

# “My bladder and bowel own my life.”

A collaborative workshop addressing the need for continence research

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# Executive summary

In 2016 a number of charities acknowledged continence problems as a major issue facing their communities. As a result, ten organisations arranged a workshop to explore the issues surrounding continence care and how they might be addressed. The workshop was attended by patients, carers, researchers and health and social care professionals. This report describes

the impact of continence issues on patients with long-term conditions and older people as discussed by workshop participants. The participating organisations make the following recommendations to researchers, research funders, charities, policy makers, commissioners, royal colleges, professional bodies and service and education providers.

## Recommendations

### For charities and research funders

#### 1 Health economic analysis

We recommend that health economic research is conducted to examine the cost of continence problems from the perspective of patients, carers, health and social care providers and the NHS.

Data on some specific conditions and their impact have been collected, predominantly in the US (appendix seven). There is evidently a need to investigate the situation in the UK.

#### 2 Prioritisation in funding

We recommend that relevant funding bodies respond to the need for research addressing continence problems for people living with long-term health conditions and older people. This can be achieved by issuing highlight notices to researchers and/

or prioritising applications received in this area. In particular, we suggest prioritisation of non-drug and non-surgical interventions that promote self-management of continence issues. See box for suggested research areas in need of more work.

#### Continence research areas in need of more work include:

- patient experience
- health economics
- clinical research into: self-management techniques, co-morbidities, continence assessment and products, the impact of education, combined urinary and bowel continence research, side-effects and interaction of medication with drugs prescribed for long term health conditions
- fundamental research to better understand bladder and bowel function
- the effect of non-surgical interventions.

See chapter seven for more details about these research areas.

## For researchers and industry

### 3 Patient and public involvement

We recommend that researchers recognise the immensely valuable insights provided by effective patient and public involvement (PPI) and incorporate PPI into their study design. To do so, we encourage researchers to involve patients and carers as early

as possible when planning a research study. Although continence problems are considered a sensitive topic, our workshop demonstrates that many people are willing to share their experiences and help to shape research (see appendix five for contact list).

### 4 Technological and innovative solutions

We recommend the investigation and development of technological and innovative solutions for continence problems, ranging from the creation of new continence aids to improving existing devices such as catheters.

We suggest the best results would be achieved by involving patients, carers and health and social care professionals in the development, use and promotion of technological and design solutions.

## 5 Research areas

Throughout the workshop a number of research questions were raised by patients, carers and health and social care professionals (see box and section seven). We recommend that researchers and funders consider these when

planning research studies and themed calls. We encourage researchers who attended the workshop and others to collaborate, explore the ideas presented and use these to inform their own research studies.

## For policy makers, commissioners, royal colleges, professional bodies and service providers

### 6 Access to services

We recommend that the need for more dedicated continence services is acknowledged and addressed.

### 7 Training and education

#### *For patients and carers*

We recommend improved access to training and education in self-management of continence. We also recommend encouraging and facilitating patients and carers to share knowledge and techniques through forums or other networks. There is a need for a single information hub for the public as well as a national awareness raising and education campaign about available support.

#### *For health and social care professionals*

We recommend health and social care professionals receive better training to improve their management of patients with continence problems and support self-management.

The area of continence care specialisation needs to be recognised as a necessary and fundamental qualification.

### 8 Public conversation

The taboo around continence issues must be broken through more public discussion and policy campaigns. This will in turn make it easier for

patients and carers to mention continence issues when talking to health and social care professionals.

# 1 Introduction to the workshop

On 2 December 2016, a joint workshop on (in)continence research was hosted by Parkinson's UK, Marie Curie, Age UK, Guts UK (formerly CORE), Alzheimer's Society, the NIHR (National Institute for Health Research) Research Design Service (RDS), the NIHR Devices for Dignity (D4D) MedTech Cooperative, the James Lind Alliance (JLA), the British Society of Gastroenterology (BSG) and The Urology Foundation (TUF). The workshop was attended by

representatives from research, clinical and patient communities and aimed to encourage collaborative, multi-disciplinary research into urinary and faecal continence problems in people with long-term health conditions and older people.

This report explores the topics covered by the workshop and presents key challenges and future steps for research in this field.



## Why the workshop?

Research into urinary and faecal continence problems has been identified by patients, carers, family members and health and social care professionals as one of several areas of unmet need. Addressing these areas of unmet need would improve the quality of life for people with a variety of conditions and circumstances, such

as long-term neurological conditions and terminal illness. The areas of unmet need have been identified in recent years in several JLA Priority Setting Partnerships (PSPs), led separately by various health research charities (see appendix one for the specific research questions identified).

### Demand for more continence research

The 2014 UK Clinical Research Collaboration (UKCRC) Health Research Classification System (HRCS) dataset was searched to review research relating to continence ([hrcsonline.net/reports/analysis-data/](http://hrcsonline.net/reports/analysis-data/)).

The HRCS dataset provides a snapshot of research active in 2014, with £2 billion of health related research grants included from 64 funders (excluding infrastructure funding).

This dataset is made up of 14,934 active grants. Of these, only 33 included the keyword search “continence” (which included “incontinence”). More details on these 33 grants are included in appendix two.

In 2014, Parkinson’s UK established a JLA Shared Learning Group (SLG), so charities who had carried out a PSP could work together to address shared areas of unmet need. The SLG agreed to focus first on continence problems in people with long-term health conditions. This area was chosen because continence issues have a profound impact on the patient groups the charities represent yet is an under-studied area of health research (see box).

To encourage continence research, the SLG agreed to hold a workshop to explore continence issues from a range of perspectives, including patients, carers, researchers and health and social care professionals. Importantly, the workshop would focus on continence problems in people with long-term health conditions and older people. More details about the organisation of the workshop and the workshop programme are included in appendix three. Biographies for the chair and all speakers are included as appendix four.

## 2 Patient and carer perspectives

The patient voice lies at the heart of the charities involved in the workshop. The event included vital input from patients and carers affected by continence problems in addition to other long-term health conditions or in later life. They welcomed the opportunity to share their experiences and explain the impact continence issues have had on their lives. They expressed their hope that research will lead to better solutions for the management and treatment of continence issues.

### 2.1 Patients’ voices

Managing continence issues alongside other long-term health conditions, such as Parkinson’s or Alzheimer’s, is an additional challenge with its own set of complexities.

**“Managing incontinence is yet another challenge on top of the other challenges of neurological conditions and is time-consuming – it can take up a large part of the day. In different diseases, people have the symptoms of the disease concerned but the symptoms of incontinence can have the bigger impact, leading to loss of dignity, productivity and quality of life.”**

Healthcare professional, workshop participant

Despite this, bladder and bowel issues rarely make it to the top of the list in discussions between patients and their GP or other healthcare professionals.

Continence problems are made worse by the associated stigma and lack of understanding. Many people, for example, don’t realise that urinary incontinence is defined as any involuntary leakage of urine. Many believe that the condition is inevitable in ageing and that it will “clear up of its own accord” or that they “just have to

accept it”. A common misconception is that people with continence problems are “old and helpless”.

People with continence problems often describe being embarrassed and can be unwilling to seek support. As a result, many people with continence problems self-manage in silence or hide the condition for a long time before seeking help. This delay often results in a narrowing of treatment options and compromises the efficacy of treatments.

### Reporting and treatment seeking statistics

It's widely believed that continence problems are under-reported. Those seeking treatment may be as low as 20% of those affected.

In a 2016 survey by The Urology Foundation (TUF), 60% of people who took part admitted they would be embarrassed to speak about urinary incontinence – more so than weight, family, money and relationship troubles.

A 2017 TUF survey showed that 18% of people who took part in the survey would not seek help for urinary incontinence at all, either because they were too embarrassed or felt there was no point.



Ben Gold/Marie Curie

Continence issues are often referred to through euphemisms, such as “whoops moments” for leakage and, as seen in a national newspaper shortly before the workshop, “water infection” for urinary tract infection. The increasing

advertisement of pads leads people to believe leakage is normal. The inadvertent effect is to trivialise and undermine the condition, which amplifies the challenges above.

**“My bladder and bowel own my life 24/7. They are a dictator and a tyrant lying in wait to cause trouble and embarrassment and social isolation. I can go nowhere and do nothing without continence preparation and planning a day ahead of an event and the locations of toilets en route. In collusion with the bowel, my bladder keeps me away from any activity where I have to queue to use facilities. Together they conspire to keep me in a cubicle or bathroom long after anyone else wants to access them. Audiences and guests go home and I am still marooned. I have nearly ended up spending the night locked in the Coliseum. I cannot go to homes with only one toilet as everyone else may be shut out while I am stuck in.”**

Patient, workshop participant.

## 2.2 Carers' voices

The impact of caring for people with continence problems is often overlooked. There is a lack of understanding about what carers face on a day-to-day basis.

**“The indignity of incontinence is often worse than the illness that has caused it, the devices are not practical or well designed, and care for people with incontinence can become a burden. We hope for a better solution for the care and management of incontinence.”**

Carer, workshop participant.

Carers can struggle to manage continence problems. Keeping the person they are caring for clean can be very hard: the person may resist this necessary invasion of privacy; having to wash additional clothes and linen is burdensome; and co-ordinating and managing pads has logistical difficulties. Secondary problems resulting from continence problems, such as skin deterioration, increase the burden.

Carers highlighted that continence problems cause them worry and stress. They feel concern about the indignity of incontinence, and find devices to manage the condition impractical and badly designed. Their situation can lead to feelings of hopelessness, increased anxiety and may jeopardise their own health. It has been reported that incontinence can be a trigger for the move into a care or nursing home.



Ben Gold/Marie Curie

## 3 Information and advice for patients and carers

Information and advice to support patients living with continence problems and their carers was perceived to be lacking in availability and varying in quality according to workshop participants. Patients often find their own methods to manage their condition and examples were shared during discussion.

### 3.1 Information and advice gaps

Workshop discussions highlighted a gap in access to knowledge around self-management of continence issues, or management by family or informal carers.

The following issues were raised:

- Regional differences in information provided to patients and carers about self-management techniques.
- Short appointment times with health and social care professionals

and lack of specialist continence expertise.

- Reports of some NHS trusts providing little support or information about how to use continence equipment or products.

This lack of information provision leads to missed opportunities for effective treatment as well as wasted time and money.

#### Drugs and side-effects



Many drugs available for incontinence treatment have unpleasant side-effects, from constipation to cognitive impairment. Patients would like more opportunity to discuss them with healthcare professionals before accepting a prescription.

#### “Prescribing a drug is easiest in a seven minute consultation”

*Patient, workshop participant*

Of additional concern is that some of the drugs worsen the symptoms of the long-term condition which prompted the continence problem in the first place, for example, in some neurological conditions, dry eyes, dry mouth and cognitive impairment.

#### Regional differences

Some regions and settings don't widely offer education about self-management techniques. Patients often feel that little help is available from GPs and the wider health and social care system, meaning they work out their own ways to deal with their continence problems.

#### Lack of support with continence equipment

In some NHS trusts, little support is given to patients and carers leaving the hospital with equipment to help manage continence. For example, people may arrive home with a catheter without knowing how to care for it, potentially resulting in infection and readmission.

#### Rushed appointments

Patients and carers stated that they struggle to have their questions answered – due to rushed health appointments or interactions with health and social care professionals who are not trained in continence management. They asserted the need for specialist health and social care professionals who are able to answer specific questions such as:

- Do particular self-management and self-training techniques work for people with multiple health conditions?
- Can anal sphincter muscles that have been damaged by radiotherapy be repaired with exercises or surgery?
- Would diet changes and having regular enemas help manage diarrhoea?



Layton Thompson/Marie Curie

Patients would also like time with a knowledgeable professional to discuss the efficacy and side-effects of drug options.

#### Awareness of information available

Some people noted the demise of the Bladder and Bowel Foundation, a charity providing information and services, which went into receivership in 2016. There is a charity, Bladder and Bowel UK, which aims to support people with bladder and bowel problems. The charity Bladder Health UK also has a helpline for patients as have most of the charities involved in this report (see links in appendix eight). Workshop participants suggested a public awareness campaign would help raise awareness of the support and information out there.

### 3.2 Patient and carer methods of self-management

Patients and carers described how they visit various websites, exchange information in support groups or improvise self-management methods. Their suggestions are listed below:

- Drinking decaffeinated tea and coffee
- No fizzy drinks or spicy food
- Exercise, including pelvic floor exercises
- Avoiding constipation through colonic irrigation, exercise, diet and plenty of fluid
- Other activities such as singing in a choir increases confidence
- Practising mindfulness meditation and massage to relieve stress
- Acupuncture to the tibial nerve that is responsible for sending signals to the bladder
- Using topical oestrogen (women)
- Medication to help sleeping through the night to avoid repeated getting up for toilet visits

### 3.3 Recommendations for addressing information needs

Several suggestions were made throughout the workshop to address the need for more continence information and guidance for patients and carers, many of which are covered in other sections of this report. It was recommended to launch a national awareness and education campaign the aims of which should include:

- improving people's recognition of continence problems

- Carrying a radar key that opens accessible toilets in public areas and places in the UK.
- Patients also shared practical tips that they have found helpful:

**“I have satin sheets and nightwear to help me slide out of bed quickly when I have to get up to go to the loo at night.”**

**“I have developed techniques to cope... in the theatre I stretch out and tense my leg to help me to control the urgency of needing to go to the toilet.”**

**Please note: we strongly recommend that patients consult with health and social care professionals before implementing changes to their medical or physical regime.**

- breaking down taboos
- encouraging those suffering in silence to seek help.

The campaign could also draw attention to the size of the problem, to encourage improvements in research and the provision of continence services. The charities involved in the workshop feel that they are well-placed to lead such a campaign.

## 4 Health and social care: training and education

Information, advice and a variety of non-surgical techniques – such as bladder training and prompted voiding – are available to help patients and carers manage bladder and bowel continence issues and improve quality of life. However, access to these types of support in the health and social care system is inconsistent.

### 4.1 Specialist continence care for all should be the norm

There are some examples of the provision of specialist continence services (see box); however, access to quality services is not available to all. Patients at the workshop cited experiences in which:

- treatment options had not been offered to them
- treatment options were offered but without sufficient explanation to decide between them
- assumptions were made about them and their treatment based on their age or other circumstances
- they felt little help was available from GPs beyond drug prescribing
- they felt they had to do their own research to find the best way to deal with their continence problems.

Workshop discussions acknowledged that changing health and social care practice is hard. However, good continence care – based on excellent education and training of health and social care professionals – could reduce

workload and save costs in healthcare provision over time. It also increases confidence, dignity and independence for people with continence issues.

#### Specialist continence care practice example

**“We are a nurse and physiotherapy service providing clinical advice, support and information to patients and health and social care professionals/carers on continence and how to treat and manage symptoms of bladder and bowel dysfunction, including incontinence. We work to improve the lives of patients even when symptoms cannot be treated. Our bladder and bowel nurse specialists have had further training in promoting and managing continence.”**

Kent Community Health Continence Service: [kentcht.nhs.uk/service/continence-service](http://kentcht.nhs.uk/service/continence-service)



## 4.2 Health and social care service needs and issues

The following issues were highlighted by workshop participants:

- **Lack of staff time**

Health and social care professionals in hospitals and care homes often don't have the time to take patients to the toilet. This can lead to people being catheterised by default, rather than out of clinical necessity, or because other management options have proven ineffective. The use of a catheter over several weeks can mean continence is never regained.

- **Lack of specialist nurses and services**

There are very few specialist continence nurses or services. These are needed to support patients, provide education in ways to improve continence and encourage self-management. Some charities are known to provide valuable helplines and advice (see appendix eight).

- **Lack of co-ordinated and holistic approaches to treating and managing multiple conditions**

In many cases of patients with multiple long-term conditions, there is no co-ordinated or holistic approach to their support and treatment, including medication. Some drugs can cause incontinence or constipation. It is unclear who is responsible for the overview of all medications and their potential side-effects and interactions. Sharing information between appropriate agencies and medical

professionals, while maintaining confidentiality, was seen as key.

- **Potential for nurse-led educational interventions**

Examples in other countries were highlighted. In Canada, for instance, patients take part in group sessions led by nurses highlighting helpful lifestyle modifications. Such educational sessions are mandatory before a continence specialist is seen.

- **Lack of training for health and social care professionals**

It was stressed that training of health and social care professionals needs to be refreshed, as many only receive a couple of hours training at early career stages.

### Lack of training in continence issues for professionals

A health and social care professional at the workshop highlighted the lack of training opportunities for professionals in continence issues. They reported that for instance there is little guidance available in clinical practice for helping stroke patients with incontinence. They described one large city with only one specialist nurse, who has a long waiting list. "Locally everyone acknowledges the problem, but little is done to address it."

Nurse, workshop participant

## 4.3 Training needs for health and social care professionals

In addition to the need for more general training in continence issues, a number of specific suggestions were made:

- **Communication skills**

Patients are often reluctant to talk about continence issues in consultations. They may not offer relevant information spontaneously, either through embarrassment, lack of confidence, or not having the language to express themselves in a way that they think will be understood. Health and social care professionals are encouraged to proactively enquire. Training and guidance would be needed to incorporate this into their routine.

- **Alternatives to urinary catheters**

More training of health and social care professionals in alternatives to catheters is desperately needed. Some patients, especially older people, are catheterised on admittance to hospital rather than having their continence issues managed by less invasive means. The procedure may be carried out for a number of reasons, for example, a heightened risk that the patient could fall when getting out of bed and going to the toilet. However, catheters are often not removed and there is little guidance or information for patients when leaving hospital with a catheter. This means patients and carers may leave hospital poorly prepared. An overuse of catheters in dementia care in particular was noted.



Katie Hyams/Marie Curie

- **Continent with assistance**

Many people can be continent with assistance. Unfortunately, there are many instances in hospitals and care homes where people are unnecessarily treated as incontinent. There needs to be more continence training for staff, in particular night staff. Further, there is little access to, and training in the use of, tools and devices that would help with continence management.

### Developing educational tools

*Developing and evaluating an educational intervention for the management of constipation: a feasibility intervention study (DEMCoN), funded by Marie Curie.*

For people with palliative care needs, constipation can be a significant burden causing considerable suffering as a direct result of physical symptoms or related social and psychological problems. In this three-year study, Professor Sonja McIlfatrick of the University of Ulster is carrying out research to develop and put into practice an educational tool aimed at healthcare professionals to assist them in the management of constipation in people with advanced cancer. [mariecurie.org.uk/research/funded-projects](http://mariecurie.org.uk/research/funded-projects)



The workshop identified that training and education on self-management of continence problems is vitally important. Better training needs to be available for health and social care professionals in ways in which they can support patients and carers. The box left shows research funded by Marie Curie on the issue of constipation, which is closely related to incontinence.

## 5 Treatments and care to improve quality of life

Treatments and care available for people living with continence problems was a focus for discussion at the workshop. There was a consensus that existing options are limited and that new strategies to manage continence for people living with additional long-term health conditions are urgently needed.

### 5.1 Limitations of treatment and care options

- **Medication**

Workshop participants felt GPs often prescribe drugs as a frontline treatment for continence. This can be an easy and quick solution in the limited consultation time they have available, especially if lifestyle changes have already been attempted. However, a thorough assessment after the patient has completed a bladder diary for three days would provide a better basis for diagnosis and prescribing a treatment.

Drug therapies can have deleterious side-effects. For example, anti-muscarinic drugs frequently prescribed for overactive bladder might not be effective for a large proportion of patients and can have unpleasant side effects. Participants thought that clinical decisions needed to weigh up the potential benefit against potential side-effects of the treatment. Patients also noted concern about adding more drugs, for continence issues, to those they already have to take

for other long-term conditions, especially when there is limited information on potential drug interactions.

- **Inconsistency in treatments offered**

Workshop participants noted inconsistency in what is offered to patients. In some regions, bladder retraining is offered as a first-line option whereas in other areas pads are first-line (see box on the next page for research funded by Parkinson's UK). The latter are perceived to be reactive rather than proactive and therefore workshop participants felt that they should not be the first response.

- **Anal irrigation**

There was consensus that this can be an effective strategy for bowel management, but that information is lacking on its suitability for use in different circumstances, for example, for bedbound patients.

- **Surgery**

Known risks are associated with surgical treatment of incontinence. While surgery is an acceptable option for some patients, in the case of people with multiple long-term conditions there was felt to be a need for a holistic review of the patient and their history in order to best assess the risks when deciding whether to proceed with surgery.

- **Wearing and potential overuse of pads**

Wearing pads has limitations for users concerned about pads being visible through clothing. With the wide range of pads available, many users are thought to use pads that are less-than-optimal for their care. For instance, they might use larger pads for longer periods, when in reality a given patient may manage better with slimmer pads for part of the day.

Pads also have practical limitations. Their bulk can make them difficult to store, conceal and dispose of in the home and during travel, including in public toilets. Patients mentioned that, for example, men's toilets often don't have waste bins.

Concerns were also raised by a number of attendees around the continence pad industry. The fact that many continence specialists have links to pad companies was raised and that this may influence their practice. It was mentioned that current advertisements of continence pads are normalising

pad use, which may encourage people to believe (often incorrectly) that this is an easy, effective first-line option for self-management.

Discussion also focussed on challenges and questions around the impact of co-morbidities on the treatment and management of continence problems. For example, people with dementia, learning disabilities or other cognitive impairments have additional needs that can affect their continence. These include: not remembering the sequencing of steps involved in going to the toilet; not recognising toilets or confusing other objects for toilets; loss of inhibitions; pulling out catheters; and removing pads or disposing of them inappropriately. Workshop attendees agreed these issues are difficult to address and research is needed.

### Bladder training research

*Improving Parkinson's Related Overactive Bladder*, Dr Claire Macdonald, Newcastle University, funded by Parkinson's UK.

The first study to examine bladder training for Parkinson's, this research will provide the first signs as to whether this approach could be effective for treating urinary problems. The results of this study will also help highlight any potential issues with this new training programme and be used to inform future larger studies.

[www.isrctn.com/ISRCTN13217913](http://www.isrctn.com/ISRCTN13217913)

## 5.2 Improving treatment and care

Workshop participants mentioned alternative and complementary strategies that could benefit from research (or further research).

These included:

- cognitive training
- improved physiotherapy for patients, such as people with pelvic floor neuropathy
- the use of osteopathy, craniosacral therapy or hypnotherapy to reduce urinary frequency
- behavioural modification through psychological interventions such as mindfulness, sleep and stress management therapies
- exercise therapy such as pilates or yoga

- education on lifestyle modifications that could improve symptoms
- exploration of the efficacy of "grandmother's remedies" such as heating the bladder.
- tibial nerve stimulation (see box below for research funded by NIHR Devices for Dignity).

In addition, participants considered how existing treatments used in specific conditions could be investigated for wider use in people with continence problems. One existing treatment mentioned was nerve stimulation using an external (rather than internal electrical) stimulator.

### Overactive bladder research

*Home based therapeutic application of non-invasive posterior tibial nerve stimulation in the treatment of overactive bladder (OAB) symptoms*, M. Slovak, C. Hillary, T. Barker, C.Chapple

20 patients with OAB symptoms were randomized and completed various non-invasive forms of posterior tibial nerve stimulation (PTSN). Self-administered 40 minute stimulation was applied every day over a period of four weeks using a conventional TENS machine and a pair of surface electrodes. Patients were assessed using standardized OAB questionnaires and a three-day bladder diary. Six patients were classified as responders at the

end of the study with responders being defined as a combination of a decrease by 30% in daily micturations and/or urgency episodes compared to baseline plus a patient-reported improvement of his/her bladder condition. The study recommended that NHS Trusts and patient care organisations introduce this technique using a standard evaluation protocol to allow its benefits to be evaluated locally and globally using meta-analysis.

**Funded by NIHR Devices for Dignity**  
[devicesfordignity.org.uk/portfolio-item/home-based-application-of-non-invasive-tibial-nerve-stimulation-in-the-treatment-of-overactive-bladder](http://devicesfordignity.org.uk/portfolio-item/home-based-application-of-non-invasive-tibial-nerve-stimulation-in-the-treatment-of-overactive-bladder)

There was also much discussion about the need to better understand continence in the context of the life course, addressing people's needs from birth to death. At present, the patient journey is neither clear nor joined up, and much more needs to be done to find solutions that can improve the lives of people affected by incontinence on a day-to-day basis.

To address this, research needs to involve patients to ensure new treatment approaches answer the right questions. In addition, funders need to understand that quality of life research is important – they need to strike a balance between complex, long-term projects and projects that can help patients in the shorter term.



Brian Morrison/Marie Curie

## 6 Technological and design solutions

Managing continence problems is an issue both within and outside the home. Throughout the workshop, there was keen interest in how design and technology could improve the management of continence issues.

### 6.1 The challenges

Below are a list of challenges highlighted by workshop participants that could potentially be addressed by design and technology based research:

- People with continence issues have to plan carefully before leaving the house to ensure they will be able to reach a toilet.
- Shops and restaurants often don't allow non-customers to use their toilets.
- Many toilets are too small to allow carers to go in at the same time.
- Unsuitability of toilets. For example, the unsuitability of aircraft toilets for people with disabilities makes long-distance travel virtually impossible.
- The cost and stigma of incontinence products.
- The impact of using incontinence products on quality of life.
- A lack of support for patients leaving hospital on the use of products and equipment.
- Limited access to devices and aids for people who are bedbound.
- The use of pads as a substitute for taking people to the toilet, as using pads is quicker.
- The quality of pads is variable. Pads provided by the NHS were felt to be poor compared to those available at own cost.
- There are no pads that are effective in collecting a high volume of liquid faeces
- Use of pads can lead to skin problems.



Michael Luhrenberg

## 6.2 How design and technology could help

Design and technology-based research could potentially be applied to the following areas:

- **Diagnosing urinary incontinence**

For example through:

- development of an intelligent toilet that could automatically capture data about urine volumes
- electronic bladder diaries.

- **Treating urinary incontinence**

For example through:

- external stimulants such as electrical stimulation
- continual urine volume sensors.

- **Providing information and support for people with continence issues**

Apps could be developed, to support:

- prevention of continence issues
- recognition of continence problems and self-assessment, which may encourage people to seek help and initiate conversations about their symptoms
- self-management information for people with continence issues and carers e.g. step-by-step guides
- education of health and social care professionals in continence issues, with support tools to aid their practice
- self-reported data collection about the impact of continence problems on people's lives.

- **Create a better environment for people with continence issues**

Design and technology could improve:

- access to public toilets
- the utility of space inside public toilets for people with continence issues and other conditions.



Kate Hyams/Marie Curie

The **wish list** below features suggestions by workshop participants for new or improved devices:

- Better designed catheters, learning from technologies designed for astronauts.
- Bespoke meshes that would overcome erosion or fixation problems.
- External collection devices for women, for both urine and faeces.
- Better sheaths for penile retraction, in a material other than latex.
- Watches to remind people of when to go to the toilet.
- External vibrating devices to make the bladder contract (often needed when neuropathy means not emptying).
- Artificial sphincter development.
- A speedy zip to help remove garments quickly to address urgency.
- Improved anal plugs.

Workshop participants stressed that patient and carer involvement in the innovative approach of design and technology could result in more user-friendly, effective treatments and projects. It was recognised that multi-disciplinary research teams are needed to tackle the issues, with help from experts such as medical engineers. Further, it would make sense to link with developments in other fields where there may be mutual strength to be gained by collaboration e.g. the development of dementia-friendly environments and communities.

## 7 Emerging research ideas

Workshop discussions identified potential research questions and themes. Participants agreed that a collaborative approach is needed between patients, carers, researchers, health and social care professionals and industry to achieve research that takes into account the complexities of continence problems for people with long-term health conditions. We hope these emerging ideas provide inspiration for new and further research studies.

### 7.1 Patient experience

Workshop attendees agreed that anecdotal evidence of patients' and carers' experiences have been under-represented in research to date. Large-scale, in-depth, qualitative research to capture people's experiences about the impact of continence problems was felt to be important. This could inform

future research and help to highlight the issues people face.

It was also agreed that involving patients and carers in designing, managing and disseminating the projects could help to address the problem of recruitment to studies.

### 7.2 Health economics

Examining and presenting the cost of continence issues to patients, carers, health and social care providers and the

NHS would highlight the need for better treatments, care and self-management techniques.

The health economic perspective could assess and review the costs involved in:

- working age people leaving the workforce because of poorly managed incontinence and the impact of their potential loss of income
- continence problems leading to isolation, resulting in patients and carers avoiding public activities such as socialising and shopping
- patients requiring increased use of health services to treat infection, depression and/or anxiety as a result of their continence problems
- patients requiring medication for continence problems in addition to that required to treat additional long-term health conditions

- patients requiring paid carer support to manage their continence problems
- patients moving into paid residential care homes as a result of their continence problems
- family members co-ordinating hygiene care, alongside maintaining their own health
- poor continence management resulting in health complications, for example skin ulcers which are difficult to treat
- incontinent patients hiding their symptoms for a long time before seeking help or advice, by which time more intrusive and costly interventions, such as surgery, may be required.

### 7.3 Clinical research

Workshop attendees suggested research into the following areas should be conducted:

- **Self-management techniques**

Research is needed to assess the most effective self-management techniques, such as bladder training or urge suppression, and their suitability to early intervene. It could investigate:

- How well do they work?
- What else is available?
- Is it better to use these techniques before resorting to pads or catheters?

- **Co-morbidities and translational studies**

Workshop participants wanted to know if self-management and self-training work across a range of co-morbidities. For example, research for stroke patients has measured the behaviour changes required and created individualised plans. Could transferable management techniques be assessed across a range of different health conditions?

Attendees wanted to see more interdisciplinary collaboration and asked how this can be achieved outside of large multi-disciplinary institutes.

- **Continence products**

A cost/benefit analysis and implementation project could rate the standard of continence products (such as pads, enema kits and catheters) that are already available. Patients, carers and nurses could provide valuable insight into areas of need and availability of appropriate products. Part of this work could be conducted through direct engagement with industry. NIHR D4D have experience in commercial engagement in this area, they for instance support development of new continence products; have access to patient, carer and clinical input; and assist with the set-up of clinical trials.

Industry engagement would support routes to impact (e.g. project collaboration and licensing/ exploitation of project outcomes) ensuring the NHS, academia, and charities benefit from industry know-how.

- **Continence assessments**

Research could also focus on rating the clinical approach to continence assessments in different regions of the UK. Many attendees highlighted a current lack of consistency. What is the best approach for ensuring patients receive the correct diagnosis and treatment?

- **The impact of education**

Research is needed to assess the impact of good continence education in hospitals. Attendees suggested that continence is not currently a training priority for health and social care professionals. There is very little literature looking at acute continence services. Research could explore how lack of training in continence issues impacts patient experience and the time spent in hospital. For example, what is the impact of routine catheterization in A&E and what are the implications on longer term patient health and experience? There is a need to demonstrate the potential financial benefit of improvements in this area.

- **Combined urinary and bowel continence research**

Most attendees were supportive of research looking simultaneously at urinary and bowel problems. Many patients stated that they experience both constipation and incontinence due to their health conditions and require investigations into better treatments for both.

- **Medication**

Research is needed into side-effects of continence medication, as well as the interaction of drugs prescribed for long term health conditions.

**“Who is in charge of the overview of medication for patients with multi-morbidities? Patients? Carers? GPs? Consultants? Nurses? Pharmacists?”**

Workshop participants in conversation, including patients, health care professionals and researchers.

Attendees discussed two common responses to side-effects of drugs given for incontinence:

- Patients stop taking the drugs because of side-effects, but feel guilty and will not seek further help/treatment.
- Patients continue taking the drug as prescribed, even if there is no improvement to their incontinence, and experience potential side-effects.

Although these responses are anecdotally reported as common, attendees felt that there is little research.

## 7.4 Fundamental research

Overall, fundamental research is needed to better understand bowel and bladder function in a healthy person as well as in the various conditions relevant to this workshop.

- **Bladder and bowel neuropathy**

Attendees suggested the relationship between specific neurological conditions and incontinence should be researched. A number of patients at the workshop with neurological conditions stated that they had not realised what was happening to them neurologically was affecting their bladder and/or bowel. They thought it was due to increasing age. It was suggested that research on bladder and bowel neuropathy

should also focus on particular long-term neurological conditions such as Parkinson’s and Alzheimer’s.

- **Tibial nerve stimulation**

Attendees queried whether research could be conducted on the benefits of electrical stimulation on the tibial nerve – utilising both subcutaneous and transcutaneous methods. A research study could evaluate the effectiveness of these methods when applied across a range of long-term health conditions.

## 7.5 Non-surgical interventions

Workshop attendees suggested many patients would support research into the effectiveness of non-surgical interventions, such as:



Kieran Dodds/Marie Curie

- Psychological treatment, e.g. training in behaviour modification techniques
- Pilates to increase core strength and bladder/bowel control
- Hypnotherapy
- Mindfulness
- Urge suppression.

## 8 Challenges in researching continence problems

Participants identified the following obstacles to addressing the vital need of research into continence issues and how they might be overcome.

### 8.1 Addressing continence issues holistically

The complexity of living with continence problems in addition to other health conditions calls for a holistic care approach. Treatments and self-management need to optimise

quality of life by reducing pain, indignity and inconvenience. In addition, researchers need to take into account the variation between individual people and their circumstances and symptoms.

### 8.2 Recruiting and involving patients in studies

The stigma surrounding continence issues can make recruitment to studies difficult. Patients may have dignity and privacy concerns, due to embarrassment about their continence problems. This calls for support and understanding from research funders and, on the part of researchers, well considered recruitment methodology.

An additional issue is that the patient group may be very diverse, which might impact on the way individuals view or experience participation in research, for example if they have a cognitive impairment. In such cases, the involvement of someone close to the patient who can support their participation can be a solution.

Some researchers have found success by approaching charities, recruiting from local venues including hairdressing salons, places of worship and a range of community groups. Another approach is to work with people affected by continence problems, who might have more success engaging their peers. An example of involving people as co-investigators is shown in the box on the next page.

Depending on the project in question, gaining ethical approval may be challenging. This is especially so for investigation of invasive interventions. It is imperative that patients are involved as early in the development of research projects as possible, to ensure that the design and proposed methodology is acceptable and sensitive to the needs of participants.

### Case study – older people as co-investigators in Manchester

A participatory design was used in research on age-friendly communities led by Dr Tine Buffel at the University of Manchester. Stepping beyond the traditional roles as research participants or consultees, a diverse group of 18 older people were trained as researchers with a key role in research planning, design and execution. They were able to reach deeply into their local communities, carrying out 68 in-depth interviews with “hard to reach” older people – including people living in isolation or with mobility and health problems – that academic researchers are unlikely to have been able to contact.

As a result of the research, the University of Manchester, in partnership with Age UK and Manchester City Council, produced a guide on working with older people as co-researchers: [hummedia.manchester.ac.uk/schools/soss/research/micra/Researching-Age-Friendly-Communities-Booklet.pdf](http://hummedia.manchester.ac.uk/schools/soss/research/micra/Researching-Age-Friendly-Communities-Booklet.pdf)

### 8.3 Cost of randomised controlled trials

Randomised controlled trials (RCTs) for interventions for use in the home or care homes can be expensive when conducted in those settings, and recruitment may be challenging. This should not preclude the funding of such RCTs, but researchers might want to consider other approaches or economies where appropriate.

For example:

- embedding trials in existing cohorts of people or patients
- modelling data from observational studies of younger people to older people
- observational studies through linking existing relevant datasets, e.g. Clinical Practice Research Datalink, Biobank, HES.

### 8.4 Access to human tissues



iStock

For researchers undertaking fundamental research, access to suitable human tissue can be challenging. A mechanism for better information sharing on available tissue and/or tissue banking could be helpful.



## 8.5 Funding

There is a lack of funding for continence research – both historical and present – compared to funding for the search of a cure for common conditions. Limited funding, on top of the taboo attached to incontinence, makes it more difficult to attract researchers into the field. Funding streams tend to

relate to specific conditions, whereas a broader approach might be desirable in many aspects of continence research. The fact that a number of charities and relevant other organisations have come together to look at this problem is a first step in the right direction.

# 9 Our recommendations

## For charities and research funders

### 1 Health economic analysis

We recommend that health economic research is conducted to examine the cost of continence problems from the perspective of patients, carers, health and social care providers and the NHS.

Data on some specific conditions and their impact have been collected, predominantly in the US (appendix seven). There is evidently a need to investigate the situation in the UK.

### 2 Prioritisation in funding

We recommend that relevant funding bodies respond to the need for research addressing continence problems for people living with long-term health conditions and older people. This can be achieved by issuing highlight notices to researchers and/

or prioritising applications received in this area. In particular, we suggest prioritisation of non-drug and non-surgical interventions that promote self-management of continence issues. See box for suggested research areas in need of more work.

#### Continence research areas in need of more work include:

- patient experience
- health economics
- clinical research into: self-management techniques, co-morbidities, continence assessment and products, the impact of education, combined urinary and bowel continence research, side-effects and interaction of medication with drugs prescribed for long term health conditions
- fundamental research to better understand bladder and bowel function
- the effect of non-surgical interventions.

See chapter seven for more details about these research areas.

## For researchers and industry

### 3 Patient and public involvement

We recommend that researchers recognise the immensely valuable insights provided by effective patient and public involvement (PPI) and incorporate PPI into their study design. To do so, we encourage researchers to involve patients and carers as early

as possible when planning a research study. Although continence problems are considered a sensitive topic, our workshop demonstrates that many people are willing to share their experiences and help to shape research (see appendix five for contact list).

### 4 Technological and innovative solutions

We recommend the investigation and development of technological and innovative solutions for continence problems, ranging from the creation of new continence aids to improving existing devices such as catheters.

We suggest the best results would be achieved by involving patients, carers and health and social care professionals in the development, use and promotion of technological and design solutions.

### 5 Research areas

Throughout the workshop a number of research questions were raised by patients, carers and health and social care professionals (see box and section seven). We recommend that researchers and funders consider these when

planning research studies and themed calls. We encourage researchers who attended the workshop and others to collaborate, explore the ideas presented and use these to inform their own research studies.

## For policy makers, commissioners, royal colleges, professional bodies and service providers

### 6 Access to services

We recommend that the need for more dedicated continence services is acknowledged and addressed.

### 7 Training and education

#### *For patients and carers*

We recommend improved access to training and education in self-management of continence. We also recommend encouraging and facilitating patients and carers to share knowledge and techniques through forums or other networks. There is a need for a single information hub for the public as well as a national awareness raising and education campaign about available support.

#### *For health and social care professionals*

We recommend health and social care professionals receive better training to improve their management of patients with continence problems and support self-management.

The area of continence care specialisation needs to be recognised as a necessary and fundamental qualification.

### 8 Public conversation

The taboo around continence issues must be broken through more public discussion and policy campaigns. This will in turn make it easier for patients and carers to mention continence issues when talking to health and social care professionals.

## 10 One step forward

Following the workshop, a number of participant researchers have already submitted relevant research proposals to the funders involved. A successful proposal (see below) was recently funded by the Alzheimer’s Society. This project directly addresses one of the recommended research areas and we hope that more projects and programmes of research will be forthcoming in the months and years following the workshop.

### Helping people affected by dementia to make decisions about continence products

*The development and evaluation of a continence product decision aid for people with dementia and their caregivers.*

Dr Catherine Murphy is a health sciences research fellow with a background in nursing. She attended the incontinence workshop and this project grew from both her own work experience and her interactions with and understanding of the needs of the people there.

There are a wide range of continence products available. It can be difficult to identify the best continence product for a person’s specific needs, mobility and degree of dependence on a carer. Further, the advice that is given by medical and care staff can be inconsistent. In the course of her research Dr Murphy will create a both paper-based and online ‘Product Decision Aid (PDA)’ to help people choose between continence products.

During this fellowship this PDA will be tested by people with dementia and incontinence who live at home. Dr Murphy aims to show that by using the PDA people with incontinence are better able to socialise, sleep, exercise and participate fully in life with the security of well-contained bladder or bowel leakage. The findings from this research will help to gain a consensus on the needs of people affected by incontinence. This information will be shared with the NHS for their evaluation and to determine whether the products which they currently supply are the most effective.

Dr Murphy’s research was granted funding by Alzheimer’s Society with a letter of support signed by Parkinson’s UK, Marie Curie, Age UK, Guts UK (formerly CORE), The Urology Foundation and Crohn’s and Colitis UK, most of whom were members of the workshop organising group.

## Appendix 1

Unanswered questions on continence problems from patients, carers and health and social care professionals, collated from James Lind Alliance Research Priority Setting Partnerships (PSPs).<sup>1</sup>

### Urinary incontinence

Question	Which PSP was this question raised in?
How is incontinence best managed in people who are approaching the end of life (including those with Parkinson’s disease)?	Palliative and end of life care
What treatments are helpful in reducing urinary problems (urgency, irritable bladder, incontinence) in people with Parkinson’s?	Parkinson’s UK
What are the best ways to manage incontinence in people with dementia?	Alzheimer’s Society
What are the optimal pelvic floor muscle training protocols (frequency and duration of therapy) for treating different patterns of urinary incontinence?	Urinary incontinence
Can guidance or training for GPs on appropriate care pathways improve management of people with urinary incontinence?	Urinary incontinence
What is best practice for treating combined stress urinary incontinence and detrusor overactivity?	Urinary incontinence
Which catheter regimens are most effective in preventing urinary tract infections in people using intermittent self-catheterisation for the management of a neurogenic bladder? What is the effectiveness and safety of prophylactic versus symptomatic antibiotic therapy in people with neurogenic bladder dysfunction using intermittent self-catheterisation?	Urinary incontinence
Which treatment is most effective for reducing urinary frequency and urgency?	Urinary incontinence
Is urodynamic testing before surgery for urinary incontinence associated with better continence rates and quality of life, than surgery indicated without such testing?	Urinary incontinence
What is best practice for managing stress urinary incontinence following failed tension free vaginal tape surgery?	Urinary incontinence

1 jla.nihr.ac.uk

Question	Which PSP was this question raised in?
Are disposable catheters more or less acceptable than reusable catheters, in terms of effective bladder management, patient experience and urinary tract infections?	Urinary incontinence
In women with prolapse and stress urinary incontinence, should suburethral tapes be inserted at the same time as repairing the prolapse?	Urinary incontinence

### Bowel issues

Question	Which PSP was this question raised in?
What are the best ways to manage incontinence in people with dementia?	Alzheimer's Society
How is incontinence best managed in people who are approaching the end of life (including those with Parkinson's disease)?	Palliative and end of life care
What is the best treatment for controlling diarrhoea and/or incontinence symptoms in people with IBD, including novel pharmacological and non-pharmacological options? Is high-dose Loperamide safe and effective in the treatment of diarrhoea in IBD?	Inflammatory Bowel Disease
What treatments are helpful in reducing bowel problems (constipation, incontinence) in people with Parkinson's?	Parkinson's UK

### Spinal cord injury

Question	Which PSP was this question raised in?
What are the effects of ageing after spinal cord injury on the development of complications, including spasticity and bladder and bowel incontinence, and need for home-based support?	Spinal Cord Injury

## Appendix 2

### (In)continence research grants identified in the 2014 UKCRC HRCS dataset.<sup>2</sup>

The 2014 UK Clinical Research Collaboration (UKCRC) Health Research Classification System (HRCS) dataset was scanned to review research relating to (in)continence. The HRCS dataset provides a snapshot of research active in 2014, with £2 billion of health related research included from 64 funders (excluding infrastructure funding). The dataset is made up of 14,934 active grants.

Of these, only 33 unique grants included the keyword search 'continence' (which includes 'incontinence') in their title and/or abstract, totalling £4,474,441 of funding. This amounts to only 0.22% of the total funding included in the HRCS dataset.

### What did the grants look at?

Some of the grants which use the word 'continence' address issues that are not related to people experiencing continence problems with life limiting illnesses. They look at childhood incontinence or continence problems surrounding child birth. However, the research conducted in areas beyond life limiting diseases may be able to add knowledge and context to a massively underfunded area, with devices designed for one community useful to another. The below analysis summarises the grants that address (in)continence in a series of categories.

- 1 Six of these grants looked at **devices to help manage continence problems**, with two looking at slings for stress urinary incontinence (SUI). One of these focussed on SUI in men after prostate surgery, and the other in SUI in women over the age of 18 for whom SUI was an issue. Of the remaining four, one looked at fabric in incontinence pads, one looked to develop reusable catheter packages, one sought to create an electronic urine flow metre and the last looked at a magnetic device for male faecal incontinence. These grants account for 28% (£1,242,087) of the funding to incontinence research in 2014.
- 2 Eight grants looked at **techniques to manage incontinence**. Two of these looked at pelvic floor exercises for MS patients, three looked at electrical nerve stimulation and the remaining three looked at

<sup>2</sup> [hrcsonline.net/reports/analysis-data/](http://hrcsonline.net/reports/analysis-data/)

abdominal massage for MS patients, pilates for urinary incontinence and voiding training after stroke. These grants account for 21% (£932,642) of the funding to incontinence research in 2014.

- 3 One grant looked at **stigma, patient experience and quality of life** in older women with urinary incontinence. Along with this, one grant looked at developing **quality of life outcome measures** for faecal incontinence following spinal cord injury. These accounted for 1% (£51,712) of the funding to incontinence in 2014.
- 4 Four grants looked at **treatment**. However, of these, one focussed on mouse models, one on child birth and one on childhood incontinence. The remaining grant looked at perianal fistulas. These account for 12% (£558,884) of the funding to incontinence in 2014.
- 5 There were two grants conducting **systematic reviews**. One to look at overactive bladder treatments, and one looking at the management of faecal incontinence in people with dementia. These systematic reviews account for 3% (£130,640) of the funding to incontinence in 2014.
- 6 One further grant sought to create a network for incontinence (IMPRESS), one looked at risk factors of incontinence in children and the remaining three were **basic science** grants, looking at incontinence in children and women in childbirth. These account for 9% (£385,610) of funding relating to incontinence in 2014.
- 7 The remaining six grants used incontinence as an **exclusion criterion** or as a remote link to the aims of the research (for example listing incontinence as a possible symptom of a condition in the background). These account for the remaining 26% (£1,172,867) of the funding to incontinence in 2014.

## Appendix 3

### Workshop organisation

#### Planning and programme development

Workshop planning began in February 2016 and the workshop was held on 2 December 2016 at Guy's Hospital, London.

SLG members invited other charities and organisations with an interest in continence research for people with long-term health conditions to join a planning committee for the workshop. The committee comprised Parkinson's UK, Marie Curie, Alzheimer's Society, Age UK, Guts UK (formerly CORE), the BSG, the NIHR RDS London and NIHR D4D MIC. A member of the JLA team also attended the committee's meetings.

An online survey was designed to gauge people's interest in attending a workshop about urinary and faecal continence problems for people with

long-term health conditions and older people. Each charity sent relevant contacts an invitation to complete the survey and the link to the survey was highlighted on the JLA website and in charity newsletters.

The 239 responses revealed a great deal of interest in attending a workshop, along with insights into what respondents would like the workshop to cover and which organisations they would expect to be present.

Informed by the responses, the planning committee chose the format of a day-long workshop for 80 delegates. The workshop comprised plenary presentations in the morning followed by a networking lunch and guided group work in the afternoon.

#### Chair and speakers

The workshop was chaired by **Katherine Cowan** who has also chaired a wide range of PSPs, including for dementia, Parkinson's, palliative and end of life care, spinal cord injury and depression.

The first speaker was **Derek Stewart OBE**. Derek discussed the importance of patient and public involvement in research. He encouraged delegates

to appreciate that patients are true experts in their conditions and their involvement is necessary to produce high-quality research that ultimately benefits those who need it.

The keynote speaker was **Professor Marcus Drake**. He explored the challenges of researching continence problems and presented a case for the

urgent need for improved treatments.

**Kevin Campbell** covered the variety of funding streams and programmes available to researchers from the NIHR, with advice on how to prepare applications in order to maximise chances of success.

**Professor Luke Vale** then explained how the Cochrane Incontinence Group prepares, maintains and promotes the accessibility of systematic reviews. He discussed how these reviews are valuable as research in their own

### Guided group work

For the afternoon session, workshop participants were arranged into mixed groups of 10, comprising: researchers, patients, carers and health and social care professionals. The groups were guided by facilitators to explore potential research questions and

right, and how summaries of existing evidence are often required by research funders before funding new trials.

The final speaker, **Isabelle Abbey-Vital**, focussed on the importance of patient and public involvement in research. Using the Parkinson's UK Patient and Public Involvement programme as a case study, she outlined how she had established and supported a network of patients, carers and researchers to work in partnership to improve the relevance and quality of research funded by Parkinson's UK.

identify collaborative opportunities and multi-disciplinary approaches to address urinary and faecal continence problems.

## Incontinence research workshop programme

2 December 2016, King's College London

Time	Title	Location	Speaker
9.30am – 10am	Registration and networking Tea and coffee	Roben's Suite	All attendees
10am – 10.10am	Chair welcome	In the lecture theatre	Katherine Cowan James Lind Alliance Consultant
10.10am – 10.30am	The importance of Patient and Public Involvement at every stage of research	In the lecture theatre	Derek Stewart OBE Associate Director for Patient & Public Involvement and Engagement NIHR
10.30am – 11.10am	Challenges and opportunities for incontinence research	In the lecture theatre	Professor Marcus Drake Professor of Physiological Urology Bristol University
11.10am – 11.25am	NIHR funding streams (note, other funders will have information stands in the lunch session)	In the lecture theatre	Kevin Campbell Senior Research Manager NIHR
11.25am – 11.35am	The Cochrane Incontinence Group	In the lecture theatre	Professor Luke Vale Coordinating Editor Cochrane Incontinence
11:35am – 11:50am	Research Funding and Patient and Public Involvement – the charity perspective		Isabelle Abbey-Vital Research Involvement Officer Parkinson's UK

11.50am – 12.15pm	Panel session – Q&A	In the lecture theatre	All speakers
12.15pm – 1.15pm	Lunch and networking and funder stands	Roben’s Suite	All attendees
1.15pm – 1.30pm	Chair introduce and explain the break-out sessions	Roben’s Suite	Katherine Cowan
1.30pm – 2.45pm	Each table will be guided by a facilitator to address and discuss one theme: 1. Causes of incontinence 2. Developing treatments – pharmaceutical and non-pharmaceutical 3. Health and social care services in different settings 4. Self-management of incontinence at home	Break out tables, Roben’s Suite	All attendees
2.45pm – 3pm	Break		
3pm – 3:30pm	Feedback from each table to the room		Facilitators
3.30pm – 3.45pm	Chair round up and close	Roben’s Suite	Katherine Cowan
3.45pm – 5.00pm	Refreshments and networking	Roben’s Suite	All attendees

## Appendix four

### Incontinence research workshop

#### Speaker biographies



#### **Katherine Cowan**

Katherine is an independent facilitator and Senior Advisor to the James Lind Alliance (JLA). She has been working with the JLA since 2008, developing methods for involving patients, carers and clinicians in setting priorities for research. She co-wrote the JLA Guidebook and has chaired a wide range of Priority Setting Partnerships, including for dementia, Parkinson’s, palliative care, spinal cord injury and depression. Her background is in social research and policy development, and much of her work focuses on public participation and inclusion.



#### **Marcus Drake**

Marcus is Professor of Physiological Urology at the University of Bristol, and Honorary Consultant Surgeon at the Bristol Urological Institute at Southmead Hospital, North Bristol NHS Trust. He undertook his medical training at the Universities of Cambridge and Oxford and was awarded his Doctorate Thesis by the University of Oxford.

He is active in research. He is Chief Investigator of the national randomised trial of urodynamics in male LUTS (UPSTREAM) and a study of melatonin for nocturia in MS. He was co-ordinating investigator of the multinational studies of combination therapy for male LUTS (NEPTUNE-2) and overactive bladder (BESIDE) for Astellas. He leads a basic science research programme in integrative neurophysiology, with major grant funding from the US NIH. He has published over 120 research papers and reviews, a book and 20 book chapters.

He is Chairman of the International Continence Society’s Standardisation Steering Committee, a board member of the European School of Urology, and of the European Society of Female and Functional Urology. He is also a member of the European Association of Urology Guidelines committee for Male LUTS. In 2012, he chaired the Nocturia committee at the Consultation on Male LUTS and the Neurogenic Incontinence committee at the International Consultation on Incontinence, co-chairing the latter committee in 2016. He is former Chairman for Urology/Urogynaecology in the UK National Health Service’s Comprehensive Clinical Research Network.



### Derek C Stewart, OBE

Born in Ayr, Scotland, Derek was treated successfully for throat cancer in 1995. A former teacher, he became involved in numerous aspects of patient advocacy at a local, regional and national level, being the founder Chair of the Consumer Liaison Group for Cancer Research.

Currently Derek is the Associate Director for Patient & Public Involvement and Engagement at the National Institute for Health Research – Clinical Research Network (NIHR CRN) for England. Derek is a Member of Cancer Research UK.



### Kevin Campbell

Kevin is a Senior Research Manager at the National Institute for Health Research (NIHR). He served in the Army Medical Services for 22 years before joining the NIHR in 2008. As a member of the Evaluation, Trials and Studies Coordinating Centre, Kevin has worked in the monitoring

team, assisting projects during their active study phases and has provided the lead role for application and funding for the Service Delivery and Organisation and Health Services and Delivery Research programmes since 2010.



### Isabelle Abbey-Vital

Isabelle is the Senior Research Involvement Officer at Parkinson's UK. After completing a Neuroscience degree at the University of Manchester, Isabelle joined Parkinson's UK, where she was responsible for developing initiatives to better involve people affected by Parkinson's in the

charity's funding decisions.

Isabelle has since then been leading the charity's Patient and Public Involvement programme, where she has established and supported a network of patients, carers and researchers to better work in partnership to improve the relevance and quality of Parkinson's research.



### Luke Vale

Professor Luke Vale is the Co-Director of the NIHR Research Design Service in the North East. In 2016 he became the Co-ordinating Editor of the Cochrane Incontinence Group having previously been an editor and active researcher in the group from 1998. He is a panel member for the

NIHR Health Technology Assessment CET panel and from 2008-2016 was a panel member for NIHR Programme Grants. His research interests include health technology assessment, trial design and evidence synthesis. He leads a large health economics group at the Institute of Health and Society where he holds the Health Foundation Chair in Health Economics.

## Appendix five

### Patient and carer representatives

We are very grateful to the patients and carers who were attending the workshop to provide their perspective and talk about their experience of continence issues. For research moving forward, we encourage you to get in touch with the relevant charity representative to facilitate contact with any of the patient and public involvement contributors who took part.

Name	Organisation	Named contact	Email
Mr George Foster	Parkinson's UK	Liz Nash	lnash@parkinsons.org.uk
Mrs Dorothy Hatfield	Parkinson's UK	Liz Nash	lnash@parkinsons.org.uk
Mr Andrew Tyrrell	Parkinson's UK	Liz Nash	lnash@parkinsons.org.uk
Mrs Paula Scurfield	Parkinson's UK	Liz Nash	lnash@parkinsons.org.uk
Mrs Val Benn	Parkinson's UK	Liz Nash	lnash@parkinsons.org.uk
Mrs Laretta Harris	Parkinson's UK	Liz Nash	lnash@parkinsons.org.uk
Dr Angela McCullagh	Marie Curie	Sabine Best	sabine.best@mariecurie.org.uk
Ms Asmina Verjee	Guts UK (formerly CORE)	Julie Harrington	jharrington@gutscharity.org.uk
Mr Yusuf Gulamhusein	Age UK	Lesley Carter	lesley.carter@ageuk.org.uk
Mr Kurban Haji	Age UK	Lesley Carter	lesley.carter@ageuk.org.uk
Ms Jan Oliver	Enfield Over 50s Forum	Lesley Carter	lesley.carter@ageuk.org.uk
Ms Katrina Patterson	Brunel Older People's Reference Group	Lesley Carter	lesley.carter@ageuk.org.uk
Ms Hilda Singh	Enfield Over 50s Forum	Lesley Carter	lesley.carter@ageuk.org.uk
Mr Michael Moss	Brunel Older People's Reference Group	Lesley Carter	lesley.carter@ageuk.org.uk
Mr Peter Riley	Alzheimer's Society	Katherine Gray	katherine.gray@alzheimers.org.uk
Ms Sheila Carr	Alzheimer's Society	Katherine Gray	katherine.gray@alzheimers.org.uk
Ms Sara Davies	Alzheimer's Society	Katherine Gray	katherine.gray@alzheimers.org.uk



# Appendix six

## Incontinence research workshop planning group

This event was initially conceived by a shared learning group of charities who had completed James Lind Alliance Priority Setting Partnerships. These enable clinicians, patients and carers to work together to identify and prioritise questions that could be answered by research. Incontinence has been cited by patients with long-term health conditions as an area of priority to address their unmet needs in improving quality of life. As a result, a

group of charities and other interested organisations came together to host this landmark workshop for the research community, to encourage more research, more collaboration and more multi-disciplinary approaches for both urinary and bowel incontinence.

Below are the details of the members of the group who organised the incontinence research workshop.

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# Appendix seven

## Brief economic commentary

An example of the economic burden of a specific type of incontinence, by Patricia Aluko, Institute of Health and Society (Cochrane Review) Newcastle University.

Stress Urinary Incontinence (SUI) constitutes a huge financial economic burden to the society. In the U.S, the annual total direct costs of urinary incontinence in both male and female is over \$16 billion (1995 USD) (Chong 2011) with a societal costs of \$26.2billion (1995 USD) (Wagner 1998). Approximately \$13.12billion of the total direct costs of urinary incontinence is spent on SUI (Kunkle 2015; Chong 2011).

About 70% of this \$13.12 billion is borne by the patients mainly through routine care (purchasing pads, diapers, laundry and dry cleaning). This constitutes a significant individual financial burden. Of the remaining 30%, 14% is spent on nursing home admission, 9% on treatment, 6% on addressing complications and 1% on diagnosis (Chong 2011).

A study reported that about 1% of the median annual household income (\$50,000-\$59,999) was spent by women on incontinence management. This study estimated that women spent an annual mean cost of \$751-\$1,277(2006 USD) on incontinence. This cost increases based on severity of the symptoms (Subak 2008).

The indirect cost associated exerts social and psychological burden which is unquantifiable. This indirect cost cannot be easily estimated due to inaccessibility of such data (Chong 2011; Kilonzo 2004). Nevertheless, Birnbaum 2004 estimated that the annual average direct medical costs of SUI for one year (1998 USD) was \$5,642 and \$4,208 for indirect workplace costs.

The cost of and management and treatment of SUI increases over the years due to increasing prevalence, increased desire for improved QOL, improved recognition of the condition, as well as increased use of surgical and non-surgical management.

### References

Birnbaum, H. G., et al. (2004). "Cost of stress urinary incontinence: a claims data analysis." *Pharmacoeconomics* 22(2): 95-105.

Chong, E., Khan, A. and Anger, J. (2011). The Financial Burden of Stress Urinary Incontinence Among Women in the United States. *Current Urology Reports*, 12(5), pp.358-362.

Kilonzo, M., Vale, L., Stearns, S., Grant, A., Cody, J., Glazener, C., Wallace, S. and McCormack, K. (2004). Cost effectiveness of tension-free vaginal tape for the surgical management of female stress incontinence. *International Journal of Technology Assessment in Health Care*, 20(04), pp.455-463.

Kunkle, C., Hallock, J., Hu, X., Blomquist, J., Thung, S. and Werner, E. (2015). Cost Utility Analysis of Urethral Bulking Agents Versus Midurethral Sling in Stress Urinary Incontinence. *Female Pelvic Medicine & Reconstructive Surgery*, 21(3), pp.154-159.

Subak, L., Brubaker, L., Chai, T., Creasman, J., Diokno, A., Goode, P., Kraus, S., Kusek, J., Leng, W., Lukacz, E., Norton, P. and Tennstedt, S. (2008). High Costs of Urinary Incontinence Among Women Electing Surgery to Treat Stress Incontinence. *Obstetrics & Gynecology*, 111(4), pp.899-907.

Wagner, T. and Hu, T. (1998). Economic costs of urinary incontinence in 1995. *Urology*, 51(3), pp.355-361.

## Appendix eight

### Abbreviations, definitions and useful links

#### Abbreviations

**BSG** British Society of Gastroenterology  
**D4D** Devices for Dignity  
**HRCS** Health Research Classification System  
**MIC** MedTech Cooperative  
**JLA** James Lind Alliance  
**NIHR** National Institute for Health Research

**PPI** Patient and Public Involvement  
**PSP** Priority Setting Partnership  
**RCT** Randomised controlled trial  
**RDS** Research Design Service  
**SLG** Shared Learning Group  
**SUI** Stress Urinary Incontinence  
**UKCRC** UK Clinical Research Collaboration

#### Definitions

**Urinary incontinence** is the unintentional or accidental loss of urine. When and how urine is lost varies depending on the type or cause of incontinence. The most common forms are:

- **Stress incontinence** – accidental loss of urine that occurs when you cough, sneeze, laugh, or exercise
- **Urge incontinence** – strong and sudden urges to urinate accompanied with, or closely followed by, some leakage
- **Mixed incontinence** – a

combination of the symptoms of stress and urge incontinence

- **Overflow incontinence** – overflow of the bladder causing leakage

**Faecal incontinence** is when a person is unable to control a liquid stool (diarrhoea) or a solid motion. This may be a daily problem or happen from time to time. Someone with faecal incontinence may also experience involuntary passage or loss of wind.

## Useful links

Continence information: [continenceinfo.net](http://continenceinfo.net)

Patient and public involvement: [invo.org.uk/find-out-more/what-is-public-involvement-in-research-2](http://invo.org.uk/find-out-more/what-is-public-involvement-in-research-2)

The Urology Foundation: <http://theurologyfoundation.org/urologyhealth/bladder/urinary-incontinence>

Bladder Health UK: [bladderhealthuk.org/bladder-conditions/continence-support](http://bladderhealthuk.org/bladder-conditions/continence-support)

Bladder and Bowel UK: [bladderandboweluk.co.uk](http://bladderandboweluk.co.uk)

Parkinson's UK helpline: [parkinsons.org.uk/information-and-support/helpline-and-local-advisers](http://parkinsons.org.uk/information-and-support/helpline-and-local-advisers)

Alzheimer's Society support: [alzheimers.org.uk/getsupport](http://alzheimers.org.uk/getsupport)

Marie Curie support line: [mariecurie.org.uk/help](http://mariecurie.org.uk/help)




Continence Foundation of Australia: [continence.org.au/pages/key-statistics.html](http://continence.org.au/pages/key-statistics.html)

Research Design Service: [nihr.ac.uk/rds](http://nihr.ac.uk/rds)




Cochrane Incontinence Group: [incontinence.cochrane.org](http://incontinence.cochrane.org)

 [mariecurie.org.uk](http://mariecurie.org.uk)  
 MarieCurieEOLC  [mariecurieuk](https://www.facebook.com/mariecurieuk)  
 [research.info@mariecurie.org.uk](mailto:research.info@mariecurie.org.uk)





We're here for people living with any terminal illness, and their families.

 [bsg.org.uk](http://bsg.org.uk)  
 BritSocGastro  
 [j.solomon@bsg.org.uk](mailto:j.solomon@bsg.org.uk)




The British Society of Gastroenterology is an organisation focused on the promotion of gastroenterology within the UK.

 [jla.nihr.ac.uk](http://jla.nihr.ac.uk)  
 LindAlliance  
 [JLA@southampton.ac.uk](mailto:JLA@southampton.ac.uk)





The James Lind Alliance is a non-profit making initiative bringing patients, carers and clinicians together in Priority Setting Partnerships to identify and prioritise the top ten uncertainties, or unanswered questions, about the effects of treatments.

 [alzheimers.org.uk](http://alzheimers.org.uk)  
 [alzheimerssocietyuk](https://www.facebook.com/alzheimerssocietyuk)  
 [alzheimerssoc](https://twitter.com/alzheimerssoc)  
 [enquiries@alzheimers.org.uk](mailto:enquiries@alzheimers.org.uk)




Our mission is to transform the landscape of dementia forever. Until the day we find a cure, we will strive to create a society where those affected by dementia are supported and accepted, able to live in their community without fear or prejudice.

 [rds.nihr.ac.uk](http://rds.nihr.ac.uk)  
 NIHR\_RDS  
 [rds@nihr.ac.uk](mailto:rds@nihr.ac.uk)





Research Design Service gives free advice for researchers preparing applications to peer-reviewed funding competitions for applied health or social care research.

 [ageuk.org.uk](http://ageuk.org.uk)  
 [age\\_uk](https://twitter.com/age_uk)  [ageuk](https://www.facebook.com/ageuk)  
 [lesley.carter@ageuk.org.uk](mailto:lesley.carter@ageuk.org.uk)





Age UK is the country's largest charity dedicated to helping everyone make the most of later life.

 [devicesfordignity.org.uk](http://devicesfordignity.org.uk)  
 Devices4Dignity  
 [enquiries@devicesfordignity.org.uk](mailto:enquiries@devicesfordignity.org.uk)





D4D is funded by the NIHR to act as a catalyst within the NHS for the development of new medical devices, healthcare technologies and technology-dependent interventions.

 [parkinsons.org.uk](http://parkinsons.org.uk)  
  [parkinsonsuk](https://www.facebook.com/parkinsonsuk)  
 [research@parkinsons.org.uk](mailto:research@parkinsons.org.uk)

Our vision – our ultimate ambition – is to find a cure, and improve life for everyone affected by Parkinson's

 [theurologyfoundation.org](http://theurologyfoundation.org)  
 TheUrologyFoundation  
 TUF\_Tweets  
 [info@theurologyfoundation.org](mailto:info@theurologyfoundation.org)

Leading the fight against urology disease.

 [gutscharity.org.uk](http://gutscharity.org.uk)  
  GutsCharityUK  
 [research@gutscharity.org.uk](mailto:research@gutscharity.org.uk)

Funding research into diseases of the gut, liver and pancreas.