



THE SAHLGRENKA ACADEMY

Masters thesis

The infected question of sterile needles **A qualitative study of policy change regarding the** **needle exchange program of Gothenburg, Sweden**

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Master's Thesis in Public Health Science with Health Economics, 30 hec

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Abbreviations

CESCR - International Covenant on Economic, Social and Cultural Rights

HCV – Hepatitis C virus

HIV- Human immunodeficiency virus

PWID -People who inject drugs

UNAIDS – United Nations Programme on HIV/AIDS

UNODC – United Nations office on drugs and crime

WHO – World health organization

Part A.

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INTRODUCTION

The first needle exchange programs in Sweden started up in Lund in 1986 and Malmö in 1987, in the early days of harm reduction. It would take another 27 years before Stockholm's first official needle exchange opened in 2013 and another five years still before Gothenburg followed their example in 2018. How can this delay of over three decades be understood and what were the events leading to this policy change?

Needle exchange

Needle exchange is a low threshold health care service aimed at people who inject drugs (PWID) with the purpose of preventing the transmission of infectious diseases through infected needles. (WHO, 2012) The practise of needle exchange has been implemented around the world since the middle of the 1980s as a respond to the threatening epidemic of Human immunodeficiency virus (HIV). (Bowen 2012) PWID was early identified as an important risk group to target in HIV-prevention, being exposed to both the direct risk through drug injection and indirect through sexual intercourse with drug users. The world health organization has recommended needle exchange to prevent HIV among PWID since 1987. (Stenström 2008)

The principle of needle exchange is to offer sterile needles and syringes in return for used and possible infected equipment. Another purpose is to provide basic health care services for a vulnerable patient group with high morbidity and mortality (WHO 2019). In 2018 25% of the new HIV cases globally was transmitted through injection with unsterile equipment. PWIDs are also disproportionally affected by Hepatitis C, HCV and 67% of all patients with HCV has been infected through drug injection. (Folkhälsomyndigheten, 2017)

The use of needle exchange programs (in combination with other harm reducing activities) is advocated by the WHO, UNAIDS, UNODC (WHO, 2012) as well as the Swedish Public health agency (Folkhälsomyndigheten, 2015) and the National Board on Health and Welfare. (Socialstyrelsen , 2017)

The effectiveness of needle exchange has been the subject of a vast number of studies the last decades. (Fernandes et al, 2017) A few studies has questioned the effectivity of needle exchange when it comes to preventing HCV, mainly due to the high level of contagiousness of the virus and the fact that needle exchange does not guarantee that infected needles are not used as well. (Palmateer et al, 2010) Those studies still recommend needle exchange for prevention of HIV and to increase the overall health in the target group. As of today, there is a strong scientific consensus about the importance of needle exchange to prevent HIV and improve the overall health within the risk group. (UNAIDS, 2016)

Needle exchange in Sweden

In 1988 there was a WHO meeting on HIV-prevention in Stockholm where needle exchange programs were suggested to be a global strategy for HIV-prevention in the risk group PWID. All nations attending agreed on this apart from Sweden. (Stenström, 2008) Sweden is also the only European nation where a suspected drug users are prohibited from purchasing needles and syringes from the pharmacies. (SOU, 2011) The national board of health and welfare has estimated the number of PWIDs in Sweden to approximately 8000 persons, low calculated. (Socialstyrelsen, 2013) The estimation is based on data from the Swedish patient data

register,¹ the Swedish cause of death register² and criminal register³ The majority of known PWIDs in Sweden are living in the three major municipalities; Stockholm, Gothenburg and Malmoe. The first needle exchange programs in Sweden started up in Lund in 1986 and Malmoe in 1987 about the same time as did similar services all over Europe. The needle exchange programs of Malmoe and Lund were run in the form of projects, one year at a time until 2006. Five other municipalities in Sweden adopted to this method of prevention but were considered not to live up to the conditions formulated by the national board of health and welfare and had to close.

In 2002 the Swedish government was investigating whether needle exchange could be considered to be compatible with the national drug politics at all or if it should be banned. A few years later in 2005 needle exchange was suggested to be a part of the national strategy of HIV-prevention (proposition 2005/06:60) and in 2006 a new law was stated on exchange of needles and syringes (2006:323) In short, the law opened up for regions to apply for needle exchanges nationally but the municipalities had a veto in the issue. The region needs to make sure to have drug rehabilitation accessible. Sterile needles and syringes can only be distributed if the same number of used needles and syringes are handed in. The needle exchange is available to PWID over the age of 20 who are currently registered living in the municipality. The needle and syringes from the exchange programmes needed to be clearly marked. (Regeringskansliet , 2006) In 2012 and 2013 (following a big HIV-outbreak in the PWID-community) a couple of municipalities implemented needle exchange, including the capital of Sweden Stockholm. (Folkhälsomyndigheten , 2018)

¹ <https://www.socialstyrelsen.se/register/halsodataregister/patientregistret>

² <https://www.socialstyrelsen.se/register/dodsorsaksregistret>

³ <https://www.bra.se/statistik/kriminalstatistik.html>

Six years after the law of needle exchange (2006:323) only six Swedish municipalities⁴ had implemented needle exchange. In 2017 changes were made to the of the law of needle exchange (2017:17) which among other things removed the municipal veto and opened up for PWID from the age of 18.

In some municipalities the question of needle exchange has hardly been on the political agenda at all because the number of PWIDs has been estimated as very small. In other municipalities needle exchange has been the matter of an agitated ongoing debate for over a decade. Sweden's second largest city Gothenburg is an example of the latter.

Needle exchange in Gothenburg

The municipalities of Sweden have a very high level of political autonomy. Even though the Swedish government decided on the law of change of needles (2006:323) with the purpose of encouraging the regions to start needle exchange programs, the mandate to decide has been that of the municipalities.

In Gothenburg there has been a strong resistance towards needle exchange program from a majority of political parties from left to right. (Göteborg stad KF, 2012) The regional politicians of Västra Götalands regionen, the political organization in charge of health care, has argued in favor of a needle exchange program (Västra Götalandsregionen 2018) but until recently lacked mandate in the question.

⁴ Malmö, Lund, Stockholm, Helsingborg, Kalmar och Jönköping

The possible implementation of needle exchange has been debated in the Gothenburg town council several times the last decade. (Appendix 1.) The Liberals (L) have raised the question referring to arguments of infectious disease control (Göteborgs stad, 2013) and they receive support from the left party (V) and the environment party (Mp) with the arguments of right to health. The two largest political parties, the Social democrats (S) and the Conservatives (M) have been strongly against it with support from the Christian democrats (KD) and Swedish democrats (SD). Their main argument has been that harm reduction is incompatible with Swedish drug politics and that needle exchange is the first step on the slippery slope towards drug liberalization. (Göteborgs stad, 2014)

When the municipal veto was removed through the law change in 2017, Gothenburg was the only one of the three larger cities (>300 000 inhabitants) in Sweden without a needle exchange. In the end of 2018 the first needle exchange opened in Gothenburg after a political decision in the Regional board in 2017 as well as in Gothenburg town council (three weeks after the municipal veto had been removed).

Swedish drug politics, a retrospective

To understand the process surrounding the policy change on needle exchange in Gothenburg it is necessary to gain insight of the last decades of Swedish drug politics. Swedish laws and public health policies concerning drug addiction are quite different compared to the other European nations and can be described along the line of zero tolerance. As of today the overarching goal for the Swedish drug politics is a drug free society. (Regeringskansliet , 2015) Drug addiction which up to the 1960s was regarded as more of a medical and individual issue of relevance for a very small group of the population, in the 1970s transformed into a social and highly political question described in the political debate as a

threat to the entire welfare state (Olsson, 1994). As such the focus has also shifted from harm reduction within the group of drug users and risk groups around, to preventing an epidemic of drug abuse to spread from the drug users to the rest of the population. (Edman, 2013) With this came a change in the view of the drug user from a vulnerable person in need of help or a person with a habit that does not necessary define their whole character to a degenerated parasite to which the law abiding, hardworking citizen could be compared. (Björkman, 2001)

In his research of the Swedish drug political debate climate from 1965-2000 Johan Edman describes this dehumanization of the drug users through the language and also speaks of the phenomenon of “othering”, where the drug users become “culturally strange” an opposite of what is morally desirable in the citizen. (Edman, 2013)

The zero tolerance politics can be seen as a reaction against an earlier movement of social liberalism and progressivity during the 1960s and early 1970s. The failed experiment of legal drug prescription in small group of drug users in Stockholm 1965-1967 is frequently used as an example of naive politics and as proof that harm reduction in total does not work. (Linton, 2015) Strongly influential in this development was the lobby organization *Riksförbundet narkotikafritt samhälle RNS*, (National association for a society free from narcotics) and its founder Nils Bejerot. His thesis *Narkotimissbruk och narkotikapolitik* (Drug abuse and drug politic) from 1974 strongly influenced the Swedish zero tolerance drug politics which came to shape policies and laws the coming four decades. It can simplified be explained in these points:

- Drug addiction is a societal problem that can and should be solved by eliminating the presence of narcotics in the nation all together.
- All narcotics must be regarded as equally harmful. There are no “lighter” drugs only gateway drugs.

- All use is abuse.
- All kinds of involvement with drugs is a criminal act and drug users are criminals per se.
- A political consensus and cooperating mass media, loyal to the problem image is crucial to win the war against drugs. (Edman 2013)
- The overarching goal for the Swedish drug politics is a society free from narcotics. (Regeringskansliet , 2015)

With the shift from normalized and even high status to degenerated and low status, illicit drugs and drug users become the perfect “good enemy” for society to unite in the struggle against. (Bruun, 1985) This also became a problem formulation that came to legislate the solution of higher control and punishment. (Edman, 2013)

The zero tolerance drug policy makes perhaps the strongest imprint in the criminalization of all contact with drugs. Since 1988 being in possession but also under the influence of drugs is punishable by law (Regeringskansliet, 2016). In 1993 the penalty scale increased and thereby made it possible for the police to demand blood or urine samples from suspected drug users of all ages. Rather than being an issue for the health care services, drug abuse has been the responsibility of the social services and the police force. Drug related crimes are the second most common reason for imprisonment in Sweden. (Folkhälsomyndigheten, 2019) The vast majority of drug related arrests during the last couple of years has been people being under the influence of drugs, 50% or being in possession of drugs, 39% (and the drug in question is most commonly cannabis). Smuggling, manufacturing or dealing with drugs, together stands for less than 11% of the drug related arrests. (Folkhälsomyndigheten 2018)

Harm reduction

“Harm reduction refers to policies, programs and practices that aim to minimize negative health, social and legal impacts associated with drug use, drug policies and drug laws. Harm reduction is grounded in justice and human rights.” (Harm reduction international , 2019)

In the Swedish drug political debates harm reduction has been presented as incompatible with the zero tolerance drug politics. This has resulted in a cold or defensive reception of harm reducing initiatives such as the prescription of substitution drugs or needle exchange. It has been regarded as enabling a criminal act or opening up for drug liberalization. (Edman & Eriksson 2016) Until the middle of the 1990s all of the Scandinavian nations had a more demand reductions strategy in drug politics, but the last decade Sweden has been the only exception from a harm reduction approach in all of Europe. An important departure from this path was noticed when the former Swedish minister of health Gabriel Wikström, at the United Nations general assembly special on the world drug problem in 2016, expressed support to the declaration to reduce world drug problems, ensuring that with its focus on public health and human rights, was in line with Swedish drug politics. “We need to ensure that access and treatment. Access to risk- and harm reduction in a broader public health approach.”

(Government offices of Sweden, 2016)

Public health implications

The overall health status of the population of Sweden ranks high in international comparison with an increasing life expectancy (WHO, 2018) and a decreasing overall mortality due to the most common forms of cancer, cardiovascular disease and accidents. (Folkhälsomyndigheten, 2019) Comparing groups within the population however there is a growing disparity in health.

The overall national goal of public health in Sweden is to provide societal prerequisites for a good and equal health for the whole population. (Regeringskansliet , 2017)

Even though the overall health status of the Swedish population is good, the health of some marginalized groups is far worse compared to most European countries. Despite the fact that Sweden has a fairly low number of persons with problematic drug use⁵ in an international comparison, about 30 000 or 3,2/1000 persons, (Folkhälsomyndigheten , 2010) the number of drug related deaths is five times the European average and the second highest in Europe (>900 persons 2018) (Socialstyrelsen, 2019). The mortality in the group PWIDs is over five times higher compared to the population in general. 90% of the drug related deaths are connected to the use of opioids (Socialstyrelsen, 2019) and over one third of those who die are under the age of 30 years. (Folkhälsomyndigheten , 2018)

HIV and HCV

Human immunodeficiency virus (HIV) is a retrovirus that targets the immune system and weakens the defense systems against infections and cancer. If left untreated, HIV causes acquired immunodeficiency syndrome (AIDS) which is a chronic disease. (WHO, 2018) In comparison with other European nations Sweden has a fairly low prevalence of HIV and HCV in the general population but the highest prevalence of HIV and HVC among PWIDs in Scandinavia. (Stone, 2008)

⁵ The Swedish national agency of public health defines persons with problematic drug use as those who have a received a psychiatric diagnosis of drug addiction or has been classified as a heavy drug user by correctional.

The third of the United Nations Sustainable Development Goal⁶ is to *ensure healthy lives and promote well-being for all at all ages* and has the target goal: 3.3 *By 2030, end the epidemics of AIDS, measured by number of newly HIV-infected.* (UN, 2015) Among people who use drugs the number of newly infected has not been declining. (UNAIDS, 2016). PWIDs are a high risk group for blood spread infectious diseases through sharing of needles. “The provision of access to sterile injection equipment for injecting drug users and the encouragement of its use are essential components of HIV/AIDS prevention programs.” (UN, 2015)

Hepatitis C, HCV, is a bloodborne virus that causes an inflammation in the liver and can lead to a chronic liver infection, cirrhosis and liver cancer. The most common way for the virus to spread is through infected needles among PWIDs. The prevalence of HCV among Swedish PWIDs is 82%⁷ (Stone, 2008) The incident cases of HCV during 2017 was 1666 among which 603 new infections were caused by infected needles. This was the lowest number in a decade. The Swedish board of public health links this decrease to the increasing access to needle exchange in combination with increased possibilities of screening and treatment. (Folkhälsomyndigheten, 2017) The World Health Organization has a goal of eliminating HCV in the year 2030 (WHO, 2017) It is also one of the target goals under Sustainable Development Goal number 3. Health. (UN, 2015)

Human rights implications

Sweden has received international critique on repeated occasions for not living up to the treaty of CESCR - International Covenant on Economic, Social and Cultural Rights when it

⁶ Adopted by all nations within UN including Sweden

⁷ To be compared with 52% in Denmark.

comes to the right to health. (UN, 2006) Among other things the lack of preventive and harm reducing policies such as needle exchange programs is underlined. It is noted that Sweden has earlier referred to multilevel system of political organization with autonomic municipalities, but it is suggested that the knowledge about CESCRC has failed to reach the municipal level. (United Nations, 2016)

The public health goals of Sweden has had an increased focus on equity in health with a focus on closing the avoidable health gaps within one generation. (Folkhälsomyndigheten, 2019)

The right to equal, need-based health is statutory (Hälso- och sjukvårdslag (2017:30)

The right to health should not be conditional. (UN, 2000) PWIDs are a stigmatized group in society with a lower trust in authorities. The restrictions of the right to health for PWID relates to the criminalisation and the demonization of the drug user. (UNAIDS, 2016)

Policy change

Ideally a public health policy change is the result of utility and new evidence in combination with cost-effectiveness analysis. This is evidently not the case when it comes to the case of needle exchange where different municipalities within the same nation developed disparate policies based on the same evidence.

In their research on the Swedish needle exchange debate Lena Eriksson and Johan Edman found that evidence often was neglected by policymakers. (Edman & Eriksson, 2016) Going through the political bills regarding needle exchange there are several attempts to support a policy change or a status quo referring to evidence or lack of evidence. (Göteborg Stad, 2014) However the burden of evidence is very unequally divided. With only one exception (Social

resursförvaltning, 2014), it is those who argue for a needle exchange who must provide the evidence. Most of the debate and the conclusions however tend to be value based. This corresponds well to previous research on evidence-based policy change. There is a “knowledge to action gap” between public health research and public health policy making. (Smith, 2013) There is relatively little sign of evidence making much impact on decision making. (Mays, 2015) It thus makes more sense to study the influence of ideas. The over morbidity and over mortality among PWIDs has been regarded as drug politics rather than infectious disease control. Since the problem formulation generates the proposed solution (Bacchi, 2012) the solution in the Swedish context has been regarded as a need for demand reduction rather than harm reduction.

Conclusions

People who inject drugs, PWIDs is one of the main risk groups for blood borne infectious diseases. Needle exchange together with low threshold health care services is recommended by, WHO, UNAIDS, UNODC, the Swedish Public health agency and National Board of Health and Welfare in order to prevent HIV and HCV. Since 2006 all Swedish municipalities has had the possibility to implement needle exchange. Until 2017 there has been a slow response from most municipalities and a strong opposition against needle exchange in some municipalities including Gothenburg. In 2017 the law on needle exchange was changed so that the municipal veto was removed and the Health care regions got the mandate to apply for a needle exchange.

Since the Gothenburg needle exchange program has been open less than half a year there has been no previous research focusing on the Gothenburg program itself but a couple of studies focusing on the needle exchange debate that preceded the program. (Boije, 2011) There is

quite a lot of research done on the earlier needle exchanges in Sweden as well as international studies of the effectiveness of needle exchange when it comes to reaching out to PWIDs and preventing HIV or HCV. I also found studies focusing on the long-spun debate about a possible needle exchange in Gothenburg as well as studies focusing on the moralization of the needle exchange. (Bowen, 2012)

The needle exchange that could have been regarded as a way of preventing infectious diseases and providing a low threshold health care service for a vulnerable patients has mostly been discussed as a drug politic issue. The zero-tolerance consensus has effectively put a lid on the debate and has not been affected by evidence. Even those who have argued for a needle exchange has to start their argumentation by assuring the audience that they are not in any way drug liberal and do not wish to challenge the Swedish drug politics. (Göteborg Stad, 2012, 2013, 2014)

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ABSTRACT

The first needle exchange programs in Sweden started up in Lund in 1986 and Malmoe in 1987.

It would take 27 years before Stockholm's first official needle exchange opened in 2013 and another five years before Gothenburg followed their example in 2018. How can this delay of over three decades be understood and what were the events leading to this policy change?

I have been analyzing political documents concerning the question of needle exchange in Gothenburg as well as interviewing relevant decisionmakers, civil servants and health care staff about the process. I have made a thematic analysis of the data and interpreted the result through the framework of Walts and Gilson's policy analysis triangle.

The findings suggest that the needle exchange of Gothenburg was delayed due to a strong opposition from a majority of the local decision makers, against harm reduction of all kinds. The opposition is based in the idea that harm reduction is incompatible with Swedish drug politics and the vision of a drug free society. The policy change was made possible because a change in the law on needle exchange that removed the municipal veto in the question and shifted the responsibility to the politicians in charge of health care issues. The changing of the law was preceded by a number of changes in the Swedish government in combination with international critique concerning the lack of needle exchanges among other harm reducing efforts. With the example of the Gothenburg needle exchange, this thesis attempts to describe a potentially radical change in the Swedish approach to harm reduction.

Keywords: Needle exchange program, Swedish drug politics, harm reduction, zero tolerance, policy change,

1. INTRODUCTION/BACKGROUND

The first needle exchange programs in Sweden started up in Lund in 1986 and Malmö in 1987. It would take 27 years before Stockholm's first official needle exchange opened in 2013 and another five years before Gothenburg followed their example in 2018. How can this delay of over three decades be understood and what were the events leading to this policy change? This thesis aims to describe the process leading to the policy change surrounding the needle exchange program of Gothenburg.

The use of needle exchange programs (in combination with other harm reducing activities) as a method to prevent the transmission of chronic infectious diseases such as HIV and HCV, is strongly recommended by the WHO, UNAIDS, UNODC (WHO, 2012) as well as the Swedish Public health agency (Folkhälsomyndigheten, 2015) and the national board on health and welfare. (Socialstyrelsen, 2017)

Sweden has the second highest drug related mortality in Europe (Folkhälsomyndigheten, 2018) and has received repeated international critique for not using harm reducing strategies in order to prevent drug related morbidity and mortality. The lack of needle exchange programs has been highlighted. (United Nations, 2016)

A needle exchange is where people who inject drugs (PWID) can change their old needles for new ones. Apart from preventing the spread of blood borne diseases such as human immunodeficiency virus, HIV and Hepatitis C, HCV needle exchanges also serve as a low threshold health care service for a vulnerable group of patients. (WHO, 2019) The needle exchange of Lund and Malmö started during the eighties as did many of the needle exchanges all around Europe in an effort to prevent a rapid spread of HIV. A majority of

Swedish municipalities decided not to introduce needle exchange since harm reducing strategies was considered to clash with the national overarching goal for the drug politics of a drug free society. (Edman & Eriksson, 2016)

In Gothenburg needle exchange did not become a reality until 2018 and the process was preceded by a long and infected conflict of ideologies between both politicians and civil servants on the municipal- regional- and national level.

2. AIM

The aim of this paper is to study the policy change concerning the needle exchange program of Gothenburg, Sweden.

2.1 Research questions:

- What were the main reasons for the delay of the needle exchange program in Gothenburg?
- What were the most important factors leading to the policy change?

3. MATERIAL AND METHODS

I have done a qualitative study where I have read through the political documents related to the needle exchange of Gothenburg and complemented with an interview study. I have made nine semi-structured interviews with expert interviewees (Bogner, 2018) who are all connected to the policy change in different ways. I found the interviewees through the political documents and through previous research. The interviewees were politicians as well as civil servants and health care professionals on a local-, regional- and national level.

I made an interview guide with open questions about

- the interviewees relationship to the needle exchange process in Gothenburg
- their general view of the needle exchange process
- their thoughts on the delay of the needle exchange process and
- their view on the relation between needle exchange and Swedish drug politics in general. (Appendix 3)

In most of the interviews I only asked the first question and the interviewees gave me their view on the follow up questions by themselves. The interviews lasted between 35-65 minutes and were recorded and transcribed.⁸

I chose an interview study since I wanted to be able to describe the policy change concerning the needle exchange and the the process prior to it as transparent as possible and the published documents only provided me with the official version of the events rather than how different factors interacted. The interviews helped me fill in the gaps that the official documents leave as well as underlining which events led to the policy change.

3.1 Thematic analysis

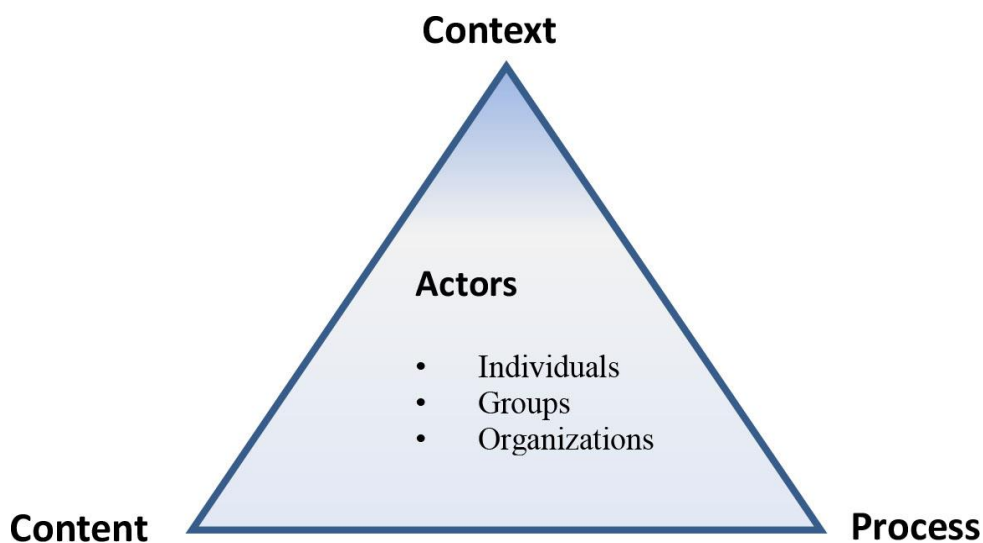
I made an inductive thematic analysis (Fejes, 2015) from my data, both documents and interviews. I condensed the data, coded it and structured the codes into themes. I modelled the themes and codes into a basic theme analysis chart (Appendix 2) supplemented with a timeline (Appendix 3) to illustrate events of important to the process.

⁸ Including pauses, laughter, intonation and gestures.

The codes were chosen either based on frequency⁹ or based on the interviewees stresses a factor or an event as particularly important to the policy changes.

3.2 Theoretical framework

I interpreted the result deductively through the framework of Walt's and Gilson's policy analysis triangle (below).



This model theorizes how the *content* only is one part of a policy and that it should be observed related to the *process* of creating the policy, the *actors* who make or influence the policy and the *context* in which these actors and processes interact.

The actors is seldom only the actual decisionmakers but all who have been involved in or influenced the process in anyway. This multidimensional tool of policy analysis is developed for health care policy's characterized by conflicts rather than consensus. (Walt & Gilson, 1994)

⁹ The number of times the code appear in the data.

I believe the framework of Walt and Gilson is suitable for policy change regarding the needle exchange in Gothenburg since I know the content of the policy to be very similar to that of Stockholm or Malmoe for instance but the process to be completely different. What can be said about the context or the actors?

4. Ethical considerations

The interviewees, who are all on an elite/ expert level (Bogner, 2018), have been informed that the participation in the interviews is completely voluntary and that they can cancel or discontinue the interview at any time without having to motivate it in any way.

The interviewees are anonymous and all material from the interviews (sound files and transcribed documents) are kept inaccessible from unauthorized listeners/readers.

I chose not to include quotes that might identify the interviewee or quotes that stated information that I could not confirm.

5 RESULTS

The nine interviews together with the political documents related to needle exchange in Gothenburg, resulted in three major themes based on 15 codes (Appendix 2.):

- Theme 1 – Drug Politics
- Theme 2 – Infectious disease control and
- Theme 3 – Human rights

5.1 Theme 1 Drug politics

Codes: Zero tolerance, Criminalisation, Harm reduction, Debate climate

The first theme, drug politics, reoccurs in all interviews and documents. It relates to Swedish drug politics as a ground for the opposition in Gothenburg and explaining the delay (research question one). It is also brought up in comparison with international drug politics affecting the Swedish debate and contributing to some of the factors leading to the policy change (research question two). As an example, interviewee 6 describes her own reflections when representing the Swedish zero tolerance drug politics in international assemblies:

5.1.1 Zero tolerance

“Why are we so lonely and why is it only nations lacking in democracy that shares our side?

It becomes an eye-opener” (Interviewee 6. 190416 p.21 Code: Zero tolerance)

5.1.2 Criminalisation

Five of the interviewees problematized the repressive drug politics and the criminalisation of drug use. They questioned the idea that PWID would be discouraged to use drugs because of high punishments or the lack of sterile needles.

“This is a really weird politic. I think the idea is not to enable drug use in any way. I think that is the main idea. But I mean, how successful has Swedish drug politics been really?”

(Interviewee 1. 190311. p. 6, code: Swedish drug politics)

“Today it sounds just like the criminalisation is invented by God. There is no other thinkable option. But it was preceded by one hell of a debate, particularly within the Social democrat

party. And we who were critical, ... all our fears has actually been fulfilled” (Interviewee 3 190325 p.30 code: Criminalisation)

5.1.3 Harm reduction

Harm reduction was mainly discussed and problematized by the interviewees who were against the needle exchange program, as a first step on a slippery slope towards capitulation regarding the drug free society vision.

“In Gothenburg at this time we were confident that we should not work with harm reduction. It is a bit like giving in to the drugs, as a society.” (Interviewee 4. 190327 p.9. code: Harm reduction)

“Take Oslo for instance, they were early with implementation of needle exchange, then came the rooms for injection and then they realized it was not enough because we don’t know what they are injecting and now they are discussing providing heroine! And then what?”

(Interviewee 5. 190409 p.8. code: slippery slope)

5.1.4 Debate climate

The interviewees who have been involved in the political debate surrounding the needle exchange all describe the debate climate as emotional and in some cases even aggressive.

“When I had presented my proposition to the government, there was a flood of these terrible e-mails telling me what a drug liberal I was.” (Interviewee 3. 190325, p.6 Code: debate climate)

5.2 Theme 2 - Infectious disease control

Codes: HIV & HCV Medical vs Social issue, Evidence, Low threshold

Theme two, infectious disease control was also discussed in all interviews. First as the origin need of needle exchange. Then the fact that needle exchange has been treated as a drug-/social political issue instead as a Health care- /Public health-/ infectious disease control issue.

5.2.1 HIV and HCV

Several interviewees pointed out the fact that different HIV-outbreaks in the risk group PWIDs has come to affect local politics¹⁰ and the fact that Gothenburg has avoided such outbreaks is just a matter of chance since we know that a majority of the PWIDs have been infected with HCV which has the same infection path. Four of the interviewees discussed the shifted focus regarding the need for needle exchange, from HIV-prevention to HCV screening. One of the interviewees brought up the difference in HIV-prevalence as an argument against needle exchange:

“We didn’t have that type, heroin addicts, who are the major risk group for infectious diseases. We had very little of HCV and HIV among our drug addicts.” (Interviewee 4. p.2

Code: Infectious diseases)

Another interviewee pointed out that since there has never been a needle exchange in Gothenburg there has neither been the prerequisites to make a estimation of the number of PWID nor the prevalence of HCV or HIV within the risk group.

¹⁰ Stockholm in 2006 and Kalmar in 2012 being two examples.

“The opponents have argued that HIV is not spread in this group.” ... “But if you don’t meet this group and test them. How can you make such a statement? It might be a very unpleasant surprise now when the testing starts, but it is so important that it is done!” (Interviewee 8. p.2 Code: Infectious diseases)

5.2.2 Medical vs Social issue

A majority of the interviewees discussed the fact that needle exchange has been discussed as a social question and not a medical one. Those who have been working for the needle exchange describes this as one of the main reasons for the delay of the needle exchange though it has resulted in the wrong political level deciding in the matter. Those who have been against a needle exchange expresses worry that the recent shift from a social to a medical issue might lead to a dismantling of the preventive efforts surrounding PWID. One of the interviewees suggested that those in charge of health care only see the infectious disease control of it and cares about the public health in general while the health of PWID is less interesting.

“In the late 1980s there was a debate between two sides of professionals.” ... “One was social services and the other one the medical profession. And it ended with the social service-side winning, so to speak.” (s.5 Interviewee 6 190416 Code: Medical vs social issue)

“The question is always: Will it increase the drug use? Perhaps it will but if they don’t get infected or spread Hepatitis, maybe it is worth it? Of course no research shows that needle exchange increases the drug use but there has never even been a proper discussion about it. It is such a low level of the debate!” (s.5 Interviewee 2 190320 Code: HCV)

5.2.3 Evidence

The evidence of the effectiveness of needle exchange is mentioned in most of the interviews as well as in the Gothenburg town council debates. The burden of evidence is with one exception¹¹ (Social resurs förvaltning, 2014) on those who propose needle exchange while the ones who wants to keep status quo can simply question the evidence without a proposal of their own as to how HIV and HCV shall be prevented in the risk group PWID. (Göteborg stad, 2014) The counterargument is that the risk group should be offered drug rehabilitation, but it is never discussed how to prevent infectious disease among those who are unable or unwilling to quit.

“Some local politicians in Gothenburg argued that there was no evidence for the effectiveness of needle exchange. I remember that was their argument and I believe they were pretty alone claiming that.” (Interviewee 6. 190416 p.4 Code: Evidence)

5.3.4 Low threshold

A majority of the interviewees mentioned the low threshold-part of the needle exchange programs as an accessible health care service with testing, screening, vaccinating and the distribution of contraceptives. Three of the interviewees brought up the new possibilities connected to needle exchange programs in terms of research, screening, naloxone distribution and treatment of HCV. The politicians and civil servants arguing against needle exchange refers to Gothenburg’s own model with investments in early prevention and drug rehabilitation units as an alternative low threshold service.

¹¹ An expert opinion from a Gothenburg city civil servant in Alcohol- and drugrelated issues.

“There was a big difference between Stockholm, Gothenburg and Malmoe, because despite the cutbacks on basically everything our politicians decided to develop our (drug prevention and rehabilitation) activities.” (Interviewee 5. 190409 p.4 Code: Priorities)

5.3 Theme 3 Human rights

Codes: Human value, Perspective on PWID, International critique

Human rights and human value is used as an argument from both sides. From those who argue for a needle exchange it is discussed related to the right to health and an equal and need-based health care. Those who argue against express that that needle exchange as well as harm reduction of all kinds is a way of giving up the believe in human power to change. Four of the interviewees brings up the international critic as an example of how Sweden fail live up to the convention on human rights (United Nations International covenant on economic, social and cultural rights, CESCR, 2016)

5.3.1 Human value

“Really, what kind of signal do we send when we say to these people who are the most vulnerable in their misuse: Go ahead killing yourself but use a clean needle, all right?” Gothenburg town council politician (S) 140508 (Göteborg stad KF, 2014)

“Perhaps statistics will show that the number of drug users have increased due to the fact that an increased share are surviving. Is that a bad thing?” (Interviewee 9 190507, s.3 Code: Hidden statistics, Human value)

I found three different perspectives on the human value and dignity of PWID in the data:

1. PWID have a human value and dignity unconditional of their use

“For the left party (V) human value is absolute and every human has the right to be treated based on their needs. That is society’s responsibility when it comes to health care, which this is a matter of by the way, to improve every human’s chances in life, no matter what the circumstances are – misuse or not!” Gothenburg town council politician (V) 140508 (Göteborg stad KF, 2014)

2. PWID have a human value and could have their dignity back with the help of drug rehabilitation

“We must always have respect for the target group the drug addicts, who actually needs health care and rehabilitation – but we do not believe that the way to a dignified and drug free life can be achieved by distributing needles. Gothenburg town council politician (KD) 140508 (Göteborg stad KF, 2014)

3. Their drug use stands in the way of their human value

“In this debate they are practically saying that these people have themselves to blame! They are not worth struggling for. If they don’t want to quit their misuse so let them kill themselves! I thought, this is not real! How can you take that stand in 2013?” (Interviewee 9. 190507 p.7. code: Human value / indifference)

“She had never seen how judgemental a society can be! And she had certainly not expected that from Sweden!” ...” being so humanistic in so many other matters but when it comes to THIS group!”¹²(Interviewee 7. 190416, p.6 Code: Human value / Perspective on PWID)

5.3.2 Perspective on PWID

Both sides discuss the very low social status of PWID and refers to the over mortality of the group and the fact that it is so seldom mentioned in political debates or in the media.

“We have a drug related mortality in Sweden that use to be around 250-300 persons per year but now it is over 900, a tripling! I use to say, what if we saw this development in traffic accidents? It would have been an outcry in the media. No all you see is some small news item occasionally.” (Interviewee 5. 190409 p.7 Code: Over mortality / Perspective on PWID.)

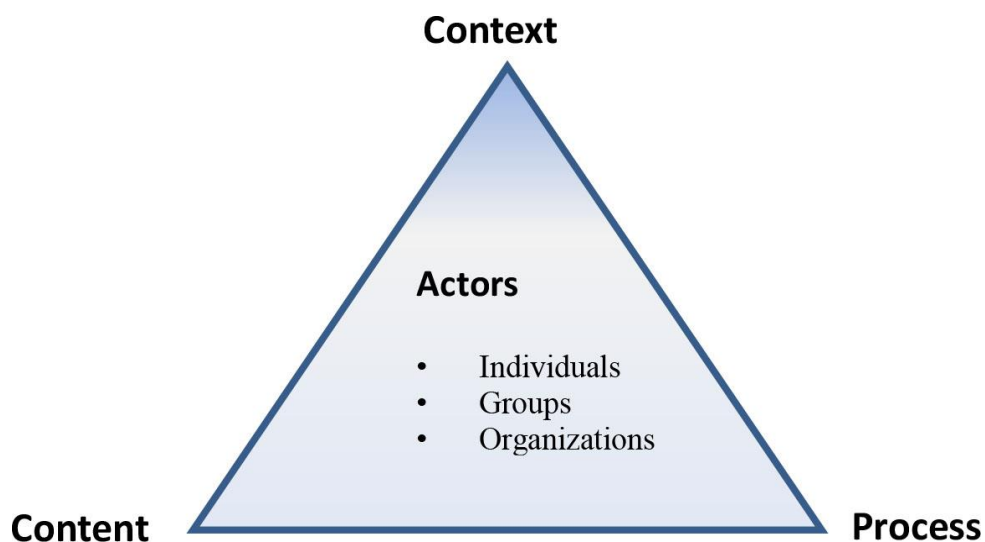
“The mortality in this risk group is 2-3% per year and if that would have been another group of patients I believe we would have seen big headlines!” ...” It is a young population as well with an over mortality if you compare to the population in general. Eight times higher for the group that injects amphetamine. But no one cares about that. (Interviewee 2. 190320 p.5. Code: Perspective on PWID / over mortality)

¹² The interviewee is referring to a foreign researcher studying needle exchange, on her first encounter with Swedish drug politics.

6. DISCUSSION

6.1 Policy analysis

Observing the results through Walt's and Gilson's Policy change triangle.



6.1.1 Content

The content of the policy is very much the same as the one formulated in Malmoe over thirty years ago: Needle exchange as a way of preventing infectious diseases and avoidable costs for society, as well as a low threshold health care service for a vulnerable patient group with high levels of morbidity and mortality.

The difference is that the law change of 2017 (Socialstyrelsen , 2017) made it possible for PWIDs from the age of 18 to visit the needle exchange. Also the national medical guidelines on Naloxon as well as the latest years development of Hepatitis treatment (Agency of dental care and drug benefits, 2017) has brought an extra value to the needle exchange.

6.1.2 Context

Most interviewees describe a noticeable change in the debate climate surrounding harm reduction since about five years back in time. As possible sources of this change of context the interviewees mentioned the fact that the other Nordic countries has taken harm reduction action leaving Sweden the only European country and only democracy maintaining zero tolerance.

One of the interviewees underlines the importance of the agency of infectious disease control incorporated in the national agency of public health in 2014, thus increasing the focus on infectious disease control.

6.1.3 Process

The law change 2017 that removed the municipal veto and made the policy change possible was preceded by several small changes that together made the process.

One of the interviewees describe the first law of needle exchange from 2006 as deliberately cautious to open up for harm reduction rather than prolonging the process or causing a backlash. The suggested ban on needle exchange was so recent and that to suggest needle exchange all over the nation without the municipalities' approval would be to radical.

Then there was the opening of needle exchanges in other municipalities, where the development of the needle exchange in Stockholm can partly be understood as a late reaction to an outbreak of HIV within the injecting drug users in 2005 and 2006.

Two interviewees brings up the governmental investigation of misuse (SOU, 2011) where harm reduction efforts are advocated. The fact that the vast amount of suggestions in the

report was neglected by the government resulted in a renewed interest from both media, medical profession and decisionmakers responsible of health care.

Västra Götalandsregionen has proposed a needle change program in Gothenburg on several occasions the last decade and even though Gothenburg city has rejected the proposition it has generated a debate which has caught the interest of both the media and the political parties on a national level.

In 2015 the Public health agency with their new influence from infectious disease control, released a guidance on needle exchange.¹³ (Folkhälsomyndigheten, 2015)

6.1.4 Actors

Eight of the interviewees stressed the municipal veto together with the strong opposition as the two greatest hinders for a needle exchange in Gothenburg.

Four of the interviewees brought up the fact that the mandate has been on the wrong level and the debate focused on drug politics rather than health care politics. This can also be seen expressed in the protocols of the Gothenburg city board:

“It is not possible to divide this between a health care issue and an ideological statement.

It is not possible! If it would have been that simple, then why would the town council have the mandate to decide in the matter?” Gothenburg town council politician (S) 140508 (Göteborg stad KF, 2014)

¹³ Which led to a debate in the national media between a local politician at Gothenburg town council and the national epidemiologist .

There was a real change among the actors since the municipal veto was taken away and the political mandate over the policy was shifted from municipal to regional level. The same year there is a shift in within the municipal government.

“The threat of the veto being removed” ... ” AND the fact that there was a change in the governing layer and the new governance did not have the same prestige in the matter. From one day to another they simply changed their mind.” (Interviewee 9, s.2 Code: Hidden statistics, Human value)

Eight of the interviewees stress the importance of the former minister of public health Gabriel Wikström as a new actor and his statements that harm reduction is compatible with the Swedish public health goal. The interviewees who were for a needle exchange describe him as courageous and progressive whereas those who have been against needle exchange describe him as ignorant or naive.

Four of the interviewees talked about the influence of non-governmental organisations, NGOs and their influence on drug politics in general as well as specific politicians. Most frequently mentioned was RNS (National association for a society free from narcotics).

” The RNS were the ones behind the criminalisation” ... they are almost a militant organization in that way and they were very much against harm reduction. “)
Interviewee 4 190403, p.3 Code: NGOs)

“The RNS are not so active any more and that is because we have finally made it a question of infectious disease control.” (Interviewee 3. 190325, code: NGOs / infectious disease control)

6.2 Methodological considerations and limitations

I have only had the possibility to interview nine persons, due to the time consuming transcribing and analyzing of the interviews but also due to the fact that one group of thought interviewees, local politicians, proved to be very hard to get in contact with. I have chosen interviewees representing both politicians and civil servants and from all three levels of political decision making in Sweden (municipal-, regional- and national level.) I have made sure to interview both those who have argued for and those who have argued against a needle exchange program taking place in Gothenburg. However, I cannot be entirely sure why the interviewees agreed to be interviewed (or not). Generally, those who have been working for a realization of the needle exchange program have been easier to get a hold on and been more willing to be interviewed.

6.2.1 Loss

I contacted 28 possible interviewees and nine agreed to be interviewed. Two declined and 17 did not answer despite reminders. Of those who did not answer 15 were local Gothenburg city politicians and two were Gothenburg city civil servant in managing positions.

The results is not a claim to be the whole picture of the policy change regarding the needle exchange of Gothenburg but merely my interpretation of the process based on the interviews together with the political documents and previous research. The selection and interpretation of statements from both interviews and political documents are my own and so is all possible mistranslations from Swedish to English.

6.2.2 Biases

My own background from working in psychiatry (dependent care) and HIV-prevention has most likely shaped my preunderstanding regarding needle exchange program.

7. CONCLUSIONS

The main reason that it took over a decade from the law of needle exchange in 2006 to the implementation of a needle exchange in Gothenburg has been resistance of a majority of the local politicians together with the municipal veto. Needle exchange has been debated as a question concerning drug politics rather than infectious disease control or access to health care. The consensus and the arguments against the needle exchange correspond well with the Swedish positioning when it comes to drug politics the last four decades, of demand reduction rather than harm reduction. Zero tolerance and the vision of a drug free society has been the consensus blocking out most debate in the matter. Researchers, health care professionals and the public opinion has been absent and even more so the view of the target group of PWID. The public health goals of equity in health and the Health care goals of a need-based health care has had to stand back which might very well have resulted in avoidable morbidity and mortality within the target group, and avoidable and vast costs on the health care budget for decades past and decades to come.

The last years development of needle exchange in Sweden opens up for more precise approximations of the target group PWID which will make it possible to estimate their morbidity and needs of health care related to changes in society such as economic crises.

For further research I would like to follow the long-time effects of this policy change on the access to health and overall health of the target group PWID in the Gothenburg region. I would especially like to follow the development of Hepatitis C treatment and access to Naloxon for preventing overdoses. I would also like to have the target groups perspective on this change.

I believe this policy change will have a big impact on the health of the target group and I also see it as a step closer to compliance the right to health. My hope is that this policy change symbolizes a paradigm shift towards a bigger influence of evidence and human rights in public health policy making.

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In loving memory of my father, Carl-Gustaf Sundin 1947-2018

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1. Schedule of arguments in the Gothenburg needle exchange debate

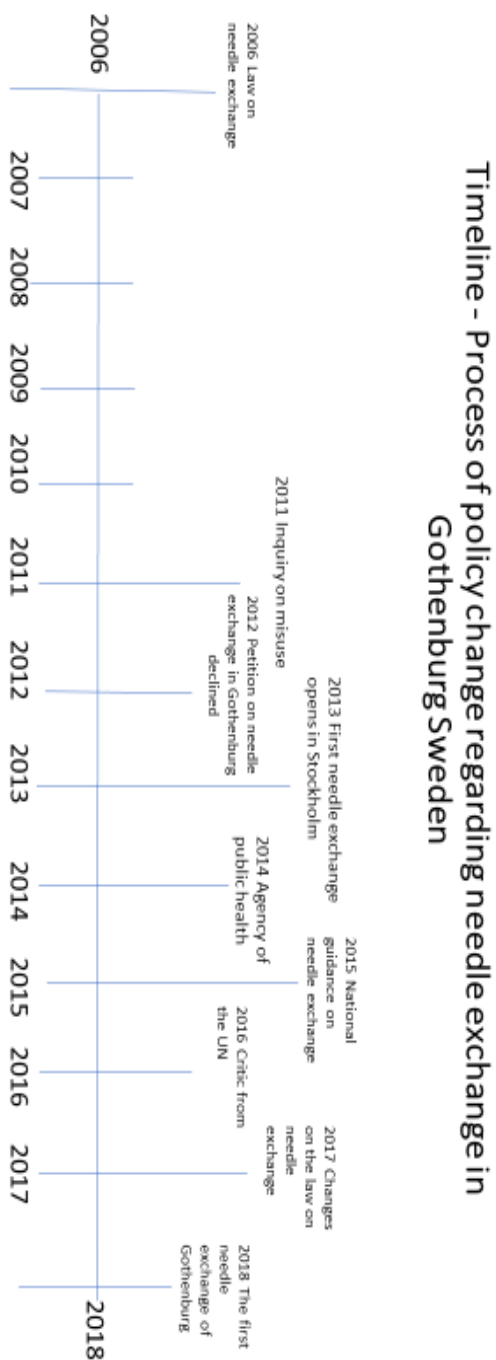
<u>Arguments for</u>	<u>Shared arguments</u>	<u>Arguments against</u>
Infectious disease control		The vision of a drug free society
Access to low threshold health care	Concern about the target group	Fear of an increase in drug use and overdoses
Harm reduction		Fear of slippery slope towards drug liberalisation
The unconditional right to health	The human rights of PWID	Harm reduction signals giving up on PWID ability to become drug free
	PWID have a very low priority	
Over mortality as a reason for increased harm reduction	Over mortality in the target group	Over mortality as a signal of the importance to strive towards a drug free society

2. Schedule of themes and codes

<u>Theme</u>	<u>Codes</u>
Drug politics	Zero tolerance Criminalisation Harm reduction Debate climate NGOs
Infectious disease control	HIV & HCV Medical vs social issue Low threshold
Human rights	Right to health Human value Perspective on PWID International critic

Timeline - process of policy change regarding the needle exchange in Gothenburg

The timeline merely illustrates when the events occurred. The events are independent and not causal.



1. Could you please tell me a bit about yourself and the relation you have to the needle exchange of Gothenburg. *(Kan du berätta närmare om vem du är och vilket förhållande du har till sprutbytesprogrammet i Göteborg?)*
2. What do you believe is the main reason that the needle exchange has been realized only just the other year when the opportunity has been there since 2006? *Vad tror du är främsta orsaken till att Göteborgs sprutbytesprogram kunnat verkställas först nu trots att möjligheten funnits sedan 2006?*
3. What do you believe are the main opportunities/ challenges with the needle exchange? *Vad ser du för vinster/ utmaningar med sprututbytesprogrammet?*
4. What is your view on needle exchange related to Swedish drug politics in general? *Hur ser du på sprutbytet relaterat till svensk narkotikapolitik i stort?*

Information letter to interviewees

Interview study regarding the needle exchange of Gothenburg

Thank you for taking the time for an interview concerning the needle exchange program of Gothenburg! My name is Charlotta Sundin- Andersson and I am a master student of Public health with health economy at the university of Gothenburg. The aim of the interview study is to describe the process prior to the needle exchange of Gothenburg and it is part of my Master's thesis. The interview will take approximately 45 minutes. With your consent, the interview will be recorded to facilitate transcription and to secure the validity. No unauthorized person will have access to the interview material as a whole. You will be anonymous. Participating in the study is voluntary and you have the option to, at any time and without motivation, terminate your participation.

If you have any questions about the study, please contact me on:

E-mail: gusschar@student.gu.se Cellphone: 0768-430648

Intervjustudie gällande sprututbytesprogrammet i Göteborg

Tack för att du tar dig tid för en intervju angående sprututbytesprogrammet i Göteborg!

Jag som genomför den här intervjustudien heter Charlotta Sundin-Andersson och jag läser en master i Folkhälsa och hälsoekonomi vid Göteborgs universitet. Studien syftar till att beskriva processen som föregick sprutbytesprogrammet i Göteborg och är en del av min masteruppsats.

Intervjun tar uppskattningsvis 45 minuter. Med ditt samtycke kommer intervjun att spelas in för att underlätta transkribering och för att säkra validiteten. Ingen obehörig kommer att ha tillgång till intervjumaterialet i sin helhet. Du som deltar är anonym. Deltagandet i studien är frivillig och du kan när som helst avbryta din medverkan utan motivering. Om du önskar ytterligare information om studien så är du välkommen att kontakta mig på;

E-post: gusschar@student.gu.se Tel: 0768-430648