Towards independent and dignified living

A Summary of Stakeholder Perspectives on a Quality Framework for the Day-to-Day Management of Incontinence

Introduction

The 6th Global Forum on Incontinence (GFI) took place in Berlin on 19-20 April 2016. Over 350 participants representing policy makers, payers, experts, patient- and civil society organizations, and health professional and carer groups from more than 30 countries came together to discuss the role of the day-to-day management of incontinence in enabling independent and dignified living at home and in the community in today’s societal context of ageing societies, de-institutionalization of health and social care, and a shift from formal to informal care.

On the second day of the conference, GFI participants were split into small country-by-country groups each reflecting on what is needed to improve continence care in their country/region. Guided by a moderator, each group aspired to identify the outlines of a Quality and Outcome Framework for the day-to-day management of incontinence in order to improve the care for people at home and in the community. This document summarizes the key outcomes of the group discussions.

A Quality Framework for the Day-to-Day Management of Incontinence

Incontinence in all its forms affects the lives of about 400 million people worldwide today. An ageing population, an increased burden of chronic diseases and a shift from formal to informal care provided by family and friends all suggest the number of people in need of continence care will sharply increase in the coming years.

During the break-out sessions, stakeholders debated and reflected on key Quality principles and Key Performance Indicators that will enable people with incontinence to preserve their independence and live a fulfilled and dignified life - avoiding dependence and informal/formal care for as long as possible. Key questions in developing a future quality and outcome framework included:

- How do we improve the day-to-day care for people with incontinence that will enable them to live active, independent and dignified lives at home and in the community?
- What do we need to put in place to make this happen?
- How do we measure the outcomes for the individual (both patient and carer) and for society as a whole in the following outcome areas: social participation / functional ability, health / clinical, economic / financial?

The discussion focused in particular on the management of incontinence with containment products such as pads, catheters, and plugs and wider containment interventions including fluid intake management and bladder training.
Participants identified the following key quality principles to improve the quality of care and well-being of people with incontinence at home and in the community:

- **Person-centered**
  - Focusing on the goals, wishes, needs and (home) environment of the individual through individual assessment and care plan
  - Focusing on a person’s health and functional abilities, rather than his or her illness or incapacities
  - Respecting the rights of people with incontinence to lead a life of dignity and independence and participate in the community

- **Choice, involvement and empowerment**
  - Empowering patients and their carers to express their wishes and needs
  - Actively involving patients and carers in the decision-making about the care options that are available to them including product selection
  - Having (timely) access to a wide range of products and provisions so as to provide patients and carers with a choice that best meet their needs, including appropriate financial support

- **Information, education and communication**
  - Having access to comprehensive information on incontinence, the availability and use of containment products so that patients and carers are well informed
  - Emphasizing the important role of information in empowering patients and carers to make informed decisions about the management of their condition, including choice of containment products
  - Providing training to all primary-care based health and social care professionals to improve their competence in delivering continence care and enhancing the dialogue between health professionals, patients and carers
  - Promoting the education and training of specialist nurses in primary care (working across a number or network of family physicians and / or community care professionals)

- **Outcome-oriented**
  - Developing a strong evidence base with a focus on the [potential] benefits of more person-centered care provisions and also early / earlier intervention in primary care
  - Regularly monitoring and assessing the patient’s [changing] needs, experiences, outcomes and satisfaction
  - Collecting and measuring the patient experience [with the provisions / products] and his or her health and well-being based on patient reported outcomes
  - Improving standards of continence care across regions / geographies including a quality and outcome framework for day-to-day management that includes health / clinical, social / functional and economic / financial end points.

- **Re-enablement and enabling environments**
  - Promoting an incontinence-friendly environment at home, at work and in the community that supports independent living and social participation, including easy access to clean public toilets
  - Promoting an environment that supports people with incontinence and their cares to access products that help achieve personal goals and wishes and that enables independence from care of others
  - Supporting [guided] self-management and encouraging the use of enabling technologies at home and in the community including, for example, products with sensor technology, toilet finding and other mobile apps
  - Engaging and coordinating care between health and social care and between multi-disciplinary teams [looping back to family physicians / continence care specialists in primary care]
  - Supporting informal carers by accessing product solutions that enable independence of the person with incontinence, or that meets the carer’s needs in terms of easy and discrete handling and ergonomics.

Stakeholders also agreed that a Quality and Outcome framework should contribute to raising awareness of and de-stigmatizing incontinence amongst the general public.
First of all incontinence should be diagnosed as a disease and not as a symptom. Reimbursement should be possible for incontinence without needing a reference to Alzheimer’s disease or other diseases that are linked to incontinence. GFI participants, Poland

Examples of good practice in relation to international publications, standards and guidelines:

- The Optimum Continence Service Specification (OCSS) to improve the organization and delivery of continence care services
- Individual continence care plans based on individual assessment in community care in Sweden (the Optimum Continence Service Specification (OCSS))
- Specialist nurses / nurse continence advisors in primary care in the UK, Canada and Nordic countries (the OCSS)
- Patient access to wide assortment of product types in Nordics (ISO 15621)
- Senior Alert quality register for prevention of falls, urinary incontinence, pressure ulcers, malnutrition and poor oral health in Sweden
- New WHO guidelines on integrated care for older people (ICOPE) that focus on common ‘issues’ including incontinence, that matter most for older people and that may cause functional decline

Key Performance Indicators and desired End Points

1. Social participation and functional ability:

Participants viewed social participation and functional ability at the level desired indicated by the individual patient as a key indicator area in achieving better quality and outcomes from the provisions for the day-to-day management of incontinence. They highlighted enhanced quality of life and well-being based on individual life goals as the desired end points - measured by the number of people with incontinence that are able to maintain or recover their autonomy taking part in work and social activities. Individual care plans were regarded as the most suitable tool for setting, tracking and measuring a person’s well-being and quality of life. It was suggested that these should be included in (electronic) patient records. In fact, many participants believed that goal orientated personal health care plans should be on the first page of (e) health records moving forward.

A person’s individual goals should also be at the heart of the assessment and evaluation of reported outcomes and wishes of the patients (through patient / carer questionnaires). Stakeholders identified increased involvement of patients and carers in product choice as a pre-requisite in improving a person’s ability to stay active and independent in society and take part in social life. Stakeholders also identified supporting an enabling environment, including increased accessibility to clean toilets, as a key end point.

Patient should be enabled to access products that help achieve their personal life goals
GFI participants, United Kingdom

Patients should be involved in the design of their individual care plan and product selection. A patient centered and integrated pathway would ensure communication between professionals across healthcare systems.
GFI participants, Denmark & Norway

Full social inclusion should be our objective, meaning that people with incontinence should be able to participate confidently in activities they would have participated in before becoming incontinent.
GFI participants, United Arab Emirates, Mexico and India
There is an urgent need to address the gap between funding provisions for acute care and long term care in the home environment.

GFI participants, Canada

Containment products should provide protection against medical complications, be suitable for the relevant user profile and helpful to carers in its application, handling and disposal.

GFI participants, Korea

2. Improved health and clinical outcomes:

Participants indicated the following KPIs and endpoints for improved health and clinical outcomes: reduction in the number of complications (urinary tract infections, falls, sores, etc.); improved skin health; successful avoidance of falls as well as a reduction of unplanned hospital (re)admissions.

Participants also identified the need for well-trained family physicians and more continence nurse specialists. Suggested KPIs include the number of continence nurse specialists in primary care working closely with family physicians and community workers; continence care training and curriculum development and the number of health and social care professionals trained; and the number of continence care assessments evaluating the patient’s needs and how containment provisions and products meet these needs. They identified education and training of all primary care-based health and social care workers as a key end point to help patients best manage their incontinence day-to-day from both a health and social participation point of view.

Stakeholders furthermore reiterated the importance of measuring the patient experience of care with a focus on patient-reported outcomes. They also called for more / better guidance on the day-to-day management for containment in existing and new guidelines.

3. Improved economic/financial outcomes:

Participants agreed that improving access to more person-centered containment products in home and community care settings should be regarded as a sound investment instead of a cost. Hospital and institutional care settings are significantly more costly than the investment required to keep people with incontinence and their carers active and contributing to society. KPIs identified by participants included the ability to stay at work, a reduction in number of GP visits and a delay of institutionalization, i.e. a change in the number of people that are being admitted to nursing / care homes due to their incontinence.

Stakeholders agreed that a desired endpoint would be to have sustainable funding mechanisms in place that provide people with incontinence or their carers, with a personal budget or lump sum enabling them to purchase the containment products that best matches their patient profile and personal goals and needs. Participants also identified a more efficient use of resources as a key economic outcome in terms of optimizing product choice and quality.

Finally, stakeholders all agreed that the biggest economic / financial benefit would come from indirect efficiency gains through a reduction of social work / carer support, more participation in work and voluntary activities and fewer days in hospital / care settings. A number of participants also highlighted more Quality-Adjusted Life-Years (QALYs) at home and in the community as an improved economic outcome requiring close collaboration between all relevant stakeholders including patients and carers, health insurers, etc.
Currently most attention is put on budget limitations and ways to reduce short-term costs, whereas we should pursue a friendlier, patient-oriented reimbursement system that is sustainable in the long term. 

GFI participants, Poland

Current Situation and desired Changes to Improve Continence Care

**Equity:** When describing the current situation for the day-to-day management of incontinence care participants referred to the term “postcode lottery”, meaning that the level and quality of support that is received highly depends on where you live. Continence care provisions vary greatly between and even within countries leading to big differences in terms of health equity and outcomes. Participants agreed on the need for a more person-centered approach to continence care including better, more consistent and more equitable use of technology in assessment and care support. Improvement in this area could be measured by universal application and adherence to international standards of care.

**Communication:** Another characteristic of the current system for the day-to-day management of incontinence was found in the inadequate communication between patient, carer and family physicians. The health and social needs of continence containment should be coordinated with a defined professional (e.g. continence nurse specialist) taking responsibility for this. Caregivers need to be more involved and users should have better access to good quality information about what to expect in support and what is available in terms of containment products adapted to the person’s needs. Participants identified technology as potential tool to support and measure improvement.

**Investment:** When discussing the system of containment provisions, stakeholders generally agreed that decision makers currently regard containment products as short-term costs, while they should realize the long term savings that could be achieved through the development of a more person-centered reimbursement system. Increased focus on prevention and early diagnosis and guided self-management will help transform day-to-day management of incontinence from a cost into a sound investment, they argued. Critical elements identified by the participants were the need for more choice and individual budgets for selecting containment products that truly match the patient / carer needs.

At the moment an approval from the sick fund is needed to get reimbursed for incontinence containment products, but the queue for applying is very long and discouraging people to get support.

GFI participants, Baltic countries
Healthcare staff currently lacks the competence and confidence to facilitate a patient-centric pathway. There is a need for greater management focus on assessment, knowledge sharing between HCPs and (informal) carers and better use of available technology for assessment and care.

Key obstacles and requirements for change

Participants identified the following obstacles in implementing a person-centered quality and outcome framework for the day-to-day management of incontinence at home and in the community in their region/country:

- **Fragmentation and silo thinking**: a separation between health and social care and a lack of coordination and communication between and across health and social care services
- **A lack of awareness and recognition** of incontinence as a key health and social care issue - a weak patient / carer voice
- **Budgetary / cost constraints**: cost versus value thinking; insufficient or lack of budgetary provisions / support resulting in high ‘out-of-pocket’ costs for and limited choice of adequate containment products.
- **A focus on illness vs. a person’s health and abilities** - a focus on ‘problem-oriented’ cure vs. ‘goal-oriented’ care.
- **Leadership and vision** requiring a transition from treatment and cure into better day-to-day management and the prevention of long term care

Consequently, stakeholders identified the following key drivers of change:

- **Integrated continence care and support**: for care and containment management support to be truly person-centered and ‘integrated’, it must be locally driven / coordinated by people ‘on the ground’ and tailored to the health and social needs and preferences of the individual
- **Strengthen the patient and informal carer voice**
- **Educate policy makers and payers** of the hidden costs of incontinence and of the value of day-to-day management of incontinence at home and in the community
- **Shifting the focus from the disease to a person’s functional capabilities**, individual needs and goals to maintain or regain the ability to live independently and in dignity
- **Training and education** of primary-care based healthcare and social care workers
- **Enhancing the communication between healthcare professionals, patients and informal carers**. All stakeholders should be motivated, aligned and dedicated to improving the lives of people with incontinence based on their personal life goals.
- **Political will to promote and ‘test’ new funding options and opportunities** including individual care budgets

There is a lack of sufficient public money for both health and social care and need to implement integrated health and social care standards in order to break down the silos.

GFI participants, Poland

Incontinence still is a taboo topic that does not attract key opinion leaders, decision-makers and media.

GFI participants, Czech Republic & Slovakia

Incontinence not fully included in the care plan and still considered as a “cleaning activity”. Training on incontinence should be included in nursing and HCP training with a link to economical and emotional impact of continence care.

GFI participants, France

Existing care paradigm is “production based” and not “outcome based”. Discussion should not be about costs but about value.

GFI participants, Sweden
Key quotes about the GFI
GFI Partners and Endorsers – WHO panelist

“In today’s context of population ageing, it is urgent to pay more attention to the needs and challenges faced by persons living with incontinence and their carers. Adequate continence care must be part of age-friendly policies and services to empower everyone to enjoy a dignified ageing and combat the risk of social exclusion associated with incontinence.”
Anne-Sophie Parent, Secretary General of AGE Platform Europe

“Incontinence is a prime example of a challenge to restore independence and dignity and keep people active in, and contributing to society. It is a matter of human, social and economic concern. Continence care provisions should empower and enable individuals and carers to remain independent at home and in the community”.
Stecy Yghemonos, Executive Director at Eurocarers - European Association Working for Carers

“Incontinence is a detrimental condition, which has profound negative impact on functional ability and quality of life of older people. Particularly in developing countries, this condition is overlooked, and older persons are not offered non-pharmacological interventions. Therefore, there is pressing need now than ever to support older persons and family caregivers with integrated and continuum of care at community level.”
Dr Jotheeswaran A. Thiyagarajan, Technical Officer (Epidemiologist), Department of Ageing and Life Course at the World Health Organization (WHO)

“The Global forum brought together a range of experts on Continence from across the world. Through debate and discussion about the latest research and practice, we all shared our experiences and returned to our countries better informed and able to renew our commitment to improving understanding of continence issues and how to support people to live well with this condition.”
Professor Martin Green, Chief Executive of Care England

“It was a great opportunity to talk about an issue that rarely features when patient centered health care is being considered. GFI was about taking the embarrassment out of a very important issue for many of our patients.”
Kawaldip Sehmi, CEO of International Alliance of Patients’ Organizations (IAPO)

“It is time incontinence came out of the shadows, where stigma, neglect and failure to recognize it as a disease have placed it for far too long. My fellow policy makers need to hear and understand the voices of people who know the problems at first hand.”
John Bowis, former UK Health Minister and MEP, President of Health First Europe (HFE)

“Improved continence care is possible. Nurse continence advisors are committed to working with patients and caregivers to achieve the individual’s continence goals that will improve their quality of life.”
Dr. Jennifer Skelly, President of Canadian Nurse Continence Advisors Association (CNCA)
National delegations represented at the 6th GFI included the following countries: Austria, Belgium, Canada, China, Czech Republic, Denmark, Estonia, Finland, France, Germany, India, Italy, Japan, Kazakhstan, Latvia, Lithuania, Mexico, The Netherlands, Norway, Poland, Portugal, Russia, Singapore, Slovakia, South Korea, Spain, Sweden, Switzerland, United Kingdom, United Arab Emirates, USA.

Partners:

Endorsers:

Supported by: