed many different emotional, structural and interpersonal components. As a consequence the overall rating attached to an event was seen as too crude a measure and consensus between researchers was problematic. What was clear however was that no more attributes were identified through the 56 events observed.

However, at the heart of the emerging reliability and validity problems were concerns that the schedule was not necessarily reflective of the patient experience. When discussing the event with some of the participants afterwards as part of the 'validation check', issues were revealed that contradicted the rating and were 'hidden'. These issues largely related to the disempowerment that can occur through loss of independence, relating to individual patient choice and the lack of patient-centredness (e.g. patient wanting an air freshener, another wanting to walk to the toilet but feeling unable to ask). This was not picked up through a check list of variables alone, however detailed. During the observation spans, validation checks were not generally possible; in addition to the overall frailty, participants were settled or too weary, or it was night time. Also, spending time validating an event meant that the researcher could miss another event with a different participant. Given the difficulties with recruitment, this was avoided at all costs. When validation was possible, in some cases however, patients seemed happier to talk about the event rather than being observed, and it has served to enrich the data and give insight into the complexity.

2.8.3 Ethical dilemmas

There is no doubt that this project came close to the ethical 'boundary'; this had an impact on the accuracy of the recordings and raised moral issues for the research team. During the planning stage, advice was sought from professionals and agreement was reached that participants would not be observed while they were on the toilet, as this would cross over that boundary. There are of course many other intimate observations that need to be observed in order for a valid judgement to be made about dignity, such as how the participant was washed or helped to change. A dilemma was evident; on the one hand there were increasing concerns that the observation phase was itself having an effect on the patient's dignity; on the other hand, by being sensitive to reactions of individual patients and withdrawing at certain times in the event, researchers were unable to capture important details sufficiently well.

2.8.4 Revisions to the plan of investigation

Given the above, the project was re-orientated more towards securing greater participant validation. This was done in order to avoid decreasing methodological merit; to maintain a high ethical standard of research execution and to ensure a valid and implementable outcome. Observations were halted following 56 events and further fieldwork concentrated upon the patient experience and perceptions through the use of a validation interview schedule created from the most prominent emerging domains relating to patient-centredness. This next section provides more detail of the method approach and findings.

3: Stage 2: Validation of dignity criteria in the care settings

This stage concentrated upon conducting a series of validation interviews with participants in nursing home and hospital settings in East Kent using an interview schedule. This served to check that the discreet criteria identified and tested in the previous stages of the project were complete, reflective of and compatible with the patient experience in order to develop meaningful guidelines relating to dignity in continence care.

3.1 Recruitment and Access to the sample

This was similar to the previous piloting phase using the same method for recruitment and access in each hospital and nursing home. Prospective participants were approached either by a senior member of the ward staff or the home manager. Information letters to staff (appendices 8 and 9), patients (appendix 10), and residents (appendix 11) along with the consent form (appendix 6) were supplied. Given the difficulties in stage 1, careful liaison with staff at the sites took place to ensure they had a full understanding of the processes involved and were aware of the movements and purpose of the researchers. At the first visit, the researcher checked the individual's suitability and having ascertained this, gained consent.

3.2 Sample

A total of four participants took part, two men and two women. This included two participants from each setting. All participants completed three interviews following a continence event (n=12). Their ages ranged from 72 to 95 years. The study criteria used were the same as for the first phase. The sample size was well below the planned number of 20 due to similar difficulties of population frailty and gaining access to the settings.

3.3 Instrumentation and Data Collection

While observation generated rich data, it was difficult to undertake sufficient observations to ensure that the emerging criteria were valid and reliable. It therefore became important to confirm these tentative findings to see if the researchers' perceptions of what was important matched participants' experiences.

An interview schedule was developed that built upon a blend of emergent patient-centred themes from the interview data, the more detailed observed variables, and the field notes collected during piloting in stage 1. The variables isolated for the observation schedule were also included in the form of prompts to ascertain their relevance to participants. As the purpose was to confirm emerging findings, the key domains were the focus of the interviews, namely dignity in general, communication, choice, privacy and hygiene (see appendix 12 for interview schedule).

The process of validating criteria with participants through interview needed to be carefully considered to avoid a tendency to agree. The schedule therefore applied different interview techniques combined with open questions, such as the use of specific quotations or observations from these earlier phases (Pope and Mays, 2000).

Participants were interviewed three times over a relatively short period of time (maximum three days) in order to establish a rapport. The interviews needed to be conducted after toileting episodes so that participants' recollections were fresh. When arranging the interviews, there were a number of considerations to be made. In both settings subjects did not want to upset their routine and interviews were planned around visitors, visits to other departments, activities and rest times. The researchers sought to be flexible and negotiated times and most interviews were done either late morning or early afternoon. The relationship between the participant and researcher developed over the three interviews and resulted in more openness and reflection.

3.4 Analysis and Validation

The methodological processes used in this study were hampered by the lack of published guidance in the area in particular for validation procedures. Therefore different methods of analysis were tested in order to ensure an approach that would represent the data.

Analysis of the validation interviews was initially structured using a tool to quantify the interviews developed using the variables from the observation schedule. The purpose of the tool was to identify whether these variables truly captured factors that were relevant to a participant's dignity from their point of view. The tool went through five iterations, but proved to be difficult to use in practice and so was eventually abandoned. Lack of rigour manifested itself in a number of ways. Discreet criteria were not always discussed and there was a danger of bias; any variables that were mentioned by participants for example could have been an artefact of asking the question rather than true feelings. This would have ultimately led to assumptions being made about the meaning of dignity to the participants.

There were a number of other reasons for abandoning this approach, which highlighted the general difficulty in trying to apply a measure to a concept such as dignity. Participants often contradicted their statements or expressed contradictory feelings; therefore it was hard to judge a person's real perception. For instance, people often seemed to be comfortable with being exposed, which seemed to contravene the essence of dignified care. For others, perceptions of dignity altered in response to external stimuli. In this example, one participant linked dignity to institutionalisation:

> *'I was the most, stroppiest unpleasant person you could ever wish for. And they threatened to discharge me, they said 'we can't treat you, you're too awkward and unreasonable, you're too demanding, we're going to discharge you into a nursing home and let them get on with it'. So then my wife came in and said 'oh no, you're not. You will behave yourself from now on', so I did. And I think I changed my ways a little bit.'* (H2:15:V3:p2)

This statement demonstrates how difficult it is to validate dignity criteria in a quantitative manner. In this case, the participant's perception of dignity and subsequent behaviour were somewhat reshaped by direct staff communication and a self-awareness to conform. This in turn can be linked to issues of acceptance and resignation highlighted in phase 1, arguably the antithesis of dignified care. Tools attempting to quantify dignity cannot allow for a linear change in perception or account for the external factors that can re-orientate perceptions.

A qualitative approach was therefore adopted using content analysis (Flick, 1998). In this approach, a pre-determined template using themes that have been empirically derived is applied to the data. Data not fitting with the pre-determined themes are collated and analysed separately. The interview schedule domains were therefore used, having been derived from phase 1 data, field notes and observation. Interviews were recorded and perceptions sorted under these themes; in addition they were member-checked between researchers and an external steering group.

The transcripts were checked with the variables on the observation schedule to achieve a broad impression of the extent to which there were connections between the two in terms of importance.

3.5 Findings

The findings are presented within the predominant domains of dignity, choice and care, communication and care, privacy, and hygiene and comfort.

3.5.1 Dignity

Participants were asked first if they felt 'you left your dignity at the door when you came into hospital'. Interestingly, after initially denying that this was the case, three of the participants went on to agree with the statement. For example, this 72 year old hospital patient explained:

Participant *I don't think you think much about it really. If you can't do for yourself, there's no sense in thinking about dignity.*

Researcher Well, it is important.

Participant *Yes, it is. I did worry about it, well I still do but I try not to, I try not to…..Yes, I mean, I've never been like this before, I've always had pretty good health and not thought much about it but now its hit me I realise what its like for people.*

Researcher It's a bit of a question out of the blue that, 'do you leave your dignity at the door.'

Participant *Well, I think you do. I've always been a person that, I wouldn't strip off in front of anybody but you can't help it, you've got to. And they don't make you feel out of the way, they don't take any notice of you, they say, 'don't worry', but its still something I would prefer to do it with my wife.* (H2:16:V1:p2)

Losing his health, independence and having to take off clothes in front strangers all added to his loss of dignity. This participant needed help to get to the toilet and as he did not like accepting help, he used to wait until his wife came to visit which caused him some discomfort:

Researcher Will you hold on [till your wife comes] rather than have somebody else?

Participant *I've never had to have somebody else…they give me medicine because I was bound right up, I couldn't go at all. They gave me medicine so I could go through the eye of a needle, I couldn't hold onto it but luckily it happened while she was here. It was really good. (* H2:16:V3:p4)

During observation specific problems had been noted with the use of the hoist during continence care and again these were evident in this series of interviews. One participant described the experience of the hoist as being 'like a spatchcock chicken', when he was up in the air. A nursing home resident, referring to a previous hospital admission explained:

> *I mean some people have to be hoisted to the toilet, well I'd hate that. That's what happened when I went into xxxxx hospital for the two weeks, they hoisted me everywhere and boy did I get sick and tired of that. …..They took all your dignity away. Well as they say you've got no dignity left, I said 'No, all the dignity's gone, stand up, pull your pants down, pull them up when you get up. (NH3:4:v3:p6)*

As in the earlier parts of the study, participants did not restrict dignity to continence care but felt that it permeated all aspects of care. Indeed dignity was more evident in other aspects, because to some extent continence care had become a familiar, routine and necessary part of their care. One 95 year old nursing home resident felt there was no dignity in the care home she lived in as she was not given her preferred title and was made to feel like a nuisance when she made requests for basic care. A hospital patient spoke about dignity as being a 'two-edged sword' – a 50/50 relationship between self and nurses and he felt he took responsibility for his part of the relationship. Participants reflected on the fact that they had never anticipated going into hospital or a nursing home and becoming dependent was a new occurrence, so there was some adjustment to be made.

3.5.2 Choice and care

In these interviews the issue of choice was explored. Again participants felt that they had little real choice either in general or continence care. In both the hospital and nursing home, participants felt that their choice was limited by lack of resources. In hospital, participants noted that they were dependent on busy staff. One 74 year old participant described how his mobility problems affected his continence care. He had two apparent choices, using a bed pan in bed which was very uncomfortable because the hard edge cut his bottom, or being lowered from a hoist onto a bedpan in the wheelchair which meant he could sit upright and was more comfortable. In reality there was no choice:

> *No. There wouldn't be a choice. The reason is that the hoist is in constant use with other patients and trying to get hold of it is very difficult and I think if you wanted the bed pan, invariably that means that you need to go so they're quite quick with it and they don't hang about, they might take 5 minutes or maybe 10 but there is not a choice, you only get the hoist if you have already got it and you make the opportunity of it. It's not a toilet requisite if you like, its not, we'll hoist him out and he can go to the toilet, that doesn't happen.* (H2:15:V1:p3).

This participant developed opportunistic strategies to deal this situation. Whenever he was being hoisted out of bed he asked to use the bedpan on the wheelchair, and also developed an 'alert' system whereby he would attract the attention of nurses before his needs became urgent.

As we noted in the earlier phase of the study, in most settings patients found it easy to access care which was "routine", such as using the toilet before bedtime.

However such care is not personalised nor based on patient's choice. Participants reported difficulty in getting personalised care, for example being able to use the toilet when and how they wanted. They did not see this as a personal failing of individual staff, more as a system failure due to staff shortages so they often had to wait for care, both to be helped on to the toilet and to be taken off afterwards.

3.5.3 Communication and care

As in the first phase of the study, participants reported that they valued time talking to caregivers and that they tried to develop relationships with staff by chatting, finding out about caregivers lives, and joking with them. However they were often disappointed as much of the talk was functional:

> *They're very busy. They haven't got time to stop and chat to me.* (H2:16:V3:p3)

The problems of moving communication and relationships beyond the impersonal and functional to the more supportive kind that would give some protection against the indignity of care were very clear in participants' accounts of dealing with new staff:

> *Yes, I've got to learn that because I don't know them it doesn't mean they're any the less competent or any the less experienced. It's just, I don't know you and when they strip you and you're lying there with your legs akimbo it can be a little embarrassing but I must say, 9/10 of the nurses here cover you up with a towel.* (H2:15:V3:p2).

Not being cared for by a person with whom one had a relationship and felt some degree of empathy with was experienced as a disappointment. In the following extract, the participant clearly describes her distress at not receiving care from the person she knew and liked especially when she realised that this individual was on duty and had not looked after her. Instead she received care from an unfamiliar male caregiver with whom she could not communicate properly. Despite asking she never really obtained an explanation for the change of caregiver and was left to wonder if it was somehow her fault and some sort of punishment.

> *This morning I was very disappointed because usually I have the sister and instead I had the man from the Congo who speaks French. And he dashed in and he said 'wakey wakey!', I said 'are you going to get me up?', he said 'yes'. I said 'isn't sister here?', I didn't hear what he said so I thought she wasn't here….. So I had a word with her later and I said 'have I upset you? And she said 'no'. So I said 'well, have you deserted me or are you going to help me another day?' and she said 'yes'. So I don't know why it wasn't today.* (NH5:1:V2:p1)

3.5.4 Privacy

As in the earlier phases, participants valued their privacy and there were some differences between those people in nursing homes and hospitals wards. In the nursing homes the participants had their own rooms; the door was closed if they were receiving care and staff knocked before entering. Although participants valued privacy in such circumstances, one participant liked to have her door open at other times as it allowed her to observe the staff as they went about their work and prevented her from feeling so isolated.

> *I want the door open, the reason I sit as I am is to see people going by – there is a sluice room and a medical room and they have to come there to do their job, so I see people and they wave as they go by that's why I sit here.* (NH5:1:V1:p4)

In the hospital wards space was public and special measures had to be taken to create private areas. Patients were reliant on the curtains to provide privacy unless they were taken to a bathroom or toilet. Participants described how curtains provided protection from some, but not all surveillance. They reported that staff were careful about making sure the curtains were completely closed so they could not be seen but were less careful about how loudly they spoke behind them:

> *I'm not saying that is confidential information, on the other hand it may well be. And they say things like, 'you're legs are getting better now and we've had a word with the doctor', you can hear every word. These curtains don't help.* (H2:15:V2:p5)

Lack of any activity or background noise meant there was little distraction from hearing what was going on behind others' curtains and confidentiality was compromised.

3.5.5 Hygiene and comfort

Again all participants stressed the importance of feeling clean and comfortable and living in an environment that was hygienic. The nursing home residents appeared to receive the physical care and hygiene that they wished for. One participant described in detail the regular baths she had and the pleasure she experienced.

> *As I say Wednesday is my bath day. You can have a shower, but I like my weekly bath. Get in the bath and soak and the Jacuzzi goes (laughs) bubbled up.* (NH3:4:V2:p1)

Hospital patients appeared to 'settle for' bed baths or strip washes. This participant was asked if he ever had a bath or a shower:

> *I can't because of the stump, its got to be. They did say to me if it's desperate we could probably put it in a plastic bag. I have a good wash all over so that's probably as good as a shower*. (H2:15:V3:p5)

3.6 Commentary Stage 2

The interviews supported the author's previous findings and added more detail to the existing body of evidence about the patient/resident experience of dignity in care and the difficulties of interpreting this as a researcher. More insight was gained into the sorts of management strategies participants develop to help them cope with undignified experiences. The purpose of the validation interviews was to confirm that the observation schedule captured items that were important to dignity. Approximately a third of the detailed items on the schedule were not discussed in the interviews, but this did not mean that they were not relevant to the participants' dignity judgements. Getting validation of this detail would have necessitated the use of direct and perhaps leading questioning and this needed to be avoided.

The remaining two thirds of items on the observation schedule were discussed in some form during the interviews or were related to something that was discussed. Of those, about a third seemed rather important (response time to toileting requests, the availability of equipment). However, many themes identified in the interviews did not appear in the observation schedule, nor could they likely be observed (how comfortable the person felt with the caregiver who was providing care, how the person felt about being exposed). Overall, while some aspects of toileting can be observed and measured, their meaning to a person's dignity may be trivial and what really matters (relationships with staff, feelings of respect) cannot be measured. This process validated some items on the observation schedule, but mostly showed us that dignity cannot be quantified as there are too many underlying issues to unravel.

4: Conclusions

This aim of phase 2 of this project was to develop and refine person-centred attributes of dignity in continence care through observation and validation processes in nursing home and hospital settings. Without doubt, the methodological pathway of this phase was very challenging, hampered by expected, but also unexpected difficulties. The authors will reflect on these challenges, offer recommendations for future research in this area, and provide a short commentary on the way forward for phase 3.

The contribution of this phase was to report that dignity in continence care cannot be measured, despite rigorous planning, and that any clinical outcomes for training and education in this area need to be in the form of reflective guidelines. Thus, in promptly recognising and responding to the methods challenges here, phase 2 was successful in providing rich, credible and person-centred qualitative thematic domains upon which reflective guidelines can be developed in the next phase of the project.

In terms of expected challenges to this phase, the issue of recruitment in the NHS and from other health sectors has long been perceived to be problematic due to access by a third party, motivation and perceived risk (Grant et al 1999; Lingler et al 2009). However focusing on very frail and vulnerable older people, poses added problems of understanding, consent, suitability and willingness. Nystrom & Segeston (1994) emphasised well the sense of powerlessness felt by residents in nursing homes, hence the ethical dimensions of research of this nature are brought to the fore in this kind of environment. With reference to the hospital settings, increasing services in the community geared towards preventing admission (e.g. Rapid Response, Community Matrons), has meant that those older people who are admitted are very ill or seriously compromised by multiple medical conditions. Recruitment was also impeded by ward closures (norovirus infections) and sudden discharge of recruits to rehabilitation wards or other locations. So not only were there few eligible recruits, potential recruits identified by staff were frequently moved. Recruitment in both settings did however suffer from lack of understanding of what the research entailed and those consenting withdrew or changed their minds. Despite the frustration of low numbers and the potential for drop-out, the moral conduct of the researchers was important here, to ensure full understanding at all times given the intrusive nature of the project. There was indeed a clear paradox that was difficult to circumnavigate; the project sought to investigate dignity but in itself added to the threats to dignity – observation can be an undignified action.

The above highlights that observation method can be problematic; some of these problems are well documented and were anticipated at the planning stage, such as observer effects. A less expected difficulty was encountered with care staff in both hospital and nursing homes. This was more concerned with a sense of paternalistic ‘protecting’ of patients entered into the study, through perceived ‘blocking’ of observations, or subtle persuading patients or residents to withdraw or not take part. A limitation of the research was insufficient resources to explore this interesting process in greater detail. One can only assume that it stemmed from a justifiable moral conflict borne out of not being sufficiently engaged in the purpose of the project and perceiving it as threatening. In addition to this, locations of care for older people are busy areas and all too frequently understaffed.

Other authors offer some interesting perspectives on this; Tuckett (2006) comments on the relationship between paternalism, autonomy and ‘best interests’ in the context

of older residents in nursing homes in Australia. He critically reviews the tendency of nurses to make daily decisions about what is in the patient's best interests, stating that nurses are placed in a very powerful position and this can jeopardise patient autonomy. Tuckett challenges nurses to consider their capacity to really know another's best interests, especially in a nursing home. In addition, Prout et al's (2007) study on stroke patients rehabilitating in a nursing home, demonstrated that nurses were unable to relinquish a sense of control and move from a paternalistic approach towards one that gave residents more autonomy in decision-making. For research activity to be successful, these dimensions of the nurse-patient relationship need to be taken into consideration, especially when there is a burden placed on staff to recruit.

With respect to the topic under study, in the planning stage the complexity of dignity had been clearly understood, and it was envisaged that the focus on continence care would provide a sharper focus to determine, quantify and ultimately rate attributes of dignity. However there were difficulties that militated against this hypothesis. An overarching issue that became evident in phase 1, reinforced in the validation interviews, was that dignity in continence was inseparable from how dignity was generally perceived. Thus it remains a broad concept, difficult to 'pin down' in detail. While some elements could be extracted for the observation schedule, they were testing to validate with older people and indeed highlighted areas that could not be captured in a specific way. Gaining the specificity needed posed methods problems with the potential for bias. An important and successful variation to the methods therefore was to embrace the qualitative exploratory approach more.

When considering future recommendations for research, there are two issues that stand out. In this current NHS climate of performance indicators, measurement of clinical outcomes and audit, phase 2 would suggest that there are limitations to what can be meaningfully quantified. It must be recognised that there will always be the need for more qualitative evaluation of outcomes in patient care, particularly in relation to important personal areas where interpretations can have wide variation.

In terms of research planning, the potential challenges of recruiting vulnerable older people to projects cannot be underestimated. Crucial to success is smooth and on-going access procedures and dialogue with practitioners at the study sites in order to support recruitment. This is particularly so in nursing homes where research activity has yet to equal that in more acute setting. In hindsight, as access to recruits must be through key workers and there were clearly problems in this area, a strategy could be to enlist site practitioners at an early stage of the project to infuse a sense of ownership. This could have benefits at the access and recruitment stage, and may have also weakened the sense of threat felt by the nurses and their desire to protect their patients from the research process.

Overall, despite the challenges, this phase has been successful in providing the information needed for the next phase, concerned with developing reflective guidelines for practice with practitioners. The observation and validation stages have served to strengthen and sharpen the domains which will act as a good foundation upon which to build a resource for practice to support dignity in continence care.

5: Key points

General Findings

- Phase 2 has served to underline the findings from phase 1; the definition of dignity remains a complex, shifting concept, dependent upon individual context and interpretation.

- While aspects of dignity can directly relate to continence, such as privacy and hygiene, in general it interrelates to all aspects of care and cannot be separated.

- Phase 2 added strength and validity to the themes developed in phase 1 which will form the foundations for the reflective guidelines for phase 3. These were defining dignity, management of incontinence: coping strategies, and professional care (communication, personal care, personal care and time, choice and privacy, hygiene).

Methods Issues

- Dignity in relation to continence cannot be measured using direct observation. While some aspects of toileting can be observed and quantified, their meaning to a person's dignity may be trivial and what really matters such as relationships with staff and feelings of respect, cannot be quantified.

- Key methodological, moral and ethical challenges arose
    - Patients, who were vulnerable and unable to grasp the implications of being observed and withdraw from the study;
    - Staff, who acted as moral custodians of their patients which made access and recruitment testing;
    - Researchers, who encountered obstacles in the field, difficulties with inter-rater reliability, and moral dilemmas when undertaking valid and ethical observational research.

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Appendices

APPENDIX 1 – Quality of life questionnaire

Section 1: About you…..

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

65 – 69	☐
70 - 79	☐
80 - 89	☐
90 and over	☐

b) Are you male ☐ female ☐

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

White	☐	
Black Caribbean	☐	
Black African	☐	
Black - other	☐	
Indian	☐	
Pakistani	☐	
Bangladeshi	☐	
Chinese	☐	
Other ethnic group	☐	Please specify……

d) Please could you tell us if you worked.

Please specify your occupation ……..

e) Please rate what you feel is your quality of hearing

Very good	☐
Good	☐
Fair	☐
Poor	☐

e) Please rate what you feel is your quality of vision (with glasses or contact lenses)

Very good	☐
Good	☐

Fair ☐

Poor ☐

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:

e) Bladder problems…..

Passing water more than about 8 times a day ☐

Feeling an urgent need to pass water ☐

Getting up more than twice a night to pass water ☐

Having problems emptying your bladder ☐

Accidentally wetting yourself ☐

Accidentally wetting yourself if you laugh or cough ☐

Having a catheter ☐

Any others? Please describe them below. ☐

……

e) Bowel problems…..

Often having an urgent need to open your bowels ☐
Having to strain to open your bowels ☐

Being constipated ☐

Accidentally loosing control of your bowels ☐

If you have ticked this one, is it
a) when you pass wind? ☐
b) liquid? ☐
c) solid? ☐

Having a stoma bag ☐

Any others? Please describe them below. ☐

……

Section 2: 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	**Slightly**	**Moderately**	**A at all lot**
c) Does your problem limit your social life?	☐	☐	☐	☐
d) Does your problem limit your ability to see or visit friends?	☐	☐	☐	☐
e) Is it a problem having to change your underwear if it gets soiled?	☐	☐	☐	☐
f) Do you worry in case you smell?	☐	☐	☐	☐
g) Do you get embarrassed because of your problem?	☐	☐	☐	☐

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

Thank you for completing this questionnaire.

APPENDIX 2 – Barthel Index

The Barthel Index

Patient Name ……

Rater Name ……

Date: ……

Activity	Score
BOWELS **2** = continent (for preceding week). **1** = occasional accident (once a week or less). **0** = any worse grade of incontinence (or needs enemas for continence).	
BLADDER **2** = continent (for preceding week), or able to manage any device (e.g. catheter and bag) without help. **1** = occasional accident (once a day or less), or catheterized and needs help with device. **0** = any worse grade of incontinence	
FEEDING Food placed within reach by others: **2** = able to cup up food, spread butter etc, without help. **1** = needs some help cutting or spreading. **0** = needs to be fed.	
GROOMING **1** = independent washing face, combing hair, shaving, & cleaning teeth (when implements are provided). **0** = needs help.	
DRESSING **2** = independent putting on all clothes, incl. fastening buttons, zips etc (clothes may be adapted). **1** = needs some help, but can do at least half. **0** = needs more help than this.	
TRANSFER: Bed to chair and back: **3** = needs no help. **2** = needs minor help, verbal or physical. Can transfer with one person easily, or needs supervision. **1** = needs major help: two people or one strong/trained person, but can sit unaided. **0** = cannot sit; needs skilled lift by two people (or hoist).	
TOILET USE: **2** = to be able to get on and off toilet or commode, undress and dress sufficiently and wipe self without physical or verbal help. **1** = needs some help, can wipe self and do some of the rest with minimal help only.	

0 = needs more help than this.	
MOBILITY: Around house or ward, indoors: **3** = may use aid (stick or frame etc., but not wheelchair). **2** = needs help of one person, verbal or physical, including help standing up. **1** = independent in wheelchair, incl. able to negotiate doors and corners unaided. Needs help, verbal or physical or help carrying aid. **0** = needs more help than this.	
BATHING: **1** = Able to get in and out of bath or shower, wash self without any help (may use aids). **0** = unable.	

The following guidelines will also help allocate a patient to a category:

Mild: slight disability, unable to carry out all previous activities, but able to look after own affairs without assistance.

Moderate: requiring some help, but able to walk without assistance and unable to attend to own bodily needs without assistance.

Severe: bedridden, incontinent and requiring constant nursing and attention.

APPENDIX 3 – Abbreviated Mental Test Score (AMTS)

Abbreviated Mental Test Score (AMTS)

EACH QUESTION SCORES ONE POINT

1. Age (must be correct) ☐
2. Time to nearest hour (without looking at timepiece – correct to nearest hour) ☐
3. An address - 42 West Street – Ask patient to repeat to ensure understanding (memory to be checked at end of test) ☐
4. Month (Exact) ☐
5. Year (Exact, except in Jan/Feb when previous year ok) ☐
6. Name of place, if not in hospital ask type of place or area of town. ☐
7. Date of birth (Exact) ☐
8. Year first world war started (Exact) ☐
9. Name of present monarch (Exact) ☐
10. Count backwards from 20 to 1 (Can prompt with 20-19-18, but no further prompts) ☐

Total score _____

Patient can hesitate and self correct but no other errors.

Score: 8-10 Normal
7 Probably abnormal
<6 Abnormal

APPENDIX 4 – Staff Information Sheet

Staff Information Sheet

A study of privacy and dignity in continence care: developing patient based standards and recommendations for care (Phase 2)

My name is [name] and I am a researcher at the University of Kent. I will shortly be conducting a research study in your ward/nursing home. The aim of the study is to identify how older people with continence problems can best maintain their dignity. This study has three parts to it. Firstly we asked groups of people with continence issues to help us identify what preserving dignity meant to them. We then used this information and current literature to develop and pilot an observation schedule. We are now ready to do an observation phase of the project and your ward/nursing home has been selected.

What is the purpose of the study?

This study is all about finding out the best way for older people who have difficulties with their bladders or bowels to keep their dignity in a hospital ward/nursing home. One of the best ways of finding this out is to observe people while they are having their bladder or bowel care. I am particularly interested in finding out about how people's dignity is maintained in nursing homes and on hospital wards. This research will help us to develop some standards of care to help people maintain their dignity during bladder and bowel care in the future.

The study will last for 2 years and it is anticipated that observations in your ward/nursing home will take place over approximately 12 days in a seven week period. The results may be published in journals and talked about in research seminars and conferences. The study has been approved by ethics committees and is jointly run by the University of Kent and the Royal College of Physicians, who are funding the research.

What will I have to do?

I would be grateful if you could help us to identify at least 5 patients/residents with continence problems for this study, and see if they might be interested in taking part. I will give you an information sheet for the patient/resident which you may need to read through with them. If they are interested, we would like you to pass on their details to us and we will explain the study in full and get their consent. I will visit you to discuss this further and talk through any queries you may have about this study. I will then return a week later and speak to any patients/residents who have agreed to take part. During my time at the study if there any new patients/residents with continence problems in the ward/nursing home I would be very grateful if you could continue to ask them if they would like to participate.

Patients agreeing to take part will also have to fill out a questionnaire and we may need you to help them fill this in. A Barthel Index score and an Abbreviated Mental Test Score will also be taken for each patient/resident and we may also need your help with getting this information.

Which patients will be chosen?

The following is a list of inclusion criteria for patients to take part in the study :

- 65 years or older
- Cognitively or linguistically able to give consent to take part in the observation study.
- Any of: urinary and/or faecal incontinence; requiring assistance with toileting; assistance with the use of maintenance products or assistance with catheter or bowel care.
- Will be in your ward/nursing home for at least four days before commencement of the study

What will happen during the course of the observation study?

It is expected that the observation phase will take place over 12 days within a seven week period. This may be subject to change, depending upon the need for further observations and I will keep you informed at all times. However, I anticipate that I will visit your ward/nursing home and will observe for four hours each day over six consecutive days. I will do this on two different occasions. On the very first day of all observation periods, I will observe for two four hourly spans and this is to allow patients/residents to become accustomed to me being on the ward/nursing home.

The time periods will cover all hours of the day and night and I will let you know in advance when I will be coming. I will be looking at privacy and dignity issues centred on bladder and bowel events such as toileting and catheter care and recording my observations on a schedule. I will be observing different patients/residents at different times and will not be observing patients/residents who do not give consent. I would be grateful if you could completely ignore me when I am in your ward.

This is a sensitive research study and it will mean that I will be observing patients/residents during toileting episodes, however, I will withdraw at the same time as the nurse. It may be possible that patients/residents become very distressed during observation. I will be very sensitive to this and if this should happen I will ask for your help in reassuring them and making sure that they still want to continue with the observations. If patients/residents continue to be distressed then I will withdraw completely from observation of that patient/resident.

I would like to reassure you that I will not intrude on any aspect of the care you are giving patients/residents and I will not obstruct or interrupt you in your work, unless an emergency occurs where I may need to intervene to call for assistance (such as a cardiac or respiratory arrest, or a person about to fall). I am there purely to observe and identify criteria for best practice.

Alongside the observation I will be collecting other pieces of information. This will consist of a map of the area I will be observing, some details about the number and grades of staff on duty, the number of people in the on the ward/nursing home and numbers of visitors.

How confidential is this information?

All information collected about the study site or staff and patients/residents within the site during the course of this research will be kept strictly confidential. It will be stored in a password protected computer and accessed by one researcher. Once the study has finished, we will destroy any data collected. The site, patients/residents or staff will not be identifiable in any reports that we publish from this research.

Contact for further information

If you have any questions please contact Charlotte Hastie at:

Centre for Health Services Studies, University of Kent, George Allen Wing
Canterbury, Kent, CT2 2NF
Tel: 01227 823680
Fax: 01227 827868
E-mail: C.L.Hastie@kent.ac.uk

Thank you for your assistance.

APPENDIX 5 – Patient Information Sheet

Patient Information Sheet

A study of privacy and dignity in continence care: developing patient based standards and recommendations for care (Phase 2)

My name is [name] and I am a researcher at the University of Kent. I would like to invite you to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others such as friends, family and staff if you wish. I will be happy to give you some more information about the study, and my contact details are at the end of this information sheet.

What is the purpose of the study?

This study aims to find out the best way for older people who have difficulties with their bladders or bowels to keep their dignity in a nursing home or in a hospital ward. One way of finding this out is to observe events of bladder and bowel care. I am particularly interested in finding out about how people's dignity is maintained in nursing homes and on hospital wards. Incontinence is a common problem which affects people from all walks of life. Lots of people suffer from incontinence although it is not often talked about. This research will help us to develop some standards of care to help people maintain their dignity during bladder and bowel care in the future.

Your participation in the study will be up to 12 days over a seven week period. The results may be published in journals and talked about in research seminars and conferences. The study will run for 2 years has been approved by ethics committees and is jointly run by the University of Kent and the Royal College of Physicians, who are funding the research.

Why have I been chosen?

You are being invited to take part because you have some bladder or bowel difficulties. Also because you expressed an interest to staff that you may take part. We will also be inviting other patients with similar problems to take part in this study, and there should be approximately 5 people in your ward/nursing home in total.

Do I have to take part?

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

What will happen to me if I take part?

If you do decide to take part you will be asked to sign a consent form. You will then be asked to fill in a questionnaire that records information about your bladder and bowel difficulties and some questions about your quality of life. Either myself or the nurses can help you fill out this questionnaire if you want. There will be another two very short assessments of your physical and mental health. All of these will help us to find out whether you are able to take part in this study and this should take no more than a few minutes of your time.

I will then be present in the ward/nursing home and will be in the background looking to see what happens when you have any bladder or bowel care, and recording this on a schedule. The type of things on the schedule could be things such as looking at the general environment you are in, interactions you have with other people, how many people are on the ward/nursing home, etc. I would be grateful if you could completely ignore me when I am around. I will not intrude in your care in any way and am only there to observe just like a 'fly on the wall'. All patients who consent to taking part in this study will be observed during this time.

I may ask you to have a look at the schedule sometimes to see if you agree with what I am recording about your bladder and bowel care and how dignity is maintained.

I would like to point out that taking part in this research will mean that I will be observing you during toileting episodes, but I will not actually observe you whilst you are on the toilet. If at any point during the observation you suddenly decide that you don't like being watched any more and it is upsetting you then please let me know. If you decide that you really don't want to take part in the study any more then I will stop observing you.

I will be observing a number of patients/residents over approximately 12 days in a seven week period I will observe for four hours each day over six consecutive days covering all times during the day and night. I may do this twice. I may be there for a shorter or longer period but I will let you know in advance when I will be coming. I will be recording observations for four hours at a time. On the very first day of observation I will observe for two four hourly spans and this is to allow you and other patients/residents to become accustomed to me being on the ward/nursing home.

Will my taking part in this study be kept confidential?

I would like to reassure you that any information collected about you will be strictly confidential. It will be stored in a password protected computer and accessed by one researcher. Once the study has finished, we will destroy any data collected about you and you will not be identifiable in any written report.

Who do I contact for further information?

If you have any questions please contact Charlotte Hastie at:
Centre for Health Services Studies, University of Kent
George Allen Wing
Canterbury, Kent, CT2 2NF
Tel: 01227 823680 E-mail: C.L.Hastie@kent.ac.uk

APPENDIX 6 – Consent form for study

Consent Form

Title of the Project: A study of privacy and dignity in continence care: developing patient based standards and recommendations for care.

Please initial the boxes on the right, write your name in capitals and sign over the page and for the last question circle either yes or no. Please include your address and telephone number so we can contact you. Thank you.

1. I confirm that I have read and understand the patient 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. Are you taking part in any other projects?

Yes No

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

…… ……

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

Address……
……
……

Telephone Number……..

APPENDIX 7 – Observation Schedule

1. Environmental Factors

Centre ID…… Date…….
Researcher……

Communal toilet cubicles

The toilets are easily accessible: yes ☐ no ☐
……

The toilets are: single sex ☐ unisex ☐
……

Space in the cubicles are: ample ☐ adequate ☐ cramped ☐
……..

The doorways are: narrow ☐ average width ☐ wide ☐
……

The toilet doors can be locked: yes ☐ no ☐
……

The toilet doors have an 'engaged' sign when locked: yes ☐ no ☐
……..

The doors can be opened and shut easily: yes ☐ no ☐
……..

Is there a step/steps to go up or down: yes ☐ no ☐
……

Is there assistive equipment available: yes ☐ no ☐ If yes, this is……

What height are the toilets: high ☐ adequate ☐ low ☐
……

Are there facilities to wash bottoms: yes ☐ no ☐
……

Is there toilet paper available: yes ☐ no ☐
……

Toilet paper is in easy reach: yes ☐ no ☐
……

Flush systems are easy to activate: yes ☐ no ☐
……

Wash basins are close by: yes ☐ no ☐ different room ☐
……

Soap is available: yes ☐ no ☐
……
Soap dispenser in easy reach: yes ☐ no ☐
……

Drying facilities are available/working: yes ☐ no ☐
……
Facilities to dry hands: hand dryer ☐ towel ☐ paper towel ☐
……

Are hand drying facilities in easy reach: yes ☐ no ☐
……

Buzzer/alarm in place: yes ☐ no ☐
……

If yes, is buzzer/alarm in easy reach: yes ☐ no ☐
……

Lighting is acceptable: yes ☐ no ☐
……

Cleanliness acceptable standard: yes ☐ no ☐
……

Any unpleasant odours: yes ☐ no ☐
……

Any hazards: yes ☐ no ☐
……

Notes:

Space

Is the space between beds ample ☐ adequate ☐ cramped ☐
……

Is space in the rooms ample ☐ adequate ☐ cramped ☐
……..

Curtains and Screens

Curtains and/or screens are: long enough ☐ adequate ☐ too short ☐
……..

Environment at night

Is the noise level acceptable: yes ☐ no ☐
Describe……

……

Is the lighting used acceptable: yes ☐ no ☐
Describe……

……

Notes:

2. Organisational Factors

Centre ID…… Date……
Researcher……

Observation period …… Day of the week……..
Start time……End time……..

Number of patients/residents…… Total number of staff on duty……..
Number of bank/ agency staff on duty……....

Are they short of staff: yes ☐ no ☐
……

Staff change over: yes ☐ no ☐
If yes, when occurred …… where occurred…….. Time taken……

Do patients/residents have a named carer or nurse: yes ☐ no ☐
……

What is the toileting and checking regime (*e.g. every 2 hours*)……

Organisational factors observed that promote dignity *(e.g. Standards of care used)*
……

Organisational factors observed that compromise dignity (*e.g. Buzzers going all night or storeroom in participants room)*
……

Notes:

3. Participant Information

Centre ID……Observation Start date……
Researcher……

Participant ID……Participants chosen name……....
Participant Location……

Is this: Ward bay ☐ Shared room ☐ En-suite shared room ☐
Private room ☐ En-suite private room ☐

Sex : Male ☐ Female ☐ Date of Birth……..
Age……..

Date of admission…… Reason for admission……

Type of incontinence: urinary ☐ faecal ☐
Reason for incontinence……..

Has/wears: Pads ☐ Incontinence pants ☐ Sheath ☐ Catheter ☐
Colostomy ☐ Urostomy ☐

Barthel Score……. Mini-mental test score…….

Mobility: Mobile ☐ Mobile with frame ☐ Frame+1 ☐ Frame+2 ☐
Transfers +1 ☐ Transfers+2 ☐ Wheelchair ☐ Bed ☐

Notes (e.g. *care plan information, preference to be changed by female or male, hearing/sight problems, language, post-stroke):*

4. Event

Centre ID……. Date…….
Researcher……

Observation period……. … Day of the week…….
Start time……End time…….

Participant ID…… Event ID…….

Length of event
Start time…… End time……..

Response time *(e.g. time it takes to be taken to the toilet/commode or changed after asking)……*min

Was the length of event considered to be appropriate *(e.g. time left on the toilet/commode, time to settle, ok for participant)*

Yes ☐ Somewhat ☐ No ☐
Describe…….

Overall rating of event Most dignified 1 2 3 4 5 Most undignified

Notes:

Start of Event

Ward/home is: Busy ☐ Average ☐ Quiet ☐

Ward/home activity at time of request: Mealtime ☐ Medicine round ☐ Ward round ☐ Handover ☐ Other ☐
If other, describe ……..

Participant Location: Bed ☐ Chair by bed ☐ Dayroom ☐
Corridor ☐ Private room ☐ Other ☐
If other, describe ……..

Participant activity at start of event: Asleep ☐ Lying ☐ Sitting ☐
Reading/TV ☐ Chatting to others ☐ therapy ☐ Other ☐
If other, describe ……..

Participant dressed in: Day clothes (own) ☐ Day clothes (hospital) ☐
Nightclothes (own) ☐ Hospital gown ☐

Has/wearing: Pad ☐ Incontinence pants ☐ Sheath ☐ Catheter bag ☐
Leg Bag ☐ Colostomy bag ☐ Urostomy bag ☐

Is this visible before or at start of event: Yes ☐ No ☐
Is there an unpleasant smell: Yes ☐ No ☐

If wearing a pad, have they: Been wet for a long time ☐ Overflowing ☐

Notes:

Start of Event

Event started by: Buzzer/call bell ☐ Participant asks for assistance ☐
Another person asks on their behalf ☐ Staff initiate episode ☐

If relevant, staff knocked before entering room: Yes ☐ No ☐
Was the knock dignified (*i.e. not thumping)* Yes ☐ No ☐

Staff member was a: Nurse ☐ Care staff ☐ Other professional ☐
If other, describe……

Number of staff involved…… Male ☐ Female ☐

Participant was called by their preferred name: Yes ☐ No ☐
Good or friendly approach: Yes ☐ No ☐

If relevant, participant given choice of toileting event *e.g. between toilet, commode or bed pan*
Yes ☐ No ☐

What is used/to be done: Toilet ☐ Commode ☐ Bed pan ☐
Slipper pan ☐ Pad change ☐ Catheter care ☐ Bowel care ☐

The staff explained what they were going to do: Yes ☐ Partly ☐ No ☐
Describe……

Staff were discreet *e.g. talking loudly about toileting or when moving them for toileting:*
Yes ☐ Sometimes ☐ No ☐
Describe……

Staff were gentle *e.g. when moving them out of bed or taking them to the toilet*
Yes ☐ Sometimes ☐ No ☐

Describe……

Notes:

Middle of event

If participant taken to the toilet:

They are taken: On own ☐ With Frame ☐ Frame+1 ☐ Frame+2 ☐
Wheelchair ☐ Hoist ☐

They are taken to: Preferred toilet ☐ Nearest toilet ☐ Next available toilet ☐

If participant using commode/bed pan:
Where was this located at start: Sluice ☐ Bed side / in room ☐

They are taken: On own ☐ With Frame ☐ Frame+1 ☐ Frame+2 ☐
Transfer+1 ☐ Transfer+2 ☐ Hoist ☐

During toileting, changing and washing:

The door was: Closed ☐ Locked ☐ Unlocked ☐ Ajar ☐ Open ☐
Privacy sign used ☐

Curtain/screen was: Drawn ☐ Apart ☐ Open ☐ Pegs used ☐
Privacy sign used ☐

Toileting, changing or washing was done **gently** *(not rushed*):
Yes ☐ Sometimes ☐ No ☐
Describe…….

Toileting, changing or washing was done **discreetly**: Yes ☐ Sometimes ☐
No ☐
Describe…….

The participant was kept covered up: Yes ☐ Sometimes ☐ No ☐
Describe…….

Notes:

End of Event

Washing and Cleanliness:

Participant was washed in: Bath ☐ Shower ☐ By the bed ☐ On the bed ☐

Participant allowed or offered opportunity to wash or wipe self *(wiping bottom)*
Yes ☐ No ☐

The participant washed or wiped: themselves ☐ by nurse/carer ☐

The participant was: Washed thoroughly ☐ Properly wiped ☐ Properly dried ☐

Skin Care: Cream was offered ☐ Cream was used ☐
Talc was offered ☐ Talc was used ☐

Appearance and Smell: Fragrant/spray offered ☐ Fragrant/spray used ☐ Hair combing offered ☐ Hair combed ☐ Other ☐
If other, describe ……

Settling:

If relevant: Pad changed: Yes ☐ No ☐ Pad or other aid not showing through clothes ☐

If relevant: Changed into clean clothes/night gown Yes ☐ No ☐ Dressed properly Yes ☐ No ☐

If necessary: Bed Changed Yes ☐ No ☐
Changed properly Yes ☐ No ☐

At end of event: All equipment/supplies taken away ☐ Area left clean ☐ Area left smelling OK ☐

Buzzer accessible ☐ Belongs/drinks left in reach ☐
Participant looks comfortable/settled ☐

Staff respond to requests at end of event *(e.g. asking for juice)*: Yes ☐ No ☐
Describe…….

Notes:

Staff communication and interaction with participant during event

When possible/needed participants were given: Privacy ☐ Independence ☐ Dignity ☐ Information repeated ☐

Describe……

Staff awareness of participant's individual needs (*e.g. mental health, mobility, character)*……

Positive Communication

Person:

	1	2
Respectful	☐	☐
Non-intrusive	☐	☐
Polite	☐	☐
Courteous	☐	☐
Thoughtful/ considerate	☐	☐
Gentle manner	☐	☐
Reassuring	☐	☐
Bubbly	☐	☐
Energetic	☐	☐
Friendly	☐	☐
Sociable	☐	☐
Joking/laughing/ teasing	☐	☐
Small talk/chat	☐	☐
Patient	☐	☐
Easy going	☐	☐
Not hassled/ not in a panic	☐	☐
On top of job	☐	☐
Efficient	☐	☐
Clear	☐	☐

Negative Communication

Person:

	1	2
Disrespectful	☐	☐
Intrusive	☐	☐
Rude	☐	☐
Patronising	☐	☐
Inconsiderate	☐	☐
Abrupt	☐	☐
Unsettling	☐	☐
Miserable	☐	☐
Narky	☐	☐
Unfriendly	☐	☐
Unsociable	☐	☐
Grumpy	☐	☐
Sharp	☐	☐
Impatient	☐	☐
Moaning	☐	☐
Hassled/ rushed	☐	☐
Not on top of job	☐	☐
Inefficient	☐	☐
Unclear *(e.g. used jargon)*	☐	☐

Interaction

Person:

	1	2
Smiling	☐	☐
Eye contact	☐	☐
Treated as an equal	☐	☐
Treated as an individual	☐	☐
Ignored	☐	☐
Listened to	☐	☐
Concerns taken seriously	☐	☐

Tone of voice:

Person:

	1	2
Soft	☐	☐
Adequate	☐	☐
Loud	☐	☐
Shouting	☐	☐

Describe *(e.g. body language)*…… ……. ……

Good language used (*words like 'not a problem' or 'don't worry')* …… ……..

Poor language used *(words like nuisance or 'what do you want')* …… ……..

Notes:

APPENDIX 8 – Hospital Staff Information Sheet validation
Revised version 2

Hospital Staff Information Sheet - validation

A study of privacy and dignity in continence care for older people: developing patient based standards and recommendations for care

My name is **Helen Alaszewski** and I am a researcher at the University of Kent. I will shortly be conducting a research study in your ward. The aim of the study is to identify how older people with continence problems can best maintain their dignity. This study has three parts to it. Firstly we asked groups of people with continence issues to help us identify what preserving dignity meant to them. We then used this information and current literature to develop and pilot an observation schedule. We have completed the first two phases and need to check that what we have observed reflects the patient's views.

What is the purpose of the study?

This study is all about finding out the best way for older people who have difficulties with their bladders or bowels to keep their dignity in their nursing homes/a hospital ward. One of the best ways of finding this out is to observe people while they are having their bladder or bowel care. Having carried out the observations and analysed the data, we need to check our findings with patients to validate how people's dignity is maintained in nursing homes and on hospital wards. This research will help us to develop some standards of care to help people maintain their dignity during bladder and bowel care in the future.

The study will last for 2 years in total but for this validation phase we will come to the ward to carry out short interviews with patients on three separate occasions. The results may be published in journals and talked about in research seminars and conferences. The study has been approved by ethics committees and is jointly run by the University of Kent and the Royal College of Physicians, who are funding the research.

What will I have to do?

I would be grateful if you could help us to identify at least 5 patients with continence problems for this study, and see if they might be interested in taking part. I will give you an information sheet for the patient which you may need to read through with them. If they are interested, we would like you to pass on their details to us and we will explain the study in full and get their consent. I will visit you to discuss this further and talk through any queries you may have about this study. I will then return a week later and speak to any patients who have agreed to take part. During my time at the study if there any new patients with continence problems in the ward I would be very grateful if you could continue to ask them if they would like to participate.

Which patients will be chosen?

The following is a list of inclusion criteria for patients to take part in the study :

- 65 years or older
- Cognitively and linguistically able to give consent to take part in the observation study.
- Any of: urinary and/or faecal incontinence; requiring assistance with toileting; assistance with the use of maintenance products or assistance with catheter or bowel care.
- Will be in your ward for at least four days before commencement of the study.

What will happen during the course of the *validation study?*

It is expected that this validation phase will take place over 3 days within a one week period. I anticipate that I will visit your ward and will carry out a short interview with the 5 patients after 3 occasions of receiving personal care. I will vary the times I am present on the ward to cover busy and quiet times.

The time periods will cover all hours of the day and I will let you know in advance when I will be coming. I will be talking to patients about privacy and dignity issues centred on bladder and bowel events such as toileting and catheter care and also making field notes.

This is a sensitive research study and it will mean speaking to patients after 3 toileting episodes. After gaining initial consent, I will check with patients before doing each validation interview that they are happy to proceed and reinforce that they may withdraw from the research if they wish to.

I would like to reassure you that I will not intrude on any aspect of the care you are giving patients and I will not obstruct or interrupt you in your work, unless an emergency occurs where I may need to intervene to call for assistance (such as a cardiac or respiratory arrest, or a person about to fall). I am there purely to speak to patients and identify criteria for best practice.

As well as speaking to the patients I will be collecting other pieces of information. This will consist of a map of the area I will be observing, some details about the number and grades of staff on duty, the number of people in the on the ward and numbers of visitors.

How confidential is this information?

All information collected about the study site or staff and patients within the site during the course of this research will be kept strictly confidential. It will be stored in a password protected computer and accessed by one researcher. Once the study has finished, we will destroy any data collected. The site, patients or staff will not be identifiable in any reports that we publish from this research.

Contact for further information

If you have any questions please contact **Helen Alaszewski** at:

Centre for Health Services Studies, University of Kent, George Allen Wing
Canterbury, Kent, CT2 2NF
Tel: 01227 **827641**
Fax: 01227 827868
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Thank you for your assistance.

APPENDIX 9 – Nursing home Staff Information Sheet
Revised version 2

Nursing Home Staff Information Sheet - validation

A study of privacy and dignity in continence care for older people: developing patient based standards and recommendations for care

My name is **Helen Alaszewski** and I am a researcher at the University of Kent. I will shortly be conducting a research study in your nursing home. The aim of the study is to identify how older people with continence problems can best maintain their dignity. This study has three parts to it. Firstly we asked groups of people with continence issues to help us identify what preserving dignity meant to them. We then used this information and current literature to develop and pilot an observation schedule. We have completed the first two phases and need to check that what we have observed reflects the residents' views.

What is the purpose of the study?

This study is all about finding out the best way for older people who have difficulties with their bladders or bowels to keep their dignity in their nursing homes/a hospital ward. One of the best ways of finding this out is to observe people while they are having their bladder or bowel care. Having carried out the observations and analysed the data, we need to check our findings with patients/residents to validate how people's dignity is maintained in nursing homes and on hospital wards. This research will help us to develop some standards of care to help people maintain their dignity during bladder and bowel care in the future.

The study will last for 2 years but for this validation phase we will come to your nursing home to carry out short interviews with residents on three separate occasions. The results may be published in journals and talked about in research seminars and conferences. The study has been approved by ethics committees and is jointly run by the University of Kent and the Royal College of Physicians, who are funding the research.

What will I have to do?

I would be grateful if you could help us to identify at least 5 residents with continence problems for this study, and see if they might be interested in taking part. I will give you an information sheet for the resident which you may need to read through with them. If they are interested, we would like you to pass on their details to us and we will explain the study in full and get their consent. I will visit you to discuss this further and talk through any queries you may have about this study. I will then return a week later and speak to any residents who have agreed to take part. During my time at the home if there any new residents with continence problems in the home I would be very grateful if you could continue to ask them if they would like to participate.

Which residents will be chosen?

The following is a list of inclusion criteria for residents to take part in the study :

- 65 years or older

- Cognitively and linguistically able to give consent to take part in the study.
- Any of: urinary and/or faecal incontinence; requiring assistance with toileting; assistance with the use of maintenance products or assistance with catheter or bowel care.
- Will be in your nursing home for at least four days before commencement of the study.

What will happen during the course of the *validation study?*

It is expected that this validation phase will take place over 3 days within a one week period. I anticipate that I will visit your nursing home and will carry out a short interview with the 5 residents after each of 3 occasions of receiving personal care. I will vary the times I am present at the nursing home to cover busy and quiet times.

The time periods will cover all hours of the day and I will let you know in advance when I will be coming. I will be talking to residents about privacy and dignity issues centred on bladder and bowel events such as toileting and catheter care and also making field notes.

This is a sensitive research study and it will mean speaking to residents after each of 3 toileting episodes. After gaining initial consent, I will check with residents before doing each validation interview that they are happy to proceed and reinforce that they may withdraw from the research if they wish to.

I would like to reassure you that I will not intrude on any aspect of the care you are giving residents and I will not obstruct or interrupt you in your work, unless an emergency occurs where I may need to intervene to call for assistance (such as a cardiac or respiratory arrest, or a person about to fall). I am there purely to observe and identify criteria for best practice.

As well as speaking to the residents I will be collecting other pieces of information. This will consist of a map of the area I will be observing, some details about the number and grades of staff on duty, the number of people in the nursing home and numbers of visitors.

How confidential is this information?

All information collected about the study site or staff and residents within the site during the course of this research will be kept strictly confidential. It will be stored in a password protected computer and accessed by one researcher. Once the study has finished, we will destroy any data collected. The site, residents or staff will not be identifiable in any reports that we publish from this research.

Contact for further information

If you have any questions please contact **Helen Alaszewski** at:

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Thank you for your assistance.

APPENDIX 10 – Hospital Patient Information Sheet
Revised version 2

Hospital Patient Information Sheet - validation

A study of privacy and dignity in continence care for older people: developing patient based standards and recommendations for care.

My name is **Helen Alaszewski** and I am a researcher at the University of Kent. I would like to invite you to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others such as friends, family and staff if you wish. I will be happy to give you some more information about the study, and my contact details are at the end of this information sheet.

What is the purpose of the study?

This study aims to find out the best way for older people who have difficulties with their bladders or bowels to keep their dignity in a nursing home or in a hospital ward. One way of finding this out is to ask patients how they felt about the care they have been receiving. I am particularly interested in finding out about how people's dignity is maintained in nursing homes and on hospital wards. Incontinence is a common problem which affects people from all walks of life. Lots of people suffer from incontinence although it is not often talked about. This research will help us to develop some standards of care to help people maintain their dignity during bladder and bowel care in the future.

Your participation in the study will be up to 3 days over a one week period. The results may be published in journals and talked about in research seminars and conferences. The study will run for 2 years has been approved by ethics committees and is jointly run by the University of Kent and the Royal College of Physicians, who are funding the research.

Why have I been chosen?

You are being invited to take part because you have some bladder or bowel difficulties. Also because you expressed an interest to staff that you may take part. We will also be inviting other patients with similar problems to take part in this study, and there should be approximately 5 people in your ward in total.

Do I have to take part?

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

What will happen to me if I take part?

If you do decide to take part you will be asked to sign a consent form.

I will then be present in the ward over 3 days in a one week period. On 3 occasions when you have some personal care given during the 3 days I am on the ward, I will come and check whether you felt your privacy and dignity were maintained. This will involve having a short conversation with you of about 15 minutes. With your permission I will record this interview. The purpose of this is to check that what we recorded in the observation phase of the study accurately reflects what patients feel.

I will be chatting to a number of patients over 3 days in a one week period. I will be on the ward for a number of hours for each of the 3 days covering all times during the day I will let you know in advance when I will be coming.

Will my taking part in this study be kept confidential?

I would like to reassure you that any information collected about you will be strictly confidential. It will be stored in a password protected computer and accessed by one researcher. Once the study has finished, we will destroy any data collected about you and you will not be identifiable in any written report.

Who do I contact for further information?

If you have any questions please contact **Helen Alaszewski** at:
Centre for Health Services Studies
University of Kent
George Allen Wing
Canterbury, Kent, CT2 2NF
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APPENDIX 11 – Nursing Home Resident Information Sheet
Revised version 2

Nursing Home Resident Information Sheet - validation

A study of privacy and dignity in continence care for older people: developing patient based standards and recommendations for care.

My name is **Helen Alaszewski** and I am a researcher at the University of Kent. I would like to invite you to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others such as friends, family and staff if you wish. I will be happy to give you some more information about the study, and my contact details are at the end of this information sheet.

What is the purpose of the study?

This study aims to find out the best way for older people who have difficulties with their bladders or bowels to keep their dignity in a nursing home or in a hospital ward. I am particularly interested in finding out about how people's dignity is maintained in nursing homes and on hospital wards. One way of finding this out is to ask residents how they felt about the care they have been receiving. Incontinence is a common problem which affects people from all walks of life. Lots of people suffer from incontinence although it is not often talked about. This research will help us to develop some standards of care to help people maintain their dignity during bladder and bowel care in the future.

Your participation in the study will be up to 3 days over a one week period. The results may be published in journals and talked about in research seminars and conferences. The study will run for 2 years has been approved by ethics committees and is jointly run by the University of Kent and the Royal College of Physicians, who are funding the research.

Why have I been chosen?

You are being invited to take part because you have some bladder or bowel difficulties. Also because you expressed an interest to staff that you may take part. We will also be inviting other residents with similar problems to take part in this study, and there should be approximately 5 people in your home in total.

Do I have to take part?

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

What will happen to me if I take part?

If you do decide to take part you will be asked to sign a consent form.

I will then be present in the home over 3 days in a one week period. On 3 occasions when you have some personal care given during the 3 days I am in the home, I will come and check whether you felt your privacy and dignity were maintained. This will involve having a short conversation with you of about 15 minutes. With your permission I will record the interview. The purpose of this is to check that what we recorded in the observation phase of the study accurately reflects what residents feel.

I will be chatting to a number of residents over 3 days in a one week period. I will be on the ward for a number of hours for each of the 3 days covering all times during the day I will let you know in advance when I will be coming.

Will my taking part in this study be kept confidential?

I would like to reassure you that any information collected about you will be strictly confidential. It will be stored in a password protected computer and accessed by one researcher. Once the study has finished, we will destroy any data collected about you and you will not be identifiable in any written report.

Who do I contact for further information?

If you have any questions please contact **Helen Alaszewski** at:
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APPENDIX 12 Interview Schedule for Validation

Privacy and Dignity in Continence Care
Validation Interview Schedule Version 7

In this interview we would like to talk to you about the personal care you are getting and what factors are important to you in helping you maintain your dignity.

1. **Dignity**
   One person in the study said she felt you left your dignity at the door when you went into hospital – how do you feel about this? (*only ask once*)

Thinking about the personal care you have just received:

2. **Needing help**
   Please could you tell me a little bit about what help you needed?
   - how do you feel about being helped to go to the toilet? *(ask only on first interview)*

3. **Choice and care**
   Was the care carried out in the way you wished it to be?
   - was there anything you would have preferred i.e. did you have to wait; would you have liked more time; what would more staff mean for your care; were you able to do things for yourself; were you handled in the way you wished to be?

4. **Communication and care**
   Thinking about the care you have just had, do you talk to the staff while they are giving you care?
   - what kinds of things did you talk about; did they explain things; in what way did they what they explain

5. **Privacy**
   I'd like to ask you about privacy now, did you feel that you had privacy when you were being helped?
   - Was the door closed/ curtains shut, covered up, voice

6. **Hygiene and comfort**
   Thinking about cleanliness, how do you feel now?
   - were you able to wash your hands, do you feel comfortable

Was there anything in the care you just received that you felt added to or took away from your dignity?