



Breaking the Silence On Women’s Experiences of Urinary Incontinence

First Project Report

Dr Dani Barrington, Dr Lena Jaspersen and Isobel Sale

Contents

Introduction	1
Agenda-setting workshops	2
Challenges	2
Social incontinence	3
Continence products.....	3
Health and dignity.....	4
Exercises and treatments.....	5
Information access.....	5
Opportunities.....	6
Communication.....	6
Information access.....	7
Interventions.....	7
Conclusions and way forward	8
Appendix: Overview of challenges and opportunities.....	10

Introduction

Urinary incontinence (UI) disproportionately affects women. It is estimated that about one in three women experience the involuntary leakage of urine at some point in their life. Although the condition is discussed in the medical literature,



little is known about the experiences, needs and coping strategies of women, especially those who are not hospitalised or in care. Leakage can evoke feelings of embarrassment and shame. Many women affected by UI hesitate to seek medical assistance, and if they do, diagnosis can be difficult because UI is a symptom with varying causes. Resource constraints, gendered sociocultural norms, and a lack of institutional infrastructure restrict access to healthcare technologies that can improve the quality of life for women experiencing UI.

We are a team of early-career researchers developing an inter-disciplinary research agenda for collaborative innovation to address UI in women. To do so, we need to better understand the experiences of the women affected, as well as the broader innovation ecosystem of researchers, healthcare providers, family members and carers, charities, and firms developing continence products.

Agenda-setting workshops

Supported by the University of Leeds Research Development Fund and [IMPRESS](#), in October 2018 we facilitated three agenda-setting workshops; one with women who experience UI and two with stakeholders working in this field, including nurses, midwives, physiotherapists, activists, yoga instructors and researchers. Nineteen participants took part in our informal workshops. Each workshop involved open discussion and a brainstorming exercise. The workshops began with a short talk about the emerging research agenda of the research team. At two of the workshops, Isobel Sale, a research student intern, [presented her analysis of how women discuss UI on the online forum “mumsnet”](#). Her analysis showed how experiences of UI can fill women with misery and despair, and how persistent stigma and the silence surrounding UI can make it difficult for women to seek help. However, Isobel also highlighted expressions of positive emotions such as relief, compassion and encouragement, which could be found in most threads she analysed. Her emergent findings suggest that online forums can develop into virtual communities where anonymous users create bonds of mutual respect and understanding, even though they may only have two things in common – the experience of urinary incontinence and of being a mother.

The presentation was followed by an open discussion and an exercise where all participants were asked to note down the challenges and opportunities associated with their experience and understanding of UI, which were then grouped according to their feasibility and potential for impact. This report presents emerging findings from the three workshops. It begins with an overview of the manifold challenges identified by workshop participants in relation to their experiences of UI, followed by a summary of related opportunities. The report concludes with a summary of key findings and a draft roadmap for future research. An appendix provides an overview of the challenges and opportunities identified.

Challenges

Most of the participants agreed that overcoming the stigma of UI is one of the key challenges. The silence and embarrassment surrounding UI does not only prevent women from seeking help, but also healthcare practitioners from offering it to them. Several participants reported that when they had sought to discuss the matter with a doctor or nurse, they had been “fobbed off,” or that healthcare professionals had been too embarrassed to have a meaningful conversation. Some noted that it appears relatively common to talk about leakage when it comes to young children. However, when it comes to adults, lacking full control over bladder function is associated with failure, old age and disability and widely seen as deeply shameful. We also heard about many instances of healthcare professionals lacking compassion and normalising what is for many women a deeply troubling situation. Several participants recalled situations where women were extremely worried about leakage but were then told that as women and mothers their experiences were “normal” and that they would have to “get used to

it". Others noted a lack of clear responsibilities, with women being sent from nurse to doctor and vice versa. Healthcare professionals noted that amid growing pressures on the healthcare system, matters of life and death would be prioritised. While women may not die as a direct result of UI, several workshop participants acknowledged the severe impact UI can have on women's quality of life, including mental health. This raises important questions about the value assigned to women's physical and emotional well-being.

Social incontinence

Several women reported how they organise their daily lives around routes determined by the availability of toilets. This relates to the phenomenon of social incontinence, where a lack of accessible toilets causes or aggravates fears and experiences of leakage. In such cases, UI is as much a societal issue as it is a personal one. However, given the absence of UI in public discourse, the severe impact the closure of public toilets has on the lives of many women often goes unnoticed. Many owners of shops, cafes, public houses and petrol stations limit access to customers. While some charities offer cards that flag the importance of prompt access for those experiencing UI and similar conditions (Figure 1), many women are not aware of the availability of such cards, or shy away from using them. One participant reported that at her church elderly patrons had requested the construction of an accessible toilet, as the current one cannot be accessed during services and is difficult to use. They were told by those wishing to preserve the church's historical appearance that if they could not use the existing facilities, they should use the toilets in an information centre a few houses down the road. This and similar examples demonstrate a widespread lack of understanding encountered by those affected by UI and other conditions requiring quick and easy access to toilets.



Figure 1: Screenshot of the smartphone version of the Bladder & Bowel Community "Just Can't Wait" card (also available in hardcopy from <https://www.bladderandbowel.org/help-information/just-cant-wait-card/>).

Continence products

The silence surrounding UI also appears to inhibit the development of more appropriate products. For example, many women associate the size, shape and colour of typical continence pads with negative sensations surrounding disability, old age and death, from which they would prefer to distance themselves. One participant commented that her family had been relieved that her mother, who was fatally ill, died before she had to use such products, which she would have considered undignified. Another reported that some younger women prefer wet pants to using products they associate with old people. Continence products like bulky white pads limit the types of underwear that can be used, affecting self-esteem and aggravating what is already a difficult situation when it comes to sexual encounters and relationships. Participants suggested that a redesign of continence products to be discreet and pretty, in addition to functional, would go some way to addressing the social needs of women experiencing a sometimes debilitating physical condition. Many reported how a fear of 'smelling bad' would prevent them from social engagements, and how better products were needed to deal with this sensitive issue.

It was also noted that the purchase and storage of continence products are not without difficulties. Many women struggle to identify the right product for them, not knowing who to consult with on the matter. Even where a suitable product has been found, there are significant costs associated with its regular purchase. Several participants highlighted that new solutions have to be found to make continence products both more affordable and easier to access. Some expressed anger that their desperation for a dignified solution allowed businesses to set prices that guaranteed a healthy profit. According to current NHS policy, adequate products should be provided to those who cannot afford them. However, the quality of low-cost products provided by the NHS is poor, the pads are delivered in bulk (a delivery can take up a spare room) and in order to cut costs, healthcare professionals are instructed to only provide such products if no other solutions are available, and with a cap on the amount of product provided per day. Combined with a general lack of awareness of how to access continence care and related products, it appears likely that those who already find themselves in a vulnerable position are likely to suffer from social isolation as a result of UI.

Health and dignity

In all three workshops participants discussed quotes from [Isobel's work](#) or their own experience, where women have likened the severity of incontinence to that of dementia and life threatening conditions. Two workshop participants gave sobering accounts of how they felt that UI was dominating their lives in soul-destroying ways, despite their best efforts to manage the condition. Many participants reported that the medical procedures and assessments they experienced were deeply humiliating. Some of these included urodynamics assessments where women were asked to undress and demonstrate their lack of bladder control in front of healthcare professionals. In what she termed a "pit of indignity", one woman described performing star jumps whilst being watched involuntarily urinating on a pad, which was afterwards weighed to determine whether her UI 'qualified' for medical intervention. Another reported that she had been told that it was "all in her head"; that she was either not really incontinent or was bringing it on herself psychologically. A gynaecologist sent her to see a psychiatrist rather than a specialist nurse, arguing that she was just trying to draw attention to herself. Listening to these and similar accounts, some historical but others more recent, we better understood why so many women suffer in silence and do not seek support.

Participants in all workshops repeatedly emphasised the importance of overcoming isolation, and how the experience of being able to talk to someone can reduce stress and anxiety. Everyone agreed that there is a need for a shared and safe environment for women to talk about their experiences of UI. While it is not entirely clear what such environment might look like, it was deemed important to avoid language that further problematizes the condition (e.g. 'incontinence sufferers'). Instead of making women victims of their condition, there should be an emphasis on self-respect and dignity. One woman reported how after many years she finally managed to hit the "sweet spot of communication" with a practitioner "who saved my [her] life". This and related comments once again emphasise the importance of communication and trusted relationships for finding appropriate solutions to UI.

Several participants reported that jokes and humour had helped them to deal with challenging situations. However, further discussions indicated that humour can be a double-edged sword. Jokes, metaphors and indirect references (e.g. "my trampoline days are over...") make it easier

to start a conversation, yet they can also reinforce taboo avoidance. Similarly, emoticons are used in online forums to communicate emotions such as embarrassment, but they also stand in for elements that are seen to be too shameful to be expressed. Referring to a particularly humiliating assessment, one woman noted that “you have to make a joke in order to bear it”, suggesting that at times the use of humour may not be a matter of choice. Others provided examples of situations where humour helped them to distance themselves from their condition and feelings of misery. One participant reported that comedians are increasingly picking up on the issue, and how she hoped that having a good laugh about the stigma associated with UI could bring about a more open public discourse.

Exercises and treatments

Pelvic floor exercises and problems around exercising more generally were addressed by many stakeholders. Two healthcare practitioners suggested that the majority of women who undertake pelvic floor exercises get them wrong. This may have something to do with the language in which instructions are provided, but also with women lacking a more detailed understanding of their own physiology. It was suggested that metaphorical language (e.g. “pulsating movements like a jellyfish”) can assist women in visualising and translating instructions into more successful practice. However, as noted by a yoga instructor, pelvic strength alone may not suffice to alleviate symptoms, the flexibility of pelvic muscles is also important – and not every yoga instructor is a specialist in incontinence. While women are increasingly encouraged by GPs and other healthcare professionals to engage in specialist exercises to manage UI, often they are not referred to the right professionals. Exercises can also be part of the problem. In particular, running can put an additional strain on the bladder, and many women are frustrated when they cannot return to their established exercise routines following pregnancy.

At two workshops, women described having been recommended inappropriate treatments including surgery. Some of these accounts were rather disturbing in that treatments had (or could have had) devastating consequences. It may not surprise that recent scandals around the use of vaginal mesh have increased uneasiness among patients and healthcare professionals. According to a nurse, many doctors now avoid surgery – only including surgery where positive outcomes are almost certain – because they are afraid of being sued. This suggests a lack of trust on both sides. One participant reported that she had taken part in a trial of a medical device that she experienced as helpful, only to be asked to return the device at the end of the trial, and had not received follow-up information about how she could obtain such a device for the longer term. Overall, there was a degree of suspicion among participants as to the efforts and intentions of both surgeons and the medical device industry. However, there were also accounts of women who had benefitted from surgical interventions, or who had waited for many years for a relatively simple surgery that increased their quality of life in significant ways.

Information access

Several participants felt that there is a lack of available information that could help them to evaluate the merits of different treatment options in relation to their condition. However, because UI can have so many underlying causes, and manifests in different ways, even for healthcare professionals it can be difficult to assess the relative benefit of different treatments.

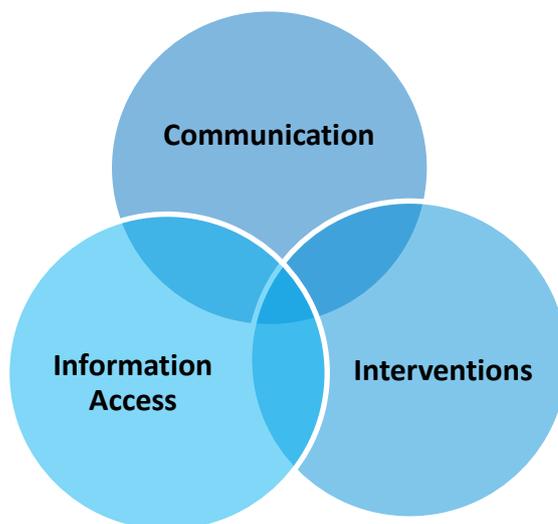
There is no one-stop solution to UI and many healthcare practitioners delivering frontline services (e.g. GPs, nurses and midwives) have not received specialist training on UI. While most NHS trusts employ incontinence nurses, few women experiencing UI seem to be aware of the specialist service they provide, and how to access them via a (self-) referral system. There seems to be a gap between expert information (such as the National Institute for Health and Care Excellence (NICE) guideline on UI in women) and online forums providing anecdotal evidence and practical support.

Most stakeholders seem to search for information online. While media articles and online forums are a useful source of information on alternative treatment options, they can also be a source of misinformation, for example when treatments are recommended irrespective of the underlying cause. This said, online forums and groups (e.g. dedicated groups on Facebook) help women with UI to learn from the experience of others and to access tacit knowledge on how to manage UI, how to raise it with others, and how to access specialists when needed. Local support groups also provide opportunities to share and discuss experiences of UI, and to find out about continence products and strategies for managing the condition. However, charities supporting women with UI have gone through several reincarnations and mergers, and in the face of severe funding constraints, in many areas such groups do not exist or can be difficult to locate.

Opportunities

All three workshop involved in-depth discussion of the challenges associated with breaking the silence on UI, and the many barriers preventing women from receiving adequate help and support. Discussions and a participatory exercise also yielded important insights about how these barriers may be addressed. Participants came up with a broad range of ideas as to how the situation for women with UI could be improved, and what research may be needed to inform better solutions. These can be grouped into three overlapping areas – communication, information access, and interventions (Figure 2).

Communication



There was widespread agreement that social norms have to change in order to allow for more meaningful exchanges around experiences of UI. As the level of stigma associated with UI appears to vary across settings, comparative research could provide new insights into how stigma and taboo avoidance could be reduced. Participants suggested the creation of dedicated online communities that could facilitate the sharing of experiences, advice and support. Others proposed for UI to be addressed through more awareness

Figure 2: Opportunities - Overview of main areas identified

raising activities, breaking down the traditional barriers of “acceptable” discussion topics. This could be achieved through social media campaigns or by addressing UI in soap operas for different audiences. Television programmes such as “Embarrassing Bodies”¹ could inform the public that UI is both common and often treatable.

It was felt that scientific research would be more likely to make a positive impact if researchers would work in partnership with patients and listen to their experiences and concerns. Healthcare practitioners should be educated on how to address UI in ways that invite women to respond rather than making them feel uncomfortable or rejected, and that research could be undertaken to inform such training. It was also noted that the success of such training and related communication strategies is likely to depend on the development of a common terminology that is accessible, yet avoids problematizing UI (e.g. using the term ‘experiences incontinence’ rather than ‘incontinence sufferer’) or reinforcing taboo avoidance. Such language would be a pre-condition for more effective communication among stakeholders, including those who provide care or seek to develop new solutions and products.

Information access

While most participants agreed that more research into causes, prevention and treatments would be needed to inform better interventions, there were also suggestions that such research may be already available - but not *accessible*. Many participants identified opportunities for improvements relating to information access and the provision of advice and guidance. Existing resources such as NICE guidelines, and the websites of the NHS and UI related charities could be made more accessible, organised in a way that makes them easier to navigate, and supply more detailed information. Research is needed into what types of information women need at which points in time. Such research could inform the development of an app for women experiencing UI, which could enhance information access, support the collection of relevant health data, and serve as a gateway to an open forum for exchange and discussion. Information access is not just an issue for those directly affected by UI. By facilitating access to relevant information through the development of a code of conduct, enhanced tools for the data collection, clearer healthcare pathways, and information sheets for different patient groups, practitioners could be supported in providing the right advice and level of care to their patients.

Interventions

As pregnancy and child birth are some of the main causes of UI, it may not surprise that many participants suggested that guidance on UI and pelvic floor exercises be incorporated into existing antenatal care packages, as it is already common practice in some other European countries. Two participants mentioned a post-natal check or “mother MOT”, which could cover UI-related issues and, where needed, facilitate referrals to physiotherapists and incontinence nurses. Other ideas related to interventions enhancing the understanding of UI and related issues among the providers of frontline services, in particular midwives and GPs, and training in how to address the issue in a more engaging and sensitive manner. It was also suggested that women should be allowed to request a female specialist if they feel uncomfortable discussing

¹ Embarrassing Bodies is a British reality television programme that addresses medical issues which are stigmatising and/or misunderstood. For more information visit <https://www.channel4.com/programmes/embarrassing-bodies/>

their experience of UI with a man. Several participants suggested that different age groups may require different interventions. Research which is currently conducted at the School of Healthcare of the University of Leeds evaluates the use of UI packages that combine products with accessible information and guidance for elderly women. Similarly tailored packages and related self-help groups could be designed for other target groups (e.g. young women) and for different types of UI and levels of severity.

Conclusions and way forward

Many findings from the workshop, as well as the difficulties experienced by the research team to recruit participants, testify to persistent barriers preventing us from having a more open discourse on UI. The emergent findings summarised in this report highlight the importance of overcoming these barriers and breaking the silence surrounding UI. They also indicate a need to increase awareness, expert knowledge and empathic understanding in order to improve the lives of those affected by UI. More research is needed into how experiences of UI can be communicated in ways that are both meaningful and empowering. It appears that women can overcome the stigma of UI by sharing experiences and “trouble telling”, and that when they discuss UI they seek compassion and companionship as much as competent advice. An analysis of existing exchanges on UI on public forums like mumsnet could provide more detailed insight into how the silence surrounding UI can be broken in ways that encourage continuous engagement and open up public discourse.

While the development of the right language and engagement strategy is a precondition for collaborative innovation in this field, it also needs to be acknowledged that most workshop participants reported a lack of trusted relationships among stakeholders. Many women experiencing UI deem it unfair that providers of medical devices profit from their misery. Similarly, they also reported difficult relationships with healthcare practitioners. The relational configuration, lack of connectivity and quality of relationships characterising this innovation system need to be better understood in order to develop an agenda for collaborative research and innovation which could inform better products and treatments.

Albeit in a more indirect manner, the workshops also highlighted a lack of available information on management strategies, the use of products and the way women approach different exercise regimes and treatments. This affects the ability of healthcare professionals to identify suitable treatments, but also the women themselves as they seek to better understand and manage their condition. The development of new data collection tools like smartphone apps could enable a more systematic collection of data on experiences of UI. They could make it easier for women to document their condition and management strategies in ways that are useful to them and to healthcare practitioners attending to their needs. They could also feed into collaborative research and innovation. However, any collaborative research agenda in the tradition of participatory engagement and citizen science depends on the creation of a shared language and trusted relationships. Moreover, data collection on conditions that are experienced as both personal and stigmatizing requires special attention to be paid to ethical concerns and data protection.

All three workshops identified practical opportunities for interventions, which we will communicate to a broad range of stakeholders. However, with a view to our own research

agenda, we feel that our findings around *language and communication, stakeholder relations,* and *information and data access* in particular call for more in-depth and inter-disciplinary research. We are now in the process of developing an incremental research strategy to investigate these three aspects, starting with a project that examines more in detail how women communicate about UI using online forums. With the launch of this project, we hope to create a project website to increase transparency and facilitate continuous follow-up. All of our grant applications relating to this research initiative will be driven by a pro-active engagement strategy. We are incredibly grateful to the all nineteen participants who took part in our workshops, and everyone who supported us in this first phase of the research. Thank you for reminding us that in order to break a silence one first needs to listen. We are always keen to hear from you and from others who wish to join us in our ambition to enable collaborative research and innovation for new solutions to urinary incontinence. Please do not hesitate to get in touch if you wish to join us on our journey.

Dr Dani Barrington, Dr Lena Jaspersen and Isobel Sale

Leeds, January 2019

Contact: D.Barrington@leeds.ac.uk or L.J.Jaspersen@leeds.ac.uk

Appendix: Overview of challenges and opportunities

The table below provides an overview of the challenges and opportunities identified in the main exercise.

Challenges	Opportunities
Theme I: Healthcare	
<ul style="list-style-type: none"> • Lack of empathy and understanding from HCPs • Empathy whether with personal experience or to relate professionally • Attitudes of people + doctors – “It’s to be expected” because: 1. You’ve had a baby; 2. You’re peri/menopausal • GPs should have more in depth info + knowledge about UI • We should have more contact with hospital consultants, registrar doctors + specialist nurses at appointments • Hospital team should give us more time + full info before making lifetime changing operation • GP + hospital team should be more open to referring us patients to alternative therapies • Early conversations with GPs/health care teams • Access to the most up to date medicine, equipment and advice that is available • Hospital should be able to give out supplies of catheters in emergency • A show and tell approach for them to learn how to self-manage this problem • Non-specialist healthcare professionals’ knowledge + attitudes • Healthcare professionals (obstetricians and midwives) lack of understanding of ‘abnormal’ UI in the child-bearing years, and treatment options/prevention plans • Read out to front line services to convince them to take the matter more seriously • ‘Just something to live with’ • Assumption that it’s automatically going to be “fixed” or “improved” by pelvic floor exercises 	<ul style="list-style-type: none"> • Hospital should have more female doctors, such as colorectal department at Mid Yorkshire • “Mummy MOTs” • Clearer antenatal guidance • Clearer healthcare pathways • Understand health professionals’ perspectives to support them working in partnership with their patients • Educate undergraduate health students about communicating about incontinence • Use engineering and scientific invention to improve control • NHS provided pelvic floor physiotherapy for all women post-natally • Include support programmes for UI with mothers and maternity support programmes • UI-specific antenatal and postnatal workshops/classes as part of standard care plan (offered to all) • A range of strategies for access to help – which meet individual needs (GP appt, etc, not easy for all) • Identifying the causes • Develop an information sheet and code of conduct about how to address UI issues • Investigate prevention • Effectively matching solutions to incontinence problems
Theme II: Public Toilets	
<ul style="list-style-type: none"> • Public/restaurant toilets 	

<ul style="list-style-type: none"> • Lack of (inclusive) public toilets • Disabled loos often key controlled • ↓ amount of public toilets (access) 	
Theme III: Cost/affordability	
<ul style="list-style-type: none"> • Cost of continence care in terms of products, services, treatments + new modalities coming along • Costs of incontinence products and services 	
Theme IV: Access to information	
<ul style="list-style-type: none"> • Cost of continence care in terms of products, services, treatments + new modalities coming along • Costs of incontinence products and services • Access to information • Lack of knowledge of the general population re the number of men and women who suffer UI • Access sufficient info that can support UI management • Awareness of treatment options • *covered* open up a space for talking about UI • You are not alone! Very common! • Access to information (scientifically proven) on treatments + products • Unclear, contradictory, misleading 'advice' given to women in the childbearing years about what to expect regarding UI • Persistent silence on the matter • Effective communication • Advertisements only cover the product + do not advise that there is help 	<ul style="list-style-type: none"> • Simple measures/advice can make big difference • Recognition that individual experience is individual – no broad brush strokes • Access more useful/relevant resources, e.g. NICE guidance on management of UI • *first line is covered* NOT old wives tales and newspaper/media poor advice
Theme IV: Non-medical support	
<ul style="list-style-type: none"> • We should have at least support groups for us locally in West Yorkshire • Lack of support for women • As it might be more prevalent among women – it is not considered a priority. Just like sanitary pads 	<ul style="list-style-type: none"> • Need better apps/online forums, e.g. “Embarrassing Bodies” • Anonymous communities (for discussion) • Women to not feel alone, and to understand their UI • Sharing experiences and mutual support and empathy • Using post-natal discussions to engage with women experiencing UI, self help groups • Create social cohesion (groups) • Support workshops • Support groups/fora

Theme V: Sense of self	
<ul style="list-style-type: none"> • A lack of evidence which clearly shows the impact of UI on identity • Feeling others won't understand how it makes me feel • People having the courage to admit to themselves that they have a problem they need help with • Challenging personal shame and secrecy (the bladder and bowel are simply parts of anatomy. Can dysfunction like heart/lungs etc) • Lack of control of something so personal 	<ul style="list-style-type: none"> • Encouraging self-help + onwards into professional help and treatments
Theme VI: Continence products	
<ul style="list-style-type: none"> • The social aspects of process of using absorbent products is not fully considered by any professional or company – whole product life cycle • Commercial companies normalisation of symptoms to sell products and prevent help-seeking 	<ul style="list-style-type: none"> • Nappies should be more small and discreet and easy to wear under clothes • Products + associated items which meet social need in addition to physical • Use groups to design functional and pretty underwear
Theme VII: Social aspects	
<ul style="list-style-type: none"> • Stigma. Shame. Embarrassment. • The taboo of UI in today's society for the sufferer • Product advertising older women • Personal shame + need for secrecy • Public stigma remains • Stigma around talking about UI/FI • The social taboo is more from our mindsets, thus more work is needed! • Tackle social stigma • Openness 	<ul style="list-style-type: none"> • Investigate toilet training • For the UI sufferer to take control of their UI with support and back-up • Show range of people with incontinence • Use of internet for freedom of speech – breaking down traditional barriers • Possible entrance onto TV soaps with themes/social issues as has been done before, but not on incontinence • Project with marketing students for a plastic awareness campaign (a bit like "this girl can...") • Employing more interactive methods and activities to break the stigma • Raise awareness • "not all disabilities are visible" – notice on disabled-use toilet doors