

**FINAL Media Backgrounder to accompany the GFI 2018 Press Release**

13 February 2018

***What is incontinence?***

- The World Health Organisation (WHO) has identified incontinence as a set of diseases.<sup>i</sup> The International Classification of Functioning, Disability and Health (ICF) defines incontinence as failure or breakdown of the bodily functions of continence – urinary and faecal. The International Continence Society (ICS) defines urinary incontinence as "the complaint of any involuntary loss of urine".
- Incontinence is a serious and debilitating medical condition that affects the lives of over 400 million people globally.<sup>ii</sup> This accounts for 4-8% of the population. In Europe, there are between 25 and 50 million people living with incontinence<sup>iii</sup>, many of whom are over 60 years old.
- It is one of the most common medical problems affecting the ageing population and is only set to rise<sup>iv</sup>. Significantly the number of people in their 80s is growing faster than any younger segment of the older population<sup>v</sup>.
- Incontinence is often seen as a symptom of other conditions, rather than a condition in its own right – so it is often overshadowed by other diseases<sup>vi</sup> when it comes to allocating health and social care budgets.
- It is still poorly understood by the general public, non-specialist health and social care professionals, policy makers and payers.
- Because those affected by incontinence feel shame and embarrassment about having it, they do not speak out<sup>vii</sup>. As a result, it is a largely 'hidden condition' and is not seen as a priority for policy makers today.<sup>viii</sup>

***Can incontinence be cured and what can be done to support people with the condition?***

- While clinical advances are improving the range of treatment options available for people with incontinence, relatively few find a cure and many stay dependent on toileting and containment strategies to manage their incontinence on a daily basis.
- A toileting and containment strategy is a personalized care routine composed of planned toilet visits (assisted if necessary) in combination with access to a choice of containment products (absorbent pads, pants or devices or other continence aids) according to an individual's particular needs.
- Contrary to the perception held by some care providers, continence products should not be seen as a replacement for a toilet. Ensuring someone can use a toilet for as long as possible is important for their dignity and independence, and will secure optimal use of available resources for continence care.
- A continence assessment undertaken by a nurse or other care professional is needed to develop an effective toileting and containment strategy. This is a set of questions for

understanding what factors influence the daily management of incontinence such as the individual's state of health and other external environmental factors such as where they live, the type of life they lead, and whether they have or require assistance to use a toilet.

***About the study: "Measuring Outcomes to Improve the Management of Continence Care"***

**What was the purpose of the study?**

- Initiated by Essity<sup>1</sup>, led by an expert panel and facilitated by KPMG's Global Strategy Group, this ground-breaking study identifies outcome measures and the tangible Key Performance Indicators (KPIs) which, if embedded in local care settings and country quality frameworks, will help to advance standards of care for people with incontinence.

**How was the study conducted?**

- The process started with a comprehensive literature review by an international expert panel to identify existing performance indicators to measure outcomes for the management of toileting and containment strategies. These findings were then debated as part of a broad stakeholder engagement exercise involving over 60 patient and carer representatives, nurses, clinicians, payers, policymakers, and care providers, culminating in a recommended list of 14 KPIs selected by the expert panel.
- Outcome measures are a measure of the success of a specific aspect of a toileting and containment strategy whereas KPIs are an outcome, structure or process measure used to evaluate the performance of a toileting and containment strategy.
- In addition to the list of KPIs, the study produced an accompanying document which provides practical guidance and a detailed description of how the KPIs can be implemented effectively.

**What are the 14 recommended KPIs?**

- The KPIs distinguish between people who are able to manage their incontinence and containment needs independently from others, and care dependent people who can or cannot express their need to use a toilet or change/remove or apply containment products.
- The underlying ambition with developing this set of KPIs is to have people affected leading independent and dignified lives for as long as possible.
- The 14 KPIs are divided into different areas: 1 KPI is structural, 5 KPIs are around process and 8 KPIs are outcome related (covering clinical, quality of life and economic factors).
- The 14 KPIs are set out below:

**Structural KPIs**

1. Proportion of staff with the skills to perform a continence assessment and prescribe a toileting and containment strategy.

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<sup>1</sup> A leading global hygiene and health company

### **Process KPIs**

2. Proportion of persons with incontinence in receipt of pads with a documented assessment and formulation of a toileting and containment strategy.
3. Mean number of days from referral to assessment for people with incontinence who require a toileting and containment strategy.
4. Proportions of persons whose toileting and containment strategy is reviewed.
5. Proportion of persons with incontinence who receive education on toileting and containment strategies.
6. Proportion of persons with incontinence deemed eligible for a toileting and containment strategy who are offered a choice of product type following assessment of incontinence .

### **Outcome KPIs**

#### **Clinical**

7. Proportion of care dependent persons with incontinence in receipt of a toileting and containment strategy who are able to independently manage their incontinence.
8. Proportion of persons with incontinence and Incontinence Associated Dermatitis (IAD) who receive a toileting and containment strategy.
9. Proportion of persons with incontinence with an indwelling catheter to manage incontinence.
10. Proportion of persons with incontinence managed with a toileting and containment strategy who report “good” or “acceptable” levels of access and support to toilet facilities in their daily lives.

#### **Quality of Life**

11. People with incontinence managed with a toileting and containment strategy who report sustained or improved emotional well-being.
12. Proportion of persons managing incontinence with a toileting and containment strategy who are either able to remain in work or take up work.
13. Proportion of caregiving relatives of people with incontinence who report an acceptable level of emotional well-being.

#### **Economic**

14. Cost of hospital admissions and re-admissions related to poor management with toileting and containment strategies for incontinence.

### **How can the KPIs be applied in practice?**

- Health care systems in Europe are seeking to embrace the potential of ‘value-based health care’ which rewards health providers based on measuring health outcomes against the cost of delivery.
- The set of Key Performance Indicators (KPIs) produced by the study will give care providers and policy makers clear outcomes to aim for and a way to assess continuous improvement for people living with incontinence.

- It will also facilitate the creation of a powerful bank of benchmarking data to provide the basis for value-based health care procurement of toileting and containment strategies.

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<sup>i</sup> WHO International Statistical Classification of Diseases and Related Health Problems, 10th Revision

<http://apps.who.int/classifications/icd10/browse/2010/en>

<sup>ii</sup> Irwin DE, Kopp ZS, Agatep B, Milsom I, Abrams P. Worldwide prevalence estimates of lower urinary tract symptoms, overactive bladder, urinary incontinence and bladder outlet obstruction. *BJU Int.*, 2011; 108: 1132-8.

<sup>iii</sup> An estimate by Essity, the leading global hygiene and health company, based on several studies among care giving relatives from 2013.

<sup>iv</sup> Wagg AS, Newman DK, Leichsenring K, van Houten P. Developing an Internationally-Applicable Service Specification for Continence Care: Systematic Review, Evidence Synthesis and Expert Consensus. *PLoS ONE*, 2014; 9(8): e104129. doi:10.1371/journal.pone.0104129

<sup>v</sup> World Health Organization, Ageing and Health, September 2015

<sup>vi</sup> Swahn C and Sundström C. The comorbidity effects of urinary incontinence and its impact on informal and formal care costs in Sweden, 2015; not yet published

<sup>vii</sup> Minassian VA, Devore E, Hagan K, et al. Severity of urinary incontinence and effect on quality of life in women by incontinence type. *Obstet Gynecol*, 2013; 121(5): 1083-1090

<sup>viii</sup> Aguzzi G, Bartoli S., Tarricone R. Systematic Review of Urinary Incontinence and Overactive Bladder Cost-of-Illness Studies. *The Eopn Pharmoeconomics and Health Economics Journal*, 2010; 2: 11-