CONFERENCE SUMMARY REPORT

Introduction

This report summarises the highlights of the 7th Global Forum on Incontinence ‘Driving outcomes in continence care – creating a win-win for patients, carers and health systems’ which took place in Rome, Italy on 17-18 April 2018.

The conference was organized by Essity in partnership with AGE Platform Europe, Eurocarers and the International Alliance of Patients’ Organizations (IAPO), with the endorsement of numerous international, regional and national organizations with an interest in the topic of incontinence and continence care. It brought together more than 300 patients, carers, policy-makers, payers, health and social care professionals and NGOs from all over the world to hear from a wide range of experts on what good care for toileting and containment strategies looks like and how this can be planned and delivered.

The forum aimed to build on the work of the preceding six events over the past decade, each of which focused on a specific incontinence related theme and were designed to drive positive change at a local country level.
The conference theme

This year’s event examined the role that KPIs can play to ensure the delivery of good quality outcomes in the daily management of incontinence – at home, in the community and in institutional care settings.

It aimed to explore the different perspectives of the various stakeholders involved in planning, delivering and receiving care, encourage greater alignment, and promote awareness and understanding of the fact that delivering good care isn’t just a priority for patients and carers. It is also in the best interest of health systems as they strive to deliver ‘value based healthcare’. As a result, it represents a ‘win-win’ for all concerned.

Conference highlights

Why should incontinence be a policy priority?

The 7th GFI began with a series of presentations to underline why incontinence needs to be on the radar of policymakers. Opening messages from Mattias Abrahamsson, Vice President for the Global Hygiene Category, Incontinence Care at Essity and Professor Adrian Wagg Conference Chair, provided background on the forum, its aims and aspirations and set out the conference theme.

An opening address from the Medical Director of the Italian Ministry of Health, Fiammetta Landoni provided an insight into the Italian Government’s commitment to address the growing challenge of incontinence at a national and regional level. Professor Ian Milsom from the Gothenburg Continence Research Centre in Sweden, presented on the scale of the incontinence challenge stating that: “If incontinence were a country, it would be the 3rd largest in the world.”

Professor Wagg then talked about the modifiable risk factors for incontinence in an ageing population. He mentioned the “complex process of successful toileting” which elderly people need to grapple with, which is reliant on a combination of “mobility, visual and manual dexterity and cognition”. He delivered a strong public health message around prevention and the importance of diet and exercise to ensure that people age successfully and are able to maintain their independence and avoid becoming incontinent. Ultimately, while there is a need to “normalize the conversation around incontinence” to overcome the associated stigma, this should not also constitute “normalizing the condition” and seeing it as an inevitable consequence of ageing.
Continence Care where are we today

The second session of the conference took the form of a panel discussion moderated by Cathy Smith involving representatives from AGE Platform Europe (Anne-Sophie Parent), Eurocarers (Stecy Yghemonos) and IAPO (Kawaldip Sehmi), each of whom presented their groups’ perspectives on today’s focus concerning prevention, cure and care.

Dr Paul Van Houten a leading specialist in elderly care provided context with a focus on frail elderly people where factors such a biological age, multi-morbidities, medication, mobility and cognitive disorders can increase the chances of someone becoming incontinent. He stressed the importance of nurse and doctor education to create the right attitude to encourage the type of interventions which will avoid this happening. He also spoke about the findings of a recent study which shows that a cure for incontinence is only achieved by a very limited group of people which makes a focus on toileting and containment strategies important.

Ms Parent championed the interests of the ageing population by calling for a better focus on prevention to delay onset and the need to create continence friendly environments in public places with access to more clean public toilets which she described as “a human right”. This point was supported by Mr Sehmi who said he would like to see more investment in primary care and prevention. In his opinion optimal care shouldn’t just be about treating the disease, it needs to focus on enabling patient dignity, reducing isolation and enabling greater integration into society. This means looking at a person’s living and working environment and taking a holistic approach.

Mr Yghemonos raised the need to focus on the daily management of incontinence and provide adequate support for carers– many of whom (over 80%) are informal carers, 75% of whom are women. These people must often make significant personal sacrifices to perform their roles and suffer isolation, poverty and health issues as a result. This represents a significant socio-economic issue and society needs to value the contribution that these people make.

Dr Van Houten stressed the importance of adopting a patient focused approach to care and see the patient as “much more than his or her incontinence”. This means really understanding what patients value most. This includes things like feeling less isolated and being able to participate more in society.

An important topic debated by the panel was how to get policymakers to pay more attention to the topic of incontinence. All agreed on the need to talk about the financial impact this has on the public purse. Mr Sehmi suggested that by integrating incontinence into existing health policy standards it can be brought “out of the shadows into the mainstream”.

Next, Joan Ostaszkiewicz, a registered Nurse and academic at Deakin University, Australia, spoke about the role of good toileting and containment strategies in safeguarding patient dignity and the importance of “person centred continence care bundles” to provide people with a personalized care routine including assisted toileting where necessary.

Catherine Murphy from the University of Southampton, UK, provided an overview of the current standards and outcome measures that are currently available in management for
containment and **Professor Dimitri Beeckman** from Ghent University, Belgium, delivered a highly informative presentation on the often under-estimated problem of Incontinence Associated Dermatitis including diagnosis, treatment and prevention.

**What good care looks like and how it should be measured**

The afternoon session began with a recap by **Professor Wagg** of the Optimum Continence Service Specification launched in 2014, which set out the ideal model for structuring and delivering care for people with incontinence. He framed the debate around ways of measuring quality care by referencing the Donabedian model that was created in 1966 and continues to be the dominant paradigm for examining health services and evaluating quality of care according to three categories - structure, process and outcomes. He highlighted the need to focus on outcomes and to have performance measures for the whole care pathway.

The three presentations which followed provided further inspiration on possible outcome measures for continence care.

**Tiago Cravo Oliveira** described the OECD framework to measure the success of healthcare known as the PaRIS Framework - Patient Reported Indicator Surveys. While the success of healthcare is typically measured by survival rates or rates of cure after treatment, it is only when outcomes reported by patients themselves (such as quality of life), are measured, that important differences in the outcomes of care emerge. As a result, he called for greater emphasis on measuring what patients really value in order to deliver truly patient centred care.

This message was further underlined by the presentation from **Holly Harmon** who offered the perspective of a US care provider and emphasized the importance of focusing on outcomes based on patient experience not just clinical outcomes. She gave the practical example of having involved the residents of a care facility in the selection of continence products. “The user’s perspective on ‘comfort’ is very different from a carer’s perspective on ‘fit’”, she explained. By involving the people who would actually wear a product the care home was able to identify a completely new product line which increased patient satisfaction without increasing costs.

Member of the Portuguese Parliament **Ricardo Baptiste Leite** provided his perspective via a video presentation. He too stressed the need to talk to patients and remember that for them quality of life is as important as survival. He talked about the need to rethink the model on which conventional health systems are developed and funded and revolutionise ways of working, including the strengthening of primary care.

Building on the theme of improving care provision, KPMG’s **Adrienne Rivlin** unveiled the findings of a potentially ground-breaking study ‘Measuring Outcomes to Improve the Management of Continence Care’, which for the very first time gives care providers and policymakers clear outcomes to aim for and a way to inform provisions, provide a starting point for value based healthcare and assess continuous improvement for people living with incontinence. The study was based on a review of published literature to identify existing
performance indicators to measure outcomes for the management of toileting and containment strategies. Through a process of expert consensus 14 KPIs were selected to be shared with the health and social care community.

During the Q&A which followed, speakers offered their advice on implementing the KPIs.

**Ms Harmon** counselled against having too many measures: “*quality improvement is founded in data and measurement but needs to be value added*”. She advised focusing on the KPIs that would be the easiest to implement to ensure that the process is “*the least burdensome*”, but also likely to have “*the highest impact for patients*”. **Mr Cravo Oliveira** advised starting slowly to get things right so as not to compromise the whole exercise. **Professor Wagg** reminded the audience that the idea is not to put all 14 KPIs in place immediately, but to put patients at the centre (echoing the point made by several of the patient testimonials that the patient’s voice is not heard enough).

**Competence and tools to drive good outcomes**

Plenary session 3, the final session of day one, examined ways to drive good outcomes, particularly focusing on delivering effective toileting and containment strategies.

**Jennifer Skelly**, Associate Professor in the School of Nursing and Director of the Continence Program at St Joseph’s Healthcare Hamilton, Canada, offered her perspective on the role of nurses and professional carers. Having spent the past 20 years developing specialist continence training for nurses she said that these nurses have a vital role to play in improving the quality of care that patients receive. Providing nurses and professional carers with the appropriate level of specialist knowledge makes a fundamental difference to their ability to display empathy towards patients and means they are more likely to dedicate time to preventative measures such as assisted toileting for elderly patients rather than leaving in a pad.

**Helle Wijk** a registered nurse, senior lecturer and Associate Professor in nursing at the University of Gothenburg, Sweden, spoke about a set of questions that can be used by professional carers and those who lack specialist knowledge to assess an individual’s needs to inform an effective toileting and containment strategy.

Physiotherapist **Sara Rosager Mortensen** from Denmark talked about some of the game-changing technologies which can accelerate improvement in care delivery and what it takes to put them into practice. Examples included sensor technology to assess when a pad needs to be changed for care dependent people who are unable to express their needs, and specially adapted toilets for those with mobility and/or cognition issues which are being used in Japan.

**Richard Humphries** from the Kings Fund highlighted the shortcomings of funding for continence care and explored ways in which these could be addressed. He called for better integration and consolidation of services, the community not the hospital to be the central focus, emphasis on value and outcomes rather than a short-term fixation on cost and activity, a
willingness to experiment with different payment mechanisms and creative solutions where patients have much more choice.

Ms Parent revealed the findings of an AGE Platform Europe Barometer study conducted in 4 countries among partly dependent older people with incontinence looking at the variety of support people receive and the impact this has on quality of life. Conclusions include the need for a better match between what people need and what they receive, greater emphasis on helping people to stay independent and be socially included. She called for the development of a more continence friendly society.

**Different perspectives coming together**

Day two began with an interactive debate involving four experts with different perspectives on outcome measures offering their take on the 14 KPIs for measuring toileting and containment strategies that were unveiled on day one.

**Jan van Ginneken**, Senior Policy Advisor at the Dutch Ministry of Health, Welfare and Sports said he believed them to be “essential to ensure adequate continence care and measure outcomes”, but that there is a need to strike a balance on the “administrative burden associated with measuring and monitoring KPIs”. He advised starting small and talked about the need to involve all stakeholders to develop guidelines and create the right incentives to strive for better outcomes.

Given the structure of healthcare provision in the US, which does not fund expenses unless patients are covered by the Medicaid system, **Susan C Reinhard** from AARP recommended including care giving relative KPIs in the implementation process.

**Rhona Agnew** a registered general nurse and clinical research Fellow at Glasgow Caledonian University explained that NHS Scotland already has outcome measures in place which are being implemented on an ad-hoc basis, but that the 14 KPIs will provide a potentially helpful framework to work with. She spoke of the need to keep people out of hospital in primary care for as long as possible, the importance of personalization of services (within the confines of budgetary constraints) to support more complex needs. In situations where people don’t like the products they are given access to she said they should receive money or vouchers to be able to purchase products of their choice.

**Mr Cravo Oliveira** felt the KPIs were very important and a “step in the right direction”. However, in order to convince politicians and policymakers to act he said it would be important to make arguments robust so they can compete effectively with the many other priorities these people need to consider.

When it comes to operationalising the KPIs top tips from the panel included: involving all stakeholders, creating the right incentives; using digital solutions; starting small initially and expanding over time; prioritising the KPIs to focus on the most important and impactful ones; building KPIs into existing quality standards and data collection systems so as not to reinvent
the wheel; getting third party endorsement and working with partners and wider stakeholder
groups; introducing a pathway to assess individual needs and offer a range of products to meet
them; investing in prevention and self-management; having a clear vision and thinking long
term.

Conclusions and way forward

The 7th GFI provided delegates with access to a wealth of thought provoking content in the form
of new studies, data and diverse opinions from across the stakeholder landscape. It also saw
the launch of a call for abstracts process designed to recognise and celebrate good practice in
continence care. AGE Platform Europe’s representative and member of the abstract committee
Bozidar Voljc presented two awards, one for the best abstract as judged by the Abstract
Committee and one as voted for by the conference delegates.

To round off the conference chair Professor Wagg provided a summary of the key takeaway
messages:

- This GFI has been an important step forward in advancing the continence care debate
  and building on the achievement of previous years.
- There is a need to normalise the conversation around incontinence to raise awareness
  about it globally and ensure it gets on the radar of policy makers and payers as a
  priority.
- Because few people find a total cure for incontinence today, there needs to be a greater
  emphasis on providing the right care at the tight time in a way that meets the complex
  needs of the individual. This includes providing tailored toileting and containment
  strategies which are based on thorough patient assessments and tools exist to do this.
- The importance of investing in the ongoing education of care giving relatives,
  professional carers, nurses, doctors and ensuring they are able to make the best use of
  the available technology in caring for patients
- KPIs and outcome measure are essential to improve standards of care and evaluate
  progress. This conference has made great strides by providing the first ever framework
  of outcomes to aim for. Now it is a case of securing widespread adoption which can be
  achieved more rapidly if KPIs are built in to existing quality measurement frameworks at
  a local level.
- Improving continence care and driving better outcomes is a win-win for patients, carers
  and health systems.
Patient testimonials

Caregiving relative Eszter Vidor spoke about the experience of helping her mother keep her dignity in the face of the combined stigma of incontinence and mental illness. She described the trauma her mother faced over a number of years as she struggled to get help from unsympathetic doctors until she was able to join a self-help group in Budapest. This was a turning point which eventually enabled her to pursue her love of painting, achieve a painting diploma at the age of 69 and set up her own therapy group to help other incontinence sufferers.

As a caregiver in Hungary Ms Vidor experienced many challenges accessing reliable information and access to care. She called for better access to a comprehensive ‘How to survive it’ guide in the form of simple leaflets rather than an over-reliance on the internet and resources such as Facebook which are less acceptable to older people.

Derick Fage spoke about his experience as a patient living with the stigma of faecal incontinence. Born without an anal sphincter he had to go through several surgical interventions which led to anxiety, panic attacks and depression. He wore diapers until he was 13 years old and experienced bullying, shame and isolation, leading to mental health issues.

Mr Fage finally broke his silence at the age of 40 while on air working as the host of Breakfast Television at CityTV in Montreal. His goal is to make people walk away with empathy understanding the mental health issues and isolation that people with incontinence face. He also serves as an inspiration to those living with incontinence to show it is something which they can manage and enjoy an active life.

Elena Weber, is a mother of three who has first-hand experience of living with urinary incontinence and spoke about it for the very first time. She works as a nursing home director of an institute for the blind and visually impaired.

In an eloquent presentation she used a number of hashtags to highlight her key messages: # women, #prevention, # rehabilitation, #social acceptance, # solution. People with incontinence should not feel ashamed!

Mario Sel has Spina bifida and hydrocephalus. An active campaigner for the Flemish patient association VSH and father of twins Mr Sel stressed the need for more information about continence care and financial support to pay for products to manage his condition.

He spoke of the challenges of the working environment – the need for longer break times and more accessible toilets for people with disabilities. He talked about his hope that the next generation will have a better life with incontinence.