

5th GLOBAL FORUM ON INCONTINENCE

Better care, better health – towards a framework for better continence solutions

CONFERENCE SUMMARY REPORT



Adrian Wagg, Co-Chair at the 5th GFI conference and professor of Healthy Ageing at the Department of Medicine of the University of Alberta, Canada

The 5th Global Forum on Incontinence (GFI) '**Better care, better health - towards a framework for better continence solutions**' took place in Madrid on 8-9 April 2014.

Over 300 participants from more than 30 countries came together to learn more about the burden of incontinence on patients and society in today's socio-economic context, and to discuss a future framework for patient-centred, high quality and sustainable continence care.

The Forum was organised by SCA in partnership with the International Continence Society (ICS) and with the endorsement of Eurocarers, the European Health Management Association (EHMA), the International Alliance of Patients' Organisations (IAPO), the European Centre for Social Welfare Policy and Research, the Canadian Nurse Continence Advisors Association (CNCA), the US Society of Urologic Nurses and Associates (SUNA), the European Association

for Directors and Providers of Long Term Care Services for the Elderly (E.D.E.), and the European Union Geriatric Medicine Society (EUGMS). The Forum was chaired by Ian Milsom, Professor of Obstetrics and Gynecology, at the University of Gothenburg, Sweden and Adrian Wagg, Professor of Healthy Ageing and Divisional Director for Geriatric Medicine at the University of Alberta, Canada.

The Forum brought together policymakers, private and public payers, experts and representatives from patient groups, carer and civil society organisations, healthcare and social care associations, and academia. The Forum provided a platform for discussion and debate with the aim to exchange ideas and discuss concrete solutions to improve and deliver the best possible care for people living with incontinence.

The format of the conference involved plenary sessions with presentations by participants, panel discussions, Q&A sessions, and smaller working groups which involved more in-depth discussion of the ideal organisation of continence care based on the for the first time presented **Optimum Continence Service Specification**.

This report provides a summary of the sessions and the discussions that took place during the two days of the Forum. The report is ordered thematically and does not necessarily follow the order of the GFI programme. Over the course of two days, conference delegates discussed issues related to: the emotional, physical and financial burden of incontinence; incontinence in today's context of ageing societies and long term care; incontinence as a health and social policy priority; the integration of health and social care services; the awareness of incontinence among policy leaders, payers and the general public; and, marking the launch of the Optimum Continence Service Specification, the ideal organisation and delivery of continence care.

The burden of incontinence on patients and society

Opening the conference, **Co-Chair of the GFI Ian Milson** explained that incontinence is a serious medical condition and a silent disease that affects the lives of almost 400 million people worldwide. It carries an enormous stigma, with many people suffering in silence due to shame and a belief that incontinence is a normal part of ageing.

The emotional and physical impact of incontinence

Karin Coyne, Senior Researcher in the field of Urinary Incontinence and its relationship to Mental health and health-related Quality of Life, highlighted the multi-faceted *emotional impact* of urinary incontinence (UI) on both men and women citing embarrassment, fear of odour and accidents, a lack of self-esteem, decreased or limited physical and social activities, anxiety and depression, and social isolation. She called for more research and interventions to fully understand the longitudinal impact of UI and reduce the emotional burden on patients and their family.

Kari Bø of the **Norwegian School of Sport Sciences** focused on the *physical impact* of incontinence in women, highlighting urinary leakage as a key barrier for physical exercise. She emphasised the importance of physical activity throughout the life span, especially in the wake of an ageing population. Women with UI should be encouraged to continue with non-strenuous, low impact activities while exercising the pelvic floor muscles. In addition, there is a need for education of fitness instructors and encouraging pelvic floor muscle training as part of women's fitness programmes.

In his key note speech, **Dr. D. Agustín Rivero Cuadrado, Director General de la Cartera Básica de Servicios del Sistema** in Spain, stated that 80% of the Spanish population with incontinence feels socially rejected, experiencing isolation and depression. The impact therefore, is not only physical but also psychological and emotional. He stated: “We need to start talking about incontinence and openly discuss what living with incontinence means for patients, carers and society. We will then be able to revert this trend.”

Three patient panellists from the Netherlands, Sweden and Spain and an **informal caregiver** from Ireland shared their personal experiences of living and coping with incontinence. In addition to the anxiety, depression and limitations they experienced, all three patients stressed the importance of coming to terms with their condition and taking back full control over their lives. Caring for her incontinent mother, Carolyn Akintola highlighted the emotional issues surrounding the dignity of the cared for person. She explained that “all of a sudden the roles had changed. I was doing the type of intimate physical care that a lot of us don’t really want to do. And I’m lucky as I’m looking after my mother who is of the same gender.” She also highlighted the lack of manual handling training and information about accessing and putting products and services as key barriers to overcome: “everything I learnt, I learnt from other carers.”



The 5th GFI conference was held in Madrid in April 2014

The economic impact of incontinence

In addition to the emotional and physical impact, incontinence also presents a significant financial and economic burden on society.

Barry Cahill of the **Continenence Foundation of Australia** presented the key findings of a recent study on *the economic impact of incontinence in Australia* (2011). Nearly 4.8 million Australians, or a quarter of the population aged 15 years or over, are living with incontinence. “Looking at the costs, it is a truly hidden financial burden and while free of charge, informal care is not free in an economic sense.” With a total cost of AUD \$66.7 billion or \$14,014 per person, the most significant cost is the loss of productivity in people with incontinence including loss in earnings, lower taxation revenue and lower productivity. Other costs include: informal caregiver costs, residential and nursing care costs, costs to the health system and ‘burden of disease’ costs measured in disability-adjusted life years’ costs.

Conference delegates widely agreed that the economic impact of incontinence is expected to grow considerably as the world population ages. In addition, there was broad consensus that

the cost of not taking action would be significantly higher than the investment required to address incontinence and improve the current organisation and delivery of continence care.

Incontinence, ageing societies and long term care

During the two days of the Forum, speakers and panellists highlighted the importance of increasing knowledge and awareness about incontinence and placing it as a priority on the health and social policy agenda. In addition, they addressed the need to integrate health and social care services to improve continence care, especially in the context of ageing societies, comorbidities and the complexity of long term care for older people with continence problems.

Educating non-expert stakeholders at the Forum, **Ruth Kirschner Hermanns** of the **University of Bonn**, delivered a brief medical overview of incontinence. In her presentation she addressed the definitions of urinary and faecal incontinence, the anatomic structures of men and women, prevalence, and the different types of and treatment options for incontinence. She identified four patient profiles: urinary, neurological, frail elderly/cognitively impaired, and faecal. Each profile has its own therapeutical options and care pathway. She reiterated that incontinence can occur at any age. It is more prevalent in women and in the elderly, especially in frail elderly, but, she cautioned, “never normal.”

Adrian Wagg, Co-Chair of the GFI, delivered a presentation on the complexity of incontinence in older people. Although not an inevitable consequence of later life, incontinence is more common and more severe in older people. It is associated with many other diseases including Parkinson’s, diabetes, heart failure, stroke, and dementia and has significant consequences on an older person’s health and well-being. However, he continued, “incontinence in older people is not a priority and resources are limited in a day and age where we are hoping older people are going to be more economically productive in life”. He concluded: “we have a burden on ourselves to act as advocates for older people and for frail older people with incontinence problems.”

Awareness of incontinence among the general public, policy makers, policy influencers and payers

Despite its high prevalence compared to other major chronic diseases, incontinence is one of the least discussed and, consequently, most poorly understood issues in public, health professional, policy maker and payer circles. Consequently, incontinence is under-reported, under-diagnosed and appropriate treatment and care is often not provided.

Two recent awareness surveys presented at the GFI indicate low levels of knowledge about the disease, its prevalence, the types of incontinence, and the available treatment and management options.

A **TNS survey** among the **general population** (including patients and caregivers) in Germany, Sweden, the UK and the Tamil Nadu region in India, demonstrated high awareness of incontinence and the burden of incontinence. Across all four countries, 80-90% of all interviewees agreed that urinary incontinence has a severe impact on quality of life. However, the survey revealed little knowledge of incontinence as a medical condition, especially in comparison to other chronic diseases such as diabetes. In addition, respondents showed low awareness of possible prevention, cure and management options.

Bryan Dumont of **APCO Insight** presented the findings of a recent study among **policy makers, policy influencers and payers** in 6 markets across Europe (UK, Germany, Spain, Denmark, Poland and Italy) and at EU level. He shared the following findings:

- Most respondents were **not aware of the WHO's classification** of incontinence as a "set of diseases."
- **Policy Makers**, in particular, are **less likely to classify incontinence as a disease**; rather, they see incontinence as a symptom of other diseases (*e.g. neurological disorders, chronic conditions*) or, simply, a natural part of ageing.
- **Influencers and Payers**, on the other hand, are **more likely to consider incontinence to be a disease** – largely because treatment options are available
- All respondents acknowledge that incontinence can have a **significant impact on patients' lives**, as well as their **family members**.
- **Influencers** focus on the **shame and embarrassment** associated with incontinence while **Policy Makers** focus on its **social impact** – both in terms of personal relationships and interactions in a work setting. Nearly all agree there is a significant individual **financial burden** associated with incontinence.
- Respondents have difficulty describing the consequences as they relate to **society**. **Policy Makers** and **Payers** mention the financial and economic impact of incontinence on society, especially as it relates to **long-term care costs** and **impact on job participation**.
- A clear majority believe incontinence can be **prevented**, but not all types (i.e. neurological).
- Across member states and stakeholder audiences, nearly everyone agrees that **incontinence is manageable**.
- A majority of respondents believe that incontinence **can be cured** – again, in some, but not all, cases.
- The need for reform is understood by the respondents when confronted with the **burden and identified care needs** for patients suffering from incontinence
- Most respondents recognise the need to adapt to a system that is more conducive to long-term care options.
- Policy makers are looking outside for solutions and need support from stakeholders, including industry.
- Healthcare providers and payers are all aware of the **need for more coordination** between **health and social care services**, but no one is taking the lead on this.

Panellists and conference participants widely agreed that more efforts are needed to raise awareness, address stigma, and educate the general public, policy makers and health professionals about incontinence.

Incontinence as a health and social policy priority

Eva Nilsson Bågenholm of the **Ministry of Health and Social Affairs in Sweden** called for incontinence as a health and social policy priority with a view to the impact on quality of life, the financial consequences of incontinence, its high prevalence, and ageing populations. Echoed by several speakers throughout the Forum, she identified stigma, the absence of a strong patient advocacy voice and lack of knowledge amongst policy makers as key barriers.

Presenting Sweden as an example, Eva Nilsson Bågenholm explained how social and health services work together so that the needs of the person with incontinence are met. Sweden's 'Senior Alert - National Quality Register' initiative is a national policy initiative that focuses on

preventative care in older people and improving quality of life for senior citizens. It covers the care and support of people with incontinence including prevention, treatment, toileting assistance and incontinence products.



Eva Nilsson Bågenholm of the Swedish Ministry of Health and Social Affairs, keynote speaker at the 5th GFI conference

Antonella Biroli of San Giovanni Bosco Hospital, Turin, Italy, presented a best practice example of prioritising incontinence and integrated continence care on the agenda of policy makers in the region of Piedmont in Italy. She emphasised the importance of stakeholder dialogue and collaboration. The collaboration between the Italian Incontinence Foundation and the Health Council gave life to the Piedmont Continence Care project creating a network of multidisciplinary centres for the prevention, diagnosis and therapy of incontinence spread over the region.

John Bowis, Honorary President of Health First Europe, former Member of the European Parliament and former Minister of Health and Social Services, England, UK, remarked that one of the keys to overcoming stigma is to ensure that incontinence is recognised as a disease and not a mere side effect of other conditions: “this will give it the priority it does not currently have.” Overcoming stigma and its counterpart embarrassment, clear diagnosis of the condition, better understanding by policy makers, budget managers, health professionals and patients, guided self-management and finally access to treatment and counselling in local community settings are key elements of a pathway to better continence services.

A **panel** bringing together representatives of **Eurocarers, AGE Platform Europe, the European Patients Forum, E.D.E. and the Continence Foundation of Australia** discussed what could be done to connect patients with policy makers in order to drive incontinence up the policy agenda. Panellists agreed that individual testimonials and the collective voice of patients

is critical: “when patients talk, the policy maker listens,” Robert Andrew Johnstone of the EPF said. This was reiterated by Hussain Jafri of IAPO who emphasised the importance of empowering patients to step forward and advocate.

The panel furthermore highlighted the need to bring incontinence to the forefront of the policy debate and engage in key discussions. Rapidly ageing societies and long term care are areas where very little is currently said about incontinence with policy-makers. Anne-Sophie Parent of Age Platform Europe furthermore emphasised the importance of presenting solutions to policy makers, citing the European Quality Framework for long-term care services¹ as an example. The Framework sets out key principles of quality services to protect the dignity and well-being of older people and provides an example of preventive and rehabilitative continence care in a nursing home in Finland.

Reflecting on the role of patients in another panel, **Chris Norton of St. Marks Hospital, UK**, suggested looking at patient advocacy differently in the case of incontinence. She pointed to a wide range of incontinence patients varying from children, women after childbirth, the frail elderly, and people with a disability. “They have little else in common and we may have to work through disease-specific organisations or get people organised on one issue such as toilets.”

Alfonso K. Cruz-Jentoft of the **EUGMS** encouraged awareness raising of incontinence as part of a wider effort to advocate for better, more comprehensive geriatric care for the frail elderly with comorbidities. **Antoine Vella of the Standing Committee of European Doctors (CPME)** recommended specialist continence nurses to champion the issue both in hospitals and in communities.

All stakeholders agreed that incontinence should not be a concern only of doctors, carers and patients: it should also be a concern for all policy makers.

The integration of health and social care services

Kai Leichsenring, Researcher at the **European Centre for Social Welfare Policy and Research** focused his presentation on the need for a new, long term care model where social care and healthcare services for older people are linked and integrated. He illustrated the complexity of long term care for older people and explained that our current health system focuses on cure of a single disease, rather than the care of patients with comorbidities. Leichsenring called upon policy and decision-makers to overcome silo-thinking and work across sectors in order to support patients and informal carers along the care pathway. Key elements that will improve long term care for people living at home with continence problems include: patient-centred support, support for informal carers, case management and prevention and rehabilitation.

An example illustrating the importance of better integrated health and social care is demonstrated by incontinence in people with dementia. It is common for people with dementia to experience incontinence. In her presentation, **Diane Gove of Alzheimers Europe**, explained that dementia and incontinence care are complex issues triggering long term care needs that have to be addressed by health and social care professionals in cooperation with informal carers and people with dementia. “Continence care must be approached from a holistic

¹ European Quality Framework for long-term care services, <http://www.wedo-partnership.eu/european-quality-framework-long-term-care-services>

perspective and must respect the dignity, integrity, well-being and autonomy of people with dementia. It must aim to improve their quality of life and also provide informal carers with the support they need.”

In collaboration with SCA and in wider consultation with people with dementia, informal carers and health and social care professionals, Alzheimers Europe is developing ‘**Care guidelines for People with Dementia and Incontinence living at home**’. The aim is to provide guidance on detecting, diagnosing and managing (in)continence amongst people with dementia living at home. The guidelines are targeted at people with dementia, informal carers, and health and social care providers and policy makers.

Joan Ostaszkiwicz of Deakin University, Melbourne, Australia spoke about the untapped potential of nurses and the importance of empowering nurses to promote continence and manage incontinence across the life span. “Education is empowerment”, she said, and “all nurses should be educationally prepared and equipped to promote continence and prevent and manage incontinence.” She also stressed the importance of Nurse Specialists sharing their knowledge and training with other nurses and healthcare workers about incontinence.

A panel of nurses from Australia, Canada, Sweden, the UK and the US discussed the gaps in nurses’ education today at different levels of nursing practice. They also discussed how to increase nurses and healthcare workers’ interest in continence care and what level of knowledge is needed for a good continence assessment.



Panel discussion with nurses specialised in continence care. From left to right: Joan Ostaszkiwicz (Deakin University, Australia), Cheryl LeCroy (SUNA - Society of Urologic Nurses and Associates, USA), Melissa Northwood (CNCA – Canadian Nurse Continence Advisors), Sharon Eustice (Peninsula Community Health, UK) and Märta Lauritzen (Karolinska University Hospital, Sweden)

The ideal organisation and delivery of continence care

The Optimum Continence Service Specification

A cornerstone of the GFI was the launch of **the Optimum Continence Service Specification**²: a continence care pathway that sets out how best to organise and deliver a truly integrated, high quality care service that is patient-centred, evidence-based, clinically driven and cost effective.

Developed by an international multidisciplinary panel of experts, Optimum Continence Service Specification aims to provide concrete guidance to both policy makers and payers for moving towards better continence care.

Presenting the key findings of the study, **Hilary Thomas** of **KPMG Healthcare and Life Sciences Strategy Group**, explained the need for a continence care service specification. She highlighted the absence of a widely recognised standard care model, poor levels of access, under-recognition of incontinence, unnecessary preponderance of specialist care, lack of focus on wider care needs, insufficient provision of containment products and finally a low priority of continence care on the policy agenda.

The Optimum Continence Service Specification defines the care pathway for incontinence as an integrated care model with **four major components**: case detection, initial assessment and treatment, case coordination, specialist treatment. Based on this integrated care model, a **menu of recommendations** is offered to improve the quality of care including:

- The use of a continence nurse specialist for initial assessment and treatment where available and where not possible, focus on training existing healthcare professionals.
- The use of a case coordinator as single point of contact to ensure a patient-centered approach along the care pathway and smooth delivery of care.
- Promote the use of self-management tools or techniques. Technology should enable self-care, connect patients and caregivers and enable providers to monitor progress and troubleshoot problems
- For payers: in order to provide the highest quality continence care, ensure care standards are incentivised.

The Forum also marked the launch of another study: **the Economic and Quality of Life Assessment of Implementing the Optimum Continence Service Specification in the Netherlands**.

Presented by **Maiwenn Al** of **Erasmus University Rotterdam**, the Netherlands, the aim of the study was to determine the costs and effects of the Optimum Continence Service Specification compared with current care in the Netherlands. Based on size, greatest unmet need, largest societal impact of improved care, the research focused on one patient profile using data for the “elderly patients” with at least 4 comorbid illnesses. The study demonstrates that the new model of care presented in the Optimum Continence Service Specification is cost saving for

² Summary of Optimum Continence Service Specification – The ideal organisation of care for people with incontinence, <http://www.gfiforum.com/Documents/Madrid-2014/Summary%20of%20Optimum%20Continence%20Service%20Specification.pdf>

both the health insurer and society as a whole and improves the quality of life of both patients and their carers.

Stakeholder perspectives on the Optimum Continence Care Specification



Panel discussion. From left to right: You-Seok Kim (Ministry of Health and Welfare, South Korea), Eva Nilsson Bågenholm (Ministry of Health and Social Affairs, Sweden), Alice Skaarup Jepsen (Region of Southern Denmark), Jennifer Bremner (EHMA - The European Health Management Association) and Nicole Koster (Buurtzorg, The Netherlands)

GFI participants had several opportunities to reflect on the Optimum Continence Service Specification, its recommendations and its possible use during a panel discussion and country break-out sessions.

A panel bringing together policy makers from South Korea, Sweden, and Denmark and representatives from EHMA and Buurtzorg in the Netherlands welcomed the Service Specification as a very helpful model.

Although it may not translate immediately into every country, the key components, principles and patient profiles were perceived as very valuable. Panelists and country delegates also agreed that it serves as a helpful tool to continue the conversation about incontinence and to reach out to policy makers, health managers and administrators.

Forum Co-Chair Adrian Wagg reminded participants that the Optimum Continence Service Specification should be considered as an important source of inspiration not only for policy makers and payer audiences, but for everybody working to improve the organisation of care for people with incontinence.

A summary document of the discussions in the working sessions representing national and international Stakeholder Perspectives will be made available on [GFI Forum](#).

Conclusion

The 5th edition of the GFI saw a lively debate over two days with a number of key learnings, conclusions and recommendations that emerged from the sessions and discussions. Summarising the event, GFI Co-Chair Adrian Wagg highlighted the following outcomes:

The session's presentations helped provide a better understanding of:

- The prevalence of incontinence with approximately 400 million people living with incontinence
- The socio-demographic context of incontinence with regard to a rapidly ageing world population and rising demands for long term care;
- The stigma of incontinence with many patients and carers suffering in silence;
- The emotional and physical burden on the patient and carer impacting a person's emotional well-being and professional, social and family life;
- The negative financial and economic impact on the individual and society presenting a significant economic cost to countries with the example of Australia;
- The complexities of incontinence in the elderly and the need for better integrated health and social care services;
- The four patient profiles (urinary, neurological, elderly/cognitively impaired and faecal) and the treatment and management options for each;

The GFI also saw best practice examples of good continence care in Sweden, Italy and Australia where incontinence and better continence care are a priority on the health and social policy agenda.

The GFI furthermore identified a number of barriers to improving continence care including a lack of awareness and understanding of incontinence amongst the general public, health care professionals, policy makers and payer audiences. Strengthening the collective voice and the engagement of patients, stakeholder dialogue, and engaging in key policy discussions and debates were perceived by the audience as critical to place incontinence as a priority on the political agenda.

In addition, conference delegates identified better integrated care, empowering patients through guided self-management and enhancing the knowledge and skills of nurses and other health and social care workers including informal carers as key components of a better care pathway.

Finally, the GFI saw the launch of the Optimum Continence Service Specification providing policy makers and health managers with concrete guidance in organising the best possible care for people with incontinence, with continence nurse specialists in the lead where possible. A better organization of care can facilitate the improvement of quality of life and at the same time save costs for society.

Ian Milsom, Co-Chair of the GFI, thanked SCA, the International Continence Society, the endorsing organisations and all participants for a successful Forum.