



## PATIENT REPRESENTATIVES ROUNDTABLE

### INCONTINENCE AND THE PROVISION OF BETTER CONTINENCE CARE

#### Summary report

For internal use only

On 1 July 2015, representatives of pan-European patient and civil society groups came together to discuss the issue of incontinence and the provision of better continence care in Europe at home and in the community. The roundtable was hosted by AGE Platform Europe, Eurocarers and SCA.

A 'hidden' or 'invisible' disease today, the roundtable aimed to contribute to a better understanding of incontinence and encourage relevant policy and stakeholder action to improve continence care. In particular, the roundtable aimed to discuss and agree on a set of key policy recommendations to improve the management of care for people with incontinence and their carers at home and in the community.

The event saw a lively discussion between all participants on the burden of incontinence in people's daily lives and the barriers and solutions to better continence care that will enable people with incontinence and carers to live active, independent and dignified lives at home and in the community. There was wide consensus amongst participants of the untapped potential of better management and continence care at home and in the community, bringing value to people and society by making people *socially continent*.

This report summarises the discussion and the main outcomes of the roundtable.

#### Opening remarks

**Cathy Smith**, moderator of the roundtable, opened the meeting by welcoming the participants. She highlighted the profound impact incontinence can have on the daily lives of people who suffer from it as well as their carers and introduced the roundtable's focus: How do we improve the day-to-day care for people living with incontinence and their carers at home and in the community?

Representing **AGE Platform Europe**, **Anne-Sophie Parent** explained that AGE Platform Europe is in principle not working on specific diseases. However, she said, "incontinence and good continence care is important and links to broader issues AGE Platform Europe is working on including age-friendly environments and active, dignified and independent living."

Representing the voice of informal carers, **Stecy Yghemonos, Executive Director of Eurocarers** explained that incontinence is very burdensome for carers and “lack of information and training and lack of access to adequate incontinence products place additional strain on carers”.

**Nicole Huige** of **SCA** highlighted that SCA has been developing and bringing to market continence containment products and care solutions in over a 100 countries for more than 50 years. One of the reasons why SCA is committed to raising awareness of the burden of incontinence in people’s daily lives is that there is no strong voice or a patient group in this field. “Together we can speak up for patients and carers,” she added.

**Albert van der Zeijden**, referring to the principles of Patient Centred Care of the International Alliance of Patients’ Organizations and representing **Healt First Europe**, highlighted the importance of incontinence as a key issue for both groups, especially –in the case of HFE - within the context of community care. He emphasised the need for people with incontinence to be better informed and more involved in the decision-making process. Speaking from personal experience, Mr. van der Zeijden also pointed to the emotional impact of incontinence, causing shame and embarrassment.

Representing **Alzheimer Europe**, **Dianne Gove** stated that incontinence is common for people with dementia and highlighted the work of SCA and Alzheimer Europe in developing and promoting a Guideline on *“Improving continence care for people with dementia living at home”*.

**Hildrun Sundseth** of the **European Institute of Women’s Health (EIWH)**, explained the importance of incontinence as it affects women across the life span from giving birth to providing life-long care. She emphasised that incontinence also affects men especially after prostate surgery –“many of them do not want to admit they have this condition or do not know how to cope with it”, she said, which makes incontinence in some cases even more difficult for men than women.

**Lieven Bauwens**, representing the **International Federation for Spina Bifida and Hydrocephalus (IFSBH)** and the **European Disability Forum (EDF)**, remarked that almost all people with Spina Bifida suffer from incontinence. It is generally not well managed and causes kidney and other health-related issues. Incontinence is under-recognised and can have a significant impact on social inclusion. He concluded that incontinence is a health, human rights and chronic issue all at the same time.

**Yves Brand** of the **European Multiple Sclerosis Platform (EMSP)** said that it has only been a couple of years since EMSP started working on incontinence. Incontinence, its day-to-day management and access to containment products was identified by MS patients as one of the major issues for people living with multiple sclerosis affecting patients of both young and old age.

Representing the **European Federation of Crohn’s & Ulcerative Colitis Associations (EFCCA)**, **Luisa Avedano** explained that inflammatory bowel disease (IBD) is a chronic and growing disease, particularly among younger people. EFCCA aims to promote a patient centred approach and incontinence is an area they deal with but not yet in a consistent way. She added that IBD is associated with a lot of taboos and negatively affects the social life of people living with it due to the lack of for example toilet facilities.

## The burden of incontinence compared to other diseases: an expert perspective

**Prof. Ian Milsom** of **Sahlgrenska Academy, Gothenburg University**, gave an expert perspective on incontinence compared to other diseases and also addressed some of today's barriers and opportunities to improve continence care.

### *Prevalence & patient profiles*

In Europe it is estimated that urinary incontinence affects approximately 50 million people and an estimated 15 million care giving relatives. Recognised as a set of diseases by the WHO, Prof. Milsom highlighted 4 patient profiles for incontinence: urinary (1), fecal (2), disabled/neurologic (3), and older people/cognitive impaired (4). Although the *basic* health and social care needs of all profiles is the same, each profile has its own specific health and social care considerations in the patient care pathway. The groupings will help policy makers and payers to better plan for provisions, Prof. Milsom explained. Profile 3 for example include patients with Parkinson's disease, Multiple Sclerosis, stroke, and Spina Bifida. The elderly in the fourth profile are 65 years and older and also include people with Alzheimer's disease.

### *Incontinence compared to other chronic diseases*

Prof. Milsom highlighted that the number of people suffering from Urinary Incontinence (UI) is significantly higher than for other chronic diseases such as Alzheimer's, diabetes and stroke. In Sweden, a recent case study<sup>1</sup> shows that incontinence is the most prevalent disease in women and men over 65 compared to Alzheimer's disease, diabetes and stroke. In addition, incontinence can be described as a "hidden disease" since individuals living with incontinence show high rates of other chronic diseases (comorbidities) for which they are classified such as Alzheimer's, stroke or diabetes. The fact that their classification is not directly linked to incontinence illustrates that it is an even bigger problem than official disease statistics illustrate. "Incontinence is over-shadowed by other (underlying) chronic diseases," Prof. Milsom concluded.

### *Impact on patients and carers*

The negative impact of incontinence can be very significant and affects both women and men. It includes increased isolation, decreased self-esteem, embarrassment, fear of odor and accidents, decreased social or physical activities, depression and unhappiness, etc. Overall, the impact of incontinence on health-related quality of life is generally higher than for other chronic conditions and is significantly underestimated, Prof. Milsom warned.

In addition, the impact of incontinence on the quality of life of informal carers can also be very significant. Poor quality of life can be attributed to factors such as: low(er) income, poor access to information on incontinence and available care products and solutions, caring for an older relative for over five years, and the carer being older than the average.

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<sup>1</sup> The comorbidity effects of urinary incontinence and its impact on informal and formal care costs in Sweden, Christofer Swahn and Christoffer Sundström, Gothenburg, Sweden, April 17 2015

### *Informal and formal care costs*

Sharing data of a recently conducted case study in Sweden, Prof. Milsom also addressed the formal and informal care costs of incontinence compared to other chronic diseases. In general, informal care costs are higher than formal costs for all four chronic diseases. Whereas the formal cost of incontinence is very low, incontinence has a higher informal care impact compared to the other diseases in terms of costs due to the higher number of hours provided by informal carers.

Widely echoed by other participants, Stecy Yghemonos of Eurocarers stated that it will be of key importance to use the economic data showing the high costs for informal carers, once the study results become publically available, as they will resonate with policy-makers, illustrating the 'economic case' of incontinence

### *Treatment & management*

Prof. Milsom explained that there are different treatment options for Urinary Incontinence, including life style changes (weight reduction, better management of fluid intake), bladder training, physiotherapy, medication, surgical treatment, and containment products. He warned that "there are not many people who can be cured forever," highlighting the importance of day-to-day management and the role of containment products in managing incontinence at home, in the work place, etc. Prof. Milsom also emphasised the importance of prevention. However, "if we can't prevent it, incontinence needs to be managed in a good way," enabling active and healthy ageing and active participation of both patients and carers in society.

### *Care delivery and provisions*

Prof. Milsom pointed participants to the *Optimum Continence Service Specification (OCSS)*<sup>2</sup>, a guide developed by experts to improve the organisation and delivery of care for people with incontinence. Highlighting the importance of better integration between healthcare professionals in primary and specialist care and of health and social care services for patients and carers, he said more focus on incontinence in a primary care setting is needed to support people at home and in the community.

As an example, Prof. Milsom explained that the provisions of containment products helping patients and carers manage incontinence in daily life, vary greatly among countries in the EU, from no provision at all in Romania and Bulgaria to some kind of support in the UK, Spain, Germany and Poland. However, provisions are generally not sensitive to individual patient and carer needs, he added.

### *Barriers & opportunities*

Prof. Milsom listed a number of barriers to better continence care for people at home and in the community, including: lack of information, poor adherence to existing guidelines, no or limited financial support, and a one-size-fits all product-based approach versus freedom of choice and more customised care provisions that meet the needs of individual patients and carers. He also pointed to the absence of a clear outcomes measurement framework in the case of continence care.

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<sup>2</sup> Optimum Continence Service Specification:  
<http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0104129>

On the other hand, opportunities to improve the daily management and care for people with incontinence and their carers include an increased policy focus in recent years on care at home and in the community and the role of self-management as key enablers towards more person-centred care provisions that promote independent and dignified living. Key performance indicators (KPI's) therefore should focus on the outcome of the provision, including quality of life, social inclusion, active participation in society and independence and dignity.

In his closing remarks, Prof. Milsom reiterated that incontinence is often overshadowed by other chronic diseases. He also referred to the 'hidden' cost incurred by informal caregiving which should be considered to fully evaluate the cost-effectiveness of urinary incontinence interventions. He finally underlined that **improved containment management is an opportunity to support patients and informal carers and keep people active in society.**

### Roundtable discussion:

#### **Barriers and opportunities to improve the care for people with incontinence at home and in the community - Key policy recommendations**

Following Prof. Milsom's presentation, patient and civil society representatives engaged in a lively discussion on the barriers and opportunities to improve the care for people with incontinence and carers at home and in the community to enable active, independent and dignified living.

Please find below a summary of the debate including key policy recommendations.

#### *Awareness, understanding & stigma*

There was overall consensus that a key barrier to improved continence care is a **general lack of awareness** of and especially **stigma surrounding incontinence**. Despite its prevalence and the serious implications for patients, carers and society, incontinence is often misunderstood, generally underestimated, and almost absent in the public policy debate. It's a hidden disease with many people suffering in silence.

Incontinence is underreported since people with incontinence do not want to associate themselves with the disease or believe it's a 'normal' part of ageing or of an underlying disease or condition (disability). According to Hildrun Sundseth (EIWH), stigma is especially pertinent in the case of men. Incontinence is often considered a female disorder and men do not have the experience women have in giving birth, menstruation and menstrual hygiene, gynaecological disorders, etc.

#### Roundtable participants agreed that:

- ✓ Self-stigma and stigmatisation add to the suffering of patients and carers and delays help-seeking.
- ✓ Raising awareness and understanding of incontinence as a very common and distressing health and social care issue amongst the general public, health professionals and policy makers is an important step to overcome misperceptions and stigma.

### *The (human) right of patients and carers to better continence care*

Supported by all roundtable participants, Albert van der Zeijden of HFE and IAPO highlighted the importance of raising awareness of incontinence as a human rights and a patients' rights issue: the right of patients and carers to information, better continence care and the right to live independent and dignified lives at home and in the community. As Lieven Bauwens of IF SBH/EDF stated, the aim is to make individuals suffering from incontinence, *socially continent*. Inadequate information and continence care hampering a person's ability to lead a life of dignity and independence, may violate the basic human right of an individual suffering from incontinence.

#### Roundtable participants agreed and highlighted:

- ✓ The rights of people with incontinence to lead a life of dignity and independence and participate in the life of the community
- ✓ The right to high quality patient and carer information regarding incontinence and continence care provisions and services
- ✓ The rights of patients and carers to be actively involved in the decision-making about individual options for continence care management
- ✓ The right of patients and carers to information about and access to appropriate continence care/containment products for the management of incontinence that enable active, independent and dignified living at home and in the community

### *Information about incontinence and continence care provisions*

Participants identified the lack of access to incontinence and continence care information as one of the key barriers to better continence care at home and in the community today. Participants noted in particular, the lack of adequate dialogue between healthcare practitioners and patients or carers. Whereas patients and carers often 'do not tell', healthcare practitioners often 'do not ask'. In addition, focusing primarily on prevention and cure, participants felt that health professionals generally demonstrate poor awareness of continence care services and provisions that will help patients and carers cope with incontinence on a daily basis.

Anne-Sophie Parent of AGE Platform stressed that better informed continence care does not only provide a unique opportunity to improve the quality of life for people living with incontinence, but also adds value to the society. "This can be achieved by supporting patients and carers with the day-to-day management of their continence care, which can bring people back into the labour force, instead of focusing only on prevention and cure, which is the case today". Dianne Gove (Alzheimer Europe) added that supporting people with the management of their incontinence at home and in the community can prevent premature or unnecessary institutionalisation. Anne-Sophie Parent also expressed her concerns about a recent trend where "most of today's containment care is not even labelled health or social care, but *comfort care*".

Lieven Bauwens (IF SBH/EDF) emphasised the lack of information about incontinence in schools. "This is a very important issue because children with incontinence are not taking breaks to go to the toilet when it is necessary to do so," he said. Yves Brand of EMSP explained that incontinence is often not discussed at all as part of the patient's 10 minute conversation with the specialist, posing the question where else to obtain valuable information?

#### Roundtable participants:

- ✓ Emphasised the need for greater awareness and training among existing healthcare professionals; and agreed that, where possible, nurse specialists and case coordinators, play an important role in identifying and supporting the care needs of patients and carers (counsel).
- ✓ Stressed the importance of good communication and information to empower patients and carers to make informed decisions on management of incontinence (incl. choice of containment products)
- ✓ Highlighted the important role of representative organizations (patients and civil society) in providing high quality information and empowering patients in managing their disease

#### *Patient and carer choice and involvement*

Furthermore, participants identified a **lack of or limited choice of products and brands** for patients and carers as a barrier to the management of continence care in a home-care setting. As a consequence, patients and carers are not informed and not empowered to make their own decisions as to which products best meet their need. Participants also stressed the importance of better guidance and financial support whilst recognising the need for affordable and adequate products in all price brackets, as well as a variety and choice of brands.

Anne-Sophie Parent (AGE Platform) pointed to a possible dilemma seeking funding for more personalised containment provisions by health and social care systems on the one hand and supporting wider choice and information on the other: “the more we seek coverage and funding, the more difficult it is to run wider choice and information.” Nicole Huige of SCA explained the possibility in Germany of freedom of choice and top-up options that increase freedom of choice for patients and carers.

Stey Yghemonos of Eurocarers noted that informal carers are often not considered ‘real partners’ in the patient care pathway. In the case of continence care at home and in the community, he called for informal carer training and tailored information to carers.

#### Roundtable participants agreed:

- ✓ Patient choice and access to high quality, tailored information will help improve the care for people with incontinence at home and in the community enabling active, independent and dignified living.
- ✓ On the importance of active involvement of patients and carers in the decision-making about individual options for management, including product choice

### *Continence-friendly urban and home environments*

Roundtable participants highlighted the importance of a continence-friendly urban and home environment that enable people with incontinence to stay independent at home whilst actively participating in the community. Many cities and communities are already taking active steps towards becoming more age-friendly – supporting also continence-friendly practices such as access to clean toilets, lighting solutions, etc.

#### Roundtable participants agreed on the importance of:

- ✓ The development and planning of continence friendly urban and home environments incl.:
  - Smart cities incl. clean toilet provisions
  - Easy access to public toilets
  - Appropriate design of work and home environment (lighting, and adaptations to the toilet facilities)

## ANNEX 1 - PATIENT AND CIVIL SOCIETY REPRESENTATIVES

### ROUNDTABLE ON INCONTINENCE AND THE PROVISION OF BETTER CONTINENCE CARE

Organisation	Name
AGE Platform Europe	Anne-Sophie Parent
Alzheimer Europe	Dianne Gove
Eurocarers	Stecy Yghemonos
European Federation of Crohn's & Ulcerative Colitis Associations	Luisa Avedano
European Institute of Women's Health	Hildrun Sundseth
European Multiple Sclerosis Platform	Yves Brand
Health First Europe	Albert van der Zeijden
International Federation for Spina Bifida and Hydrocephalus/ European Disability Forum	Lieven Bauwens
European Brain Council	Mary Baker <i>Unable to attend, Mary provided valuable contributions and input before and after the roundtable meeting</i>