



PATIENT & CIVIL SOCIETY REPRESENTATIVES ROUNDTABLE

INCONTINENCE AND THE PROVISION OF BETTER CONTINENCE CARE AT HOME AND IN THE COMMUNITY

JOINT POSITION STATEMENT

On 1 July 2015, representatives of pan-European patient and civil society groups came together to discuss the burden of incontinence and the provision of better continence care in Europe, at home and in the community, in order to enable people with incontinence and their carers to live active, independent and dignified lives.

A 'hidden' or 'invisible' condition today, incontinence is often overshadowed by other chronic diseases. This Joint Position Statement aims to contribute to a better understanding of the emotional, family and social burden of incontinence in policy and stakeholder circles. In particular, we identified five areas of policy and stakeholder action that will help people with incontinence and their carers better manage their care at home and in the community, support their independence, well-being and dignity, and increase their active participation in society.

Areas of action:

1. **Increase** awareness, recognition and understanding of incontinence
2. **Recognize** continence care as a human right to live independent and dignified lives
3. **Improve** information and communication about incontinence
4. **Enable** choice, involvement and empowerment of people affected by incontinence
5. **Develop** continence-friendly urban/community and home environments
6. **Support** and prioritize a research agenda on incontinence

THE BURDEN OF INCONTINENCE

Incontinence is one of the most widespread and debilitating conditions to affect people over a lifetime. It affects approximately 4-8%¹ of the adult population or the lives of 25-50 million people and an estimated 15 million informal carers² in Europe today. The burden of incontinence is expected to grow due to an ageing population.

Incontinence can have a severe impact on the quality of life and well-being of the individual and is generally higher than for other chronic conditions. It carries an enormous stigma, with many people suffering in silence due to shame and embarrassment, which may in turn lead to stress, fear, depression, decreased social and physical activity and social isolation.³

¹ P. Abrams, et al, *5th International Consultation on Incontinence*, NeuroUrol Urodyn, 2014 Nov 15. doi: 10.1002/nau.22677.

² Estimate based on percentage of caregiving relatives involved in incontinence care retrieved from: Awareness about Incontinence among the general public, TNS study December 2013, data on file.

³ V.A. Minassian, E. Devore, K. Hagan, et al, *Severity of urinary incontinence and effect on quality of life in women by incontinence type*. Obstet Gynecol, 2013;121(5):1083-1090.

Incontinence also takes a toll on the well-being and social and workforce participation of those caring for someone with incontinence, especially in case of severe incontinence and in people with multiple care needs (disabled, older dependent person) or with an underlying cause (e.g. Alzheimer's disease, Spina Bifida, Multiple Sclerosis, Parkinson). The physical toll and strain of caring for someone with incontinence, poor access to information and support services, and the age of the carer, are some of the factors that can lead to very difficult situations for informal carers. Inappropriate care or lack of continence care also increases the risk of premature mortality, due to infections and kidney failure. For adults with Spina Bifida, renal failure is the leading cause of death.⁴

Incontinence can affect men, women and children at any age and can have a severe impact on the quality of life and well-being of individuals and carers. **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.**

1. Awareness and understanding of incontinence

The stigma surrounding incontinence is a significant barrier to improved continence care and adds to the suffering of those who experience it and their carers. Low levels of awareness and understanding of incontinence combined with a high social stigma at all levels of society and institutions, among families and within the healthcare profession itself, prevents individuals from seeking and receiving the care and support that they need.^{5 6}

Increased awareness and recognition of incontinence as an important health and social care issue through information and education and policy efforts will help generate better understanding of incontinence and overcome stigma. This in turn will help improve the quality of life and care of people with incontinence and enable them to live active, independent and dignified lives at home and in the community. At the same time, this will help improve the life of their carers by reducing the additional pressure and stress caused by lack of support and recognition.

Participants agreed that **increased awareness, recognition and understanding of the human, social and economic challenge of incontinence is an important step** to reducing stigma and improving incontinence management and care provisions. In particular, participants:

- ✓ Call on policy makers to give more political attention to incontinence in today's policy deliberations on active and healthy ageing and the future of long-term health and social care
- ✓ Promote education and awareness campaigns targeting families, carers, health and social care professionals, and the general public at large including media and policy efforts

2. A human rights-based approach to continence care

Incontinence can have a profound impact on a person's dignity and independence, especially - but not exclusively - in the case of older people and people with a disability. Maintaining a person's ability to live an independent and dignified life with incontinence therefore requires a rights-based approach to continence care based on the principles set out in the **Charter of Fundamental Rights of the European Union**⁷, the **European Charter for the Rights**

⁴ I. Ahmad, [Urological follow-up of adult spina bifida patients](#), 2007.

⁵ F. Howard and M. Steggall, *Urinary incontinence in women: quality of life and help-seeking*, British Journal of Nursing, 2010 Jun 24-Jul 7;19(12):742, 744, 746, 748-9.

⁶ C. Shaw, *A review of the psychosocial predictors of help-seeking behaviour and impact on quality of life in people with urinary incontinence*, Journal of Clinical Nursing, 2001 Jan;10(1):15-24.

⁷ European Union, [Charter of Fundamental Rights of the European Union](#), 2000.

and Responsibilities of Older People in need of Care and Assistance⁸ and other national, European and international instruments and frameworks⁹.

For that reason, continence care provisions should empower and enable individuals and carers to lead a life of dignity and independence, benefiting from provisions that are designed to ensure their independence at home and participation in the community including in schools and on the work floor.

Advocating a **rights-based approach to continence care that will enable independent and dignified living**, participants:

- ✓ Call on local and national policy makers to recognise and support the rights of people with incontinence to lead a life of dignity and independence and participate in the community on an equal basis with others
- ✓ Encourage access to reliable and comprehensive patient and carer information regarding incontinence and continence care provisions, including appropriate continence care/containment products for the management of incontinence
- ✓ Uphold the rights of patients and carers to be actively involved in the decision-making about individual options for continence care management
- ✓ Promote a more accessible environment at home, school, work and in the community supporting independent living and participation, including easy access to clean public toilets

3. Enhanced information and communication

Poor initial assessment, lack of access to information and limited communication provide key barriers to better continence care at home and in the community today. Primary-care based health professionals generally demonstrate poor awareness and understanding of incontinence and continence care provisions.¹⁰ Secondly, there is an overall lack of access to information about incontinence, available care provisions, available containment product solutions and available support services to individuals and carers.

Reliable information and impartial advice about the range of available products and services should be easily accessible to individuals and carers, enabling them to make informed decisions about the day-to-day management of their condition. In addition, there is a need for providing emotional support from healthcare and community care professionals to help people with incontinence and their carers deal with the emotional aspects of continence care.

Where possible, continence nurse specialists and case coordinators, should play an important role in identifying and supporting the care and information needs of patients and carers. Where unavailable, existing healthcare professionals should be trained in continence care.

It is furthermore important that all stakeholders understand the economic benefits of good continence care in the area of employment, health and social care.

Participants agreed on the importance of enhanced **information and communication to enable individuals and carers** to make informed decisions about the **day-to-day management of incontinence**, including choice of containment products and services. In particular, participants:

- ✓ Call on all relevant stakeholders and decision-makers to provide access to comprehensive information on incontinence and continence care provisions and containment products
- ✓ Promote training among existing primary-care based health professionals enhancing the dialogue between health professional, persons with incontinence and their carers

⁸AGE Platform Europe, EUSTACEA project, [European Charter of the rights and responsibilities of older people in need of care and assistance](#), 2010.

⁹ Including Active Citizenship Network, [European Charter of Patients' Rights](#), 2002 and United Nations, [Convention on the Rights of Persons with Disabilities](#), 2006

¹⁰ IPSOS, *551 general practitioners UK, Poland, France*, 2010, unpublished.

- ✓ Emphasise the important role of information in empowering patients and carers to make informed decisions about the management of their condition (incl. choice of containment products)
- ✓ Involve and support patient and civil society organisations in providing reliable information and empowering individuals and carers to manage their condition in daily life

4. Choice, involvement & empowerment

Optimal continence care management at home is not always possible due to a lack of or limited choice of containment products and services for people with incontinence and their carers. 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 and preference. However, there is no 'one-size-fits-all' solution to improving the management of care for people with incontinence. Each individual is best placed to define her/his needs and what can help to improve his/her wellbeing though guided self-care and, if available, supported by the carer.

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

Participants reiterated their support for an integrated **rights-based and person-centred approach to improve the management of continence care at home and in the community**. In particular, participants:

- ✓ Call on policy and decision-makers to empower individuals and carers with more choice and control over continence care provisions that best meet their needs (including appropriate financial support)
- ✓ Recall that individuals and carers should have timely access to information related to their management options, and have a leading role in product selection
- ✓ Encourage the use of self-management and enabling technologies

5. Continence-friendly urban and home environments

A significant percentage of continence care is provided at home with the objective to enable people with incontinence to remain independent and socially active in their community. Continence-friendly environments are therefore essential in enabling people with incontinence to lead active, dignified, independent and inclusive lives.

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 to prevent falls, etc.

Participants emphasized the importance of **social inclusion** and **continence-friendly urban/community and home environments** to enable active participation and involvement in the life of the community. In particular, participants:

- ✓ Welcome existing efforts to develop continence-friendly urban/community and home environments in the context of the European Innovation Partnership (EIP) on Active and Healthy Ageing, the EIP on Smart Cities and Communities and WHO's Age-friendly Environments Program
- ✓ Promote the design and accessibility to (clean) toilet facilities
- ✓ Encourage appropriate design of work and home environment (e.g. adequate lighting, bins in men's toilet facilities and adaptations to toilet facilities such as larger toilet space, extra handles, higher toilet seats, disposable toilet covers and larger hygiene bags to dispose of containment pads or other continence care products, clear signposting or town maps showing where public toilets can be found.)

- ✓ Encourage all relevant stakeholders to bring together examples, case studies and evidence of enabling technologies (apps), assistive technology and innovative design

6. A research agenda on incontinence

Further research is needed to help improve the understanding of the human, social and economic impact of incontinence on the individual and society. In particular, research is needed to measure the economic benefits and estimated savings of better organized continence care and better management of incontinence in every-day life.

In particular, participants recommend a person-centred research agenda and:

- ✓ Call for adequate levels of EU and public sector funding for collaborative research on incontinence with a focus on:
 - The impact of incontinence on daily life, including research on
 - Patient and carer needs in better managing in every-day living
 - The social inclusion and participation of people with incontinence and their carers in society
 - The costs of ill-managed incontinence and the economic benefits and estimated savings of better managed continence care
 - The long-term outcomes for different patient subgroups and the potential benefits of the following care and support measures:
 - Early identification and intervention
 - Person-centred continence care provisions
 - Training of healthcare and allied professionals on the management of incontinence
 - The development of an evidence-based quality measurement framework to improve continence care management at home and in the community

This event was initiated and supported by SCA - Svenska Cellulosa Aktiebolaget

