

## 6th Global Forum on Incontinence

# Sustainable health and social care: The role of Continence Care in enabling Independent and Dignified living

### CONFERENCE SUMMARY REPORT

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Prof. Ian Milsom, Chair of the 6<sup>th</sup> GFI

The 6<sup>th</sup> Global Forum on Incontinence (GFI) “Sustainable health and social care: The role of Continence Care in enabling Independent and Dignified living” took place in Berlin on 19-20 April 2016. Over 350 participants from more than 30 countries, including policy-makers, payers, experts, patients, caregivers, and health and social care professionals, came together to discuss how to improve care for people with incontinence at home and in the community.

Throughout the two days of the Forum, speakers and panelists highlighted the importance of addressing the need to support the [day-to-day management of incontinence at home and in the community](#) to enable people with incontinence and their caregivers to lead [active, independent and dignified lives](#) in the context of today’s ageing societies, de-institutionalization, and a shift from formal to informal care.

The Forum was organized by **SCA** in partnership with **AGE Platform Europe** and **Eurocarers** and with the support of the following organizations: *the International Continence Society (ICS), the International Alliance of Patients’ Organizations (IAPO), the European Association for Directors and Providers of Long Term Care Services for the Elderly (EDE), the European Centre for Social Welfare Policy and Research, the European Institute of Women’s Health (EIWH), the Canadian Nurse Continence Advisors Association (CNCA), the European Union Geriatric Medicine Society (EUGMS), the European Health Management Association (EHMA), Health First Europe (HFE), Zentrum für Qualität in der Pflege (ZQP), Bundesarbeitsgemeinschaft Selbsthilfe (BAG), Care England, and the International Federation for Spina Bifida and Hydrocephalus (IF).*



This report provides a summary of the sessions and the discussions that took place over the course of the two days of the conference. The 6<sup>th</sup> edition of the GFI was moderated by Cathy Smith.

## Incontinence, ageing societies and long term care

Delivering the first presentation of the GFI, **Chair Prof. Ian Milson** presented the findings of a recent study [comparing the burden of incontinence with other chronic diseases](#) and assessing its [impact on informal and formal care costs in Sweden](#). He explained that the number of people with urinary incontinence is significantly higher than those with Alzheimer's, diabetes and stroke. However, despite its prevalence, incontinence is one of the least discussed and most poorly understood conditions, often 'hidden' in statistics and overshadowed by other chronic diseases.

Furthermore, dementia and incontinence are the driving forces for nursing home admissions while informal costs for urinary incontinence are up to 10 times higher than the reported formal care costs. These 'hidden' informal care costs need to be taken into consideration when evaluating the cost-effectiveness of containment products and other interventions in urinary incontinence, he concluded.

**Ms. Maiwenn Al, Senior Researcher, Erasmus University**, presented the outcomes of a new health economic study that aimed to explore the [future impact of implementing the Optimum Continence Service Specification \(OCSS\) in the Netherlands by 2030 in four different scenarios based on the following future policy trends](#): demographic changes, a shift from formal to informal care, the expectation that informal caregivers are not able to provide the extra amount of care needed, and that additional care is bought by people out of their own pocket, and the de-institutionalization of the older population.

A previous study showed that the implementation of the OCSS would improve health outcomes and quality of life of people with incontinence, and that health and social care costs would be reduced over a period of three years by appointing a continence nurse specialist in primary care (working across a number of GP practices). The new study, based on further analysis, showed that implementing the OCSS and supporting people with incontinence at the beginning of the care pathway, would lead to even larger future cost-savings in all four scenarios - enabling people to live independent and dignified lives. The longer the implementation is postponed, the more these potential savings - €200 million from a payer (health insurer) perspective and €800 million from a societal perspective - are foregone, Ms. Al concluded.

**Niclas Jacobson, Deputy Director General, Head of Division EU and International Affairs, Ministry of Health and Social Affairs, Sweden**, shared valuable insights on the main conclusions of the Social Protection Committee report on ["Adequate social protection for long-term care needs in an ageing society"](#). He emphasized the diversity between EU Member States in the way that long-term care is organized, financed and delivered. A major gap between long-term care needs and supply is likely to emerge in the coming years.

In order to close the gap, Mr. Jacobson called on Member States to move from reactive to proactive policy approaches in order to prevent the loss of autonomy and to support independent and dignified living through re-enablement, self-management support, age-friendly environments, realizing the potential of technology, and supporting informal carers. [Incontinence](#), he concluded, deserved greater [prioritization](#) on the [long-term care policy agenda](#) due to both its impact on the individual (dignity and quality of life, independence) and on society (prevalence, financial consequences, ageing population).



The 6<sup>th</sup> GFI was held in Berlin in April 2016

## Putting the incontinence challenge in context

Presenting the findings of a systematic literature review, **Dr. Julian Spinks, GP and senior partner at Court View Surgery, UK**, focused on the question of [whether incontinence can be cured and to what extent containment strategies support people with incontinence](#) to live normal lives at home and in the community.

The ability to cure incontinence depends on the type, the intervention and the patient population. Surgery seems to give good results for persons with stress incontinence if executed by a trained and experienced surgeon, medication leaves many people uncured and pelvic floor exercise and other interventions showed limited cure rates. Most evidence of cure rates was found for urinary incontinence with few studies found for other profiles or groups of patients, i.e. older/cognitively impaired people, people with faecal incontinence, and people with a neurological disease or neurological injury.

Dr. Spinks remarked that few patients are or can be (permanently) cured and therefore rely on containment strategies throughout their lives. He called for additional research to identify how containment strategies can best support the groups of people who are not cured. His remarks were echoed by several GFI participants who emphasized the need to shift the current focus in continence



care from treatment solutions to the effective daily management of containment and to provisions that support people to lead normal and independent lives.

**Dr. Adrian Wagg, Co-chair of the GFI**, highlighted [the cost of inaction and the consequences of inadequate continence care](#) for patients, care-givers and society at large. Clinical consequences of poor incontinence care routines include pressure ulcers, urinary tract infections, falls and fractures, incontinence associated dermatitis, and depression. He reiterated that cure may not be achieved and those subject to curative intervention for their incontinence often have remaining care needs. It may also lead to a number of health-related consequences resulting in more suffering for the patient, extra care being required from carers and increased costs to health systems and society. “Cure is not perfect”, he said, “and there is a need for more focus on high quality *care* for incontinence exemplified by careful assessment and management tailored to the needs of the individual”.

**Prof. Jan De Maeseneer, GP, Head of Department of Family Medicine and Primary Healthcare, Ghent University, and Chairman of the European Forum for Primary Care**, delivered a presentation on the need to [shift the focus from the disease to a person’s functional capabilities and individual needs and goals](#), especially as multi-morbidity including incontinence becomes the rule. “What really matters to patients and people with incontinence is functional status (*the ability to function*) and social participation”, referencing the WHO’s International Classification of Functioning, Disability and Health (ICF).

This requires investing in strong primary healthcare and moving from ‘problem-oriented’ care that focuses on the disease and the physician towards ‘goal-oriented’ care based on the desirable and achievable quality and quantity of life of each individual. “Goals may change over time, but should pop up at the front page of the electronic Personal Health Record”, he advocated. In the case of incontinence, he added, it is necessary to invest in primary care, highlighting the role primary care can play in improving continence care at home and in the community, e.g. active case finding, especially in vulnerable elderly; incontinence as a model for a horizontal approach, supported by a continence nurse specialists in primary care; and the commitment of primary care in education, de-stigmatization, and advocacy.

A **panel** bringing together representatives of **AGE Platform Europe, the WHO, the International Association of Patients’ Organizations (IAPO) and Geriatric Medicine at All India Institute of Medical Sciences**, discussed how to improve day-to-day care for people with incontinence, reflecting on [new policy approaches to prevent functional decline and to provide support to patients and caregivers](#).

Panelists supported Prof. De Maeseneer’s call for a more functional, home and community-based approach to incontinence and continence care. IAPO furthermore encouraged a human rights-based approach “since the ability to enjoy full and independent lives at home and in the community should be a fundamental right for everyone”. The WHO warned against addressing chronic diseases in siloes, especially whereas older people are concerned. He referred to the new WHO guidelines on integrated care for older people (ICOPE) that focus on common ‘issues’ or challenges (including incontinence) that matter most for older people and that may cause functional decline, rather than on specific conditions.

All panelists underlined that incontinence deserves greater recognition and focus on the health and long-term care policy agenda, requiring further evidence and new studies to develop policy options in the area of continence care.

## Perspectives on the need for a new approach to continence care – The voice of patients and carers

In his presentation, **John Dunne, President of Eurocarers**, presented a recently adopted [Joint Statement<sup>1</sup>](#) of 8 leading EU patient and civil society organizations that met in Brussels in September 2015 to give a voice to people with incontinence and their carers and to discuss the issue of [incontinence and the provision of better continence care in Europe at home and in the community](#). “We share a common belief that more can and needs to be done to improve the day-to-day management and care provisions of people with incontinence and their carers at home and in the community”, he said. “Everyone will either provide or receive care at some point in their lives”. He highlighted the following recommendations of the group for further policy and stakeholder action:

- Increase awareness, recognition and understanding of incontinence
- Recognize continence care as a human right to enable independent living and dignified lives
- Improve information and communication about incontinence
- Enable choice, involvement and empowerment of people affected by incontinence
- Develop continence-friendly work, home and community environments
- Support and prioritize a research agenda on incontinence

**Anne-Sophie Parent of AGE Platform Europe** presented the results of a recent study on [the current continence care provisions](#) in six regions in Germany, England, Spain and Poland. The aim of the study was to better understand how well people manage the containment of their condition with the provisions that are available to them today. In particular, the aim was to provide an understanding of how different provision systems influence the patient and carer experience of the containment product and to what extent the product solutions provided by the state/sick funds match the needs of the patient.

The study showed that patient knowledge and involvement coupled with funding provisions based on patient profiles and individual needs were found to be key in enabling people with incontinence and their carers to live independent and dignified lives. Ms. Parent highlighted three ‘success’ factors therefore, that will lead to more autonomy and improved quality of life at home and in the community:

- Information and knowledge about the different containment product types available
- Involvement in selecting the containment product type
- Tailored funding provisions based on patient profiles and individual needs

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<sup>1</sup> [http://www.age-platform.eu/images/stories/Publications/papers/JointPositionStatement\\_on\\_Incontinence\\_2015.pdf](http://www.age-platform.eu/images/stories/Publications/papers/JointPositionStatement_on_Incontinence_2015.pdf)

**Three patient panelists from Sweden, the UK and the Netherlands and one informal caregiver from Poland** shared their [personal experiences of living with and managing incontinence on a daily basis](#). All agreed that despite some good products on the market, there are a number of key obstacles and hurdles to accessing products and provisions that truly match the needs of the patient and that support the patient's independence and also dignity.

Key obstacles include a rationing of (new) products, cost-containment (capitation) measures and public tender processes with very little say and influence for the patient and the carer in selecting the most effective containment products. One of the patients remarked, "maybe you can get the right product, but it is very stressful". Others concurred: "it's all about fighting and sometimes I don't want to, so I end up buying my own stuff" and "sometimes it's easier to buy products with my own money than filling in the paper for co-payment". All panelists agreed that we are still far from a person-centered and needs-based approach in the field of continence care and called for more choice and involvement in the decision-making process.



*Panel interview with people living with incontinence and one caregiver. From left to right: Cathy Smith (GFI moderator), Peter Andersson (Sweden), Jacqueline Emkes (UK), Albert van der Zeijden (The Netherlands), Edyta Dlugosz (Poland)*

## **Innovation in action – Best practice examples of care delivery**

Showcasing the example of Ontario, Canada, **Dr. Samir Sinha, Director of Geriatrics and Assistant Professor of Medicine, University of Toronto**, presented Ontario's 'seniors strategy' that enables ageing at home and emphasizes [the importance of screening and prevention for long-term care](#).



Regarding incontinence, in particular, Dr. Sinha said that appropriate screening and early detection is needed to prevent early institutionalization and its associated costs, which are particularly high for this disease. He added that early identification needs to be coupled with appropriate, cost-effective and easily implemented intervention strategies such as patient education materials, and reasonable and easily followed care protocols.

**Helle Wijk, registered nurse, Associate Professor in nursing, University of Gothenburg,** focused her presentation on [person-centered care in a nursing home environment and the positive outcomes for people with incontinence](#). With incontinence as a key driver of nursing home admission, continence care is a significant part of the care for people in a nursing home environment. In Sweden alone, 70-80% of older persons living in nursing homes have urinary incontinence, she remarked.

A recent research project in three residential care homes in Sweden showcased that the delivery of more person-centered support by nursing home staff led to better quality care and a better quality of life for residents with incontinence. Ten months of person centered care training and practice of all nursing home staff resulted in more and better assessments of incontinence and more person-centered care interventions for incontinence, including toileting assistance and the type of protection used. More importantly, it had a positive impact on residents' quality of life.

**Dr. George Crooks and Ms. Donna Henderson, NHS 24, Scottish Centre for Telehealth and Telecare,** focused on [the role of enabling technology in improving the delivery of continence care](#). They presented the initial findings of a research project that aimed to identify and map examples of enabling technologies in the field of continence care. Innovative technologies included a website and mobile app for pelvic floor exercises for women with urinary incontinence, toilet finding apps, a sensor technology project designed to provide data on a person's incontinence, and finally, a nurse-led telehealth service supporting young people with complex needs. Dr. Crooks also emphasized the role technology can play in education and training, coaching, and general support for people to manage their incontinence on a daily basis.

**A panel of representatives of Health First Europe, the Center for Quality in Care in Germany, the Continence Society of Singapore, and Tre Stiftelser,** a foundation with three nursing homes in Sweden, discussed how to [change policy makers' mindsets and encourage technological and systems innovation to seek more uptake of person-centered continence care](#).

John Bowis of Health First Europe remarked that "while I see a change across the board towards more person-centered care in healthcare, I am not sure this is the case yet for incontinence". All agreed that technology plays an important role in making this happen, supporting and enabling people to manage their incontinence on a daily basis. Panelists furthermore expressed support for a base provision for incontinence across all EU Member States. However, more person-centered continence care including tailored funding provisions, requires changing the mindsets of policy makers. Panelists discussed a number of ways of making this happen. One of the panelists highlighted the importance of making a compelling economic case for improved day-to-day continence care: "it is important to not only present incontinence-associated costs when speaking to policy makers, but also to show how much



governments are losing in terms of taxation from people who are not able to work and participate in society due to suboptimal incontinence management”. Demystifying incontinence, creating a “bigger community and a bigger voice”, and sharing good practices and mobilizing a community of advocates to raise awareness was also seen as key.

## Transforming the delivery and management of continence care

Opening day 2 of the conference, **Co-chair Dr. Adrian Wagg**, emphasized the [importance of a quality and outcome framework for the day-to-day management of incontinence](#) that is aimed at improving care [at home and in the community](#). “The daily use of pads and other containment products is at the heart of continence care”, he said. Measuring product performance and outcomes in people with incontinence is a key part of a quality continence care service as poor continence care and management at home can have serious clinical, social and economic consequences for patients, caregivers and society at large.

**Dr. Claire Aukim-Hastie, a Registered Adult Nurse (UK) with a PhD in Urology**, presented the key findings of a recent study on the [guidance on management for containment in existing guidelines](#) in seven countries in Europe and in Canada. Whilst many people are dependent on containment for management of incontinence, guidance is focused on treatment with scarce mention of management for containment. Few address the (daily) management of incontinence including initial assessment, care routines, and selecting the right containment products (e.g. pads, catheters, plugs). Also, there is little guidance in the evaluated guidelines on the assessment of patients’ needs or the re-assessment of how the product meets these needs.

Dr. Aukim-Hastie concluded that today’s picture on guidance for management for containment is very scattered. She noted that there is an overall lack of end points or KPIs for measuring good care for containment in community dwelling adults. She furthermore called for further alignment and standardization of best practices particularly with regard to information, assessment, product selection and education on containment product selection. She also called for further alignment between the ISO 15621 standard and the evaluated guidelines on the selection of containment products. ISO 15621 states that *individual user characteristics* (general health condition in terms of mobility and cognition, incontinence type specific characteristics), *product-related priorities* (comfort and fit, discretion, skin health, ease of handling) and *circumstances* (access to an informal caregiver, needs of a caregiver, living situation) vary and need to be taken into account when selecting a containment product.

The **final panel discussion** of the GFI brought together **representatives of the Organization for Economic Co-operation and Development (OECD), the King’s Fund, Leading Healthcare and health insurer AOK Nordost**. The discussion focused on [funding the future of continence care](#). Panelists reflected on [possible new funding opportunities and models](#) in support of helping people manage their incontinence on a daily basis and to stay independent. Funding for long term care services and incontinence varies between countries and health and social care systems. Tim Muir of OECD also

highlighted the disparity between healthcare and long term (social) care. Especially in the area of home care people are expected today to pay out of pocket.

Panelists agreed on a number of recommendations to improve the funding provisions for managing incontinence at home and in the community. First of all, they advocated placing more emphasis on (funding) primary care for diseases and 'issues' that can impact a person's ability to remain independent, active and engaged, including incontinence. Second, panelists recognized the need to shift incontinence and continence management from the periphery of health and social care to the heart of primary and home and community-based care systems. Finally, panelists considered new funding approaches and options such as personal budgets that will enable people to procure their own containment products.



*Panel discussion. From left to right: Stefanie Stoff Ahnis (AOK Nordost), Hans Winberg (Leading Healthcare), Tim Muir (OECD), Cathy Smith (GFI moderator)*

***In conclusion***, the 6<sup>th</sup> edition of the GFI saw a lively debate over two days and the launch of several new studies providing policy makers and payers with guidance and recommendations to improve the day-to-day management of incontinence. It also saw an initial discussion and debate on a possible future [Quality and Outcome Framework for the day-to-day Management of Incontinence at Home and in the Community](#). A summary document of the discussions in the working sessions representing national and international stakeholder perspectives on key quality principles and Key Performance Indicators (KPIs) and end points for the daily management for containment will be made available on [www.gfiforum.com](http://www.gfiforum.com).