Medical Technologies: A Barrier or Opportunity in Healthcare for Transgender People?

Master's thesis in Biomedical Engineering

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Cover: A picture of transgender flags tied to a fence that are waving in the wind.

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Abstract

Trans people experience discrimination in healthcare to a higher degree than cis people and as a consequence trans people tend to wait longer before seeking care. The aim of this thesis is to investigate what role medical technologies play in this. This was done through interviews with healthcare workers and people working with trans rights. Additionally, documentation from several medical technologies and documents from public procurements were investigated. The study shows that the idea of gender being static and binary is deeply rooted in medical technologies, which creates a variety of problems in healthcare for trans people. The problems range from forcing healthcare workers to misgender patients to potential incorrect measurements and completely barring trans people from medical systems. These problems could be avoided if developers and the healthcare system were more critical of gender norms and actively worked to create more inclusive solutions. This thesis gives a number of recommendations on how this could be done. Furthermore, medical technologies have the potential to make healthcare more accessible and inclusive of trans people if new technologies are designed correctly.

Keywords: medical technologies, transgender, gender, bias, healthcare.

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Jacob Lidman, Gothenburg, June 2023

Glossary

Cis person	A person who identifies with the gender they were assigned at birth.
Coherent record keeping	The aim of coherent record keeping is for different caregivers in different organisations and regions to be able to access a patient's complete health record.
Diagnosis Code	A standardised code used for a specific medical diagnosis.
Gender affirming care	Care given to alleviate gender dysphoria. This can include hormone treatment, voice training or surgeries.
Gender dysphoria	The distress that a person feels when their assigned gender at birth does not match their gender identity.
Intersex	Intersex variations are congenital variations in the sexual and reproductive anatomy that does not fit the binary gender categories.
Legal gender	The gender a person has been assigned legally. It is registered in the population register and used in ID documents.
Medical Technologies	In this thesis the term is used in a broad way and includes all technical systems or products that are used in a healthcare setting.
Misgender	The act of incorrectly gendering a person. This can be done by e.g. using the wrong name or pronouns for a person.
Passing	Used to describe that someone who breaks norms is seen as normative by others. As an example, a trans woman is passing when others cannot tell that she is trans, they just see her as a woman.
The Population Register	The Swedish register used to track e.g. social security number, address and gender of the Swedish population.
Trans person	A person who does not identify with the gender they were assigned at birth. In this thesis people with intersex variations are included in this term, although they do not always identify as trans.

List of Acronyms

Below is the list of acronyms that have been used throughout this thesis listed in alphabetical order:

DO	The Equality Ombudsman
FRA	European Union Agency for Fundamental Rights.
LGBTQI+	Lesbian, gay, bisexual, transgender, queer and intersex. The plus symbolises other identities that break the hetero norm and are not included in the listed identities.
SALAR	The Swedish Association of Local Authorities and Regions
SLSO	Stockholm County Healthcare Services
TGEU	Transgender Europe
VGR	Region Västra Götaland
WHO	World Health Organisation

Contents

Glossary **ix**

List of Acronyms **xi**

List of Figures **1**

Chapter 1: Introduction **1**

Aim 2
Research objectives 3
Scope 3

Chapter 2: Background **5**

Gender and Sex 5
Bias in Medicine and Technology 7
Trans People and the Healthcare System 9
  Discrimination, Harassment and Poor Treatment 9
  The Gatekeeper of Trans Rights 10

Chapter 3: Methods **13**

Data Collection 13
  Methods During the Interviews 13
  Selection of Interviewees 14
Data Analysis 15

Chapter 4: Results & Analysis **17**

Gender in Algorithms and Guidelines 17
Examples of Gendered Medical Technologies 20
  Electronic Health Records 20
    Gender, Name and Pronouns 21
    Privacy and Availability 23
    Deliberate Gender Barriers 28

Health Records - Evidence in the Application for Changing Legal Gender . . . 32
- Administrative Systems for Screening Programs . . . 34
- Patient Monitoring Systems . . . 35
- Devices Measuring Bladder Volume . . . 36

Public Procurements . . . 38

What is Being Done to Make Healthcare More Inclusive . . . 39

An Increasing Use of Technologies in Healthcare . . . 41
- Applications Providing Digital Care . . . 41
- Worries and Possibilities . . . 42

Chapter 5: Discussion **45**

Chapter 6: Conclusion **51**

Bibliography **53**

Chapter 1

Introduction

In a report from TGEU (Transgender Europe), written by Calderon-Cifuentes (2021, pp. 41–43), about the discrimination against transgender people in Europe it is stated that trans people are significantly less satisfied with their lives than cis people. On a scale from 1 to 10, trans people in Europe rate their life satisfaction as 5.6 compared to the EU average of 7.3. Trans people in Sweden answered 5.8 on average. For trans youth the European average is even lower being 3. These statistics are corroborated by SOU 2017:92 (pp. 167-172) which also states that trans people rate their satisfaction lower than cis people and explains that trans people experience harassment, discrimination and violence to a higher degree than cis people. It is also more common that trans people feel that their health is bad compared to cis people. Furthermore, a report from Westerlund et al. (2022, p. 408) adds that the psychological and physical health of LGBTQI youths is worse than that of the general youth population in Sweden. The life satisfaction for LGBTQI youth has also worsened between the years 2012 through 2021 according to the report.

The reasons for the lower life satisfaction are as earlier mentioned due to exposure to harassment, discrimination and violence, but also due to lack of access to healthcare (Calderon-Cifuentes, 2021) (Westerlund et al., 2022). The lack of access to healthcare is partly due to long waiting times for gender affirming care, which affects trans youth the most according to Westerlund et al. (2022, p. 408). However, access to all other healthcare is also lacking because of inadequate competence about trans issues in the healthcare sector (SOU 2017:92, p. 306) (Westerlund et al., 2022, p. 408). Here Westerlund et al. (2022, p. 408) also adds that persons with intersex variations face similar issues when receiving healthcare. The discrimination of trans people in healthcare has led it to be rated as the most unsafe space for trans people according to a survey done by Calderon-Cifuentes (2021, p. 8).

According to Swedish law everyone should have equal access and opportunities to receive care. The care should be provided with respect for the equal value of all humans and the individual's dignity. In a report from the Equality Ombudsman (DO) it is stated that Swedish healthcare is not equal and discriminates against certain groups (The Equality Ombudsman [DO], 2012). Examples of this is presented in a report from The Swedish Association of Local Authorities and Regions (SALAR, 2019) which highlights that women receive some treatments at a lower rate or at a later stage than men. A possible reason for this that is mentioned in the report is gender bias. Three different types of biases are listed: creating gender differences, overlooking gender differences and seeing people with a specific gender as a homogeneous group (SALAR, 2019, pp. 28–29). Furthermore, transgender people are also a group that is discriminated against in healthcare based on gender (SOU 2017:92, p. 317). Examples of this is poor treatment, a digital health record used in maternity care that was not able to register a male social security number and a binary division between gender in medical treatments and technologies which excludes non-binary persons.

In a time when healthcare becomes more and more dependent on technology it is important to reflect upon who the technologies are designed for and what type of person is used as the model in the designs. There is a risk that current norms about the gender binary are built into medical technology if the developers are not aware of them. Issues might not be discovered until someone who deviates from the norm enough comes in contact with it, even though it might affect more people. An example is intersex or non-binary people who do not fit in into the binary norms. These groups of people make it obvious that binary gendered medical treatments and technologies do not take everyone into account. However, there are also individual variations among cis people which leads to questions about how well the treatments and technologies work for this group as well. When something is gender-neutral or does not take gender into account it is often based on a young white man. When gender is taken into account it is often binary and based on young white men and women. This of course puts anyone who is not included in these norms, for example based on gender and/or race, at a disadvantage. This thesis presents a novel study on the effects of medical technologies on the healthcare for trans people in Sweden.

Aim

The aim of this thesis is to determine what role medical technologies play in the healthcare sector's discrimination and poor treatment of transgender individuals, as well as how these problems are tied to the design and function of the technologies.

Furthermore, the thesis aims to show what the cause of these problems are and whether they arise because of technical limitations, bias or both. Lastly, the thesis aims to present solutions to existing problems and new ways medical technologies can be utilised to improve the care for transgender people.

Research objectives

To fulfil the aim of the project the following objectives have been constructed:

- Investigate, with an intersectional approach, how E-health and medical technology impedes equal and good quality care for transgender people.
- Examine the cause of these problems and whether they exist because of technical limitations, lack of knowledge or bias.
- Investigate what is being done today by the healthcare system and developers to mitigate discrimination and bias against transgender people.
- Propose solutions for how the identified problems can be mitigated.
- Propose ideas and solutions on how technology within the healthcare can be used and designed in new ways to improve the care for transgender people.

Scope

The thesis will focus on the technical aspects of medical technologies and how they affect transgender people. The medical perspective will be taken into account but will not be as thorough. Furthermore, the effects on binary and non-binary transgender people will be the focus, although an intersectional approach will be used.

The study focuses on a Swedish context since the healthcare systems look different in different countries. Furthermore, interviews will be conducted with persons from the whole of Sweden, while the investigated contracts and devices is mainly from Region Västra Götaland. This decision was made to narrow down the amount of available material due to time constraints.

Chapter 2

Background

This chapter provides a background which the analysis later on will be built upon. It gives an introduction to differences and complexities of gender and sex, bias in medicine and technology as well as the relationship between trans people and the healthcare system.

Gender and sex

Sex is a term which is used to categorise people based on biological attributes while gender is a social construct and refers to roles, expressions and identity. The terms are however often used interchangeably in everyday language. Both are usually seen as binary in society at large, with the options man and woman. In Sweden, however, the word for sex, *kön*, is much more common in everyday language than the word for gender, *genus*. *Kön* is used to describe both sex and gender in everyday language, while *genus* is most commonly used in research and scientific fields.

The hegemonic concept of gender and sex is that sex, since it is based on biological attributes, is something fixed and binary. Gender is then constructed by society with sex as a basis. This view of gender and sex has however been challenged repeatedly. Butler (1990) proposed the idea that rather than gender stemming from sex, gender is created by and upholds societal norms and in turn constructs the idea of binary sex. Lugones (2008) has the same idea and exemplifies it by discussing how people with intersex variations are assigned to one of the unambiguous categories of binary sex based on what characteristics are traditionally seen as male or female. This she argues shows that the concept biological sex is socially constructed rather than an essential part of one's biology. Lugones further strengthens her argument by explaining that the determination of a person's gender depends on a variety of factors such as chromosomes, gonads, external morphology, internal morphology, hormonal patterns, phenotype, assigned sex and self-identified sex. The most common ones used to assign someone a sex are, according to Lugones (2008), chromosomes and genitalia. However, she points out that these factors are a matter of interpretation and are surgically constructed, since people with intersex variations are often subjects of both surgeries and hormonal treatments to better fit the binary categories of sex. Furthermore, Greenberg (2002, as cited by Lugones, 2008) discusses how an infant with XY chromosomes and an "inadeqaute" penis is assigned female, whereas an infant with XX chromosomes and an "adequate" penis is also assigned female. Greenberg's explanation for this is that manhood is defined by one's ability to penetrate a vagina, while womanhood is defined by one's ability to bear children. These criteria are clearly based on societal norms rather than biology.

Ainsworth (2015) examines how the factors that determine a person's sex work and interact in her text *Sex Redefined*. She describes how the development of the gonad and which hormones are secreted by it determines the persons external genitalia and secondary sexual characteristics, for instance growth of hair and breasts. Ainsworth goes on to explain that changes to these processes can have large effects on a person's sex. For example, mutations in genes that affect the gonad can result in the development of typically female characteristics in a person with XY chromosomes, while changes in hormone levels can result in typically male characteristics being developed in a person with XX chromosomes. A variety of different intersex variations exist ranging from combinations of XX and XY chromosomes, to gene mutations and varying hormone levels and estimations show that as many as 1 in 100 people have some type of intersex variation. Furthermore, Ainsworth (2015) discusses how the binary idea of sex is challenged at a cellular level as well. She explains how cells with XY chromosomes can lose the Y chromosome and how cells are exchanged between a fetus and the person carrying it during the pregnancy. These cells can have the opposite sets of chromosomes compared to the persons own cells and might stay in the body for decades.

Circling back to Lugones (2008), she further challenges the idea of binary gender and sex, not only through the non-binary biology of humans, but also through how the concept of gender and sex has differed greatly between different cultures. Lugones (2008) introduces a model she calls *the modern colonial gender system* to describe how the hegemonic concept of gender is Eurocentric and a product of colonialism. As an example, she describes how some African societies had no gender system and thereby no hierarchies based on gender prior to colonisation. Similarly, many native American tribes recognised a third gender, had women in leading roles and recognised homosexuality in positive terms. The enforcement of this gender system in colonised societies, Lugones (2008) explains, was a way to not only export the ways of controlling women, peoples' bodies and enforcing heterosexuality, but also to differentiate people based on race. She describes that the modern colonial gender system is based on white bourgeois men and women. Racialized people were and could thereby be exotified and seen as inferior.

The above examples shows that gender and sex is complex and cannot neatly be put into two separate categories. Additionally, the modern colonial gender system, which is the hegemonic system today, is based on white bourgeois men and women and is built to control and oppress anyone who deviates from its norms.

Bias in Medicine and Technology

In a report from SALAR (2019) it is stated that healthcare is not provided equally in Sweden. There are differences in the care that patients receive that are rooted in stereotypes and norms. These differences can be seen in statistics that show that women to a lower degree than men are treated according to guidelines, men receive more expensive drugs and women receive less implants for the same conditions. The same report discusses the result of tests that have been performed on medical students where the students all had to review a patient case. All students received the same information except in half of the cases the patient was a man and in the other half it was a woman. The results were that the man to a higher degree got laboratory test and somatic examinations while the woman was given recommendations for life-style changes.

Hamberg (2008) presents similar data, for instance she shows that especially older women are less likely to be admitted into intensive care or be given life-saving interventions than men. Furthermore, she discusses gender blindness in clinical trials. Hamberg writes that clinical trials have historically been done mostly on middle-aged white men, but that this has been criticised since the 1970s. Even though this has been long criticised Hamberg explains that there are still a lot of recommendations that are based largely on white young men and that even though studies to a greater degree include women today, they still overlook gender in the analyses.

Sjoding et al. (2020) presents an example of bias in medical technologies through a large study that was performed to evaluate racial bias in devices that measure pulse oximetry. The study compared the measured level of oxygen saturation with pulse oximetry compared to analysis of arterial blood gas. The conclusion was that pulse oximetry measurements were less accurate in black people compared to white people. In first of two groups 11.4 % of black patients had a blood gas oxygen saturation below 88 % when pulse oximetry showed a saturation between 92 and 96 %. The same figure for white people were 3.6 %. In the second group the figures were 17 and 6.2 % for black and white people respectively. The conclusion from Sjoding et al. (2020) was that the risk of undetected hypoxemia when using pulse oximetry was almost three times as high for black people compared to white people.

Hicks (2019) writes that during the 1950 and 1960s the British pension system was undergoing a digitisation process. Citizens needed a pension card to be able to receive their pensions but also to be legally employed. Therefore, many trans people applied for a change of their gender in the pension system. Hicks explains the British government recorded these applications in special records to keep track of trans people. Hicks further explains that when new computers were introduced and the system was further digitised, the decision was made to not allow for changes of one's gender in the system. When the old data was coded into the new system known trans people were given a special indicator pointing to rules that stated that trans persons were not allowed to exist in the system, and it had to be corrected. According to Hicks (2019) this is one of the earliest examples of transphobic algorithmic bias and it shows how technology can be used to strengthen and uphold the idea of static and binary gender.

The use of algorithms and AI is growing in both society at large and in healthcare. Specifically, machine learning is expected to be of great benefit. These algorithms build models based on data on which they train themselves on. This sets high requirements on the data and that it is representative for the people it will be used on. Criado Perez (2019) uses the term gender data gap to explain the lack of available data that exist on women compared to men. This translates to a risk of the algorithms performing poorly on women. Further, Criado Perez (2019) explains that the situation is even worse for women of colour, disabled women and working-class women. In other words, women who deviate from society's norms in more than one way. The reason, according to Criado Perez (2019), is that data on ethnic minorities for example, is not divided on gender, which leads to the data on women of colour being lost in this bigger data set. Moreover, Hampton (2021) raises similar problems and uses the term algorithmic oppression to describe the lack of inclusion of minorities in the design. With the use of the term oppression rather than bias, Hampton wants to emphasise that these problems are not simple mistakes in the design process and rather a consequence of the existing power structures in society. Hampton means that this realisation is necessary to combat these inequalities in algorithms and technology.

The examples in these sections show several different ways bias can take form and how bias based on separate norms and ideas can overlap. Both Criado Perez (2019) and Hampton (2021) discuss this problem and show that it can often be overlooked. To combat this Crenshaw (1991) introduced an analytical approach called intersectionality. With an intersectional perspective one can see how different norms and power structures interact. For instance a black trans woman can be discriminated based on race, gender identity and gender expression and these will often happen simultaneously. Having this perspective is important when performing clinical trials, creating medical guidelines and developing new technologies.

Trans People and the Healthcare System

As the earlier sections have showed the gender norms in today's society are rooted in ideas about binary and fixed gender categories. The norms in turn leads to bias and discrimination in society, healthcare and technology. This section builds on that and looks at the relationship between trans people and the healthcare system, with a focus on Sweden.

Discrimination, Harassment and Poor Treatment

Trans people face discrimination and harassment in many areas of life and the most unsafe one is within healthcare according to a report by TGEU (Calderon-Cifuentes, 2021). In the EU and the United Kingdom 34 % of trans people and people with intersex variations report that they have been the subject of discrimination from social and healthcare services in the last 12 months (European Union Agency for Fundamental Rights [FRA], 2020). In Sweden the figure for trans people and people with intersex variations is 38 %. Furthermore, the survey shows that the more open you are, the more likely you are to be the subject of discrimination since 68 % of Swedish trans people who are "very open" report being discriminated against, while 18 % of Swedish trans people who are never open report having been discriminated in healthcare and social services (FRA, 2020). Looking at the difference in reported discrimination based on different trans identities in Sweden, the ones with the highest reports of being discriminated against in healthcare and social services are trans men and genderqueer people (FRA, 2020). Moreover, 5 % of trans people in Sweden have been refused care because of their identities and 40 % trans people report having delayed seeking care for fear of being discriminated (The Public Health Agency of Sweden, 2015).

Some of the experiences that trans people report from healthcare services are being misgendered, receiving rude comments, being asked invasive questions and being asked to show body parts that are not relevant for the examination (SOU 2017:92, pp. 306–322) (Westerlund et al., 2022, p. 43). There is also a problem with inadequate competence about trans issues in the healthcare sector and trans people have reported having to educate the healthcare workers themselves (SOU 2017:92, pp. 306–322) (Westerlund et al., 2022, p. 408).

The Gatekeeper of Trans Rights

A report from the UN states that the United Nations High Commissioner for Human Rights recommends member states to recognise gender based on self-determination, acknowledge non-binary identities, and that the applicant does not need to fulfil abusive requirements to change their legal gender, such as medical certification, surgery, treatment or sterilisation (United Nations [UN], 2018). Sweden does not fulfil these requirements since the applicant must go through a gender assessment done by the healthcare and the application must be approved by The National Board of Health and Welfare's Legal Advisory Board (SFS 1972:119)(SOU 2017:92, p. 734). This means that healthcare in Sweden does not only help trans people when they are ill, it is also the gatekeeper for access to legal recognition of their gender identity.

The waiting times for entering the gender affirming care in Sweden is two to three years and waiting times for different steps within the gender affirming care can be additional years (RFSL & RFSL Ungdom, 2022; Summanen, 2022). Both Linander et al. (2017) and Lindén (2022) have conducted studies where they interviewed patients at gender clinics in Sweden. Both studies showed that the patients found the waiting times for care long and psychologically tearing. The studies shows that there is a relationship of dependency between the patients and the healthcare provider where the patient sometimes feel that they have to prove that they are trans enough to receive care. Linander (2018) writes that the assessments are often based on a linear, static and binary idea of gender. The study by Lindén (2022) shows similar indications and she writes that people with non-binary identities seem less satisfied and showed more worry surrounding the care. The long waiting times and lack of trust is according to Linander et al. (2017) leading to some patients taking the matters into their own hands through self-medication.

Amidst debates in society and in the medical community regarding the risks and benefits of gender affirming care, The National Board of Health and Welfare (2022) released new guidelines for treatment of children and youth with gender dysphoria with new restrictions surrounding hormone replacement therapy and puberty blockers. The National Board of Health and Welfare (2022) lists possible consequences of these guidelines which include ongoing dysphoria, higher risk of self-harm and suicide, a higher degree of self-medication and a lower level of trust towards the healthcare system. The proposed solution for mitigating these risks is psychosocial care.

Before 2013, trans people were forced under law to undergo sterilisation in order to be allowed to change their legal gender (SOU 2017:92, p. 735). The interpretation of this requirement by the healthcare was that the sterilisation had to be irreversible and that individuals were not allowed to store eggs or sperm (SOU 2017:92, p. 735). Furthermore, there are reports of healthcare workers recommending trans people to undergo sterilisations when receiving gender affirming care even after the mandate was lifted (SOU 2017:92, p. 315). Similarly, people with intersex variations may be subjects to surgeries when they still are babies to better fit into the gender binary, according to Lugones (2008). In Sweden there are no clear recommendations to when surgical interventions are warranted for people with intersex variations according to the guidelines from The National Board of Health and Welfare (2017a). The guidelines recommend that psychosocial factors and the parents' wishes are taken into consideration and the decisions that are made by different surgical teams therefore varies. In earlier guidelines it was recommended that the patient was not informed of the interventions that had been made. In a statement from OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO the write that forced sterilisations violates a person's right to be free from torture and other cruel, inhuman or degrading treatment or punishment (World Health Organisation [WHO], 2014). In the statement they also say that people with intersex variations may be subjects of cosmetic surgeries which in some cases causes or risk causing sterilisation. In these cases, they recommend that the interventions are postponed until the person themselves can make an informed decision, so long as it does not pose a risk to their health (WHO, 2014).

In summary, there is a complex relationship between trans people and healthcare. On one hand trans people should have access to the same care as everyone else from the healthcare system, on the other the healthcare system functions as a gatekeeper for access to their civil rights in regard to being able to live and be seen as the gender they identify with. Healthcare has a history of being and still is a tool used by the state to control the bodies of trans people through forced sterilisations and involuntary surgical interventions, as well as a tool for controlling legal recognition of their identities.

Chapter 3

Methods

Data Collection

The method for fulfilling the aims of the thesis is through interviews and collecting data from reports, medical guidelines and technical documentations. The interviews were designed with qualitative methods, which are used to understand and explain peoples' beliefs, actions and experiences. The interviewees were selected with the aim of gathering data from the experiences from trans patients and medical professionals in both trans specific and general healthcare. Interviews were also planned with developers of medical technologies and people involved in procurements of medical technologies. It was not possible to conduct interviews within these two areas due time constraints and contacted people declining. Data from developers were therefore collected through email communication with an application specialist at Philips Healthcare and through the collection of technical documentations. Data from the process surrounding public procurements were collected through contracts and requirement specifications from Region Västra Götaland's database for contracts called *Avtalskatalogen* during December 2022 to April 2023. For these two areas information was gathered about a few specific systems. These were selected based on information that was gathered through the interviews. Data was also collected from reports from non-governmental organisations and governmental agencies as to provide information on guidelines, trans patients' experiences of healthcare and historical problems within the healthcare sector.

Methods During the Interviews

Before the interviews the interviewees were all sent the same information about the interview. To make sure the interviewees brought their own experiences and ideas to the interviews, only broad areas that would be discussed was sent to them instead of specific questions. These areas were:

1. Problems that have risen or could arise in healthcare for trans people due to technical systems.
2. Technical systems that categorise people based on binary gender.
3. How technical systems are or can be utilised to create a more equal care for trans people.
4. The consequences of increasing digitisation within healthcare from a transgender perspective.

During the interviews the approach for formulating questions were similar. They were all asked the same broad questions, except if it was not relevant considering their background and perspective. The initial questions on each area of interest were broad as to make sure they were talking about their own experiences and ideas. Follow up questions were more specific and based on what the interviewees brought up. The later interviews also contained questions based on information given in the earlier interviews.

Selection of Interviewees

Four interviews were held in total with people from non-governmental organisations and with healthcare professionals. To preserve their anonymity, they will be given aliases in the thesis.

The first interview was held with an expert on trans issues who was working for a non-governmental organisation working with the human rights of trans people. The interviewee will in this thesis be referred to as Rue. They have a long background working with LGTBQI-rights and have had a special focus on trans issues. Rue was selected for an interview based on that they were working with trans rights and was presumed to be able to provide insight into what issues trans patients are facing in healthcare and discuss medical technologies from a trans rights perspective.

The second interview was held with a nurse specialising in intensive care. She will be referred to as Josefine throughout the report. Josefine has been working intensive care for approximately nine years and has some extra responsibilities regarding her unit's medical technologies. She has also been a part of several public procurements of medical technologies. Josefine was selected for an interview based on her work within intensive care, an area which uses a wide array of medical technologies, and based on that her professional role includes some extra responsibilities surrounding medical technologies and procurements. She was therefore thought to be able to provide information on issues that has arisen or could arise in the treatment of trans patients due to medical technologies. She was also expected to be able to provide some information on the process of public procurements of medical technologies.

The third person that was interviewed was a psychologist specialist working within trans-specific healthcare. She will be referred to as Maria in this report. Maria works with gender assessment investigations of youth, and she has more than ten years' experience of working with patients with gender dysphoria. The clinic where Maria works was contacted for an interview and the head of the clinic appointed Maria to it. The clinic was contacted to gather information from healthcare professionals who work with trans patients on a daily basis about what challenges they see tied to using medical technologies on trans patients. It was also thought to be valuable to be able to compare experiences and ideas from professionals within trans-specific healthcare and general healthcare.

The fourth interview was held with a board member from a non-governmental organisation working with trans rights. She is also a physician within oncology and identifies as trans. This interviewee will be referred to as Emma. The organisation was contacted for an interview, and they appointed Emma. Emma is active in the organisation's advocacy work and work with commenting on medical guidelines. As a physician she currently worked with breast cancer and has previously worked with prostate cancer. The organisation was selected for an interview to gather information about trans peoples' experience of healthcare and issues surrounding medical technologies. Since Emma is a physician, she was also able to provide information from the perspective of a healthcare professional.

Data Analysis

The method for analysing the collected data was qualitative analysis. This is a method for processing data and drawing conclusions about both explicit and implicit dimensions (Flick, 2014). With this method both explicit information, such as examples of problems the interviewees had seen or ideas they had, and implicit information were extracted. The implicit information was for example how the interviewees spoke: they might have talked with long pauses which could imply that they are unsure and unfamiliar with the topic and strong language could explain something about their attitudes and importance of a subject. Both the explicit and implicit information from the different interviews were compared with each other and with other data from guidelines, technical documentations, reports and scientific articles. From this, more general conclusions could be drawn, and theories could be made that explain the described situations and their differences.

Chapter 4

Results & Analysis

In this chapter the results from the interviews with Rue, the expert on trans rights, Josefine, the nurse specialist, Maria, the psychologist specialist, and Emma the physician and board member of a trans rights organisation are presented. Alongside this, results from the analysis of technical documentations and documents surrounding public procurements are presented.

Gender in Algorithms and Guidelines

Both Emma and Josefine say that most research, guidelines and algorithms in healthcare have been based on a man weighing 70 kg. Josefine adds that this has become better, and that nowadays medical technologies often use gender as a parameter. Emma says the following on the topic:

> We have a fundamental issue in medicine which is that we very often use 70 kg, 22-year-old men as a model and this results in a lot of algorithms and models being inaccurate if you aren't a 70 kg, 22-year-old man. Because of this gender has been added as a variable in quite a few models. However, I think that one forgets how blunt that is and how big the variation within the group, as the individual variation is big. I also think that one often uses gender as a proxy for what one is really interested in. (Interview with Emma, my translation)

Emma then explains how devices that measure bladder volume ask for gender instead of if the patient has a uterus, which is described in more detail in a later section. She also talks about ECG devices that sometimes says "consider female ECG pattern" in the automatic analysis of the ECG and asks what this means. She is not sure if it has to do with the patient having breasts or if it perhaps has something to do with the placement of the electrodes. It is difficult to determine what this means and if it can be a female ECG pattern if the patient has small breasts or has had a mastectomy. Emma says that it would be better to talk directly about what is medically relevant instead of using gender which becomes vague and unclear.

Rue discusses the same issue and uses the selection of levels of medication or different treatments as an example of how these choices are often based on partly weight, but also ideas of biological sex. When this is a basis for selecting treatment, one of the consequences will be that trans persons who present themselves according to their identity will get the wrong treatment. They also add that it becomes complicated when someone has altered their body or has a natural variation of their body.

Furthermore, Emma explains that she often has to estimate the risk of fractures in patients before prescribing drugs. This is done with an algorithm which has gender as a parameter and which gender gives the best medical outcome in this case can be difficult to determine. She explains that these algorithms are derived from statistics, and it is difficult to determine how well the patient she is treating fits into that statistic, adding that this situation is hard to navigate. Moreover, Emma explains that the situation becomes even more complex when the patient is a trans person, since there are no statistics on this group. The situation is further complicated by the fact that different trans persons have started their transitions in very different ages and gives the following examples:

> If someone has been treated with puberty blockers since they were a teenager and have had an increase in hormone levels consistent with the gender they identify as, then you can probably use the gender with which they identify. But say that I meet a 50-year-old trans woman and that she has had high levels of testosterone for 45 years due to not having been treated with hormones, then it will probably be more medically relevant to use an algorithm for men. Although, this risk hurting my relationship with my patient a lot. So, I would have a very difficult time doing that. It is a very difficult situation to navigate. (Interview with Emma, my translation)

Emma goes on to say that since there are no statistics or clear guidelines for trans patients, one has to perform educated guesses of what will be best in the specific situation. However, she has never heard anyone discuss these situations among colleagues and think that most simply chose either the gender assigned at birth or the one the patient identifies as without too much thought about it. Rue discusses the same issue and agrees that it is very difficult to determine what gender which would be the most beneficial from a medical perspective in different situations. They say that there too many factors to give a simple answer to this and adds that the skills of the healthcare workers are of great importance in these situations.

Josefine was asked what her thoughts on this issue are, which selection of gender in regard to algorithms and guidelines will provide the best medical outcome for trans patient. It was clear that she had a hard time answering and said the following:

> Oh, that's very difficult. Frankly, the research is mostly done on men so then maybe it would be best to choose "man". However, nowadays a lot of research is done and it has changed a lot lately. But what should one choose, it's very difficult, oh my god, no it's not possible. I don't know, frankly, what's right or wrong there. It's very difficult. (Interview with Josefine, my translation)

Furthermore, both Emma and Maria discuss issues that can arise when systems use the patient's legal gender and fetch it from the population register. They both explain that a patient who changes their legal gender during an ongoing treatment could have their treatment changed from one day to another. If systems use legal gender as a parameter in the calculation of dosage of drugs this could change when the legal gender is changed, even though nothing has changed in regard to the patient's anatomy and physiology. They also explain that the same applies to different test, e.g. blood tests. One day the patient could be within recommended limits for a certain test, while the next day, when they have a new legal gender, they could fall outside these limits if they are differentiated based on gender. Emma further questions the use of legal gender as a parameter in medicine and thinks that legal gender will be even less relevant when the process for changing legal gender might be easier in the future.

Rue discusses the same issue and thinks that guidelines based on binary gender likely are beneficial for a large group of people. However, simply automatically using the patient's legal gender without questioning it is problematic. They argue that there must exist ways to change the gender of the patient in the systems and there must exist structures and established routines on how to handle situations where the use of legal gender might not result in the best treatment of the patient. The possibility to overrule the system is vital since situations like the one with Obstetrix (discussed further in the next section) cannot be allowed to happen. They also argue that it is important that one questions the ideas on gender and biology in healthcare on a regular basis.

Emma also addresses AI and what data they are trained on. She sees a risk that data sets are differentiated based on legal gender and this could lead to the algorithms performing poorly. Partly because trans people are not taken into account, and it is therefore unclear how the algorithms work on them. However, they could also have a poor performance in general for all patients due to the oversimplification of using binary gender and not taking into account that the legal gender can be changed and considering how that might affect the data sets.

As discussed in the background section, Hamberg (2008) writes that medical research and guidelines have long been performed on and tailored to men. In this section we see that that still is the case. Furthermore, the idea of binary gender seems to be very widespread among medical guidelines and in the design of medical technologies. Additionally, the use of legal gender is often used, even though this is not tied to one's biology. This has a variety of consequences for trans people, ranging from being misgendered to getting the wrong treatment and as said by Rue, the medical system therefore needs to be more flexible. There is also a clear lack of awareness and discussion in the medical community regarding the treatment of trans patients, which is discussed by both Emma and Rue and displayed in the answers from Josefine. Emma further points out that the idea of binary gender does not only have consequences for trans people, but also cis people. Gender and sex are not, as we have seen in the background, strictly binary. It is made up of a lot of different factors which all can vary individually. Oversimplification and vagueness of what is really sought after when a guideline or algorithm is asking for gender can therefore harm the care for both trans and cis patients.

Examples of Gendered Medical Technologies

During the interviews and within literature, several different examples of technologies used in healthcare that are gendered were discussed. These will be presented and analysed in this section.

Electronic Health Records

The main purpose of a health record is stated in the third chapter of the patient data law (SFS 2008:355) and it is to contribute to a high quality and safe care of the patient. It is also a source of information for the patient, oversight and legal requirements as well as tracking outcomes and improving the organisation. Furthermore, The National Board of Health and Welfare (2017b, p. 57) adds that the health record is an important tool for those participating in the care of the patient and that the documentation of different interventions can be crucial from a patient safety perspective. The third chapter of the patient data law (SFS 2008:355) states that a health record shall contain the information that is necessary to provide high quality and safe care and lists the following items as information that should be included if it is available:

1. information about the patient's identity
2. necessary information that describes the reasons for the care
3. information about diagnoses
4. necessary information about chosen and planned interventions
5. statements about what information that has been given and to whom as well as statements about the chosen interventions
6. information about the decision from a patient to decline care

The health record should contain information about who has written a note and when. Furthermore, the third chapter in the patient data law (SFS 2008:355) states that a health record should be kept for each individual person. This has the consequence that a change of the social security number leads to a new health record needing to be created.

Gender, Name and Pronouns

During the interviews the interviewees were asked to give examples of problems related to medical technologies they had heard of or faced when patients were trans. The first problem that came to mind for Rue, Josefine and Maria, was that when entering the social security number into the electronic health record the name of the patient is fetched automatically from the population register and it might not show the patients preferred name. If the patient's preferred name is not listed in the health record the risk that the healthcare personnel use the wrong name and potentially misgender the patient is higher. Additionally, Emma, the physician and board member in an organisation working with trans rights, gave the example that in the same situation as described above the gender of the patient is also fetched from the population register. The automatically obtained gender might not be the same as the one the patient identifies with. Emma explains that this could lead to misgendering when communicating with the patient and that it also affects how the healthcare personnel act in relation to the patient. Which in turn can hurt the relationship and trust between the caregiver and the patient. She also frustratedly points out that it is not possible to change the gender in the health record and that you are therefore forced to misgender the patient in the system. She also says that if they should have important information in the health record, then they should have the patient's pronouns at the top of the records and adds that if gender is of such importance, then they should at least have all relevant information about it.

Josefine describes the same problem and must think hard about if the possibility to change the persons preferred name exist. She says that it is automatically fetched from the population register and that it is hard to override. She lists some different systems and concludes that it is not possible to change the name in those systems. The only place she can think of where they can change the name of the patient is on the physical records they use to keep track of parameters related to the intensive care. She also adds that not only trans people, but also cis people might prefer to be called something else than the name listed in the population register. Furthermore, she adds that to admit a patient and enter them into the electronic health records one has to input the gender. If they know the patient's social security number it is done automatically, but if they do not know that number they have to determine the gender in other ways. If the patient is awake they can ask, however she recalls situations when she worked in the emergency room and received unconscious patients. In some of these cases she explains that they had to resort to looking at the patient's genitals to determine the gender.

The unit for gender affirming care where Maria works have created a workaround method for dealing with these problems. They have created a template where you fill in the preferred name and pronouns of the patient, which is then put at the front of the electronic health record. They also inform the patient that if their preferred pronouns change, they should inform the healthcare personnel so that they can update it. The workaround does have its limitations though, as Maria thinks that it would be easier if it was possible to add this information in the electronic health record without a workaround. She also adds that this is only a solution for the health record. They have two other systems for scheduling appointments and sending information to the patient digitally or physically. In one of the systems, it possible to change the preferred name, however, Maria explains that it repeatedly changes back to default and that they therefore do not use the function. She thinks this is unfortunate since having the patients preferred name on the information that is sent to the patient would be beneficial for their wellbeing. Lastly, Maria expresses frustration over the amount of different digital system they have to work with and says that she does not have time to figure out different workarounds to be able to input the information they want in them.

In relation to this Rue explained that many caregivers do not know what they are allowed to write or not in the health records and adds that they are free to write any information they want about gender, name and pronouns. The patient needs to consent, but the information does not have to be the same as the legal gender and name. They go on to talk about how some caregivers who are more knowledgeable in LGBTQI+ topics talk to their patients about e.g., gender and pronouns and find ways to input this into the health record, like Maria and the clinic she works at. Rue gives an example of midwifes who talk to their patients before the delivery about what pronouns and names for different body parts they prefer. Though, this is not information the health records are built to contain, and they thereby need to find smart ways to input it so that it is easily available. They also emphasise that this being done is currently reliant on individuals to posses knowledge about these issues without formal education in LGBTQI+ topics.

The electronic health records that are being used in Sweden clearly seem to be built upon the idea of binary gender and that this is something static. The information is fetched from the population register and there are rarely any possibilities of making changes. The gender of the patient is seen, by the electronic systems, as a very central part of the treatment of the patient, since it has to be inputted to be able to admit the patient. However, the gender which is normally used is the patient's legal gender, which doesn't necessarily say anything about the patient's biology or how the patient wants to be addressed. It is clear from the interviews that the electronic health records would benefit from being more flexible and include options for changing or adding preferred name, gender and pronouns.

Privacy and Availability

During the interviews two main areas regarding the conflict between privacy and the availability of information in the health records of trans people came up. The first being the possibility to have the section of the health record that includes trans specific healthcare locked and the second surrounding the linking of the old and new health record for a person who has changed their legal gender.

In conjunction with the start of using shared electronic health records between different caregivers Rue's organisation was contacted to discuss the consequences of this for trans people. Coherent record keeping can have great medical benefits but can be problematic from the perspective of a trans person. They explain the following:

> Going to a gender assessment clinic or having received gender affirming care can be very sensitive information for some people. Coherent record keeping can therefore be good from a medical perspective, but

> problematic for some trans people. For example, if someone visits primary care and the staff ask if they can open your records, many don't know what is shown. This creates a lot of worry. It might not be visible that they have received gender affirming care as the section can be hidden. However, the way this works and what coherent record keeping means are very different in different systems and it is therefore hard to answer what is shown to the people wondering. It can be positive from a medical perspective to share more information, but it can also create a lot of worry for some trans people when the information is so public. (Interview with Rue, my translation)

Rue proposes a solution to this problem: they say that one should be able to code the system to alert the healthcare personnel when a certain value is inserted and where it might be relevant to know that the patient is trans or is undergoing gender affirming care. They suggest that it could be tied to the diagnosis codes and should alert the caregiver that a more in-depth assessment needs to be done. However, Rue realises that setting the limits for the entered values is another problem. It is hard to decide when the information might be relevant. They give an example of a trans person seeking care at a primary care clinic for pain in their wrist, then it is probably not relevant that the person is trans. On the other hand, it might be a youth who is receiving puberty blockers, which can cause osteoporosis, and then it is likely relevant that the patient is trans. In a case where the patient is unconscious or their condition is life threatening, the decision is easier and personal privacy is of a lower priority.

Emma talks about the same problem and explains that care that is carried out at the clinics for gender dysphoria is often completely hidden in the health records, something she thinks is beneficial for the patient's privacy. However, parts of a patient's gender affirming care that is carried out at other clinics might not be hidden. She explains that surgeries, for example, are usually not hidden. A patient can manually request that a part of the records is sealed, which will prevent it from being opened, but a caregiver with access to the record can still see that care has been received from that clinic. Information that has been put in the section for personal information is always visible and she explains that she has experience from situations where pronouns have been put there, and therefore were available for everyone with access to the records. On the other hand, prescribed drugs tied to the gender affirming care is often hidden, something Emma points out can be very important information to have access to. Her conclusion on this topic is therefore that an overview of what information is available and what should be available is needed.

From the information above, we see that what information that is being shown and to whom in the electronic health records is unclear. There seems to be a lack of a deeper analysis of what is medically relevant and when. On one hand it is important to protect trans peoples' privacy and their right to choose when they want to be open about their identity. In the last section the importance of being able to put in preferred name and pronouns was discussed. This section adds additional important information to that and to make sure trans people can choose when to be open, it might be beneficial to be able to have different names, genders and pronouns visible for different caregivers. Moreover, important medical information needs to be accessible to uphold patient safety. Rue proposes an interesting solution with a system that would notify the healthcare worker when some type of important limit has been passed. Creating a solution like this or in general deciding what information is medically relevant in different situations is likely hard due to the lack of research on the effects of gender affirming care.

When a trans person changes their legal gender, a new health record must be created, and they can at the same time decide if they want to link the old and the new record. When applying for a new social security number one also have the option to apply for a confidentiality marking in the population register (The Swedish Tax Agency, n.d.). The Swedish Tax Agency's recommendations, if this is done, is that the connection between the new and the old social security number and name should be protected. This means that the recommendation is that the old and new health record should not be linked in these cases. The possibility of completely merging the records so that only one exist with the new personal information does not exist today due to existing regulations and guidelines. Josefine explains that this has created problems when she used to treat patients who underwent surgical gender affirming care and the patient's social security number was changed during the period they were a patient at the clinic. It could make it difficult to find all relevant information to provide high quality care for the patient.

Rue explains that the solution for linking the old and the new health record looks very different in different systems. In some cases, some information is transferred to the new record, in others there is only a link to the old record. They go on to explain that in some system the old record still shows the old social security number and in other system this is hidden, which creates confusion. They add that, in general, these systems are not made for linking old and new records and special solutions needs to be created. Rue explains that some trans people prioritises that their whole medical history is available, while other prioritises their control over being out as trans. The fact that solutions look very different in different systems and how much of the old personal information is available varies complicates the decision. The fact that one's old pronouns and name is likely to be written in the old entries in the record is also a complicating factor and Rue suggests that this should be allowed to be changed. They say that perhaps this could be done rather simply with some algorithm, and that it does not change any medical information.

Emma gives an example of how a trans person that passes as cis will be outed if the old and new record is linked. Keeping them separate will allow the trans person to decide on their own to who they want to be out. This means that their complete medical history is not available, however it can be a well worth sacrifice to have control over very personal information. She goes on to explain that the information is not lost without a link between the old and new record, but the patient decides when the information should be available by giving the caregiver their old information. She also adds that there are ways healthcare personnel can find the old records on their own, such as by searching on birthday and name. However, she says that the legality of this is questionable. This method of finding old information about patients that have changed their legal gender is something Maria is familiar with as well and says that it is used among healthcare personnel. She says that sometimes they need access to the old health records and must improvise to find them, while adding that this way of working is not favourable.

Maria sees the lack of information when the old and the new record is not linked as a problem. It makes it hard to keep track of patients and impedes patient safety. She thinks it is very valuable to have complete records of the patient's conditions, various treatments and potential side effects. Emma on the other hand thinks the risks are exaggerated and says that the important information in the old health record will naturally be entered in the new record over time when the patient meets different caregivers and talks about their conditions. Maria further questions if the option for trans people to have their personal information confidentiality marked as easily as today is necessary. She believes that for most trans people it does more harm than good. Furthermore, Maria thinks that hiding and withholding information about one's past is likely to lead to more uncomfortable questions from healthcare personnel. Emma on the other hand thinks that the problem lies with the healthcare personnel who should not be too curious and respect the patient's privacy.

Lastly, Maria raises another issue related to the patient's privacy and health record. Patients have increasing access to read their health records. Previously you had to ask for your records in physical forms, now with electronic health records the patient can log in online and read them. Maria says that this puts more pressure on the healthcare workers who writes in the records. Especially when writing about trans patients, since the information is an assessment of their identity and if they should get access to gender affirming care. Like Rue, Maria talks about the use of a patient's previous name and pronouns in the records and thinks that this is a complex topic. While she understands the discomfort it may cause, she thinks that it is a part of that person's history and that it should not simply be erased. She says that it is a difficult situation and asks what a health record really should be and if she should write as if it were a blog since she knows that the patient is reading it. Maria says that there are requirements on what she must write in the health record, which she cannot opt out of writing because she thinks that the patient does not need to know this at this time. She therefore thinks that it can be hard to combine the idea that the patient owns their record and should have easy access to it with the requirements on what it should contain.

The question of linking the old health record to the new one is certainly a complex one. We see examples from both Josefine and Maria of issues that arise for healthcare workers and their ability to provide care if the records are not linked. On the other hand, the linking of the records will out the trans person in all their contacts with healthcare. The medical relevance of having the records linked is probably the biggest when the change of legal gender has just been done. Then over time, as Emma suggests, old information that is relevant will be inputted into the new record and the information in the old one will likely be outdated. Perhaps the best solution would be to actually merge the old and the new record. Then all information would be accessible under the patient's new name and gender. Regarding the use of the patient's old name and pronouns in old entries in the record the question must be if it is medically relevant to not change them, if the patient wishes to change them. Like Rue suggests the change could be done very easily by an algorithm.

Maria also raises the question of what the patient should be able to access and when from the electronic health record. It is of great importance that the patient has the ability and necessary information to be able to be active in shaping their care. However, if the availability of information undermines the assessment, maybe it should not be available at that specific time. On the other hand, limiting the access to information will likely make trans patients feel even less control over their care, something that was shown to already be a problem in the background.

Deliberate Gender Barriers

In the interview with Rue, they discuss problems that are an effect of diagnosis codes being gendered. They describe situations where healthcare personnel have not been able to give trans patients their correct diagnosis in their health record because the system has been built to block the code if the expected gender does not match the patient's legal gender. In some cases, warning messages pop up that says that this diagnosis code is for the opposite gender of the patient. In other cases, it is simply not possible to input the code at all. Rue explains that this has consequences both for the patient and healthcare at large. The consequence for the patient is that they will not be given the correct diagnosis. Rue also talks about how healthcare personnel find workarounds for this. Rue says that they must put in a code that is incorrect and write the correct code somewhere else in the health record. This solves the issue although some problems remain. Rue explains that this solution results in a poor overview of the patient's conditions and can hinder further care. Especially in situations where care is needed urgently and information needs to be accessed quickly, it will be easy to miss that the patient has another diagnosis than what the code states. They express their concern that this could lead to the patient receiving worse care.

The other consequence that Rue discuss is that statistics on different conditions will be incorrect or lost. Since the correct diagnosis codes is not possible to input in some cases, trans people will be excluded from the statistics of those conditions. It will also not be possible to see the incidence of a condition among trans people. Rue gives an example: if trans men diagnosed with breast cancer cannot get the right diagnosis code in their health records it will not be possible to extract information about the incidence of breast cancer among trans men from health records. They explain that these problems will lead to a situation with poor knowledge about the health of trans people.

The issue that Rue discusses is undoubtedly something that impedes patient safety for trans patients. Both in the individual case, but also on a group level since it hinders the collection of statistics and future research. Diagnosis codes should therefore not be limited to only one gender. A compromise could, however, be that a warning message is shown when the code is used for a patient with a gender which does not match the expected gender. Though, this is a solution that upholds the binary ideas of gender and signals that being trans is something abnormal.

The Swedish Government Inquiry report *Trans people in Sweden - Suggestions for strengthened position and better living conditions* (SOU 2017:92, pp. 317–318) addresses two incidents where a trans man was pregnant and giving birth, in which he could not be entered into their electronic health record due to the system not allowing a social security number of a person whose legal gender is male. The systems in question were the electronic health record Obstetrix and the fetal monitoring system Milou. The patient is registered in Obstetrix and Milou is integrated into that system and the patient is therefore only registered in Obstetrix (Medexa, 2017).

In the complaint that was filed to DO after the first incident in 2015, the informant writes that male social security numbers are barred from being entered into the system and that it supposedly is in place to keep healthcare workers from mistyping (DO, 2015a). They also say that they have been in contact with the developer, Siemens, and explained the problem. The response from Siemens was, according to the informant, that they refuse to remove the barring and that they claim that it is not a patient safety risk. Siemens further recommends that the pregnant man should be entered into the system with a reserve number, which according to the informant means that he would be entered as an undocumented woman. The informant writes that this is discriminatory and a patient safety risk, since the man would have to prove that the reserve number refers to him in an emergency situation. The solution that was presented to the man by caregiver was instead that he should have a physical health record. The informant describes how this is discriminatory by writing the following in the complaint:

> To not be included in the electronic health record is discrimination since the patient safety is not the same with a health record in paper. If an emergency situation were to occur and the physical health record was forgotten, it would result in a great risk for both the pregnant individual and the child. Healthcare injuries have already happened in Stockholm County Council as a consequence of the barring of male social security numbers in Obstetrix. Other trans men have had miscarriages and have been denied pain relief medication during childbirth. Pregnant trans men are therefore not given the same care as pregnant women which is discrimination. (DO, 2015a, my translation)

The informant further points out that Stockholm County Council (which has since then changed its name to Region Stockholm) is responsible for making sure that the electronic health records that are used in the region are safe and functions for everyone (DO, 2015a). They also say that Region Stockholm should have made sure that any barriers for the care of trans parents that existed when the forced sterilisation was removed in 2013 should have been eliminated. Lastly, the informant claims to have been in contact with people with insight into Obstetrix that say that the removal of the barring of male social security numbers would only take a programmer a single day (DO, 2015a).

The second time the man gave birth in 2016 the barring of male social security numbers was still in place, and he filed another complaint to DO (DO, 2016a). In the complaint he explains that the problem persisted even though he repeatedly, during this and the previous pregnancy, pointed out the problem to Region Stockholm and previously filed a complaint to DO. In this second complaint he explains that he again had to use a physical health record and expands on what problems this causes:

> Apart from me and my children risking serious healthcare injuries, this has caused problems with sick leave, parental benefits, the child's social security number, booking of ultrasound examination, the child's hearing test and more. Everything that is supposed to happen smoothly since Obstetrix is connected to The Swedish Tax Agency, Försäkringskassan and other electronic health records, do not work at all since I am barred from Obstetrix. (DO, 2016a, my translation)

Both Rue and Emma are familiar with these incidents and address them in their respective interviews. Rue says that when the patient could not be entered into the electronic health record system, the healthcare personnel was unsure what they were allowed to do since they could not keep records of their actions. The staff's uncertainty regarding what care they are allowed to give and on how to proceed resulted in the patient not receiving pain relief for an extended period of time. Rue explains that instead of caring for the patient the healthcare personnel spent a long time trying to solve the issues with documentation. They say that this is an example of a worst-case scenario of what can happen when technology is not inclusive and has built in barriers. The solution was eventually to use physical records on paper, which increases the risk of adverse events and complicates further care according to Rue.

Both complaints that were filed to DO resulted in DO conducting investigations of the barring of male social security systems in Obstetrix and Milou and its effects on patient safety (DO, 2016b; 2017a). During the investigations Stockholm County Healthcare Services (SLSO) was asked to submit a statement regarding the incidents. In their statements they claim that they contacted the supplier after the first incident and reported the problems (DO, 2015b; 2017b). However, the systems are used across the whole of Sweden, and they therefore claim that changes take a long time to be implemented. SLSO explains that a new version of the systems is released every year and that the process for the update begins 1.5 years before it is released and claims that this is the reason why the problem had not been resolved the second time the patient sought care (DO, 2017b). Furthermore, they identified two levels of problems: the barring of male social security numbers and the use of excluding language such as the terms mother and woman in different parts of the system. SLSO's statement also explains that the system in linked to The Swedish Tax Agency's systems to be able to send birth notifications automatically. The Swedish Tax Agency's systems were at the time of the investigation not able to receive a birth notification tied to a male social security number and SLSO declared that they would continue discussions with the supplier about this issue.

In their statements SLSO also admits that the patient safety is not of the same standard when using physical health records compared to electronic health records (DO, 2015b; 2017b). However, they still claim that the patient safety has not been set aside due to the issue and that they have routines for handling situations when an electronic health record cannot be used. SLSO says that the situation is unfortunate and that technical limitations should not be a reason for the use of physical health records.

The conclusion of DO's investigations is that the man has been the subject of discrimination by SLSO and that SLSO has broken the law against discrimination (DO, 2016b; 2017a). They also conclude that the discrimination has caused several problems for the man and that is has exposed the man to greater risk in his pregnancy, especially if an emergency would have happened and the physical records would not have been available.

In the instructions for use for Obstetrix from 2021 it is specifically stated that male social security number can be used, however a warning will pop up that points out that the number is male and asks if it has been inputted correctly (Cerner Sverige AB, 2021). The other issue that was identified by SLSO was the use of words such as woman and mother throughout the program. It is not clear from the instructions for use if this has been resolved as of 2021, but the document still uses exclusively mother and woman in certain parts.

These examples show, as Rue calls it, a worst-case scenario of what can happen when the idea of a static gender binary is allowed to exist freely in healthcare and in the development process of systems which are used therein. The consequence of not being able to receive care, e.g. receive pain relief, or exposing the pregnant person and their baby to unnecessary risk is something that cannot be allowed. The time span for correcting the issue, when it is such an urgent matter, is also very long.

Both the issue with Obstetrix, the one in The Swedish Tax Agency's system and the issue with diagnosis codes are similar to what Hicks (2019) described on how trans people were deliberately coded out of the British pension system. The barriers that have been implemented in these systems are deliberate actions that uphold the cis binary gender norm.

Health Records - Evidence in the Application for Changing Legal Gender

The application for a change of one's legal gender is done via the healthcare system and the final decision is made by The National Board of Health and Welfare's Legal Advisory Board (SOU 2017:92, p. 734). The material on which the Legal Advisory Board bases their decision is mainly an application written by the team who is conducting the gender assessment investigation of the patient. However, the board also requests the patient's complete health records and uses this as basis for their decision, which in contrast to the written application is not supposed to function as a basis for legal decisions (SOU 2017:92, p. 756). As a result of this, healthcare personnel have been reported to write information in the patient's health records which is not always relevant for the care of the patient, with the purpose of meeting the recommendations for approving a change of legal gender which is published by the Legal Advisory Board (SOU 2017:92, pp. 755–756). This is further complicated by the fact that the recommendations from the Legal Advisory Board contradict their own reasons for dismissing applications in some cases (SOU 2017:92, p. 756). Examples of information that has been written in health records and that has been used to deny an application is information about having doubts about their identity during the assessment, the patient not always presenting as their gender identity in a normative way and not passing as their gender identity (SOU 2017:92, pp. 747–750). It should also be noted, however, that the law does not have definitive requirements in these areas that need to be fulfilled.

Rue brings up the topic of the application process of changing one's legal gender and the Legal Advisory Board in their interview. They point out that the board inspects the applicant's health records and might be especially interested in what has been written by the gender assessment team, but also other physicians and healthcare personnel within psychiatric care. Furthermore, Rue says that the board might use a small detail from long ago to deny an application and that this shows that what information is put in a trans person's health record is crucial for their access to civil rights. They add that compared to other groups of patients, the health records of trans people have an additional purpose and this sets much higher standards on the information that is written there.

In the interview with Maria, she was asked how knowing that the Legal Advisory Board uses the health records as a basis for their decisions affects her work with it. She answers that that is something one must try to not think too much about, it would result in too much pressure. Maria goes on to explain that in the cases she has worked with it has not yet happened that someone has been denied a change of the legal gender due to details in the health record, but she is aware of such cases existing. She also explains that there are healthcare personnel who refrain from writing some information in the health records out of fear of the consequences it might have for the patient in the future. Lastly, she adds that the health records of trans people have transformed into a legal document instead of a tool used in their healthcare.

Emma was asked in her interview what her thoughts on this topic were. She begins with expressing her opinion that the current application process is flawed and that the Legal Advisory Board should not be involved in making the decision. She describes how the situation surrounding the health record results in a twisted power balance, since one person, the caregiver, holds all the influence over this important document. She says that the health record contains very personal information that the caregiver is supposed to use to give the patient the best possible care. In addition to this, it is also being reviewed by a third party which the patient does not have any contact with other than through the records over which they have no control of. She expresses that this is a very weird situation and a big problem, and the fault being that the Legal Advisory Board feels that they have the right to examine the applicant's health records. The whole system is in Emma's opinion based on gate keeping. First, a gender assessment team determines if a person is trans enough and then the Legal Advisory Board determines if the team has made a good enough investigation and decision on whether the person is trans enough. She adds that if the healthcare personnel are on their patient's side, they need to carefully consider what they write in the health records. She gives an example of a phrasing she has heard of to describe the patient's physical presentation of their identity: *the patient has a masculine expression within the scope of their subculture.* This phrase was used to describe a trans man who was a punk rocker and used makeup. Emma explains that the patient's appearance was described in this way so that the Legal Advisory Board would not use the information to deny the patient's future application based on using makeup, which they could consider is traditionally done by women and therefore draw the conclusion that the applicant does not live as and present as the gender they say they identify as.

The UN (2018) along with several large NGOs working with human rights recommend countries to allow change of legal gender based on self-determination. This means that it would be a simple administrative application. As we have seen this is not the case in Sweden and this has effects both on trans peoples' access to civil rights, but also on the ability to receive high quality and safe care, as an effect of how the Swedish system works. The current system has created a situation where trans people's health records have additional purposes outside its normal function of providing all relevant medical information to the caregiver. Something that has led to healthcare workers refraining from writing some information that they would otherwise write in the records. This can risk patient safety, works against the goal of equal and high-quality care and creates more mistrust between trans people and the healthcare system.

Administrative Systems for Screening Programs

To identify certain diseases at an early stage, Sweden has screening programs where people are called for testing based on gender and age. The basis for this is the population register, which has the consequence that trans people who have changed their legal gender are called to the wrong screenings (SOU 2017:92, p. 419). This is an issue that Rue talks about and explains that a trans man will get called to screening for prostate cancer even though he does not have a prostate. At the same time, he will not get called to screening for HPV or breast cancer, which is something he might need. They say that this is an issue that has been discussed for a long time in healthcare and among trans rights organisations, and a solution is still not in place. Rue proposes a solution where the normal screening program is kept intact, and trans people will have to ignore when they are called to screenings that are not relevant to them. Then, in addition to this, there could exist an additional register where one can voluntarily sign up for the screenings that are relevant for oneself. This would make it accessible for both trans people and people with intersex variations, and it could be distributed both via the gender assessment teams and trans rights organisations.

Currently the responsibility either lies on the patient them self to keep track of which screenings that is relevant to them and when they should be carried out (SOU 2017:92, p. 419) or, in some cases, the gender assessment teams sends referrals to the relevant clinic which are then responsible for contacting the patient for screenings (Region Västra Götaland [VGR], 2020).

Trans people are today kept outside the Swedish screening program and if a trans person would like to participate, they have to keep track of it themselves. Even though discussions have been ongoing for a long time, no solution has yet been presented to include trans people in screening programs that are relevant for them. Rue's suggestion of a system that would exist beside the normal system is likely something that could be implemented faster than a redesign of the existing system. However, while the use of legal gender likely works for most people in this system, it once again shows the flaws of using legal gender in medical situations.

Patient Monitoring Systems

Philips Intellivue is a widely used patient monitoring system in Swedish healthcare. The system monitors physiological parameters such as ECG, blood pressure, temperature and oxygen saturation. The system fetches a patient's name and gender from the population register by inputting their social security number. A clinical application specialist at Philips Healthcare explains when and how gender is used by the system. When taking a 12-lead diagnostic ECG, age and gender is used for determining baseline values of heart rate, PR- and QT-intervals and assessment of ischemic changes in the heart. They add that before taking the ECG the user is asked to input age and gender. Furthermore, alarm limits for ST-elevation are based on the recommendations of the American Heart Association and is gender specific. These parameters are however rarely used in a Swedish context according to the clinical application specialist. Lastly, cardiac output measurements are performed with the PiCCO algorithm. This algorithm requires that the patient's gender, age, length and weight is inputted. This is then used to calculate the body surface area according to the clinical application specialist and Getinge (2020). According to Getinge (2020) the used formula for calculating body surface was developed in 1916.

The clinical application specialist was asked what happens if no patient information is inputted into the system and they explained that the system then assumes that the patient is a 50-year-old man. They were also asked what happens if a patient has a third legal gender and the information is fetched from the population register. They explained that since this does not yet exist in Sweden, Philips does not have a solution for this and that they think it will take time before such a solution is developed.

Josefine is used to working with the Philips Intellivue system but seems unsure on how to handle a situation where a trans person's information needs to be entered into the system. She talks about the system fetching the legal name and that this might not be the preferred name of the patient. However, she does not think this is a big issue and says that they can use the last name of the patient instead. She also talks about the PiCCO measurement and that it requires the gender of the patient, which leads to the following discussion about what gender should be selected for a trans person:

> If it is a very tall and large person and one selects "woman", that would be a little odd. Then it would be better to select "man", if they were born as a man and changed to being a woman. But of course, there are men that are very small and short and then it would not matter as much. But well, then maybe choose what the person was, the gender that the person was born with. (Interview with Josefine, my translation)

The use of binary gender in the Philips Intellivue system shows how widespread the assumption is. As a developer, Philips relies on both their own research as well as research from other companies and organisations, most of which is based on binary gender. Challenging this idea would therefore not be a small task. Though, why gender is used as a parameter is often unclear for the healthcare workers, making it hard for them to determine what would be best on an individual level. Looking at the reasoning Josefine gives in the quote above; it is hard to decide what gender would give the most accurate result for a trans person. Even with the knowledge that the PiCCO algorithm uses body surface are the decision seems hard to make, especially for trans patients, but also for cis patients. What gender will give the most accurate result for a cis man or woman who deviates from the normative body sizes of their respective gender?

Devices Measuring Bladder Volume

Emma discusses devices that measure bladder volume during her interview and explains that these require you to input the gender of the patient for them to function. However, she explains that it is not the gender that the devices need to do a correct measurement, they need to know if the patient has a uterus or not.

Of six different devices that are on the market, five of them requires the user to input the gender of the patient before making the measurement (Caresono, 2015; Diagnostic Ultrasound, 1998; 2002; Verathon Medical, 2020; Vitacon, 2020a; 2020b). In two of the devices the instructions for use specifies that for a woman who has had a hysterectomy, the gender man should be selected (Diagnostic Ultrasound, 1998; 2002). For these two devices the input of the patient's gender is done by pressing one of the two figures shown in figure 1, where the one with a skirt represents a woman. In two of the other devices that require the user to input the gender of the patient, the manual specifies that man or woman should first be selected by

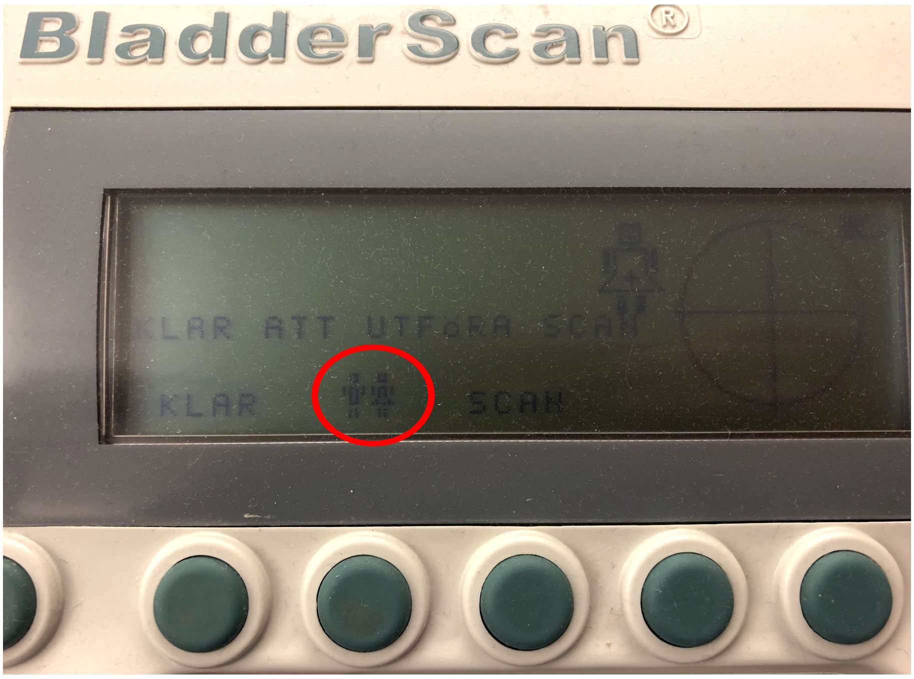

Figure 1: Picture which shows the options for selecting the gender of the patient on a Bladderscan BVI 3000.

pressing buttons with the words male or female on them (Vitacon, 2020a; 2020b). After this the manual specifies that if the patient is a woman who has undergone a hysterectomy, the button hysterectomy should be selected after selecting woman. The fifth device has options for women and women who has had a hysterectomy, as seen in figure 2. If the patient is a trans man who has not had a hysterectomy the gender woman needs to be chosen to get a correct measurement. If the patient is a trans woman without a uterus, the user of the device could select a woman that has had a hysterectomy in two of the cases and have to select man in the other two.

One of the devices does not require the patient's gender to be inputted (Verathon Medical, 2020). The reason for this is that the device uses deep learning to identify if the patient has a uterus or not (Verathon Medical, 2023). The device has been trained on more than 30.000 images where 45 % is from men, 45 % is from women and 10 % is from paediatric subjects. Scans were performed on the subjects before and after voiding their bladder (Verathon Medical, 2023). The algorithm could then be trained on the images and the measured volume differences. Expert clinicians also traced the edges of the bladder in the images from the scans which were used together with the images before tracing to train the algorithm.

The four devices that require the user to input gender before usage presents the options in a few different ways, though they all use gender as a way of asking if the patient has a uterus or not. This does not only force misgendering of some trans

Figure 2: Picture which shows the options for selecting the gender of the patient on a PadScan HD 5.

patients, but in some cases also cis patients. Furthermore, if the healthcare workers do not know why the device is asking for gender, there is a high risk of the "wrong" gender being selected and the measurement being wrong. It is also noteworthy that the PadScan HD 5 device uses the Swedish term *genus*. As discussed in the background, this term is almost exclusively used in academia and describes the social aspects of gender and the usage of the term *genus* thereby makes it even more unclear what the device is asking for.

The last of the discussed devices in this section is an example of how new technologies can be beneficial, especially for trans people but also for everyone else. The design of the device eliminates the need to ask for gender all together and the risk of making the wrong selection or misgendering the patient is therefore eliminated. As long as the device has been trained on a diverse enough data set, it shows great benefits.

Public Procurements

This thesis considers both physical medical devices and medical software. The procurement processes surrounding these two categories are quite different. In Region Västra Götaland a contract is usually valid for four years with the possibility of extending it. However, the purchase of a electronic health record system is seen as a onetime purchase, software updates are not seen as separate products. As an example, the electronic health record system Melior which is used in Region Västra Götaland has a contracted which was written in 1999. On the other hand, physical products are purchased separately or in bulk and a valid contract must exist at the time of purchase. Because of this it is easier to use the procurement process as a tool for making sure the physical products that are used in healthcare functions for all patients, than it is to use it in the same way for software. In each new procurement, new demands can be added that make sure the products that will be purchased meet the requirements of the users. For software the demands are set during the initial purchase and thereafter new demands must be added into software updates from the supplier, until a new software is purchased.

During a procurement process a team consisting of people with different specialities is writing a list of demands that need to be met by the supplier to be able to obtain a contract. The same group then evaluate the different offers provided by suppliers. Josefine has been a part of several of these groups during the procurement of different products. She is asked if there usually are demands regarding how well the product works for different types of patients, specifically regarding issues surrounding trans patients. She says that that has never been a part of a demand or even discussed in the procurements she has participated in.

The lists of demands that are written in procurements are often detailed and can have demands about what patient information the user should be able to input in the system, different IT requirements and demands regarding which patient groups the product should function for, e.g. children. Therefore, the procurement process could be used as a tool for mitigating the different problems that have been discussed earlier in this section, as long as there exists products on the market that meet these demands. For software, however, it is also important that there exists a way for the purchaser to influence the software updates. This could be accomplished in contracts for service and support of the software.

What is Being Done to Make Healthcare More Inclusive

When asked about what is being done at Josefine's workplace to be more inclusive, especially for trans persons, she answered that they are supposed to treat everyone equal no matter their background or who they are. During the interview she was told that trans people trust healthcare to a lower degree than cis people, to which she replied that that is awful and that everyone should be able to trust that the healthcare workers are there to help them. She was also asked if she feels she has access to the information she needs to meet trans people in her work. To this she replied that she does not think so. She says that there are papers that say that everyone should be treated equally well, however there is not enough knowledge among healthcare workers to do that. She says the following about the lack of knowledge:

> If I'm going to be completely honest, I don't think we have been thinking about this yet. We are probably standing still there. Or that's at least how it feels. And that's even though we have had [gender affirming] surgeries here. We can probably become better. (Interview with Josefine, my translation)

Maria says that she is not familiar with any particular work at her clinic to make it more inclusive. She explains that they never assume the identity of a patient and that they allow the patients to tell them themselves. She also mentions the template they have created for inputting name and pronouns in the electronic health record, adding that trying to change the actual electronic health record to be able to input it directly is difficult. The system is large and has too many users to be able to influence its development, she thinks.

Emma explains that in her role in the organisation working for trans rights she tries to influence the language in the National Board of Health and Welfare's guidelines to be more gender neutral. She explains that in the guidelines for treating prostate cancer the board had written a section about patients with the condition that are not men, something she sees as very positive. Regarding her workplace she says that it is not the most progressive. They work with breast and prostate cancer, and they therefore have a lot of gendered information. Emma explains that they are "a few troublesome physicians" who fight the others about at least making the information that is given to the patients more gender neutral. This has received some positive feedback, but mostly because the other physicians acknowledge that cis men can have breast cancer and not because trans people exist. She does have support from her boss, which has allowed her to make some changes. Other than that, she says not much is being done to be more inclusive and concludes the topic with the following remarks:

> I think that healthcare reflects society at large. Our society is very stuck in the idea that gender is binary, the idea that one can see

> another's gender and assume their "true" gender. There are large flaws, particularly in healthcare outside of trans specific care but also within trans specific healthcare, in the treatment of trans patients. (Interview with Emma, my translation)

The work to be more inclusive towards trans people in healthcare seems to be reliant on individual workers with an interest in the issues and who obtain knowledge on their own. There are general goals at a higher level that dictate that healthcare should be provided equally and be inclusive, but resources to make this change seems to be lacking. The work that is being done deals mostly with social aspects in the meeting with patients, which of course are important to build trust. However, discussion about medical questions about the care for trans patients seems to be almost non-existent, even more so regarding the effects of medical technologies. An exception might be AI where some ethical discussions about bias exist.

An Increasing Use of Technologies in Healthcare

During the interviews the interviewees were asked to give their thoughts on the increasing use of technologies in healthcare, and specifically what the consequences might be for trans people seeking care.

Applications Providing Digital Care

Healthcare provided digitally via applications on your phone or computer is a growing area and has great benefits when it comes to making healthcare more available. Rue discusses the possible benefits and challenges with digital healthcare for trans people in their interview and has also discussed these issues with a developer of these applications. The applications often fetch the user's personal data from the population register via the user's social security number, one parameter being their legal gender. Rue says after this the application should tell the user that your gender was fetched from the population register and that it needs additional information about if the patient is trans or have an intersex variation. They add that an explanation of what these terms mean is likely needed here since all users would get the question. If the user answers no, everything could progress as normal throughout the app. If the user answers yes, Rue explains that the application could open up more selections of symptoms, since these are often categorised by gender. They say that the symptoms of a e.g., a stroke might differ between men and women, but there is no research on what symptoms fit a trans person. Here all the symptoms could then be presented instead.

Furthermore, Rue discusses the possibility of alerting the caregiver about the fact that the patient is trans, and they might need to contact their gender identity team or that they need to ask questions about hormone treatment. Additionally, trans people and people with intersex variations tend to seek care at a lower rate than cis people. Creating an inclusive application could make it easier and more comfortable for these patients to seek care. Rue suggests that if a user selects that they are trans they could be offered to meet a physician who is more knowledgeable in that area, something that could be more easily available when meetings are held online. Then trans people could potentially be offered better care and be treated better. They also add that telling the healthcare worker that they are trans before meeting them could feel more comfortable than doing it in the meeting, it is harder to correct someone when you are talking with them than telling them the information beforehand. Rue says that it will probably be far in the future that every physician asks a patient about their identity and how they want to be addressed but programming it in an application is easy. Lastly Rue adds that since trans people and people with intersex variations wait longer before seeking care, everything that makes it easier for them is of great benefit. Should the applications be designed poorly from a trans perspective, with only binary gender options and not acknowledging trans people, the effect would be the opposite. Rue concludes the topic with saying that there is great potential for making healthcare better for trans people with digital care, but "then they damn right need to think it through".

Worries and Possibilities

All of the interviewees think that increasing use of technologies in healthcare can have great benefits for the patients. Emma and Josefine discuss how technologies can help with the handling of large amounts of information, which could then benefit the patient in terms of making more personalised decision in treatment plans. Josefine gives the example of being able to fine-tune hormone treatment. Emma explains how she today uses a complex spreadsheet to keep track of different parameters about a patient’s tumour and how these relate, something she thinks an algorithm could do a lot more efficiently.

In contrast to this Emma and Rue also expresses worries about how technologies can disfavour minorities if existing biases and norms in our society are built into the systems. Emma says the following:

> I think of facial recognition which is really bad at recognising non-white faces. What biases the person who did the programming have will affect how the program works, and this is dangerous when we have broad ideas about gender which are partly inaccurate. This could be a problem when we might use more AI and make fewer individual decisions and instead trust what the system recommends. (Interview with Emma, my translation)

We have seen throughout the results section that medical technologies have the potential to be helpful in making healthcare more inclusive for trans people. AI has helped in removing the need to input gender as a variable in a device for measuring urine levels in the bladder. Electronic health records have issues today but some rather easy changes such as making it possible to add preferred name and pronouns in the record could aid healthcare workers talk to and talk about trans patients in a respectful way. Rue gives examples of how digital care can make healthcare more accessible and inclusive for trans people. However, we have also seen examples of medical technologies that severely hinder care for trans people. Some devices and medical guidelines use gender in ways that make it unclear for the user what its purpose is, which may result in difficulties for healthcare workers in deciding what selection will best benefit the patient. Furthermore, systems have been coded in ways that completely excludes trans patients from being entered into the system. Advanced algorithms and AI can as mentioned be of benefit, though if the data sets on which they are based are not diverse the fears which Emma expresses above might become a reality.

Chapter 5

Discussion

The background and results sections of this thesis show that the dominating ideas about gender within medicine and medical technologies are what Lugones (2008) calls the *modern colonial gender system*. It provides an essentialistic and binary view about gender and sex, meaning that it is something that one is born with, that it is static and that it is an essential part of ones being which is shared with other people of the same sex and gender. This makes it easy to put people in two large groups, make statistical assumptions about them and apply these in guidelines and algorithms. This works well for most people in most situations; however it is an issue for trans people in particular, but also sometimes cis people. Additionally, since the norms are centred around white bourgeois men and women, people of colour are likely also negatively affected by them. Trans people of colour will thereby face even more negative effects as a result of these ideas. It is seldom clear what the reason for the gender divide is, which makes it difficult to determine which guideline or what gender should be inputted into an algorithm to give a trans patient the best care possible.

Challenging these ideas are difficult. It is likely easier to change the ideas in the social setting, the meeting with the patient, to be more inclusive and respectful towards trans people. However, it is likely more difficult to change the dominating ideas about gender in the more medical settings, such as examinations, treatments and technologies. It is not enough to be critical of gender norms when designing these, one must also deal with the historical research of which these are often built. If all historical data has been done with the idea of gender being binary, it will be much more difficult to design something without that idea. Without research that is inclusive of trans people it will be hard to design guidelines and technologies which works well for them.

This thesis points out a variety of different problems that trans people face in healthcare due to medical technologies. One complicating factor in several of these problems is the use of legal gender. While it is easy to only have to input the patient's social security number and then fetch name and gender, among other things, from the population register, this creates problems. It works well for most people, but the legal gender does not necessarily match the gender identity of the patient or say something about the patient's anatomy and physiology. It can also be changed which can result in a patient's recommended values or treatment plans being change from one day to another, even though no changes have occurred in the patient's condition. This shows a fundamental flaw in the use of legal gender in a medical setting, a flaw that will become even bigger if self-determination as a basis for changing legal gender is introduced.

The issues that medical technologies create in healthcare for transgender people includes misgendering, generating incorrect data and measurements, suggestion incorrect treatments and completely barring trans people from entire systems. Electronic health record creates issues in the form of not allowing changes of name, gender and pronouns. There are also issues regarding sensitive information that will out trans patients, the information must be able to be hidden from people who do not need to see it, while at the same time information that may be important for treating a patient must be accessible. Developing a standard way to do this would be beneficial both because it would be clearer for trans people what is hidden and when and also in making sure privacy and access is weighed in a way that both upholds patient safety and the patient's right to privacy. Similarly, the creation of a new patient record with the possibility of linking the new and old one after a change of legal gender, creates issues regarding the availability of information and privacy. Again, a standard solution would be beneficial. Perhaps a solution where the old and the new record are actually merged so that only the new social security number is used, sensitive sections can be hidden and one's old name and pronoun can be automatically changed upon request. Lastly, the current laws regarding change of legal gender turns the health records of trans people into legal documents which are reviewed in a process which concerns the trans persons access to civil rights. This system is something that frustrates several of the interviewees and it poses a patient safety risk. Therefore, it is vital this law and system is changed.

Trans people are in general kept outside of screening programs due to the current systems which relies on legal gender. Some gender assessment teams send referrals to the relevant clinics which then get the responsibility for contacting the patient for screenings. This solution is not a standard for all of Sweden and it leaves trans people who have not received gender affirming care at the specific clinics outside the system. Moreover, refugees and migrants who have received gender affirming care before moving to Sweden would be left outside the system even if it was made a standard solution for the whole of Sweden. If trans people's screenings cannot be handled within the normal systems for screenings and a separate is created where trans people can voluntarily sign up, it is important that this is spread widely. The information cannot be given only through the gender affirming care, as this will miss people.

Both devices measuring the level of urine in the bladder and patient monitoring system use gender in their algorithms. To the user it is often unclear what the gender parameter is used for. In the devices measuring the bladder volume, gender is used to find out if the patient has a uterus or not. Here it would be easy to simply ask directly if the patient has a uterus instead of asking the user to select a binary gender for the patient. This would eliminate the risk if misgendering the patient or performing an incorrect measurement due to selecting the "wrong" gender. The patient monitoring system Philips Intellivue on the other hand use gender in various ways in different algorithms. Here too is it often unclear for the healthcare workers to know what the gender parameter is used for. The ambiguous use of gender in algorithms make it hard for healthcare workers to make individual exceptions on what is best for a specific patient. Exceptions that might be important especially for people who fall outside the norms, such as trans people.

We have seen how AI helped remove the need to input gender in a device measuring bladder volume and efficient use of algorithms could help handle large amounts of data, which in turn could reduce the need for large statistical generalisations. Algorithms thereby have the potential of greatly benefiting trans people through making medicine more personalised and reducing the need for putting people into ambiguous categories such as binary gender. However, this also requires that the algorithms are trained on diverse data sets and that these diverse data sets are available.

Digital care also has the potential of making healthcare more accessible in general, but also specifically for trans people. Digital care could lower the threshold for seeking care and eliminate some awkward meetings with other patients and healthcare workers. Though, for digital care to be inclusive it must be designed in a way that dismantles rather than upholds norms such as gender norms.

These problems and possibilities that have been discussed throughout the thesis will not be fixed or developed on their own. Pressure to fix the problems and to develop new solutions that benefit the healthcare for trans people needs to come from both healthcare and organisations working with trans rights. Some work is being done to be more inclusive in healthcare, but it is often reliant on a few people with a special interest for the issues. The general knowledge about trans issues is low and issues related to medical technologies is even lower, seeing as this is likely the first study of its kind in Sweden. The interviews showed that it is unclear and rarely talked about how binary gender should be handled, in care for trans people, when algorithms or treatments require that it is inputted. Furthermore, when Josefine was asked questions about trans issues she often had to think long, seemed a bit nervous and had a hard time to come up with answers. This further strengthens the conclusion that healthcare workers lack knowledge about trans issues and are not used to talking about it. Josefine herself also pointed out that she does not have access to information about these issues. Therefore, more needs to be done to provide the necessary resources and educate healthcare workers on trans issues.

Even though more knowledge about trans issues is needed among healthcare workers, issues are already being noticed today. It is important that solutions to these problems are found, and pressure needs to be put on whoever is responsible to fix them. One tool that healthcare can use is procurements, where lists of demands can include demands that would eliminate problems or in other ways better the healthcare for trans people. When contracts are written with suppliers these should also include ways for healthcare workers to report problems and that these should be corrected urgently if the problems are severe. Furthermore, healthcare institutions need to carefully consider why gender might be used in certain algorithms or guidelines and ask critical questions about it. Partly to know how it is used so that they can make the best possible decisions for their patient, but also to question the usefulness of using binary gender as a parameter in that given situation.

Recommendations

- **Healthcare needs to rely less on legal gender, as this does not necessarily represent the anatomy, physiology or identity of the patient. There must always be an option to change the patient's gender in a system.**

- **A standardised solution for including trans people in screening programs that removes the responsible from the individual to the healthcare system must be implemented.**

- **Procurements and contracts should be used as a tool to make sure that the technologies that are used in healthcare are inclusive.**

- **Healthcare workers need to be educated on trans issues, especially on how being trans might effect diagnosis and treatment.**

- **Changing legal gender should be an administrative process and separate from healthcare. This is important to uphold patient safety and to rebuild trans people's trust in the healthcare system.**

- **How old and new electronic health records are linked/merged need to be standardised, and what will be visible for who must be clear.**

- **Algorithms and AI need to be trained on diverse datasets and be transparent in their decision making.**

- **The use of gender in technologies and guidelines must be questioned and its purpose clear to the user.**

Chapter 6

Conclusion

This thesis presents a novel study about the effects of medical technologies on healthcare for transgender people in Sweden. It shows that the modern colonial gender system is deeply rooted in medicine and medical technologies. As a consequence, medical technologies create a variety of different problems in healthcare for trans people, ranging from forcing healthcare workers to misgender patients to potential incorrect measurements and completely barring trans people from medical systems. In order to prevent these problems, developers of medical technologies must be critical of the binary gender norms when designing their products. Likewise, the healthcare system must be critical of gender norms and put forward demands regarding the inclusiveness of medical technologies during procurements, as well as asking critical questions about why and how gender is used in systems and devices. Furthermore, standardisation is needed in regard to how trans people's electronic health records are handled in coherent record keeping. Additionally, the use of trans people's health records as evidence in The National Board of Health and Welfare's Legal Advisory Board's ruling in cases of legal gender change needs to be stopped. It is a patient safety risk since healthcare workers refrain from writing certain information in the records, as well as a violation of trans people's civil rights. Lastly, medical technologies also have the possibility of contributing to the goal of providing equal healthcare for trans people. New technologies can help make healthcare more accessible and advanced algorithms and AI have the potential to process large amounts of data, which can make healthcare more personalised and reduce the need for generalisations based on binary gender. This however requires that the algorithms are trained on diverse data sets that represent the group it is supposed to be used on.

In summary, medical technologies are built upon the idea of static and binary gender, which results in a variety of different barriers in healthcare for transgender people. These barriers can be broken down if gender norms are challenged in the design. Medical technologies also create an opportunity for making healthcare more accessible and equal for trans people if new technologies are designed in inclusive ways.

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