

# Inclusive innovation

A MEDTECH HANDBOOK



# Welcome!

This guide has the potential to take you on a mental journey. It contains examples and references that can open up a whole world of new thoughts. It also has the potential to contribute to more accurate, relevant and powerful medical technical innovation. It can lead you to new audiences, more attractive work environments and more efficient and equal healthcare. In other words, this guide can help you to more inclusive innovation.





# What is inclusive innovation?

By inclusive innovation we mean an ability to challenge and reshape standards, to develop existing ones, or to design new solutions in the form of products, services and processes.

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For this reason the handbook is primarily aimed at those who work with research, development and innovation in Life Sciences in general, and with medtech products and services specifically. Of course, you can also read it as a user, a patient, a healthcare professional, or just out of curiosity.

Medical technology companies benefit from reflecting society. Taking account of society's concern for inclusivity and gender equality enables the discovery of new target groups, the creation of better adapted solutions and increased competitive advantages. The field of medical technology has great potential to deliver solutions that can respond to several of our major future societal challenges. However, research shows that the ability to innovate is hampered by prejudice and traditional, preconceived notions.

This may be because we fail to make an informed needs assessment because an individual or a group does not have sufficient knowledge of the questions that need to be asked at an early stage. We need to become more knowledgeable, in the innovative medical device sector, about gender equality and diversity.

To achieve this, we need to understand what is meant by inclusion and gender equality, what norms prevail in medical technology today, and learn the tools and strategies necessary to understand, challenge and reshape prevailing norms. In this way, we can create medtech innovations that include more people. [1]

A first step is to understand how norm criticism can help us to identify and minimise the risk that groups and individuals may be excluded. When we understand and see how we create and re-create norms, we can use this as a tool to work in new ways and achieve new results. It can be hard to question things around us that we take for granted. Perhaps especially in healthcare development where it can feel like risking patient safety to experiment with an ingrained approach and to question routines. But something to take into account is that Swedish healthcare of today is not equal, and that everything we do to highlight and level out inequalities will take us towards more equal, fair and above all safer healthcare for more



# Key concepts and definitions

## What is equality?

Equality means that all people have equal rights and an equal value.

## What is gender equality?

Gender equality refers to equality between the genders. Equality between the sexes or regardless of gender is an alternative way of communicating depending on the context.

## What are norms?

A norm is a rule that reflects the “normal” or accepted behaviour of a social group. It is something we learn as part of our upbringing and influences the way we use language, the way we live and the way we work. Norms form the basis of how we view the world around us. They can be classified as legal, economic, moral, aesthetic, technical and they also appear different depending on whether we are in the workplace or with family and friends. They can be hidden - based on unspoken premises and expressed as stereotypical assertions about, for example, femininity and masculinity. If a norm becomes part of one’s own morality, we can say that the norm has been internalised.

Norms facilitate interaction between people, but they can also sometimes be limiting and exclusive. It is these norms that we are seeking to change so that more people can feel included. The norms that exist in society in general carry over into healthcare and influence interactions and expectations.

## What is gender?

Gender is a social system largely based on the social and cultural attributes of the sexes; what is understood as feminine or masculine. Taking a gender perspective on medical device innovation means looking at why there are gender differences in statistics. Why do they look as they do? What norms and choices come into play? How can we change the conditions in order to create more inclusive and equal health and social care?

## What is discrimination?

Discrimination is illegal in healthcare, which means that hospitals and health centres must not discriminate against their patients. For unfair treatment to constitute discrimination under the Discrimination Act, it must be linked to one of the seven forms of discrimination: sex, transgender identity or expression, ethnicity, religion or belief, disability, sexual orientation or age.



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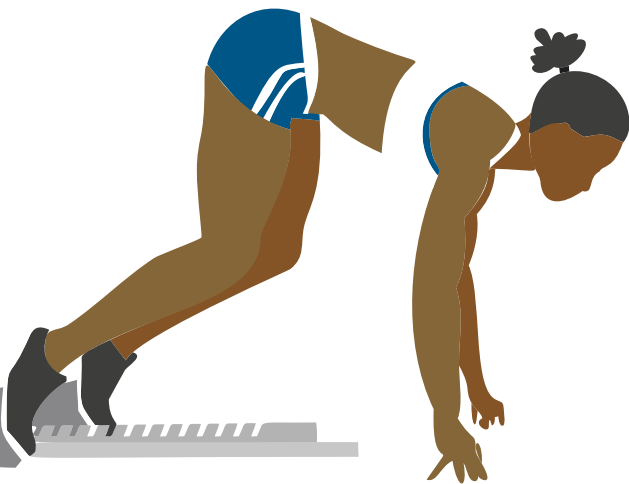
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# In search of norms in healthcare

## Norms and inequitable care

Improved diagnostics and treatment methods have enabled more patients to be treated and more people in need of assistive devices to live more independently.

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At the same time, society does not have infinite resources - there is, of course, not enough money for all the care that could be possible. Therefore, we must choose how healthcare resources are best used by prioritising. Seriously and acutely ill patients, for example, must be treated before patients that are less ill. Prioritisation must be based on the Health and Medical Care Act, (Hälso-och sjukvårdslagen) which states that healthcare should be provided on equal terms and that those most in need of care should receive it first. (1)

However, today's healthcare is not equal. Inequalities can be seen for people who are economically vulnerable, people who have experienced discriminatory treatment in the past, and people who are worried about being treated badly because they violate prevailing norms; such as transgender people, homosexuals or people who do not know the Swedish

language. It is even possible to detect differences in healthcare provision consequent on people's level of education and age.

For example, women with a lower level of education are less likely to survive breast cancer than women with a higher level education. For older people with lower levels of education, the risk is also greater to be treated with older medicines or risky drug combinations than for people with higher levels. The National Board of Health and Welfare (Socialstyrelsen) has seen trends indicating that people with low education and the unemployed experience poorer treatment in care. [2] Among other things, healthcare providers address lifestyle habits more with these patients, which may be based on cognitive biases (unconscious preconceptions) and prejudices.

To ensure equality in today's health and social care, we must constantly challenge prevailing norms and our own preconceptions. It can feel like a risk to challenge norms in an area where patient safety is always a priority, where the primary goal is to contribute to a patient's health and where possible to cure, often to relieve and always to comfort. But if we do not challenge norms, we risk missing the individuals or groups who are excluded when they do not meet our expectations, and that is also to take a risk.

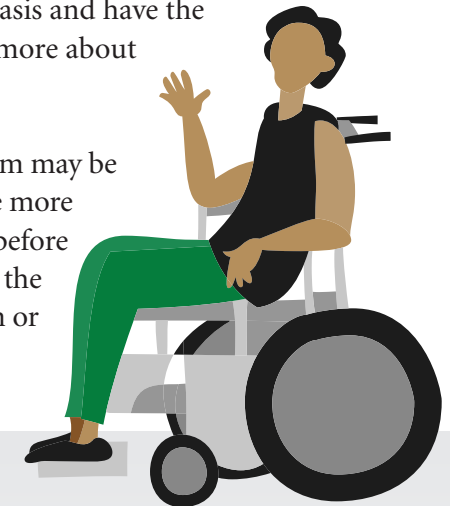


# Gender norms and unequal care

One way to approach a norm-critical method of innovation is to start from the seven forms of discrimination. You will be introduced to all seven, but one of them, which we will address here, is sex. Women and men are both equal and different. Often a form of treatment may have the same result for women as for men, but sometimes the outcomes may differ. For example, unequal care can occur when women are treated according to guidelines based on research carried out only on men. Or when doctors prescribe anti-depressants more often to women than to men. Inequitable care is detected by analysing the care itself, and also patients' experiences and outcomes of care based on sex and our notions of sex (gender). Together, these form a gender equality perspective on health and social

care, which means that women and men at a group level should have the same rights, be assessed on an equal basis and have the same power to influence their care. Read more about gender medicine on page 19.

From a gender perspective, the macho norm may be interesting to mention. Men as a group die more often of diseases because it takes too long before they first seek healthcare. This is related to the social expectation on men not to complain or ask for help – to “take it like a man”.



## Examples of inequality in healthcare

- + Women and men may be asked different questions in connection with a care visit based on the caregiver's preconceived notions about the person's gender
- + It happens that patients' complaints are assessed differently depending on norms around gender
- + Men have greater access to certain healthcare options than women
- + Some surgical procedures on women are more risky, as women have not been represented in clinical trials
- + Older women are exposed to discrimination to a greater extent than older men
- + Middle-aged men are more often offered new and more expensive medical technology and medicines first
- + Older women often live with smaller financial resources and therefore cannot pay for private services to the same extent as men
- + Women have to wait longer for an ambulance than men



## Norms to be aware of

**The HETEROSEXUAL NORM** assumes that everyone is heterosexual and that heterosexuality is the natural way to be. The norm can be summed up simply as men being expected to desire and form romantic and sexual relationships with women, and vice versa. Often this is not a problem, but for those who do not live a heterosexual life it can mean poorer treatment and care.

**The CIS NORM** assumes that everyone has a defined gender that they are born with, are comfortable with and do not want to change. Medically, it may mean that we are unprepared for people who have a biological body (sex hormones, chromosomes, genitalia) that may fall outside or between the categories of male and female, or who challenge our expectations through their choice of preferred names or gender expression. For example, the preconceptions of carers may influence the questions asked of patients and the way in which their complaints are assessed.

**FUNCTIONAL NORMS** are norms that speak specifically to which functional variation(s) are normative in society. In medical terms, this may mean that we expect everyone to be neurotypical and are unprepared for different reactions or behaviour.

The **MALE NORM** means that the male is seen as the neutral, as the starting point, as the norm that others have to conform to. Medically, it may mean that we miss symptoms of heart attack in women or autism in girls because the research that sets the norm for how symptoms of these illnesses are described is carried out on men and boys.

The **NORM OF WHITENESS** is a global phenomenon that assumes people are normally white or have light skin. Medically, it may mean that people with dark skin are misdiagnosed because doctors have not been taught to assess dark skin, or that technological innovations being developed are only reliable on lighter skin. [4]

For example, on 1177 (the Swedish national service providing health care by phone and online) there is a growing awareness of the white norm and more examples and pictures now address how, for example, skin rashes manifest themselves on different colours of skin. This is good because there are concerned parents in dark-skinned families who are also looking for answers about their children's health.



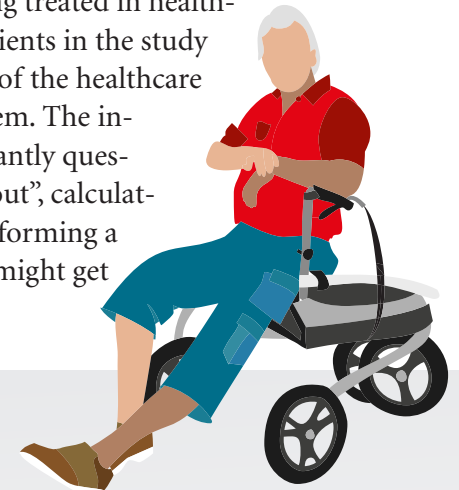




# Examples of the consequences of norms

Often being treated worse eventually creates an expectation of being treated worse. This is called minority stress and is a result of what happens when people who deviate from the norm are constantly confronted with prejudice and negative expectations. Psychologist Hanna Wallensteen describes minority stress as an experience of not being seen as equal. And when we are exposed to prolonged negative stress, the level of risk associated with a number of diseases increases. It is a drain on health, both physically and psychologically, to need to be prepared constantly to meet prejudice. The stress is chronic, it is not a stress that comes and goes. [3]

In the essay “Alla utgick från att man var hetero” (“Everyone assumed you were straight”), lesbians talk about being treated in healthcare. Something that was central for the patients in the study was how the heteronormative assumptions of the healthcare staff involved in their treatment affected them. The informants talked about how they were constantly questioning whether or not they should “come out”, calculating whether or not they could cope and performing a form of risk assessment, as they knew they might get a negative reaction. [4]



## Ethical principles

There are ethical principles in healthcare. These are priorities in the healthcare sector based on a set of values adopted by the Swedish Riksdag (Parliament). [5] The core values include three principles:

- + **The Principle of Human Dignity** recognises that all people are equally worthy and have the right to receive care, regardless of age, gender, education, social or economic status.
- + **The Principle of Need and Solidarity** requires that those with the most serious illnesses receive care first. Health professionals should pay particular attention to the most vulnerable patients, such as those who cannot speak for themselves and who do not know their rights.

- + **The Principle of Cost-effectiveness** entails a reasonable relationship between the cost and the effectiveness of treatment. For example, if two different treatments have the same effect, the one that costs less should be chosen.

In accordance with the Riksdag’s resolution, the three principles are ranked so that the Principle of Human Dignity takes precedence over the Principle of Need and Solidarity, which in turn takes precedence over the Principle of Cost-effectiveness. The Swedish Medical Association (Läkarförbundet) has also adopted a code of ethics consisting of nineteen points and dealing with fundamental values in medical ethics. These principles are intended to guide the teaching profession and to promote a good patient-doctor relationship. [6]



# Standards in medical-technical innovation

In the field of medical technology, standards relate to work groups, working methods, method selection, target groups, study groups, patient populations and so on.

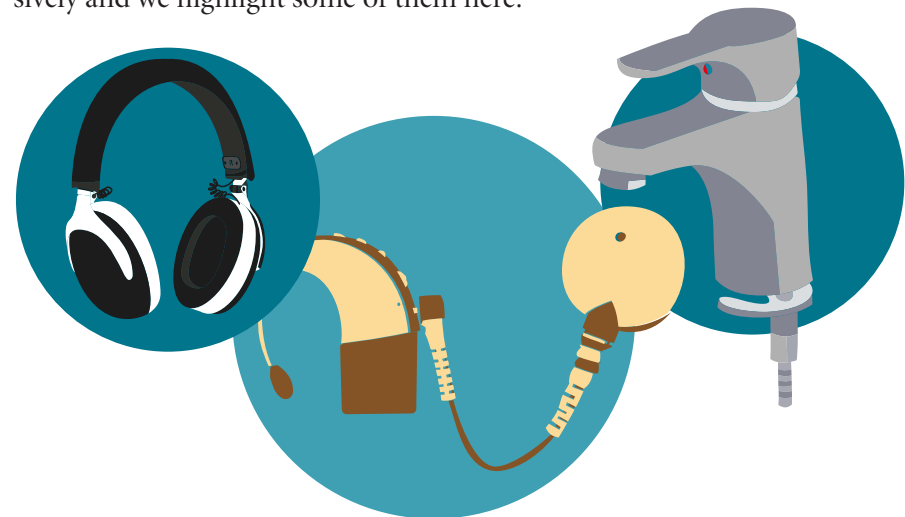
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For example, how medical device companies recruit and what profiles they seek, how innovation systems enable or restrict the development of certain types of innovations and companies, how both symptom descriptions and medicines are based on the male gender, or how innovation models support certain types of innovations and innovators. But it also concerns the way people are treated, both within teams and by patients.

When we fail to include more perspectives than the norm, we risk perpetuating power differences between groups. Our solutions can be directly or indirectly discriminatory, and in the worst case can lead to malpractice or people falling ill. The earlier in a development process we think critically about norms, the quicker we turn away from ideas and approaches that do

not benefit the many, or that risk being unconsciously exclusionary. Then we can also avoid outcomes such as a voice service that can't decipher women's voices or certain dialects, or a sensor in a soap pump that can only detect light skin colouring.

Regardless of how diverse your team is, or how important gender equality and other inclusive perspectives are in the development process of your medtech product or service, there are great benefits to working more inclusively and we highlight some of them here.





## Economic aspect

There is, of course, an economic aspect to increased inclusion, diversity and equality. Companies that are gender equal have been shown to be more profitable in many studies conducted on tens of thousands of companies around the world. [7, 8, 9] At the same time, a survey by Informa Connect Life Sciences [10] of employees in the life sciences sector shows that:

**34%**

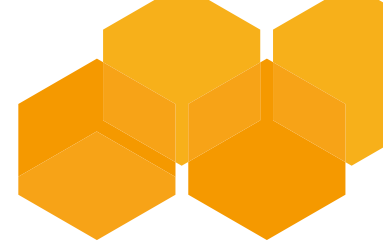
see the lack of minorities in leadership positions as the biggest problem in diversity and inclusion.

**63%**

feel that women are underrepresented in most senior roles in their own organisation.

**41%**

say they have experienced prejudice or exclusion based on gender, sexual orientation, ethnicity or other factors.



# How to work for norm-creativity and inclusivity

Norms are the invisible rules that we all follow without perhaps thinking about it.

Norms are absolutely essential for us to feel safe in our interactions with others because they give us a preliminary understanding of what is expected in different situations. But it is also because of norms that some people are at risk of exclusion.

## What is norm criticism?

Norm criticism means becoming aware of how norms work and when someone is at risk of exclusion because of entrenched norms. Thinking critically about norms is not about identifying those who deviate or challenge the norm, but about looking at the norm itself and how it works. By exploring norms and reversing concepts, we are able to gain many fascinating insights.



## What is norm-critical innovation?

Norm criticism can also help us to identify norms in our innovation process and increase our innovation capacity. Working in a norm-critical way in an innovation process is about reversing perspectives and approaching issues differently in order to find solutions. It can be about how we view target groups, about who gets to participate in the process of innovation and whose voice is heard most in meetings, about whose ideas are considered worthy of taking forward, and so on.

## What is norm-creative innovation?

But we need to move on from analysis to action in order to become norm-creative. If norm-critical processes are about making norms visible and analysing them, norm-creativity is about actively breaking those norms – doing things in a more inclusive way based on what we have learned from norm-critical analysis. When we look at the bigger picture, when we have a more comprehensive basis for decision-making based on greater understanding, we can adapt, challenge and broaden the norm so that our innovation suits more people. When we succeed, we create better, more innovative and more inclusive solutions, products and services. [15]



## Tools for inclusive medtech innovation

There is a lot of good work going on, both in the medical technology sector and in health-care in general, but as in any industry, there are things that complicate things for us.

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In the development of a medical device or service, it can be that the closer we get to a commercial product and business, the further away we are from the patient. In the worst case, we end up with a product that is good for everyone but the patient. Sometimes we don't even reach the patient, as

some patients are completely missing in reference groups for innovations. Patients are also rarely represented at trade fairs and the like, so we need to actively seek out our target groups to get the right people around the table.

Now we will review different tools to enable a more inclusive medtech service, product or innovation process:

- + **Norm-creativity in the form of micro-actions**
- + **Bring more perspectives to bear on your innovation**
- + **Conducting inclusive conversations**
- + **Roundtable discussions**

### + Norm-creativity in the form of micro-actions

When you start working creatively, the possibilities can sometimes seem dizzying, but as you begin to see your blind spots, you may feel that you are challenging too many truths and that the world is shifting. At such moments it can be a comfort to remember that it is better at least to have the skills and to have started a process of inclusion. Much can be done, but it all starts with a first step: insight.

Don't underestimate the small decisions, the so-called micro-actions. They can make a big difference too. We know that the heterosexual norm is strong.

An example of a micro-action in care or with people in focus groups might be to use the same terms as the individual does for, say, his or her life partner: cohabitant, partner, sweetheart. If you instead assume that the person has a certain sexual orientation, you may put them in a situation where they have to choose to conform, come out, or where they feel excluded.

*And remember! If you make mistakes, you will learn a lot; daring to try is always better than hesitating.*



## + Bring more perspectives to bear on your innovation

In the innovation process, getting relevant feedback on our proposed solution can be crucial. We can do this by inviting participants with varying degrees of expertise in the process to help us break established patterns, to prompt more and different questions, and to challenge norms about how patients are cared for, for example. Please invite people from other sectors who have never worked in healthcare! Ask those who don't use a product. Why don't they use the product? How can we reach them? Attitudes towards a product or service have an impact. How negative or positive people feel about the product is important in the development process. Be curious and don't get trapped into saying something is irrelevant. Get used to asking: how can we make it relevant? Dare to test the product on the user at an early stage of development. There are several stakeholder groups to draw information from, but also different ways to bring in different perspectives.

Healthcare workers are a gold mine when it comes to finding and testing medtech innovations. They often identify problems or needs in their work and may even have ideas for solutions themselves. It is then important that there are processes in place to allow them to reflect on their problems and needs, processes to capture these needs and ideas, and processes that allow healthcare personnel to be involved in developing and testing their, and other people's, ideas.

An important stakeholder group is of course the patients. By listening to patients' stories, we can identify needs that can form the basis for new innovations. A patient's experience is not limited to a healthcare visit, but starts long before the visit and continues afterwards. By taking a time-based

perspective, we can uncover needs and exclusions that are not visible within the healthcare system. If we look at the whole experience before-under-after from the perspective of norms, we can discover needs to build on.

Patient associations and interest groups often provide valuable information. How can you involve them more? Can you work with patient representatives in reference and focus groups, steering groups or boards? Remember to appreciate the time they give and find a way of working that adds value for the representative as well.





## + Conducting inclusive conversations

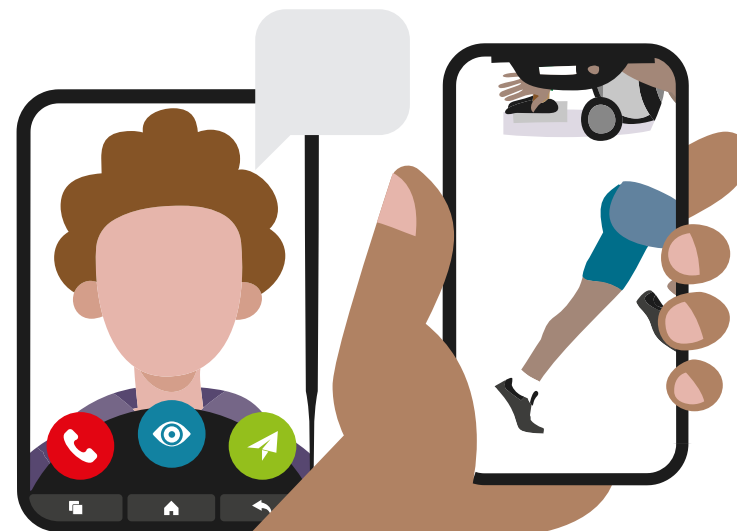
If an innovation itself is to be inclusive of the target groups, then of course the conversations leading up to the final product or service must also be inclusive. If, following the advice above, you have endeavoured to have a diverse and norm-breaking working group, development group or team, i.e. participants have been actively selected because they challenge norms in healthcare or in target groups, then it may be important to really ensure that the conversation is inclusive. Language, terminology and culture will differ between participants – as it differs between professions and disciplines, diagnostic groups and stakeholder groups.

In the work of the Inclusive Innovation project, we chose to develop four principles for inclusive conversations:

- + We enter the conversation with an open mind, a willingness to learn and an expectation of breaking ingrained thought patterns.
- + We reflect on our own position in the group and recognise that everyone's voice is equally important in a roundtable discussion; we all help to put a stop to it, if the conversation becomes disrespectful.
- + Our goal is to include all representatives from all target groups giving them all an opportunity to express themselves and contribute to the innovation process. Therefore, if we have different opinions, we encourage them, we speak clearly and explain relevant concepts so that everyone understands.
- + By following certain formalities, such as waiting until you have the floor, allowing everyone to speak to the point and keeping the discussion factual, we collectively create an innovative and relaxed environment that fosters an inclusive conversation.

Some people may find it obvious and unnecessary to agree on common principles of conversation before a meeting, while others find it easier to agree in writing on how conversations should be conducted. This may be particularly true for diverse groups. In the project, we have found that the principles of how we talk have been a success factor and this is why we share them here.

*The most important thing is not to let hierarchies and status get in the way of the purpose: to bring more perspectives to the fore and innovate better.*

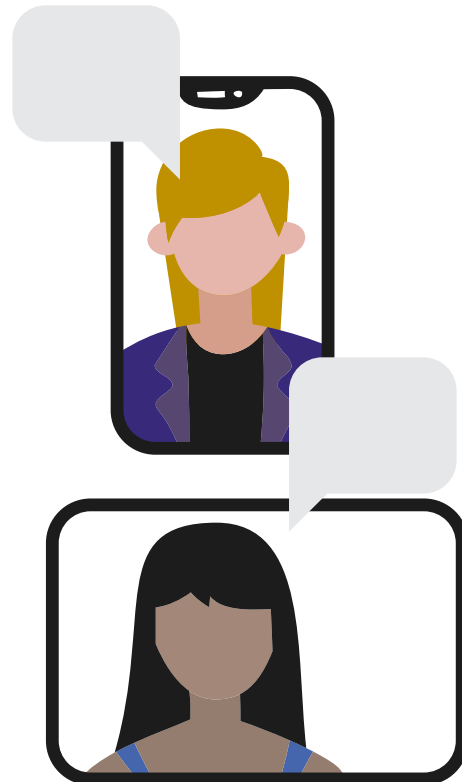




## + Roundtable discussions

A roundtable discussion is a method used in various meetings where all participants are given the same status and where no one's voice is more important than anyone else's. The method is used to resolve dilemmas and hold discussions in a constructive way with the help of different voices. For example, the material for this document was gathered during a number of roundtable discussions. In other words, a roundtable is a way of ensuring an open climate in which all participants are given equal time to express their thoughts and opinions, and share their experiences and knowledge.

This format is meant to be an invitation to conversation in which participants are permitted to ask questions and hear others in order to learn new things in a supportive atmosphere. At the roundtables, there is a chairperson who welcomes participants and explains the rules of the conversation; there are also moderators who sit in on smaller group conversations to take notes if necessary and allocate speaking time, all to allow participants to focus on the actual conversation.



In addition to the conversation principles outlined earlier – the rules of the conversation to ensure that all participants can participate on equal terms – it is also important to establish the following before a roundtable:

- + What will the participants discuss during the roundtable?
- + How can participants ask questions? Should they raise their hands or speak freely?
- + Where is the discussion expected to lead?
- + Should the discussion be summarised and if so, how?

Also, think about the timing and format of the talks when planning. Do you need to provide signed or text interpretation, review accessibility, etc.? Exclusion can be both direct and indirect. Everyone has a shared responsibility to stop if the conversation is not being conducted in a respectful manner. All participants should have the opportunity to express themselves and contribute to the outcome. Consider that instead of saying, for example, “You’re wrong!” you can ask “What do you mean?” or “Could you elaborate on that?”

This kind of conversation is important for breaking down existing norms about who can speak and when. By having a controlled conversation where everyone knows the conditions beforehand, everyone can have their say, which in turn will lead to constructive and innovative solutions.





# Good examples and further reading

Unless otherwise stated, the following material is in Swedish.

## **Socialstyrelsen (Swedish National Board of Health and Welfare)**

The National Board of Health and Welfare's website provides information on national guidelines in English. However, if you can read Swedish or are prepared to make use of on-line translation software, the site also offers educational materials, reports and open comparisons. For example, "Samlat stöd för patientsäkerhet" ("The Patient Safety Toolkit") contains information on patient safety and links to manuals, action plans, reports, statistics, training and podcasts, among other things. The website also contains an online training course aimed at increasing LGBTQ people's confidence in social services, and a glossary of LGBTQ concepts.

[www.socialstyrelsen.se](http://www.socialstyrelsen.se)

## **Sveriges Kommuner och Regioner (SKR) (Swedish Association of Local Authorities and Regions)**

On SKR's website there are several case studies, films, checklists and other support for gender equality work in municipalities and regions. Together with its members, SKR develops methods and tools for integrating gender equality into governance, management and monitoring. Through publications, films, fact sheets and case studies, SKR contributes to increased awareness and knowledge of gender equality challenges and strategies for change. For example, see their checklist for gender sensitive decision making, or learn about the challenges and success factors of local and regional Agenda 2030 work.

[www.skr.se](http://www.skr.se)

## **Kunskapscentrum för jämlik vård (KVJ) (Centre of Knowledge for Equal Care)**

KKVJ has been created in the Västra Götaland Region to ensure that health care is provided on equal terms, because people's needs and experiences are different and care is meant to vary to accommodate them. Through research, education and operational development, KVJ is shaping the conditions for levelling out unwarranted differences. KVJ identifies problems and contributes to solutions by supporting the health sector with tools and training that contribute to working towards equality. They offer tools for equal parenting, reflection tools on gender perspectives, methods for discussions on norms, and methods that contribute to good communication between patients and health professionals.

[www.vgregion.se/halsa-och-varld/vardgivarwebben/amnesomraden/jamlik-varld/](http://www.vgregion.se/halsa-och-varld/vardgivarwebben/amnesomraden/jamlik-varld/)



# Good examples and further reading

Unless otherwise stated, the following material is in Swedish.

## Region Stockholm

A text on gender medicine in which the authors describe the importance of understanding that diseases can be expressed and present differently in women and men. They describe how the analysis of disease and health is very important from a gender perspective in order to optimise healthcare for both women and men appropriately.

The authors go on to explain that women are more prone to certain diseases such as MS (multiple sclerosis), depression, migraines, eating disorders and more. Men, on the other hand, are more prone to other diseases such as, for instance, heart attacks, diabetes mellitus, schizophrenia, ADHD, alcoholism and more.

Social and normative factors therefore become very important in understanding why women and men are more likely to develop certain diseases. Behind women's propensity for eating disorders are society's fluctuating ideals of beauty that women are then expected to live up to. Beauty ideals lead to body dysmorphia which ultimately leads to eating disorders. Underlying a greater propensity for alcoholism may be the existence of masculinity norms in men with certain assumptions about how a man is supposed to live and behave.

[www.janusinfo.se/beslutsstod/janus-medkonochgenus/genus/omgenus-medicin](http://www.janusinfo.se/beslutsstod/janus-medkonochgenus/genus/omgenus-medicin)

## “Medtronic Is an Example of Why Diversity Matters”

An article (in English) on why diversity is important in medicine. The article describes the motivation of some companies to do more in their work to achieve diversity than just “count heads”. A quote in the article from Sophia Khan explains that broader diversity leads to better decisions as different perspectives highlight different challenges and possible solutions. Looking at different people's perspectives can ultimately contribute to better solutions, both for patients and for public welfare. .

[www.mddionline.com/business/medtronic-example-why-diversity-matters](http://www.mddionline.com/business/medtronic-example-why-diversity-matters)



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**[7] Is Gender Diversity Profitable? Evidence from a Global Survey**  
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# Footnotes

(1) The need for health care relates to both the severity of the illness and the patient's ability to benefit from the treatment. As a patient, you only need the care that you expect to benefit from, i.e. measures that improve your health and quality of life. Priorities are based on a ranking of conditions and measures. The more serious the condition and the more effective the treatment available, the higher the condition and the measure to be taken are ranked. The prioritisation of conditions and measures are recommendations intended to support the work of health professionals. In each individual case, it is the doctor who decides, in consultation with the patient, what the appropriate treatment should be.



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