

Changing bodies, changing needs

Ensuring health through transitional stages of life

“Being born with spina bifida means that the nerves in my spine are damaged, and this includes nerves to the bladder, which causes incontinence. It means that I always have to make sure that there are accessible toilets available, and that there’s enough time for me to visit them. If I go to another city, I have to find out where there are toilets, and if I go out with friends, I often have to go home after one drink because most restaurants do not have accessible toilets. Today my urine incontinence is mostly under control, but there are still days when I cannot leave the house due to faecal incontinence”.

Mario, Flemish Association for Spina Bifida and Hydrocephalus, Belgium

In the beginning of this report, we spoke about how children become independent, and how learning to tend to one’s physical needs is essential. Throughout life, being able to respond to and manage one’s physical needs is deeply intertwined with a sense of dignity and empowerment. Yet, full control is a state that is not attainable for every adult during all stages in their lives. Whether it is due to temporary circumstances, like childbirth or an injury, or the result of more permanent conditions, many of us find ourselves at some point in vulnerable situations where we must depend on others to tend to our hygiene and health, such as caregiving relatives or professional care staff.

In these vulnerable situations, it is essential to ensure dignity and give individuals the tools to manage their situation as much as possible. It can be a question of adapting sanitation facilities to suit the needs of all people, or supplying

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them with the right means to manage their conditions. It can also be a question of changing care routines and finding new ways to adapt to their individual needs.

As the average life expectancy continues to increase, people will lead longer and healthier lives. At the same time, however, the number of people who suffer from different conditions and depend on care will expand. This comes with numerous challenges. In this chapter, we will explore some of these challenges by looking at how society can adapt to different groups with special needs. We will look at how public policy can ensure that individual hygiene needs of people living with disabilities are responded to, how individualized care for people living with incontinence can increase quality of life as well as support efficiencies in healthcare systems, and how preventing healthcare-associated infections (HAIs) can save lives. Together these challenges affect millions of people's lives and cause unnecessary harm that can be prevented.

The United Nations' Sustainable Development Goal on health (SDG 3) emphasizes that well-being should be promoted for everyone, regardless of age or capability. We believe that ensuring adequate hygiene and health solutions for everyone, improving continence care, and preventing bacterial spread will play a significant role in achieving this. We need to work together to build further on the great progress made so far in these areas, more remains to be done.

Living well with incontinence

If incontinence would be a country, it would be the third largest country in the world. More than 400 million people are affected by incontinence, and the number keeps growing.²² It is one of the diseases that has a large impact on the quality of life for individuals, their families and their caregivers.²³ It does not matter if the affected individual is in their younger years, a pregnant woman, or an elderly person living in a nursing home, poorly managed incontinence causes both physical and social discomfort, stress that easily leads to social isolation and reduced possibilities to take part in society.²⁴ As a result, incontinence may contribute to other outcomes of poor health. Essity's global survey shows that as many as seven

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71%

worry about not being able to go to the toilet on their own as they get older or ill

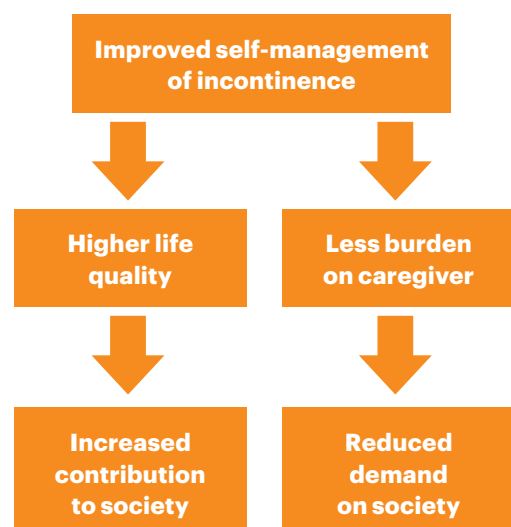
67%

worry about not being able to care for their personal hygiene

in ten respondents worry about not being able to go to the toilet on their own as they grow older.

Caring for someone with incontinence can also be burdensome for the caregivers, regardless of them being family or professional workers. Almost a third of all people that care for an elderly relative, care for a person who has incontinence.²⁵ This condition often becomes a psychological burden on the caregiver, as it takes up their time round the clock.²⁶ The prevalence of incontinence in long-term care facilities is estimated between 50-80%,²⁷ and one of the most common reasons for a person to move to a long-term institutional care²⁸.

Consequently, poorly managed incontinence can have a large impact on both the quality of life of people affected and on societal costs. One Dutch study estimated yearly healthcare costs to 7,402 euro per patient, and societal costs to 3,811 euro per patient.²⁹ The total costs are likely to rise as the number of individuals affected by incontinence increases. Enabling more people to manage their incontinence in a, for them, more suitable way, will both improve the life quality of patients, reduce costs and make better use of caregivers' time.



Today, we have a better understanding on how to manage incontinence, and what good continence care looks like in order to improve it. The Optimum Continence Service Specification (OCSS) is a modular guide on how to best care for individuals with incontinence, which was developed by a multidisciplinary expert panel and presented to the Global Forum on Incontinence. A recent analysis estimates that implementing the OCSS could lead to significant benefits both for the individual patients and for society. The study looks at the potential effects for The Netherlands and estimates that the costs related to incontinence could be reduced by 31 million euro in the healthcare sector, and a total of 125 million euro in societal expenses over a three-year period. In the future the benefits might even be larger given the ageing population. By 2030, applying the OCSS may lead to savings between 32-75 million euro in healthcare costs, and 182-251 million euro in societal costs over a three-year period, while simultaneously yielding large health benefits in elderly communities (estimated to 2,592-2,618 in Quality-Adjusted Life Years*).³⁰

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Several actions must be taken in order to achieve these results. First, we must raise the awareness of incontinence to ensure that more people affected dare to talk about their experience and seek help.³¹ Second, we need to ensure adequate pathways to navigate in the healthcare system, so that incontinence cases can be detected and assessed.³² Third, we must strive for an individualized continence care, where patients' needs are responded to, and where they can influence the care as well as the solutions to use.

Fighting healthcare-associated infections

Ten out of every 100 patients in developing countries and six out of every 100 hospitalized patients in developed countries will acquire at least one infection whilst being treated.³³ In total, the World Health Organization (WHO) puts the estimated number of affected patients in the hundreds of millions, and severely ill patients are

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disproportionately affected.³⁴ Patients with healthcare-associated infections (HAIs) are almost two times more likely to be readmitted, and 9% out of the total days spent in bed are estimated to be excess days attributed to HAIs.³⁵

Hence, HAIs leads to unnecessary suffering for individuals who are already in need of care and causes excessive costs for the healthcare system as well as to society at large. The costs of healthcare-associated infections are difficult to estimate on a global level. In the U.S. alone, however, the Centers for Disease Control and Prevention (CDC) has estimated the direct medical costs of healthcare-associated infections between USD 36-45 billion³⁶, which do not include indirect costs like lost productivity.

Up to 70% of the healthcare-associated infections can be prevented.

Another important factor adding to the toll of HAIs is the increase in antimicrobial resistance (AMR). More than 70% of bacteria causing HAIs are resistant to at least one of the drugs most commonly used to treat them.³⁷ HAIs are closely linked to AMR and are often caused by an increased risk of resistant strains of bacteria found in infections. Fighting HAIs is an important, preventive measure against AMR.

The good news is that up to 70% of the healthcare-associated infections can be prevented³⁸, and the most effective and cost-efficient way is to improve hygiene

**Every USD 1 invested
in hand hygiene
yields a return of USD 24**

standards in hospitals and hand hygiene among health-care workers³⁹. Apart from health benefits, investing in hand hygiene has a positive return on financial investment, as it is estimated at USD 24 for every USD 1 spent.⁴⁰

In theory, we know very well how to go about this. Building on Professor Didier Pittet's research (interviewed later in this chapter) and the Geneva Hand Hygiene Model, WHO has identified five moments when health-care workers should clean their hands.⁴¹ We also have a good understanding of how to successfully implement the best hand hygiene practices. Research and experience show that achieving long-term behavioral changes incorporates a combination of various strategies.⁴²

Some of the crucial elements include accessible infrastructure for hand rubbing and washing stations, and an

understanding of the importance of hand hygiene among management and healthcare workers. Innovation also has an important role to play. Digital solutions that monitor compliance and provide feedback to healthcare workers are expected to gain progress in the near future. Another opportunity area is to ensure that hospital environment and medical tools have antimicrobial properties, such as antimicrobial spools for surgery tape, self-disinfecting textiles or better solutions for wound care.

We still have a long way to go before healthcare-associated infections are eliminated in patient care, and for all people with incontinence to lead dignified lives. In this chapter, we will explore what the path ahead looks like.



Informing policy through local voices

Hygiene solutions are often not designed with regards to people with disabilities. Policy-makers, healthcare workers, family and community members rarely have the information and understanding of how best to address the needs of those who are disabled. This leads to frustration and marginalization. Much stands to be gained by including more voices in the policy process.

Nadia, 26, is an energetic and outspoken motivational speaker and corporate trainer by profession. She has been involved in welfare activities for the disabled in Pakistan and shared her experience of trying to use public toilets. As she uses a wheelchair, the biggest obstacle for her is lack of enough space while using a public toilet.

– Since the doors of public washrooms open inwards, I am often not able to enter with my wheelchair and have to wait for someone to help me and this may take too much time. The difficulties in accessing the toilets not only cause inconvenience but increase the risk of kidney infections and failure among the disabled.

Nadia's case is not unusual. Regardless of the country, there is often a lack of attention given to the hygiene needs of those who are disabled. Restrooms are only one example. Nadia must often wait for someone to assist her, even though she is independent in her wheelchair.

Nadia shared her story at a recent national consultation with the elderly and disabled in Lahore, Pakistan. The consultation was supported by Freshwater Action Network South Asia (FANSA) and WSSCC.⁴³ During the sessions, participants were encouraged to share their stories, challenges and recommendations for improved access to sanitation and better hygiene practices for policy-makers and local government officials in Pakistan.

The recommendations from these consultations were shared at the regional level, during the South Asian Conference on Sanitation (SACOSAN), which took place in Pakistan in early April 2018, with a plan to use these practical examples as foundational information for the Ministerial Declaration, which will be signed off at the end of the conference by all eight country governments in South Asia: Afghanistan, Bangladesh, Bhutan, India, the Maldives, Nepal, Pakistan, and Sri Lanka at the highest levels. This declaration then serves as a policy to encourage change at the national level.

Recommendations from the South Asia consultations include:

- Organize regular community meetings to enhance participation and collective decision-making on WASH facilities.
- Ensure availability and access to toilets in all public places, especially for women, the elderly and the disabled.
- Develop and enforce norms and standards for gender-friendly and disabled-friendly WASH facilities in public institutions.
- Facilitate convergence between various departments to ensure that vulnerable groups are represented and their needs are met through their participation and inclusion in planning and implementation of WASH programs at community level.

Source material from Rashid Mahmood, Director, Punjab Urban Resource Center, Lahore and Convener FANSA Pakistan



People with incontinence should not have to suffer in silence

Incontinence affects people of all ages, and while there are many common challenges, some are specifically related to the elderly. Paul van Houten, Head of the Medical Department of Zonnehuisgroep Amstelland in The Netherlands, shares his thoughts on the challenges connected to continence care and what can be done to improve the quality.

Van Houten has over 30 years of experience in elderly care and works mainly with frail, elderly persons living in nursing facilities. As a nursing home physician, he noticed a big share of his patients suffering from incontinence, and realized that there was little known how to care for them.

For some people experiencing incontinence, symptoms occur at a much earlier stage in their life. The main challenge for this group is to acknowledge the problem, talk about it with their spouses or family, and seek help.

– Many people think that incontinence is an inevitable result of ageing, but there are things you can do. You should not have to suffer in silence. Even though there are many types of incontinence that cannot be cured, there are many things you can do to make it easier to live with the condition.

Once incontinence has been diagnosed and it has been confirmed that it cannot be cured, the care should consist of a combination of containment products and toileting strategies.

– Having the right protection is important, but it is always better to have access to a toilet when needed. Relying only on containment products may lead to constipation, infections, or skin irritation, says van Houten.

For the elderly with limited mobility, having access to a toilet at the right time is often a challenge, especially for those who live in a nursing home. In professional elderly care, resource constraints are a real challenge. According to van Houten, three times more nurse aides would be required to ensure that all patients have access to the toilet at any given time. There are ways, however, to meet the needs of patients in a more effective way.

– First, you need to make sure that the toilets are easy to find and use. In some nursing homes, the toilets are almost hidden. Second, you need to learn the signs of patients who need to use the toilet. Third, you need to assess each patient and get a better understanding of when they usually need to use the toilet. That way, healthcare workers can adapt their schedules to suit the patients' needs. This is better for the patients and does not necessarily require more staff.

Another key factor is to take a more holistic approach to incontinence care, especially for frail, elderly people who might be suffering from a number of other conditions, like dementia or Parkinson's disease.

– You need to take several conditions into account. Incontinence may have other underlying causes. Incontinence can, for instance, be a consequence of medication taken to treat something else, but there is no awareness about this. This is why we need to have a more holistic approach; you cannot look at incontinence separately. A better understanding of each patient's needs is crucial to giving the best care possible.

Improving continence care in nursing homes:

- Ensure that toilets are easy to find and use.
- Learn the signs patients show when they need to visit the toilet.
- Understand at what time of the day patients usually need to visit the toilet and adopt the schedule to their rhythm.

Improve continence care by involving and empowering the patient

Representing the world's largest network of senior people's organizations, AGE Platform Europe, the Secretary General, Anne-Sophie Parent, has gained a lot of knowledge on success factors when it comes to elderly care. She calls for a more patient-centered and empowerment-based incontinence care.

– Incontinence is a common reason why older persons move to nursing homes. In some cases, though, they could actually stay home longer – if only they were given the right support and containment products, says Parent.

In 2016, AGE Platform Europe and Essity conducted a pan-European study among people with incontinence and informal carers. The study showed that two in five respondents felt that the products did not give them optimal support. As many as four in ten individuals experienced a disturbed sleep pattern as a result of using unsuitable products. Two in five patients felt that they had no influence on the products that were being offered by the healthcare system. Consequently, three out of four respondents ended up paying for additional products themselves.⁴⁴

Parent argues that all of these issues can be avoided with better awareness, a more person-centered assessment of needs and care and increased product choice.

– Some people have heard from their prescriber that it is normal for the protection to feel uncomfortable. Yet there is no reason for this when there are so many available products for different kinds of needs. Care providers need to offer a variety of product types adapted to each individual, and stay up to date on the latest available products on the market.

Parent wants older people given the opportunity to try out different kinds of products, influence product decisions, and make sure that products are truly adapted to their individual needs. This would not only improve product fit, but also give a feeling of empowerment.

Another way to involve and empower people with incontinence is by offering self-support groups, where

individuals can share their thoughts and experiences, and find support from others in the same situation.

– Incontinence can happen to anyone, but it does not have to prevent you from going on with your normal activities nor be the end of your social life. By showing the available solutions and lifting positive examples of people living with incontinence, they may be more inclined to seek help, and regain their dignity and role in society.

2 in 5



Two in five patients think that the containment products offered do not give them the needed support.

2 in 5



Two in five patients say that they have no influence on the containment products offered by the healthcare system.

3 in 4



Three out of four patients have paid for additional products themselves.

The benefits of having person-centered continence care

We can create a continence care that is better adapted for each individual by seeing patients as experts and equals to medical professionals. According to Helle Wijk, Senior Lecturer and Deputy Head of University of Gothenburg Centre for Person-Centred Care in Sweden, this will demand a shift of mind and power relations in the healthcare sector.

– Person-centered care is not a model or a quick fix, it is rather an approach to one's fellow humans. It is about seeing the patient as a person with a life story, rather than a collection of symptoms and diagnoses. Of course, the patient has always been at the center of healthcare, but this approach is about seeing the patient as an equal, says Helle Wijk.

There are a few principles to person-centered care. The first is listening to how the patient is experiencing his or her situation and care needs. The second is to invite the patient, and in some cases the patient's family, to partner in planning for a healthcare in which the patient has just as big a say as the physician.

Seeing the patient as an individual with a life story can lead to more creative solutions.

– In one case, an older man experienced incontinence during the night. The nursing home staff learned that the man had worked as a farmer his whole life just by talking to his relatives. His leakages would occur around five o'clock in the morning when he was used to waking up. By adapting the schedule, the incontinence incidents could be prevented.

A key to implementing a person-centered care is to require and prioritize patient involvement in policies and guidelines.

– It takes time to listen to a patient's stories, but studies show that it saves time in the end and leads to better care, says Helle Wijk.

Listening to patients, healthcare professionals and other voices in continence care is a foundation for Essity's innovation and product development process.

– The traditional innovation model is often focused on solving problems, without an actual understanding of the individual's pain points and the causes behind them. Every pain point can be broken down to a root cause; and when you find the root causes, you can begin to grasp the true essence of the matter, says Joshua Carney, Technical Innovation Manager at Essity.

It is often a long and thorough process to truly understand the needs of patients and their caregivers. It requires lots of interviewing, collecting user studies and shadowing, until you can start addressing the identified root causes and come up with new concepts.

One research endeavor resulted in a digital tool to assess the voiding patterns among patients with incontinence. Digital solutions can track when leakages occur in order to understand a patient's individual needs. This device enables people to optimize their toilet routines and select appropriate products for usage. Thereby it promotes a better health outcome among patients, creates time efficiency for nursing home staff, and reduces waste from used containment products.

– One case where the digital solutions were beneficial, was an older woman who suffered from fatigue due to disturbed sleep and as a consequence lack of appetite and energy. During the night she was woken up to either go to the toilet or to change containment product, which made it difficult for her to go back to sleep. The next day she was tired again, with no appetite and went to bed early. The digital solutions enabled the nursing staff to better understand her needs and change the hygiene routines so they did not disturb her sleep, which significantly improved her well-being. A simple change in her hygiene routines meant significantly improved quality of life, says Joshua Carney.

Hence digital solutions can be a complement to the patient life stories. Much can also be gained by combining different digital solutions and integrating the results.

– Today different players are working on different areas of care, but seldom work together. When integrating different aspects of the care, we can improve our understanding and find better solutions. For instance you could merge the information on medical intake with incontinence data to discover patterns. This will enable the staff to focus on what matters most: caring for the patient, says Joshua Carney.



**A deeper knowledge of patient's
incontinence condition can lead to**

61%

reduction of leakage

59 hours

efficiency gain in hours per year per patient

56 kg

less post use containment product
waste per year per patient ⁴⁵

A revolution in patient care

Today, there is undisputed evidence of the central role proper hand hygiene plays in healthcare, as it is regarded as one of the most important elements of infection control activities. However, just a few decades ago, the awareness of the importance of hand hygiene was not as widespread. According to infectious disease expert Professor Didier Pittet, dubbed the Father of Modern Hand Hygiene, the development in the last centuries can be described as no less than a true revolution.

Professor Pittet's own interest in hand hygiene was evoked in the late 90's when he formed an infection control program at the Geneva University Hospitals, Switzerland. By becoming aware of an alarming knowledge gap related to hand hygiene practices, he was encouraged to start working on solutions.

– It became clear to me that hand hygiene was, and still is, at the very center of healthcare practices, as it plays a central role in reducing infections and anti-microbial resistance spread. At that time, however, nobody knew exactly how important it was. So, I decided to find the most effective way to improve hand hygiene practices, says Professor Didier Pittet, who is today the Director of the Infection Control Programme and WHO Collaborating Centre on Patient Safety at the University of Geneva Hospitals and Faculty of Medicine.

Finding hand hygiene routines that reduce the rates of healthcare-associated infections has been a key motivator for Professor Pittet, who has long had a central role in the WHO's work on guidelines for hand hygiene in healthcare. Although, the guidelines themselves are not enough to change behaviors. It is equally important to develop a strategy that takes several different perspectives into account when implementing the guidelines.

During his long experience working with hand hygiene, Professor Didier Pittet has come to realize that many elements need to be in place in order for a successful change to happen. The WHO strategy consists of five elements: 1) a system change that makes hand hygiene more convenient with alcohol-based hand rub available at every point of care, 2) education for health workers, 3) continuous monitoring and performance feedback, 4) reminders in the workplace, and 5) establishing an organizational culture focused on safety.

– You need all five elements to succeed, because they enhance each other. If you remove one dimension, you will not achieve the same results.

Professor Didier Pittet compares the implementation of hand hygiene guidelines to the introduction of seat belts in the mid-twentieth century. Just like hand hygiene, the benefits of seat belts were obvious, but it still took a long time to change the public's behavior.

– Resistance to change is a universal human tendency, not just in healthcare. That is why reinforcement and feedback are so important. People feel empowered when they see results, which furthers positive reinforcement.

While there has been great progress around hand hygiene practices, Professor Pittet believes there is still room for improvement in better methods.

– We need to improve the education about the five moments, and be more innovative in promoting hand hygiene strategies to continuously remind people to follow the guidelines. There is also a lot of improvement to be done when it comes to the way we monitor compliance and give feedback. This is where technology plays an important role.

Overall, he looks positively on the matter of hand hygiene – both when looking back at what has been achieved and for future development.

– Since we started our work, we have seen a revolution in patient care. Thanks to better hand hygiene routines, we have probably saved five to eight million lives around the world each year. Today, most physicians see good hand hygiene practices as a natural aspect to their work routines. Hand hygiene has now been introduced in the student curriculum, which indicates a new generation of better informed and well-prepared physicians – hopefully leading to a new revolution in hand hygiene practices.

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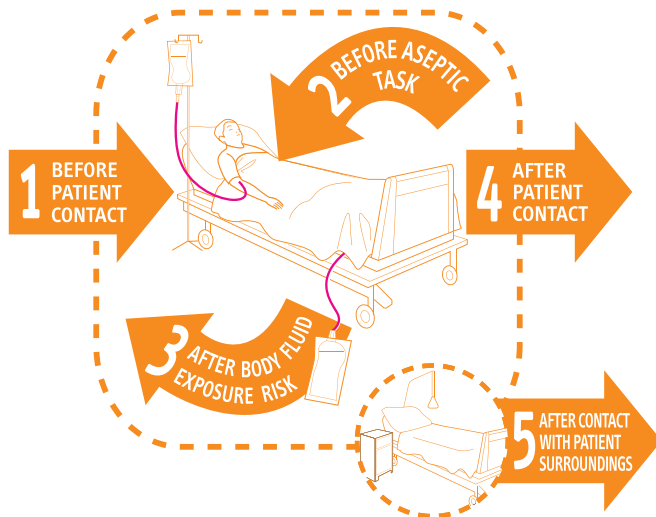


Illustration taken from WHO Guidelines on Hand Hygiene in Health Care

5 moments of hand hygiene

For effective hand hygiene, healthcare professionals should disinfect or wash their hands at five critical moments during patient care.

1. Examples: Before shaking hands, helping a patient to move around, clinical examination.
2. Examples: Before oral/dental care, secretion aspiration, wound dressing, catheter insertion, preparation of food, medications.
3. Examples: After oral/dental care, secretion aspiration, drawing and manipulating blood, clearing up urine, faeces, handling waste.
4. Examples: After shaking hands, helping a patient to move around, clinical examination.
5. Examples: After changing bed linen, perfusion speed adjustment.



Changing bodies, changing needs – next step

Hygiene and health are closely intertwined with a sense of identity and control. Ensuring dignity in vulnerable situations is critical. This is especially important for people living with disabilities, living with incontinence and for patients in healthcare settings. In all these areas it is important to take a person-centered approach and listen to the individuals who are affected.

To enable a person-centered approach, it is also important to give patients and their relatives the knowledge and power to influence their care. Especially in continence care, much can be gained by involving and empowering patients. When self-management is no longer an option, the care by caregiving relatives or professionals must adapt to each patient's needs. New care strategies and innovative solutions can play a key role in enabling individualized care, even under the conditions of resource constraints. It helps make better use of available resources.

Innovative solutions are also needed to prevent healthcare-associated infections. We have come a long way in understanding how infections can be prevented, but like any profound change, it takes time to change behaviors. We have to keep emphasizing that good hygiene is essential not only to protect ourselves, but also to protect vulnerable individuals.

Caring for, and investing in people with special needs means creating a society where everyone is cared for.

Calls for action:

- **Prioritize hygiene and health solutions for those with special needs.**

In the community, in healthcare facilities, and in national policies, all people, especially those who are most vulnerable, should be given the best possible care for their hygiene and health.

- **Enable individuals with incontinence to lead more dignified lives.**

Incontinence should be more openly discussed and made a priority for public health. A person-centered approach should be a central part of continence care.

- **Integrate hygiene practices of all healthcare.**

We need to continue deepening our knowledge on how infections can be prevented, train medical workers in good hygiene practices, ensure that all care facilities have access to clean water and hand disinfectants, follow up and monitor improvement, share best practices among institutions, and use innovative methods to improve hand hygiene compliance.