

Personal Well-being – Key to Public Progress

The Hygiene and Health Report 2018-2019



PRESENTED IN PARTNERSHIP WITH





SUSTAINABLE DEVELOPMENT GOALS

1 NO POVERTY 	2 ZERO HUNGER 	3 GOOD HEALTH AND WELL-BEING 	4 QUALITY EDUCATION 	5 GENDER EQUALITY 	6 CLEAN WATER AND SANITATION
7 AFFORDABLE AND CLEAN ENERGY 	8 DECENT WORK AND ECONOMIC GROWTH 	9 INDUSTRY, INNOVATION AND INFRASTRUCTURE 	10 REDUCED INEQUALITIES 	11 SUSTAINABLE CITIES AND COMMUNITIES 	12 RESPONSIBLE CONSUMPTION AND PRODUCTION
13 CLIMATE ACTION 	14 LIFE BELOW WATER 	15 LIFE ON LAND 	16 PEACE, JUSTICE AND STRONG INSTITUTIONS 	17 PARTNERSHIPS FOR THE GOALS 	SUSTAINABLE DEVELOPMENT GOALS

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Essity foreword

Time to put insights into actions

As a leading global hygiene and health company we, at Essity, have gathered knowledge and insights to drive a global dialogue about the strong connection between hygiene, health and well-being. In 2017 we educated more than 2.5 million people about hygiene and health, including teaching children the importance of hand hygiene to young women about puberty as well as educating people and staff at nursing homes about incontinence. We collaborate with partners, using our different perspectives, collective competences and resources to raise awareness, develop standards and influence regulations in relation to health and hygiene, thereby improving well-being and the lives of millions worldwide.

Every day, millions of people across the globe miss work, school or social interactions because of concerns or hinders relating to hygiene and health. These can be the result of a lack of access to fundamental necessities, like clean water and toilets, or limited or no access to hygiene and health products. Overcoming cultural stigmas surrounding areas such as menstruation and incontinence is essential for personal and societal progress. The United Nations' Sustainable Development Goals (SDGs) provide an excellent framework for ensuring public progress as well as individual well-being.

To be relevant and achieve the best outcome we have chosen to work specifically with the goals that are closest to our area of expertise and business. In this report we will specifically focus on three of these goals: 3, 5 and 6. As a company we contribute in different ways. We strive to supply customers and consumers with responsible and resource efficient solutions, products and knowledge. With our partners, such as the Water Supply and Sanitation Collaborative Council (WSSCC) and the United Nations Foundation, we share knowledge and raise awareness about what is needed to achieve the SDGs. We believe that delivering on the SDGs creates business opportunities that make the world a better place for everyone.

Together we have a unique understanding of what it takes with regards to hygiene and health to create a society where everyone has equal opportunities to realize their basic human needs and rights. Now we need to continue to put those insights into action. To achieve an even greater impact, we invite stakeholders to participate in the dialogue and push forward to raise hygiene and health standards worldwide.

The focus of this report is on health and hygiene throughout the course of life and what we all can do to contribute.



Magnus Groth
President and CEO
Essity

WSSCC foreword

Putting people at the centre

The Sustainable Development Goals (SDGs) are two years old, and already we are seeing incredible progress towards the 2030 agenda. Countries around the world are developing national plans to respond to the SDGs and sharing successes and lessons with others, indicating a collective spirit to transform the world. Partnerships are forming between government, international entities, private sector, academia and civil society... there seems to be a collective message: We cannot do it alone. Activists, students, influencers and citizens are working together, leading campaigns and using their voices to speak out on issues that matter to them; health, education, gender equality, climate change and peace, just to name a few. Collective action is everywhere.

Amidst the progress, there is still work to be done. SDG 6 (on Water and Sanitation) is one of these areas. 4.5 billion people globally still lack safely managed sanitation, and poor hygiene practices have devastating effects on individual health and well-being, on malnutrition and child-mortality and contribute to growing societal concerns around disease outbreaks.

Women, girls and people in vulnerable situations (SDG 6.2) are of particular concern. Imagine the young girl who menstruates for the first time at age 12. She has no prior information about her period as, contrary to common beliefs, in many countries fewer than half of the girls have been told about menstruation from their mothers before menarche. The gendered societal norms in her community indicate that she is impure and cannot participate in certain social gatherings; that she should not eat or touch certain foods; that she cannot cook or help in the kitchen or should not bathe for a week because of the mistaken belief that

washing while menstruating increases the risk of infertility. Imagine the elderly woman who works in a rural market selling her vegetables. She must stay in her stall to make money each day, and yet the market has no facilities, no toilets. Sometimes she stops drinking water, despite the heat, so she will not have to use the toilet.

We cannot talk about changing policies and practices without keeping people in mind, without consulting them, without understanding their needs and without understanding prevailing beliefs and practices. The 2030 Agenda calls us all to think differently, to act differently and to partner differently. The Water Supply and Sanitation Collaborative Council (WSSCC) and Essity formed a partnership in 2014 in order to do just this. Putting hygiene and health at the centre of the conversation means more emphasis on forgotten and taboo topics; it opens up possibilities for change that reaches far beyond just individuals, but to society as a whole. Hygiene is only the beginning.



Rolf Luyendijk
Executive Director
WSSCC

About the report and the collaboration



This report is the latest edition in a series of reports that Essity has been publishing since 2008 with the aim to raise awareness about the pivotal role hygiene, sanitation, and health play for well-being, for individuals and communities and to bring forward solutions to some of the problems we face in these areas.

Since 2014, Essity and WSSCC have partnered in the mission to encourage a global conversation about hygiene and health issues as well as opportunities across organizations, sectors, and countries. In 2016 we took the partnership further by jointly publishing the *Hygiene Matters Report: Joining Forces for Progress*.

With this edition of the report, we continue our work. We offer new insights by combining research findings, statistical evidence, successful cases and testimonies

from people whose voices are rarely heard. We also highlight solutions and actions that we find critical for improving hygiene and health standards across the globe and for every part of life's course. Our ambition is to inspire and invite more actors into the dialogue, partnership and in finding sustainable solutions going forward.

In the Sustainable Development Goal era, it is essential to work together and we are brought together by our belief that we can leverage each other's strengths. Together and individually we will put the insights and solutions of this report to use in public awareness campaigning, policy advocacy, and our community work.

You can read more about our work at www.essity.com and www.wsscc.org

**Insights
gathered
from**

**20
countries**

- Australia
- Belgium
- Brazil
- China
- France
- Germany
- India
- Italy
- Kenya
- Mexico
- The Netherlands
- Pakistan
- Russia
- Senegal
- Spain
- South Africa
- Sweden
- Switzerland
- United Kingdom
- United States



About the survey

One of the sources for this report is a global survey conducted by Essity between November 20 and December 4, 2017, through web panels in 15 countries, collecting answers from a total of 15,530 respondents. National quotas have been used to obtain an accurate representation of age and gender of the general public aged 16-85 years. The countries surveyed included Australia,

Brazil, China, France, Germany, India, Italy, Mexico, The Netherlands, Russia, Spain, South Africa, Sweden, United Kingdom, and United States. The survey was monitored and analyzed by the consulting firm, United Minds, and the data was collected through digital questionnaires with the assistance of the survey provider, Cint.

Early adopters

Ensuring a good foundation for the next generation

“As we started working with new hygiene routines, I was a bit sceptical. It felt like it demanded a lot of time, which is a limited resource working in a preschool. But once we had established the routines, it was doable and I started to notice that both the children and I did not get sick that often. However, the greatest reward is the collaboration with the parents. Discussions about preventing infections used to be a source of conflict, but now they know that we do our part in keeping their children healthy and then they take their part of the responsibility as well.” Josefine, Preschool Teacher, Sweden

One of the earliest signs of independence in childhood is learning to care for your personal hygiene and health. When children are born, every physical need is tended to by their caregivers. Giving children the understanding and tools to care for their hygiene and health is an essential part of raising them to be independent, creating healthy habits that can last a lifetime, and is an investment in the future generation. Whether it is potty training, handwashing, or understanding the changes in puberty, such as menstruation – hygiene is a prerequisite to ensure the well-being of children, no matter where and how they live.

Good hygiene practices play an essential role in achieving several of the United Nations’ Sustainable Development Goals (SDGs). Access to clean water and sanitation (SDG 6) are the preconditions for human life. The United Nations named the upcoming ten years the Water Action Decade, acknowledging that clean water,

sanitation and hygiene are vital in achieving other sustainable development goals.

Safe hygiene practices are fundamental for ensuring good health and well-being for everyone (SDG 3). This is especially important for children who are more vulnerable than adults to infections. Infectious diseases, such

Clean water, sanitation and hygiene are vital in achieving other sustainable development goals.

as diarrhea and pneumonia, threaten the lives of millions of children every year. The good news is that they can be prevented. Simple handwashing with soap removes 90% of contaminants, and safe hand hygiene could spare



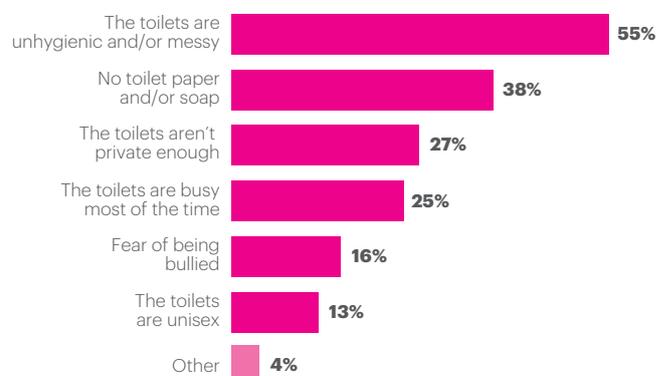
one out of three children who get sick with diarrhea,¹ and almost one out of five who get respiratory infections like pneumonia². Better hand hygiene also has a large impact in situations where infections are not life-threatening. Fewer infections among young children means fewer visits to the doctor, reduced need for antibiotics, and decreased absenteeism among parents.

A focus on hygiene is important in all arenas of a child's life, and is especially important in situations where many children are brought closely together. One such place is preschools and schools, as they can easily become playgrounds for infections. Interventions to raise the hygiene standards can prevent many infections and improve children's health and school participation. Depending on the initial hygiene standard, studies on hygiene interventions show reductions in absence rates among children, with numbers ranging from 7% up to 54%.³

Poor hygiene can also become a barrier for education and participation in the community in other ways. In many countries girls miss out on school and are in different ways excluded from their community during menstruation. Menarche, the first period, can often be a traumatic experience, since many girls are not given the knowledge to understand what they are experiencing. Learning about

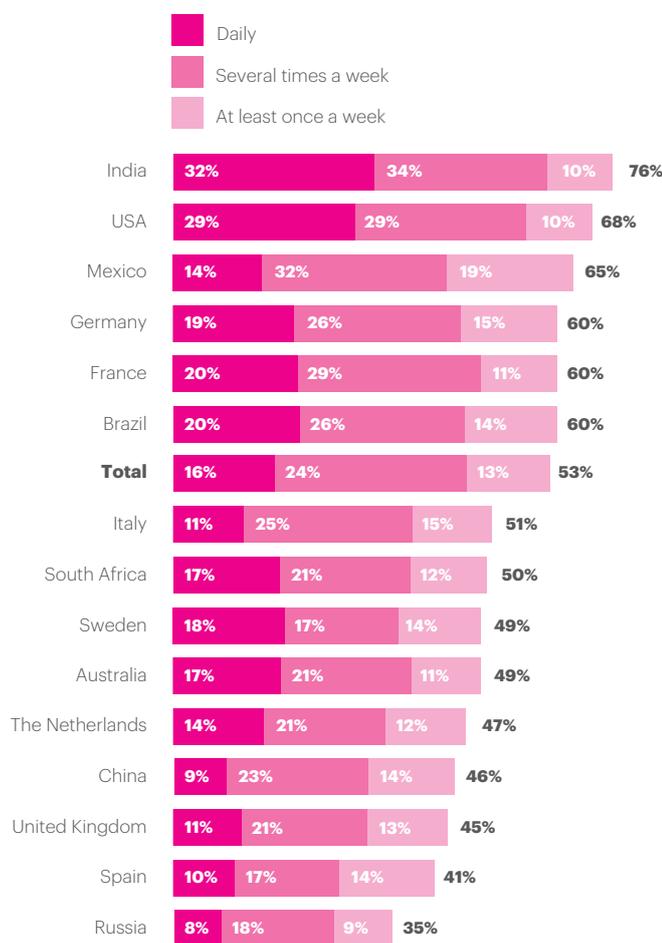
the menstruation cycle from an early age is critical, as well as ensuring that girls have the means and privacy to handle their menstruation. Safe menstruation hygiene management is therefore an important part in reaching the SDG target 6.2 on access to adequate sanitation and hygiene for all, and achieving gender equality and female empowerment (SDG 5).

Poor hygiene conditions are the main barriers for using school toilets



Good hygiene practices are thus one of the most effective and preventive methods we have to battle numerous societal challenges. A starting point is to ensure that sanitation facilities are user-friendly and accessible, regardless of age, gender or ability. Today, that is often not the case, even in countries with a generally high hygiene standard. According to Essity’s global survey, 53% of parents say that their children refrain from using toilets in schools on a weekly basis. The main reasons are that the toilets are perceived to be unhygienic (55%) and lack sanitation supplies (38%).

Many children refrain from using toilet facilities in school



However, infrastructure alone does not build good hygiene practices. Creating habits demands knowledge and perseverance from every adult in children’s lives. The responsibility for teaching children how to care for themselves is the responsibility of the parents, but also the local communities and the schools. The importance of hygiene and health has to be emphasized repeatedly in every area of a young person’s life in order to be successful. Yet, our experience is that parents do not always understand why it is important to

talk to their children about topics like personal hygiene or menstrual health. Similarly, teachers in preschools and schools rarely have the time or support to work systematically in establishing healthy hygiene practices among young people.

Infrastructure alone does not build good hygiene practices.

Still, there are successful cases in which an increased knowledge in both schools and the overall community has created a positive circle of reinforcement. In this chapter, we will explore what benefits improved hygiene standards bring to preschools and schools, how children can be engaged in a playful way, and why it is important to talk about the changes of puberty with young girls and boys from an early age.

USD 92
return for every dollar invested

In India the return for investing in handwashing programs is estimated to be 92 dollar for every dollar invested.⁴



Investing in hygiene for life

Bringing small children together in a crowded space is a recipe for spreading infections. Some infections are inevitable, but many studies show that better hygiene standards in preschools and schools have a significant impact on illness-related absence. Marianne Bengtsson, a hygiene nurse at a local disease control agency in western Sweden, has worked for over ten years with disease control in preschools, and has witnessed first-hand how hygiene can affect education quality.

– Children’s immune systems are not fully developed and exposure to infections is part of the development process, but in an environment where children are constantly exposed to infections, extra measures are needed, says Marianne Bengtsson.

One notable environment is preschools. Children in preschools are more often ill than children that are cared for at home, which among other things leads to unnecessary use of antibiotics. Since 2006, Marianne

Bengtsson has worked as a hygiene nurse assisting preschools in western Sweden. Her work was initiated as a project by the local disease control department as a way to prevent infections, reduce the usage of antibiotics, and battle antimicrobial resistance.

– They received a lot of calls from the preschools regarding infections. The staff working in preschools have not received any education in hygiene and health, and there are very limited resources available for them to gain the necessary knowledge. That’s why we have introduced specific hygiene nurses that can support the preschools.

Today, the project has been turned into a permanent branch of the local disease control department and expanded into several municipalities in the region. Among other things, the hygiene nurses educate the preschool teachers, inspect the hygiene facilities and routines, monitor the infection rates and develop education material and methods for teaching the children.

A key part of their work is monitoring the absence rate in the preschools. Statistics show significant differences between municipalities, districts, and even departments within the same preschool.

– There are preschools that have absence rates of about 20%, where the average child has missed school every fifth day, while in other schools they have only missed every tenth day. Children who attend schools with a higher absenteeism among students and teachers, miss out on a lot of opportunities to learn. Preschool lays the foundation for future education, and these children simply do not get the same chance, says Marianne Bengtsson.

Preschools that have gone through this program and learned how to achieve better hand hygiene have shown improved absence rates between 7-13%. In a region with a population of 1.7 million, the program produced yearly savings of USD 5.5 million, 10,000 fewer doctor visits and 3,000 fewer prescriptions for antibiotics.⁵

Even though there are clear benefits in improving school attendance, few preschools and schools keep track of their statistics.

– The responsible authority, in this case the municipalities, should monitor the absence rates in their preschools and schools. This is not only a tool for working with hand hygiene, by better statistics you can identify other problems as well. In our project we have found cases of mold and dampness by looking at the absence rates.

Apart from closer monitoring, Marianne Bengtsson also wishes for clearer rules in hygiene facilities in preschools and schools.

– Today there are recommendations, but they are not enforced. We visit a lot of preschools, even newly built ones, where the layout makes it difficult to achieve good hand hygiene.

USD 5.5 million

yearly savings

In a region with a population of 1.7 million, the program produced yearly savings of USD 5.5 million,

10,000

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3,000

fewer prescriptions for antibiotics.

Success factors for implementing good hand hygiene in preschools:

- **Basins, soap, and paper towels** that are **easily accessible** for both children and teachers.
- A **hygiene sponsor** among the teachers who can adapt routines to the specific school's situation.
- Educated teachers that understand **why hand hygiene is important and have enough time** to make sure all children wash their hands according to the routines.
- Parents and other adults around the children that **lead by example**.
- **Playful ways**, such as songs, rhymes, and games, to establish hand hygiene routines.

Playfulness – key to establishing good hand hygiene practices

Helping children to develop good hygiene habits early on lays a foundation for the rest of their lives. The key to success is turning the education into fun and memorable activities for the children.

Engaging children in a playful way by using storytelling and games have proved a success factor in establishing good hygiene routines. Essity has long worked with developing educational material together with and for both teachers, parents, and schools. The material includes two tool kits aimed at children, teachers, and parents. “Ella’s Hand Washing Adventure” includes an app for younger children, hygiene brochures and educational material aimed at caregivers, while “Max’s Hand Washing School” consists of educational material to be used in schools for older children.

Essity’s employees also work with and regularly visit preschools and schools to share their knowledge on hand hygiene. Key is to arouse the children’s curiosity to understand the underlying principle between germs,

hygiene and health, for instance by using experiments. One such experiment involves sticking dry and wet hands into sand to demonstrate the importance of drying the hands, while another one uses UV light to let the children see for themselves how much dirt is left after a mediocre hand wash.

Menstrual hygiene management education – the earlier, the better

Menarche, the first period, is a fundamental part of a girl’s transition from childhood to adolescence. Studies show that girls in many countries experience menarche with insufficient information and support. Girls from around the world report feeling ashamed and afraid. The potential health effects of such experiences include a weakening of girls’ sense of self-confidence, which in turn may compromise girls’ abilities to assert themselves in different situations, including their sexuality and sexual and reproductive health.⁶



“Menstruating women and girls are forced into seclusion, suffer reduced mobility and dietary restrictions, and can be prevented, through cultural norms, from participating in daily activities. Despite, or perhaps because of this, menstrual hygiene has been routinely ignored by professionals in the water sector, and in the health and education sectors too.”

Catarina de Albuquerque, former Special Rapporteur on the Human Right to Safe Drinking Water and Sanitation

According to the World Health Organization (WHO), adolescence is defined by a rapid development process from a young child into puberty, an indicative age range when it usually occurs. Puberty education, whether in school or through the community, is usually provided to children at the average age that it occurs: 12 or 13 years of age. For many girls, especially in developing countries, the information is given too late (if it is even given at all). Some girls have their first period as early as age nine. In some cultures, menarche can indicate that a girl is ready for marriage, or that she must stop engaging in child activities, such as playtime, and begin supporting the household.

Since 2012, the Water Supply and Sanitation Collaborative Council (WSSCC) has used a holistic methodology on Menstrual Hygiene Management (MHM) to ensure that women and girls have access to information about the biological processes surrounding menstruation, as well as hygienic methods for managing their periods, so that they can make informed choices. WSSCC’s methodology aims to provide information on puberty and menstruation as early as possible before puberty begins.

Asha, an 11-year-old girl from Assam, India shared her menstruation experiences and difficulties during a recent training session. She spoke not only about the lack of information and confusion when she had her first period, but how her daily life changed during each menstruation.

– Sometimes I stay away from school as it is too difficult to sit through classes all day without proper places to change and wash without my classmates and teachers knowing that I have my period, she said.

Asha and other girls participating in the session received information on the menstrual cycle from WSSCC trainers who are specialized in dispelling myths and taboos in a cultural context. Trainers also share a comprehensive visual guide entitled “As We Grow”, which

reinforces positive messages and describes physical and emotional changes for both boys and girls going through puberty. In addition to women-only discussions to ensure a safe environment for open discussion, the methodology also includes complementary training specifically targeted at boys and men.

There are three critical steps to ensuring safe MHM:

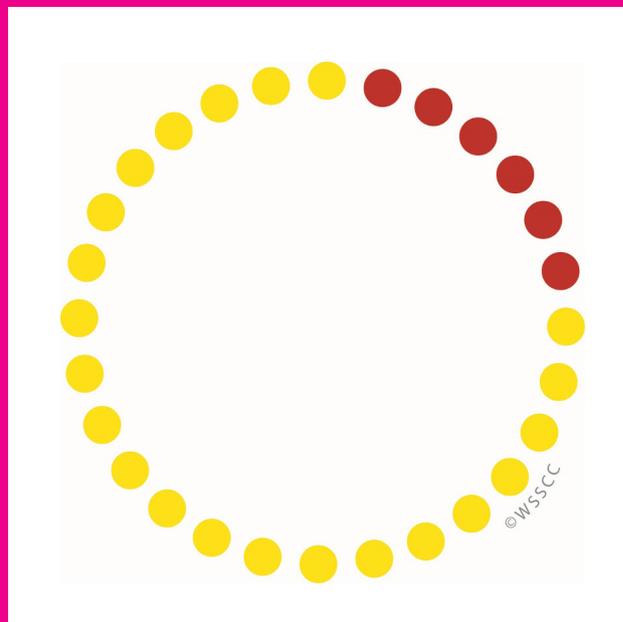
- **Breaking the silence.**
Understanding that menstruation is a fact of life, and a distinct biological female attribute that girls and women should be proud of, not ashamed by. Girls are encouraged to talk and discuss in an informed and positive manner to prepare them emotionally and physically for menarche and recurring monthly menstrual periods thereafter.
- **Managing menstruation hygienically and safely.**
Ensuring adequate water, cleansing and washing materials and private spaces for managing menstrual flows hygienically and privately, managing pain and/or any related issues with dignity, in the home and in public spaces.
- **Safe reuse and disposal.**
Ensuring mechanisms for safe reuse, collection and disposal of menstrual waste with dignity in an environmentally safe manner.

Menstrual hygiene management bracelet

To support and reinforce its work on menstrual hygiene WSSCC has developed a Menstrual Hygiene Management Ring in collaboration with the Indian designer Lakshmi Murthy. The illustration appears in reports and communications, and is also used as an advocacy bracelet in trainings with women and girls. Its beads and colors represent the menstruation cycle. The ring helps to emphasize that menstruation is something to be proud of each month and something to be discussed, not ignored.

During the MHM trainings, women and girls make the bracelets themselves according to their individual menstrual cycle, and then wear the bracelets while taking a pledge to speak about menstruation inside and outside of the home in order to break taboos. The bracelet has been worn by women and men, including government officials, champions and activists from China, Finland, India, Kenya,

The Netherlands, Niger, Portugal, Senegal, South Africa, Spain, Sweden, Tanzania, and the United States as champions for raising awareness for the importance of MHM and drive change.



Menstruation needs to be put higher on the health agendas

Dr. Venkatraman Chandra-Mouli works with Adolescent Sexual and Reproductive Health in the World Health Organization’s Department of Reproductive Health and Research. Over the last 20 years of his work on adolescent health, he has seen menstruation move from a non-issue to the fringes of the global health and development agendas. He believes that to bring out the institutional and social norm changes needed, menstruation has to be higher on both the global and national agendas.

Chandra-Mouli regrets that a perfectly normal stage of development – menarche – and a perfectly normal human function – menstruation – have been clouded by taboo and stigma.

– In different social and cultural contexts, menstruation evokes discomfort because of its association to sexuality and reproduction, shame because of girls’ inability to manage it effectively, and exclusion because of its association with impurity. This hinders girls’ abilities to carry out everyday activities, weakens their self-esteem and self-confidence, and sets a foundation for poor healthcare seeking behavior.

According to Chandra-Mouli’s research and experience, many adolescent girls in low and middle-income countries are uninformed and unprepared for menarche. They are excluded and ashamed of their periods. Lack of access to menstrual products and to water and sanitation, hinders them from taking care of themselves, and taking charge of their lives. And when they do need care at home or in a clinic, they do not get it.

– It is essential for girls, as well as boys, to be informed about puberty and menstruation from an early age. Both girls and boys need to know that puberty and menarche are normal life stages. As their bodies and minds mature, they need and have the right to understand the changes they will experience and how to manage them effectively. Ideally, information should not only be provided at homes and schools, but also from other adults, such as sports coaches, who play an influential role in adolescent lives.



Ideally, information should not only be provided at homes and schools, but also from other adults, such as sports coaches, who play an influential role in adolescent lives.

WHO advocates for girls to grow up in a context where menstruation is considered healthy and normal; where all girls are well-informed, have access to sanitary products, and receive the support they need.

– This is happening in some places through the efforts of certain individuals and organizations. In order for this to happen on a larger scale, long-term programs, thorough leadership, management and investment are needed. Parliamentarians and government leaders are crucial for making this happen. Ultimately, menstruation needs to be high on their agendas for real change to occur.

Early adopters – next step

Investing in children’s and adolescents’ hygiene and health is an investment that yields returns both short term and long term. As children are particularly vulnerable to infections, good hygiene routines is an important preventive tool to ensure healthy children here and now, but it also lays a foundation for their future lives. To establish healthy habits, children should be introduced to topics of hygiene and health from an early age and in all spheres of their lives. All adults play an important role here, whether parents, teachers or other community members. To reach children, it is thus important that adults understand the link between hygiene and health and have the tools to engage children in a playful way.

The earlier topics of hygiene and health are introduced, the better. This is particularly true for questions concerning puberty and menstruation. Far too many girls experience their first period as a traumatic event, which is not only frightening but can also lead to social exclusion. Information in time is essential so that girls have an understanding of what they are going through and have the means to handle their menstruation.

Today, we know what it takes to ensure that all young people have the means to stay healthy. To achieve these goals broad coalitions are needed where all actors come together to drive progress.

Calls for action:

- **Make access to clean water sanitation facilities a priority.**
All children and adolescents need access to clean water and safe sanitation facilities, whether it is at home, at school or out in the community. It is especially important that girls have access to gender segregated hygiene facilities where they feel safe and are able to manage their menstruation.
- **Elevate knowledge, attitudes and practices, through public policy tools.**
Parents, teachers and the wider community has to be given the resources (knowledge and time) and tools to practice safe hygiene habits and teach their children about how to do the same at an early age.
- **Make hygiene a priority at school and other places where children are present.**
All preschools, schools and other places where children are present should have the necessary facilities and training to practice good hygiene, such as hand washing. Hygiene and health-related topics should be included in the curriculum and the root cause for absence rates followed closely.

Women on the rise

Empowering women by making their needs count

“When I am at work, it can be really difficult to manage my period as there are often no bins to dispose sanitary napkins. I have to find other solutions and it can be really awkward if you are carrying something around. My friend who works in a different building complains that there is only one restroom to use and it is ten minutes away. Sometimes she waits too long to go and there is a mess, or her boss is annoyed when she is away from her desk for a long time.”

Catherine, Administrative Assistant, Kenya

The global movement towards gender equality has seemed like a steady, albeit slow moving train. However, last year we witnessed not only a halt, but a step backwards. According to the World Bank, which has measured the global gender gap since 2006, the overall global gender gap will now take 100 years to close rather than the estimated 83 years in 2016.⁷ It will take more than three generations⁸ until a baby girl is born with the same possibilities as a boy to realize her human rights.

Nonetheless, there are still some bright spots. According to the World Bank data, countries like Namibia, Nicaragua and Rwanda have managed to challenge societal structures in a relatively short period of time, making strides towards closing the gender gap. We also see more and more countries establishing their own ministries of gender equality in order to overcome the obstacles that have long held women back.

One significant obstacle that leaves many women at a disadvantage is the common perception and stigma of menstruation. At any given moment, every fourth woman of menstruating age in the world is on her period. For those who have the means to manage it,

this does not prevent them from going about their normal lives. Women who menstruate need a private space for washing and managing their menstruation, sanitary products to absorb the blood, and the ability to dispose of sanitary materials.⁹ These needs are overlooked far too often,¹⁰ making menstruation an impediment in community participation, education and working life.

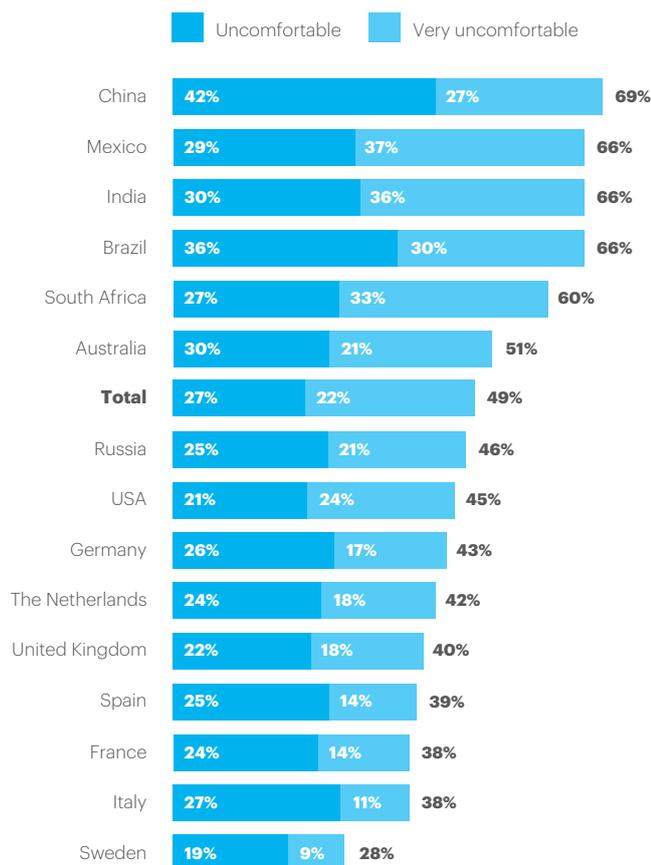
Even when they have the means and knowledge to manage their periods, menstruation stigma can put women at a disadvantage. A U.S. study called “The Tampon Experiment” clearly illustrates that being reminded that a woman is menstruating affects the perception of her competence and likeability. In this experiment, participants interacted with a female actor, who pretended to be a participant and seemingly accidentally dropped either a tampon or a hair clip. Dropping the tampon led to a lower evaluation of the actor’s competence and decreased her likeability.¹¹ The fact that the same effect did not appear when dropping a hair clip – an object strongly connected to femininity – shows that the effect was not due to the fact that participants are reminded of the actor’s gender. It rather demonstrates their paradoxical perception of menstruation as something that is

unfeminine and impure, even though it is a sign of health. Women who are not able to conceal their menstruation are seen as lacking control over their bodies.¹²

Being reminded that a woman is menstruating affects the perception of her competence and likeability.

The consequences of these perceptions are visible in Essity’s global survey. Nearly half of the female respondents experience social discomfort during their period. The social stigma around menstruation is especially strong in countries like China, Mexico, India, and Brazil where two out of three female respondents feel uncomfortable in social situations during their menstruation.

Many women feel uncomfortable in social situations during their period



Essity’s survey also shows that while menstruation can sometimes be discussed among women, it is often neglected by men. Only four out of ten fathers have ever discussed menstruation with their daughters, and even fewer have talked about it with their sons.

They tend to believe that menstruation is a topic that mainly concerns women. Women seem to share these feelings, as only three in ten mothers have explained menstruation to their sons, while seven in ten mothers have discussed it with their daughters.

Periods perceived as a woman’s business

73%

of mothers have talked to their daughter(s) about menstruation

32%

of mothers have talked to their son(s) about menstruation

40%

of fathers have talked to their daughter(s) about menstruation

30%

of fathers have talked to their son(s) about menstruation

The silence around menstruation has costs for the individual woman and for society as a whole. For instance, many women lack the menstruation health literacy to tell whether the pain or other symptoms they experience in relation to their menstruation cycle are normal. Consequently, they wait too long to seek help,¹³ and once they do, they can be misdiagnosed.¹⁴

Over the last few years, however, we have witnessed a movement to break the stigma of menstruation. Women and men around the world are speaking up about menstruation and the needs periods present. These menstruation activists are paving the way for a future where menstruation is considered a normal bodily function and discussed openly. They show us that changing the way we deal with periods is necessary to achieve the Sustainable Development Goals of ensuring women equal access to sanitation (SDG 6.2) and empower women (SDG 5). When women’s needs are taken into account, we build a society where women have the same opportunity to realize their basic human rights and close the global gender gap.

In this chapter, we will explore why it is important to look at menstruation from a human rights perspective, how lack of good sanitation facilities put working women at a disadvantage, why menstrual health literacy is essential for improving women’s health, and how different actors are working towards breaking the taboo of menstruation.

“Menstruation is inherently neither controversial nor political. It is a normal and healthy part of girls’ and women’s biology, and should never be used as a basis for discrimination, inequality or harm.”

Michelle Milford Morse, United Nations Foundation



A human rights framework on menstrual health offers new perspectives

Inga T. Winkler, a Lecturer in Human Rights at Columbia University in the U.S., argues that using a human rights framework to assess menstrual health may offer new perspectives, as it focuses on excluded, marginalized, and neglected parts of the population.

In her work, Winkler addresses questions related to socio-economic rights, development, and gender, with a significant focus on menstrual health issues. From her perspective, the Water, Sanitation and Hygiene (WASH) sector is an entry point to broader questions related to gender equality, societal norms and gender stereotypes. This became clearer to her when she worked with the UN Special Rapporteur on the Human Rights to Safe Drinking Water and Sanitation, Catarina de Albuquerque, where she met women and girls in countries across the world who described the challenges they faced in dealing with their periods, and how it affects their lives.

– Menstruation covers many facets of our life. It is deeply symbolic and associated with cultural and religious practices around the world. It is a pivotal issue that affects people’s realization of their human rights.

Winkler uses the human rights framework to assess menstrual health practices. This offers new perspectives that might otherwise be overlooked, by focusing on excluded, marginalized, or neglected parts of the population.

– The human rights framework calls on policy-makers to find solutions that work for all people who menstruate. For example, it highlights and prioritizes the experiences of refugees, homeless people, transgendered, disabled and sex workers. In addition, it provides a comprehensive framework for addressing menstrual health by balancing human rights to health, work, education, bodily autonomy, freedom of religion and many others. Most of all, it stresses agency and voice.

Winkler is positive about the increased attention of menstruation all over the world and in every societal arena, from policy-making to media. At the same time,

she stresses the need to have a critical mindset to ensure that all perspectives are taken into account. Here, researchers have an important role to play, according to Winkler.

– As academics, it is our role to be asking critical questions, such as: Do we inadvertently reinforce the perception of menstruation as ‘dirty’ and ‘impure’ when we use the term ‘menstrual hygiene’? Do we exclude genderqueer menstruators when we focus on women and girls, thereby continuing to present gender as binary? Do we exclude particular groups of the population when not considering their particular experiences?

Do we inadvertently reinforce the perception of menstruation as ‘dirty’ and ‘impure’ when we use the term ‘menstrual hygiene’?

Another important factor in changing the attitudes and practices of menstruation, Winkler argues, is to involve men.

– Gender equality is about gender relations, and men have notable stakes in reproductive health. Men constitute a significant share of head positions, making decisions that greatly impact women’s everyday lives: from policy-makers deciding on matters such as the tampon tax, to principals choosing lightly-colored school uniforms without considering girls who are afraid of their period stain visibility. Achieving gender equality will require structural changes, but to make these positive changes happen faster, we need men on board, says Winkler.

Championing policy change in West and Central Africa

30% of women in Senegal are active in the workforce. 77% of them work in the informal economy – small entrepreneurs, market vendors, etc. Many women indicate that in these workplaces, toilet facilities are either unavailable or unsafe to use.¹⁵

Lucile runs a shop in the Kaffrine market in central Senegal, where she sells fabrics and personal care products. She shared her frustrations in March 2017 about the inadequate facilities near the market:

– I have worked in the market since 2009 and I do not use the toilets because if you go in there you get sick! They are not safe, they are mixed (no separation for men/women), they are dirty and they stink. When I do not feel well in my stomach I take a motorbike taxi to go home (to relieve myself) and I pay 200F (USD 0,35) for the ride.

Lucile is not alone. Regardless of their workplace, women want security, cleanliness and satisfactory water, sanitation and hygiene products. Markets without safe sanitation facilities compromise their dignity, safety and health. Women working in informal sectors are often the most vulnerable due to a lack of standards and maintenance in public toilets (and sometimes, there are no toilets at all). Political will and leadership is required to support sustainable solutions in public spaces.

Women working in informal sectors are often the most vulnerable due to a lack of standards and maintenance in public toilets.

WSSCC seeks to address the sanitation and hygiene needs of women and girls within and outside of the home by working with local, regional and national governments across sectors to transform policy, link budgets, build capacity and integrate taboo topics into policy discussions. The Joint Programme with UN Women in West and Central Africa on Gender, Sanitation and Hygiene has achieved policy change, training and action research in three target countries: Niger, Cameroon and Senegal.

Senegal has been a particular success story, with high-level champions in many governmental departments that support the links between gender, health, sanitation and hygiene on a national level. This momentum created the space for a revised policy, which was confirmed in November 2017. The recommendations from the Joint Programme were used as inputs to the policy, and there are now standard guidelines on appropriate facility designs at the national level in Senegal, including public spaces. These guidelines are not just available for government institutions, but also the private sector and general population.

Senegal is also a success story for women: the Teen and Youth Reproductive Health Training Manual now includes information on women's hygiene, and the National Code of Environment is being revised to include provisions for menstrual hygiene throughout Senegal.



Raising awareness of the menstrual cycle's role for women's health

Multiple health conditions are affected by the menstrual cycle, but awareness about this relationship is low – both among physicians and patients – which can lead to misdiagnosis or inappropriate treatment. Therefore, Sally King set up Menstrual Matters, a research and information hub, to raise awareness about the role of the menstrual cycle, and hormonal medications, in female-prevalent chronic ill-health.

King identified this knowledge gap after experiencing health problems herself. She spent over two years struggling with severe nausea and vomiting (incorrectly diagnosed as 'anxiety') before independently deciding to track her symptoms, which revealed a cyclical pattern. As a professional researcher, she turned her skills to investigating the role of the menstrual cycle in ill-health after it became clear that there is a distinct lack of evidence-based, and unbiased, clinical information on this topic.

In addition to running Menstrual Matters, King is currently undertaking a PhD in the Sociology of Medicine at King's College London, where she is writing a thesis on Premenstrual Syndrome. She hopes to integrate clinical research with a critical analysis of historical social factors, in order to explain why medicine has sometimes tended to categorise female-prevalent symptoms, such as those associated with the menstrual cycle, as more psychological than physical in origin.

– Currently, many physicians only consider the menstrual cycle in connection to fertility, or gynaecological, issues. They are not adequately trained on the relationship between the normal functioning of the menstrual cycle, and the triggering, or worsening of female-prevalent symptoms. If a woman of reproductive age goes to the doctor with a recurring upset stomach or abdominal pain, the doctor may provide a 'most likely' diagnosis of IBS (Irritable Bowel Syndrome) without ever asking about menstrual cycle or hormonal medication.

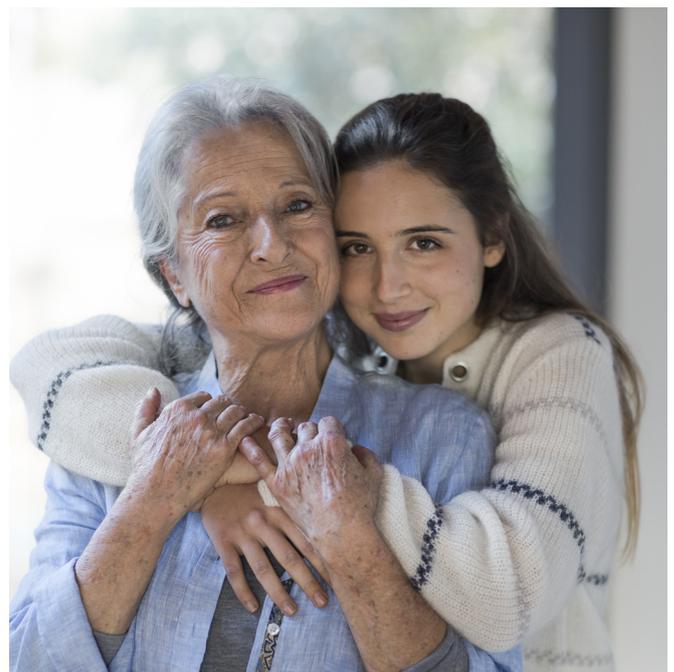
According to King, there are various reasons for this. One is the silencing effect of the menstrual taboo, which can prevent patients and physicians from mentioning the menstrual cycle (especially menstruation itself), another is that clinical research and practice is split across dif-

ferent medical specialities. A patient who experiences anxiety and digestive symptoms may be referred to either a psychiatrist or gastroenterologist, depending upon which symptoms are worse – even though the underlying cause could be hormonal, in both cases.

The solution is actually very simple. Asking patients to track symptoms over 2-3 menstrual cycles.

By raising awareness among physicians and the public about how the menstrual cycle can impact and trigger female-prevalent symptoms, King hopes to help reduce misdiagnosis and the over-medication of patients. Knowledge is key here, and the solution is actually very simple. Asking patients to track symptoms over 2-3 menstrual cycles allows the physician to better differentiate between more chronic symptoms and those that are potentially hormonal in origin.

– Once a patient is aware that their condition is perhaps hormone-related, they may start to notice patterns that can help them to manage their health. For example, asthma may worsen around ovulation, or menstruation. If doctors start asking patients about their menstrual cycle and hormonal medication as a natural part of the consultation, they might notice an improvement in their patient outcomes, whilst also helping to reduce some of the unnecessary stigma attached to the menstrual cycle, too.



Menstrual health literacy for increased knowledge and earlier diagnosis

Neglecting women’s menstrual pain has had a long history, which affects their well-being and ability to progress in societies today. By raising the menstrual health literacy, Mike Armour, Postdoctoral Research Fellow working in Women’s Health at Western Sydney University, Australia, wants to increase women’s knowledge about their menstrual cycle and reduce the delay in diagnosis for menstrual pain disorders, such as endometriosis.

– Many women have been brought up with the perception that menstruation is something that is often problematic or painful. They start believing that the pain is normal, and are less likely to speak with a doctor, or do something about it. However, it is certainly not normal to have pain that affects your day-to-day life.

The perception that period pain is normal can have severe effects. Several studies conclude that the knowledge of effective treatments is low¹⁶ and girls with period pain experience reduced classroom performance and class attendance¹⁷. However, there is often a culture of silence around periods in schools. A study conducted by Plan International UK among British girls age 14-21 found that only one in five girls feel comfortable discussing their period with a teacher, and of the girls that have missed school due to period pain, 59% made up an alternative excuse.¹⁸

With regard to work life, a recent YouGov study among Australian women found that as many as 77% of working women said that their period pain affects their ability to work. Yet, only around a third of them have discussed it with their employer.¹⁹

– Women can go through days sitting in long meetings or lectures with severe pain, but because it is not socially acceptable to talk about menstrual pain, they do not tell their teacher or boss – especially if it is a man. It can have a large impact on your life, especially if you have endometriosis, where the pain can be hard to predict.

The cost of menstrual pain disorders reaches further than personal costs. A review of studies on the eco-

nomic burden of endometriosis in different countries found that the indirect costs resulting from sick leave and unemployment were up to USD 15,737 per woman per year.²⁰

One problem identified by Armour and his colleagues is that women often lack in understanding about what happens during the menstrual cycle, despite learning about it in school.

– They mostly learn the mechanics, but not how it actually looks and feels. While menstrual cycles and symptoms vary from person to person, it is important to understand when things go beyond the realm of normalcy.

We want to empower women by giving them the knowledge about menstrual cycles, and the ability to identify problematic symptoms in earlier stages.

To address this, Armour and his research team are developing online educational materials to improve menstrual health literacy among young women. Armour hopes that it will lead to earlier diagnosis of conditions, like endometriosis.

– For endometriosis the time between the onset of symptoms and the diagnosis is around seven years. We want to empower women by giving them the knowledge about menstrual cycles, and the ability to identify problematic symptoms in earlier stages.



Period heroes

In the last few years, we have witnessed a wave of powerful and courageous women and men all across the globe who have worked in different ways to increase the awareness and knowledge about menstruation, and how it affects women’s everyday lives. By sharing their own experiences, encouraging others to talk more openly about periods, developing educational material and improving menstruation health among marginalized groups, they are all a part of a positive development that challenges misconceptions, stigmas and taboos surrounding menstruation. These “menstruation activists” or “period heroes” definitely deserve some time in the limelight. We will present a few of them and their work.

Arunachalam Muruganantham, India

Arunachalam Muruganantham, also known as “India’s menstrual man” is a social entrepreneur who invented a low-cost sanitary pad-making machine. This invention was praised as a key step in changing the lives of women in India by creating jobs and making sanitary products more affordable. His story is the subject of the Indian movie Pad Man, which was released in February 2018. The people behind the promotion of the film had challenged its audience to share a selfie with a sanitary pad, with the caption #PadManChallenge.



Photo courtesy of **Tania Herrera**

Chella Quint, UK

Chella Quint is a menstruation education researcher, science communicator, comedian, and the founder of #periodpositive – a campaign and research infoshop that promotes better education, challenges media messages on menstruation, and supports schools and organizations on tackling period poverty long term. She coined the term ‘period positive’ in 2006.

Cinta Tort Cartró, Spain

Cinta Tort Cartró, aka Zinteta, is a young Catalan artist who paints her work on her body and the bodies of other women using watercolors, tempera, and acrylics. Her work explores taboo themes about the female body, ranging from stretch marks to a woman’s menstrual cycle. By turning periods and stretch marks into rainbow works of art, Zinteta’s aim is to change the perception of and normalize things that are seen as defects, and inspire people to consider the beauty of parts of themselves they have been told to hate.





Eva Wünsch and Luisa Stömer, Germany

Eva Wünsch and Luisa Stömer are graphic designers, as well as illustrators and authors of *Ebbe & Blut* (Ebb & Blood), a book that explains the female cycle with expertise and humor without shame. It's about "the beauty of middle pain, the aesthetics of full bleached panties and the sophistication of the ovulation phase".

Liv Strömquist, Sweden

Liv Strömquist is an internationally acclaimed cartoonist and the author of the bestseller book *Fruit of Knowledge*, in which she tells the history of menstruation and how different cultures and traditions have shaped women's health. In the fall of 2017, her paintings of menstruating women were on display at subway stations in Stockholm.



Photo courtesy of **Livia Rostovanyi**.



Nadya Okamoto and Vincent Forand, U.S.

Nadya Okamoto and Vincent Forand are the founders of the non-profit organization *Period*, which works with tackling the issue of period poverty, especially among homeless women. The organization provides menstrual products to those in need, lobbies for increased access to menstrual products, and educates young people.

Roz Campbell, Australia

Roz Campbell is an Australian social entrepreneur and founder of the brand *Tsuno*, which ethically manufactures environmentally friendly sanitary pads and donates 50 percent of all profits to the International Women's Development Agency. In 2016, Campbell held the exhibition "Shark Week" in Melbourne, where she invited around 30 artists to illustrate different euphemisms of menstruation, to highlight the fact that there is still embarrassment to speak openly about menstruation.



Photo courtesy of **Hania Glapa**

Transforming the conversations about menstruation – we all have a role to play

Over the last few years, we have witnessed a transformation in how menstruation is talked about in public. The period heroes mentioned in the previous article illustrate how more and more people dare to end the silence around menstruation. They are inspiring examples that show that all of us can influence the conversations we have about menstruation. Decision-makers in both the public and private sectors have a particular responsibility to drive this change. Also companies working in this field have a role to play in challenging taboos around menstruation.

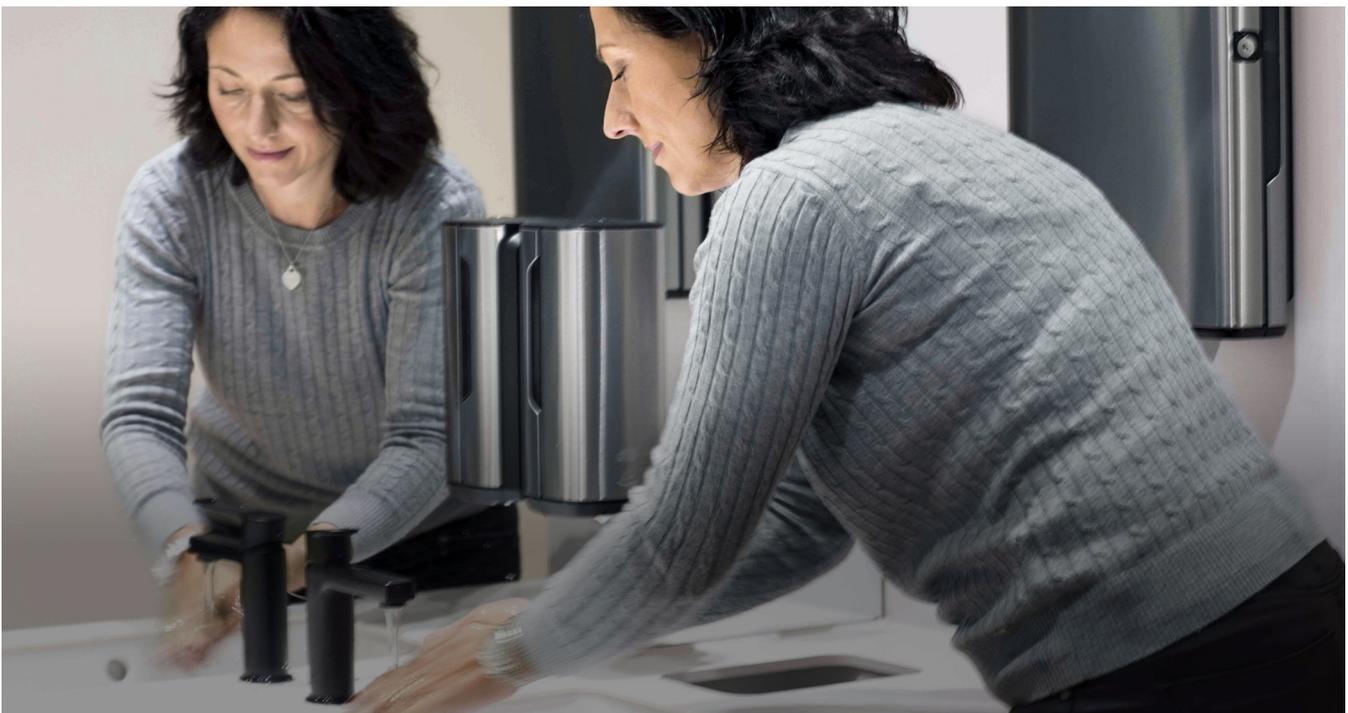
Fueled by findings on how women are deeply affected by the taboo of menstruation, Essity commissioned a study in 2017, which showed that nine in ten women go to great lengths to hide their period and four in ten think that the silence around periods hurts girls' confidence²¹. To enable conversations about periods and give more girls and women the knowledge to understand their menstruation cycle, Essity has long been involved in education programs around the globe. In 2017 Essity educated more than one million girls and young women

in Latin America on what happens to the body during puberty, and in 2016 the online course "Vagina Varsity" was launched in South Africa to inform women about their reproductive biology.

Another way to enable more open conversations and reaching vast numbers of individuals is using the external communications to challenge stigmas. One example is the "Blood normal" campaign that was launched in October 2017. The campaign pictured periods as a normal part of life, and it was the first time a campaign for menstrual products showed red liquid instead of blue as a symbol for blood.

– A lot of advertisers fuel the taboos of menstruation blood. Today, blood is a part of our everyday life – you see blood in the news, tv-series and movies, but you are never confronted with menstruation blood, even though that blood is normal and healthy. We believe that when you confront people with a subject and talk about it, you start to normalize it, and that is what we are trying to do, says Tanja Grubner, Global Marketing & Communications Director for Feminine Care at Essity.

Exchanging blue liquid for red might seem like a futile token, but many broadcast authorities have restrictions when it comes to showing period blood on screen. Yet, test screenings of the campaign have shown that women react overwhelmingly positive toward a more casual depiction of period blood. By today, the campaign has reached more than 800 million people.



Women on the rise – next step

The average woman menstruates approximately 3,000 days over her entire life. Periods can significantly impact women's lives and cause social and physical discomfort. At the same time, this is a natural and a healthy sign of life. That is why it is essential to take menstruation into account in policy and development work. A human rights framework can be a useful tool to ensure that the needs of all people who menstruate is met, especially groups that are often neglected such as transgendered or disabled.

One reason why menstruation is often overlooked is because it is still seen as something not to be discussed in public. Activists around the globe are challenging this, but they need to be joined by decision-makers in both the public and private spheres. There is also a need for more knowledge about how the menstrual cycle affects women's health. The hormone cycle can play a significant role in many types of illnesses that are more prevalent among women. Understanding how the hormone cycle can affect women's health is important both for women and physicians.

Menstruation is a powerful entry point for gender equality, empowering girls and women to understand their bodies and speak up about their needs. It is also relevant for boys and men as menstruation concerns them to. To create a society where women's hygiene and health needs are taken into account encompasses a combination of public policy, training and information, and courageous conversations in both the public and private spheres.

Calls for action:

- **Menstruation should be more talked about, let us make it our mission.**

Menstruation should not be seen as a taboo topic, but a natural part of education, development work, and other arenas. Public and private actors should use their reach and influence to enable more open conversations about menstruation.

- **Transform public places to allow all to manage their hygiene.**

In public spaces, at school, or work, girls and women need to have access to clean water, safe, clean and private hygiene facilities, essential sanitary products – cloth, pads and menstrual cups – and the means to clean them for reuse and dispose of them safely.

- **Prioritize strengthening menstrual health literacy on all levels.**

More research on how menstruation can affect women's health and how to manage potential ill-health is needed, and education and training about the menstruation cycle should be promoted.

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

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.

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.

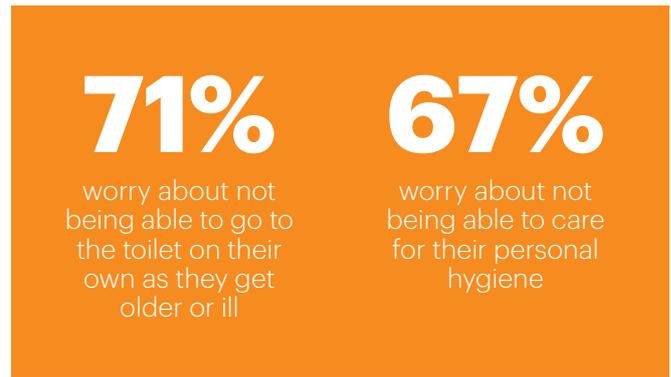
As the average life expectancy continues to increase, people will lead longer and healthier lives. At the same time, however, the number of people who suffer from different conditions and depend on care will expand. This comes with numerous challenges. In this chapter, we will explore some of these challenges 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

If incontinence would be a country, it would be the third largest country in the world.



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).

By 2030, applying the OCSS may lead to savings between 32-75 million euro in health-care costs, and 182-251 million euro in societal costs over a three-year period.

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

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.

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

* The Quality-Adjusted Life Years (QALY) is a measure of disease burden, including both the quality and quantity of life lived. One QALY equates to one year in perfect health.

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.

Thanks to better hand hygiene routines, we have probably saved five to eight million lives around the world each year.

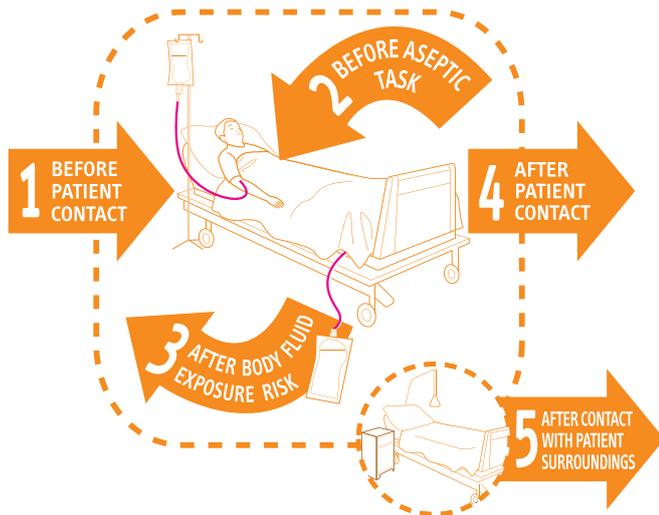


Illustration taken from WHO Guidelines on Hand Hygiene in Health Care

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.

Way forward

Personal well-being

– key to public progress

Hygiene and health are closely connected to our well-being and also our most private sphere. Therefore, it is often regarded as something that is deeply personal, and not to be discussed in public. Unfortunately, shame prospers in secrecy. The price is paid by the girl who uses dirty rags to cope with her period, the man who cannot leave his home due to a lack of accessible toilets, or the woman who goes to great lengths hiding her incontinence from her children. The highest price is paid by the most vulnerable individuals, but we are all missing out. Investing in hygiene and health means investing in strategic multipliers that enable all of us to live more dignified lives and at the same time make societies more prosperous.

It takes a multidimensional approach of different actors coming together to create a world in which everyone, everywhere can practice safe hygiene and lead healthy lives.

We must listen to, and learn from those whose voices are rarely heard. We need to understand what is actually valuable to them. A person-centered approach is key to ensuring that we start from a point of empathy, and understand how to take everyone's needs into account.

We must give everyone regardless of their physical abilities the practical means to care for their hygiene and health. Whether it is access to clean water, accessible toilets or sanitary products, caring for our bodily functions requires availability of essential means and public policies and other tools allowing for this to happen. At the same time we must be conscious of the environmental impact this can lead to. Hygiene and health products are often disposable, and we must strive to minimize the negative impact and ensure safe disposal.

We must elevate knowledge about how hygiene can affect the well-being of ourselves and others, and how to best prevent and manage ill-health. This knowledge must spread throughout the public society. We all have an important role to play, and decision and policy makers have a special responsibility to make this happen.

We must adjust attitudes and support a more open discussion at all levels. Transforming attitudes and practices will require a broad coalition. National leaders, global policy-makers, senior village and tribal leaders, CEOs, activists and others need to further prioritize menstruation, incontinence and other taboo topics related to hygiene and health far higher on the global agenda.

Partnerships are important to progress hygiene and health. We urge policy-makers and decision-makers at all levels to make this part of their global, national and local agenda, and we call upon all individuals to courageously speak up about topics related to hygiene and health. Together we can make a change.

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