

Best S<sup>1</sup>, Abbey-Vital I<sup>2</sup>, Gray K<sup>3</sup>, Archer L<sup>4</sup>, de Winter L<sup>5</sup>, Whiting C<sup>6</sup>, Todd Fordham F<sup>1</sup>, Edwards W<sup>7</sup>, Smith A<sup>2</sup>  
 1. Marie Curie UK, 2. Parkinson's UK, 3. Alzheimer's Society, 4. Age UK, 5. The Urology Foundation, 6. James Lind Alliance, 7. Crohn's and Colitis UK

## RESEARCH PRIORITIES RELATING TO INCONTINENCE IDENTIFIED BY PATIENTS, CARERS AND CLINICIANS

### Hypothesis / aims of study

The James Lind Alliance (JLA) was established in the UK in 2004 to ensure that the voices of patients, carers and clinicians are heard when establishing research priorities [1]. Initially, the emphasis was on determining 'treatment uncertainties' for particular health conditions by setting up disease-specific Priority Setting Partnerships (PSPs). However, increasingly PSPs have widened this remit by including questions that lead to evidence uncertainties such as day to day life or care for patients with a particular condition. Since 2013, the infrastructure of the JLA has been funded by the National Institute for Health Research (NIHR), the research arm of the National Health Service (NHS) in the UK.

A number of research PSPs have been carried out recently that considered research priorities for people who have physical or cognitive limitations and/or long-term or terminal health conditions, most led by charitable research funding organisations such as Parkinson's UK, Marie Curie and the Alzheimer's Society. In a number of these PSPs, incontinence was raised as an important topic. In consequence, a joint workshop was carried out by a number of participating charities for their research communities as well as patients and carers, to encourage more research, more collaboration and more multi-disciplinary approaches, for both urinary and bowel incontinence.

### Study design, materials and methods

JLA PSPs follow a standard methodology [1,2,3] consisting of an initial survey to patients, carers and clinicians to identify questions. Questions are then refined and combined, checked against systematic reviews to ensure they are not already answered and prioritised in a second survey. The final step is for patients, carers and clinicians to agree, at a face-to-face workshop, the most important questions for future research to answer.

### Results

A number of research questions / evidence priorities that relate to continence problems have been highlighted by patients, carers and clinicians in the following PSPs.

#### **Parkinson's PSP**

What treatments are helpful in reducing urinary problems (urgency, irritable bladder, incontinence) in people with Parkinson's? This question was prioritised as the 10<sup>th</sup> most important question for Parkinson's research [2].

What treatments are helpful in reducing bowel problems (constipation, incontinence) in people with Parkinson's?

#### **Palliative and end of life care PSP**

How is incontinence best managed in people who are approaching the end of life (including those with Parkinson's disease)?

#### **Dementia PSP**

What are the best ways to manage incontinence in people with dementia?

#### **Spinal Cord Injury PSP**

What bladder management strategy is most effective in reducing the number of urinary tract infections and secondary complications? This question was prioritised as the 4<sup>th</sup> most important question for Spinal Cord Injury research [3].

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? This question was prioritised as the 9<sup>th</sup> most important question for Spinal Cord Injury research [3].

#### **Inflammatory Bowel Disease PSP**

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? This question was prioritised as the 6<sup>th</sup> most important question for Inflammatory Bowel Disease research.

Alongside these recent PSPs, an older PSP on Urinary Incontinence was conducted in 2006 which generated a full list of questions relating to the treatment and management of urinary incontinence (<http://www.jla.nihr.ac.uk/priority-setting-partnerships/urinary-incontinence/top-10-priorities/>).

The workshop held jointly by a number of charities in December 2016 highlighted the inadequacy of current interventions to manage faecal and urinary incontinence - either through self-management and management by carers. A lack of training for health care professionals in continence care and a lack of information for patients and carers on treatment and self-management options were highlighted by participants. The workshop was an important next step in addressing this important priority across a range of conditions and highlighted that new strategies to manage and treat incontinence are urgently needed.

### Interpretation of results

Incontinence is a major issue impacting severely on the quality of life of people who have physical or cognitive limitations and/or long-term or terminal health conditions and for older people who may face limitations from a range of co-morbidities. More research is needed in a number of important areas, from the fundamental understanding of the mechanisms of incontinence to more non-drug and non-surgical interventions to improve self-management of patients.

### Concluding message

There is an urgent need for more patient-centred research for people who have physical or cognitive limitations and/or long-term or terminal health conditions and for older people who may face limitations from a range of co-morbidities. Interventions to improve training for health care professionals and information provision for patients and carers are needed as well as non-drug and non-surgical interventions that promote self-management.

### References

1. Cowan, K, (2010) The James Lind Alliance – Tackling treatment uncertainties together, *J. Ambulatory Care Manage* 33: 241-8
2. O Deane, K. H., Flaherty, H., Daley, D. J., Pascoe, R., Penhale, B., Clarke, C. E., Sackley, C., and Storey, S. (2014) Priority setting partnership to identify the top 10 research priorities for the management of Parkinson's disease, *BMJ Open* e006434.doi:10.1136/bmjopen-2014-006434
3. Joost J van Middendorp, JJ, Allison, H, Cowan, K (2014), Top ten research priorities for spinal cord injury, *The Lancet Neurology* 13: 1167

### Disclosures

**Funding:** Parkinson's UK; Marie Curie, AIIHPC, CR-UK, CSO, ESRC, Macmillan Cancer Support, MRC, MND Association, NIHR, Health and Care Research Wales; Alzheimer's Society; NIHR Oxford Biomedical Research Centre; BSG, Crohn's and Colitis UK, RCN, Association of Coloproctology of Great Britain and Ireland, British Dietetic Association, British Society Of Paediatric Gastroenterology, Hepatology and Nutrition, Crohn's in Childhood Research Association, Core, The Primary Care Society for Gastroenterology **Clinical Trial:** No **Subjects:** HUMAN **Ethics not Req'd:** It was considered service evaluation. **Helsinki:** Yes **Informed Consent:** Yes