

Lost in Space?

A Case Study of the HIV Epidemic in Neo-Patrimonial Russia

Julie Helseth Udal



Master's Thesis

The Department of Literature, Area Studies and European Languages
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Abstract

Over the last two decades, the number of people living with HIV in Russia has increased dramatically. While other parts of the world severely affected by HIV have been able to significantly reduce transmission rates over the last 10–15 years, primarily through effective prevention programs, Russian authorities have been unwilling to introduce such measures. As a result, the number of people testing positive for HIV in the country has now surpassed 1.2 million, and according to WHO criteria, Russia is facing a generalized HIV epidemic.

The current epidemic did not appear unannounced. Over the last 20 years, medical researchers and the global health community have emphasized the severity of the situation in Russia. However, rather than building a viable domestic response to the challenge posed by HIV, the Russian regime has instead channeled its investments in HIV/AIDS programs toward global cooperation. This policy was pursued both during Putin's two first presidential terms (2000–2004 and 2004–2008), and during Medvedev's presidency (2008–2012). Putin's re-election in 2012, however, marked a distinct shift in focus, priorities and rhetoric. While Medvedev had argued for institutional changes in order to modernize Russia and aimed at presenting Russia as a partner of the global community, Putin's return was accompanied by major cuts in Russian donations to global HIV/AIDS aid, notable efforts to limit foreign interference in Russia, an increased use of anti-Western and pro-civilizational rhetoric, and, an overall stabilization of neo-patrimonialism.

This thesis argues that Putin's shift toward cultural conservatism in 2012 has affected the regime's ability to reduce the spread of HIV in Russia negatively. The collected evidence supports that three developments in particular have contributed to this. The first is the introduction of legislation aiming to reduce foreign involvement in Russia, which has crippled civil society as main provider of prevention programs and services to key populations, and forced global agencies working on HIV/AIDS to leave the country. Secondly, Putin's post 2012 cultural conception of the state has limited agency to anyone interested in pushing Russia out of the neo-patrimonial space. As neo-patrimonialism provides highly unfavorable conditions for successful implementation of reforms, which are likely needed to curb the epidemic, its stabilization has arguably assisted inaction. Lastly, Putin's shift was accompanied by a value-based conservative rhetoric which has entailed increased access to state structures, policy crafting and governmental funding for actors opposing conventional HIV prevention.

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ABBREVIATIONS & EXPLANATIONS

AIDS – Acquired Immune Deficiency Syndrome

ART – Antiretroviral Therapy

BRIC – Brazil, Russia, India and China

FZ – Federal Law

HIV – Human Immunodeficiency Virus

Miniust – The Russian Ministry of Justice

Minzdrav – The Russian Ministry of Health

NGO – Non Governmental Organization

OST – Opioid Substitution Therapy

PC – The Public Chamber

ROC – the Russian-Orthodox Church

Roskomnadzor – The Russian Federal Service for Supervision of Communications, Information Technology and Mass Media

Rospotrebnadzor – The Russian Federal Service for Surveillance on Consumer Rights Protection and Human Wellbeing

STD – Sexually Transmitted Disease

TB - Tuberculosis

UNAIDS – The Joint United Nations Programme on HIV/AIDS

WHO – World Health Organization

1 Introduction

After Vladimir Putin was first elected president 18 years ago, Russia has moved in an increasingly authoritarian direction. During this period, a series of reforms and programs to modernize Russia has been introduced, to varying degrees of success (Ledeneva, 2013). One of the sectors in which little success has been achieved, is health care. Although the political leadership has declared improvement of the health care system a priority and tried to introduce reforms, the outcomes have been very modest compared with the stated objectives (Shishkin, 2013, p. 2). Resulting from this situation are Russian morbidity and mortality rates well above those in countries with similar degrees of socioeconomic development, and the world's fastest growing HIV epidemic (UNAIDS, 2016).

Successful implementation of policy reforms in Russia is indeed a complicated process, largely due to the country's neo-patrimonial system of governance, where a highly personalist regime exists alongside with impersonal state structures (Robinson, 2017). Regime members maneuver the system with the aim of securing power and resources for themselves, and often lack incentives to make institutional changes (Ledeneva, 2013; Gel'man, 2016). Thus, reforms frequently get tangled up in a web of competing interests, before ending up as distorted and decomposed versions of what they once were intended to be. In the specific context of HIV, a factor further complicating effective implementation of reforms and policies able to curb the ongoing epidemic is the fact that the infection is broadly understood as a problem of morality (Zigon, 2009; Pape, 2014).

However, a changing political environment also seems to have impacted Russia's ability to respond to the epidemic. While Medvedev during his presidency (2008–2012) argued for institutional changes in order to modernize Russia, and aimed at presenting the country as a partner of the global community, Putin's re-election in 2012 was marked by a distinct conservative shift (Hale, 2015; Robinson, 2017). An increasing use of anti-Western rhetoric to limit the influence and impact of Western values on Russian society has followed, and both conventional HIV prevention initiatives and Russian transmission rates are, for instance, frequently dismissed on basis of being "Western propaganda" (Shevtsova, 2015; Colborne, 2016). The regime's more hostile attitude toward foreign interference has also resulted in decreased cooperation between Russian civil society and the global community, and Russian NGOs have been forced to close, downscale or reorganize, while international agencies have been pushed out of the country. Because civil society has been the main provider of HIV

prevention and support to HIV-positive in Russia (particularly to those belonging to key populations), the regime's crackdown on NGOs is very unfortunate (Pape, 2014).

A reformation of the Russian response to HIV is essential in order to curb the epidemic. However, a liberalization of policy is likely to disturb the current regime's relationship with powerful conservative institutions such as the Russian-Orthodox Church (ROC), which it relies on to preserve its political legitimacy and domination. Thus far, it appears to be a higher political priority to maintain this conservative support base, than to ensure that programs that are able to reduce the spread of HIV in Russia are being adequately implemented. In this regard, a fundamental question is whether this priority is in fact serving Russian interests. Actors such as the ROC clearly support the regime's battle against Western influence and backs up Russia's quest for historical greatness, but if the current response to HIV is upheld, it is very likely that Russia's ability for economic and demographic growth in the near future will be impacted.

1.1 Thesis aim and research questions

Against the background of the above, this thesis sets out to examine how Russian health care policy is shaped by the diverging forces of modernization and neo-patrimonialism, and possible consequences of this dynamic for the prevention and spread of HIV in Russia. In this thesis, neo-patrimonialism is understood as a system occupying the space between four other distinct forms of rule, that is, developmental authoritarianism, developmental democracy patrimonialism, and patrimonial capitalism (Robinson, 2017, pp. 352–353). Within this space, dynamic movement will naturally occur as the system tries to deal with pressures for change. This happened during Medvedev's presidency (2008–2012), as his modernization plans entailed a push toward the developed democracy. However, he never succeeded in moving Russia out of the neo-patrimonial space altogether, mainly because Putin, who still held the informal powers, did not support his move (Robinson, 2017, pp. 357–358). In 2012, it became clear that Putin's return to presidency was accompanied by a distinct shift in priorities (Hale, 2015; Robinson, 2017). Modernization was abandoned, and replaced with cultural conservatism and the idea that Russia protects a unique civilization. This cultural conception of the state efficiently limits agency to any group interested in pushing Russia toward any of the other four forms of rule, and for now, Russia remains stuck in the neo-patrimonial space.

The underlying assumption is that Putin's cultural conservative shift in 2012 has hampered the

development of a sustainable health care policy in Russia. In this perspective, this thesis is a study of the relationship between the modernized and the conservative Russia. On basis of its current relevance and assumed potential to illustrate relevant features in this dynamic, Russia's HIV epidemic was chosen as the primary unit of analysis. As this thesis interprets political changes affecting the spread of HIV to be especially distinct between Medvedev's presidency (2008–2012) and Putin's third presidential term (2012–2018), the main focus in this study will be on these two presidencies.

I aim to shed light on the thesis statement through answering the following three research questions:

1. How, and to what extent, does the Russian government use anti-Western rhetoric to cover up problems related to the HIV epidemic in Russia?
2. Which parts of Russia's current NGO legislation are especially limiting for organizations working on health-related topics, hereunder in particular HIV and AIDS? How is this likely affecting the response to HIV in Russia?
3. To what degree does the Russian population seem to be updated on HIV issues and the epidemic that is currently unfolding in Russia?

This thesis is empirically relevant because it provides new research and empirical data on a contemporary issue that has significant consequences both at an individual and at a country-wide level. Whereas both epidemiological research on HIV in Russia and research on Russian regime dynamics are relatively sizeable, less attention has been paid to the correspondence between neo-patrimonialism and the development of health care policies. This thesis will hopefully contribute to a broader understanding of this dynamic, and elucidate in what ways a polity stuck in the neo-patrimonial space can influence the public health of its citizens. In this regard, the study's findings may also be relevant when applied to other states with a power structure of a similar kind. This thesis is also theoretically relevant, as it connects empirical findings with existing theory in an effort to contextualize and explain the data collected. Two new models illustrating the consequences of modernization (Medvedev, 2008–2012), and cultural conservatism (Putin, 2008–2012) on the development of HIV policies, will also be presented.

1.2 Thesis outline

The first chapter provided an overview of the aim of this thesis, and presented the study's research questions. In addition, the significance of this thesis and how it is empirically and theoretically relevant is also addressed in this part. *The second chapter* describes the research design of this thesis. In order to provide the reader with a more comprehensive understanding and increase the readability, an overview of key definitions has been included first in this chapter. Secondly, the methodological aspects, such as how the study is carried out and why the case study method is applied as the chosen research method in this study, follow the section on definitions. A motivation for the case selections and a description of how the data was collected and structured is also provided, before the theoretical framework employed in the analysis closes the chapter. *The third chapter* presents the narrative of the Russian HIV epidemic. In an attempt to provide a thorough contextualization, the chapter begins with an overview of both the global and Russian history of HIV. For the purpose of further clarification, a summary of preceding and present Russian HIV policy choices, and a brief presentation of the Russian HIV care system is provided. Ideally, civil society should be included as a key player in the Russian HIV response, and a section on HIV/AIDS NGOs and current legal constraints is also included. A presentation of domestic partners supporting the status quo then follows, before a brief discussion on prospects of curbing the epidemic within Russia's neo-patrimonial system of governance. Fourthly, Russian cooperation with the international health community is addressed, and a thorough examination of Russia's role as both a donor and a recipient of HIV/AIDS aid will be provided. The last part of the third chapter approaches the social context of the epidemic and addresses existing societal components affecting the spread of HIV in Russia. *The fourth chapter* introduces the empirical part of this thesis. This thesis' first embedded unit of analysis, a long-standing conflict over HIV education in Cheliabinsk, will be used to exemplify how the regime's current priorities and rhetoric affect Russia's ability to respond to HIV. *The fifth chapter* then proceeds to present this thesis' second embedded unit of analysis; state mobilization and demobilization of Russian HIV/AIDS civil society. The current situation in Sverdlovsk Oblast', Russia's federal subject most severely affected by HIV, will be used as an example of how this can occur, and also preface a discussion on broader national Russian patterns. *The sixth chapter* leaves room for conclusions and reflections.

2 Research design

The present chapter is dedicated to this thesis' research design. In essence, the research design should be a plan that logically connects the research questions to the evidence collected (Yin, 2014, pp. 27–29). This chapter will thus be used to specify how the thesis statement and research questions of this study have been approached. Chapter 2.1 includes an overview of relevant key concepts and definitions, before Chapter 2.2 proceeds to address this thesis' methodological framework. Chapter 2.3 will present the theoretical framework employed.

2.1 Key concepts and definitions

HIV stands for human immunodeficiency virus. People infected with HIV are correctly referred to as *HIV-positive* or *people living with HIV* (UNAIDS, 2015, p. 8). There are two types of the virus; HIV-1 and HIV-2. The types are similar in structure, transmission modes and resulting opportunistic infections, but have differed in their geographical patterns and disposition to progress to illness and death. HIV-2 generally has a slower, less severe clinical course than HIV-1 (UNAIDS, 2015, p. 29). HIV-1 is responsible for the vast majority of infections. Unless otherwise specified, HIV refers to both virus types in this thesis.

HIV must not be confused with *AIDS* (acquired immunodeficiency syndrome). AIDS is not a virus, but a clinical syndrome, caused by HIV. AIDS is characterized by the development of opportunistic infections as immunosuppression progresses along an HIV infection (UNAIDS, 2015, p. 4). If untreated, HIV-positive will usually develop AIDS within 10-15 years (WHO, 2017a). There is no cure for HIV, but antiretroviral therapy (ART) slows disease progression significantly by preventing viral replication. HIV-positive adhering to ART can thus expect to live long lives. As most people with HIV do not have AIDS, the joint expression HIV/AIDS can cause confusion and should be carefully employed. In this thesis, it will be used when referring to unspecified activities/units that may involve both HIV-positive and people affected by AIDS. Examples are HIV/AIDS NGOs or HIV/AIDS aid. Elsewhere, the single term most specific and appropriate in the context will be used, i.e. either HIV or AIDS.

The term *epidemic* refers to a disease or condition affecting a disproportionately large number of individuals within a population, community or region at the same time (UNAIDS, 2015, p. 19). An epidemic may be restricted to a certain area (outbreak), be more general (epidemic) or be global (pandemic). The preferred term when referring to HIV is epidemic, but one should be specific about the scale, i.e. local, regional, national or global (UNAIDS, 2015, p. 10).

A *concentrated* HIV epidemic is defined as when HIV prevalence exceeds 5% in at least one defined subgroup, but is not established in the general population or among pregnant women (prevalence <1%). A *generalized* epidemic is defined as when HIV is firmly established in the general population, and prevalence exceeds 1% among pregnant women (WHO, 2013, p. 15).

The *incidence* of HIV is a measure of new cases detected in a population within a given period of time, while *prevalence* refers to the number of people living with HIV at a specific point in time (WHO, 2013, p. 16). Thus, incidence conveys information about the risk of contracting the virus, while prevalence stipulates how widespread it is (Chang, 2014, p. 82).

The commonly used terms *vulnerable groups* or *high risk groups* should be avoided when discussing HIV, because they imply that transmission risk is contained within the group itself. Belonging to a certain group does not place the members at risk; their individual behaviors may (UNAIDS, 2015, p. 8). The term *key populations* will therefore be used in this thesis, intended to refer to groups that are key to the epidemic's dynamic and/or key to the response.

The term *HIV-related stigma* refers to “negative beliefs, feelings and attitudes towards people living with HIV, groups associated with people (e.g. the families of people living with HIV) and other key populations at higher risk of HIV infection”, while the term *HIV-related discrimination* refers to “the unfair and unjust treatment (act or omission) of an individual based on his or her real or perceived HIV status” (UNAIDS, 2015, p. 2). Stigma and discrimination can be institutionalized through a country's laws, policies or practices.

Harm reduction refers to “a comprehensive package of policies, programs and approaches that seeks to reduce the harmful health, social and economic consequences associated with the use of psychoactive substances” (UNAIDS, 2015, p. 23). This includes several initiatives, e.g. needle-exchange programs, opioid substitution therapy (OST), provision of ART to injecting drug users, and condom distribution to people injecting drugs and their sexual partners.

2.2 Methodological framework

The present section will discuss why the case study is applied as the chosen research method in this thesis, and also address the measures taken to increase this study's trustworthiness. Chapter 2.2.1 will then proceed to discuss the selection of the primary and the embedded units of analysis included in this thesis, before Chapter 2.2.2 will provide a thorough description of how the data in this study was collected, structured and analyzed.

The motivation to investigate *how, why and to what extent* the Russian regime influences the public health of its citizens set some premises for how to approach this study. Firstly, the substance and form of the thesis' aim and the research questions posed concern connections requiring to be traced over time, which cannot merely be measured by frequency or incidence. Therefore, a purely quantitative methodological approach would not be suitable. The aim is not to produce statistical generalizations, but rather to provide an in-depth examination of the dynamic between a state and its public health crisis. Secondly, the phenomenon at issue is a contemporary event, but the behaviors of relevant actors cannot be manipulated by the researcher. Thirdly, the presumed causal links in this relationship are too complex for either historical, survey or experimental methods. Lastly, this thesis' research questions call for a usage of several data sources, and a mix of qualitative and quantitative research. All of the above point to the *case study* as being a relevant research method (Gerring, 2007, pp. 19–20; Swanborn, 2010, p. 13; Yin, 2014, p. 4, pp. 9–12, p. 19; Bryman, 2016, p. 61).

A case study may be defined in several different ways. Robert Yin proposes a twofold definition. The first part defines its *scope*:

A case study is an empirical inquiry that investigates a contemporary phenomenon in depth and within its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident (Yin, 2014, p. 16).

The second part moves on to describe its *features*:

A case study inquiry copes with the technically distinctive situation in which there will be many more variables of interest than data points, and as one result relies on multiple sources of evidence, with data needing to converge in a triangulating fashion, and as another result benefits from the prior development of theoretical propositions to guide data collection and analysis (Yin, 2014, p. 17).

In the present study, Russia's HIV epidemic within its real-world context is the phenomenon examined. Because it is an in-depth inquiry that includes studying both conditions over time and contextual environments, a large number of what Yin calls "variables of interest"¹ will naturally occur. In contrast, the "data points" constitutes only the single case, i.e. the HIV epidemic in Russia (Yin, 2014, p. 212).

¹ In using the word "variable" to describe a study's relevant areas of interest, Yin does not imply that case studies are variable-based. On the contrary, he underlines that the multiplicity of variables favors holistic approaches (Yin, 2014, p. 24).

Due to the nature of the data collected, this thesis takes on a largely qualitative approach. In order to properly address the research questions, qualitative methods such as document analysis and interviews have predominantly been employed. However, a relatively substantial amount of quantitative data is also included, especially in Chapter 3.5.2 where survey data are analyzed in order to answer the third research question properly. For contextualization purposes, a significant amount of epidemiological and statistical data is also used throughout this thesis. The case study has traditionally been associated with purely qualitative methods of analysis, but this is not a correct view (Gerring, 2007, p. 11; Bryman, 2016, p. 60). On the contrary, case study research constitutes a useful approach for incorporating both qualitative and quantitative methods, as the methods can successfully complement each other and together serve to further elucidate relevant aspects of the study (Yin, 2014, p. 22).

A common criticism of case study research is that it naturally entails a lack of rigor and comparativeness, in addition to low external validity and generalizability (Swanborn, 2010, p. 41; Yin, 2014, pp. 20–21; Bryman, 2016, p. 62). For this reason, the case study has often been perceived as a less desirable research method than, for example, experiments or surveys (Yin, 2014, p. 19). Yin (2014, pp. 20–21) argues that the challenges above can be addressed by following systematic procedures, reporting all evidence fairly and having a structured and creative composition. Furthermore, the motivation for a case study should not be to estimate probability and generalize to a wider universe, but rather to expand and generalize theories. In this regard, the theoretical reasoning is especially important. The data collected must support the theoretical arguments properly, and the theoretical analysis should be incisive (Bryman, 2014, p. 64). A prevalent pitfall is to consider the case study an “easy” research strategy, as it has no fixed procedure that must be followed. This is not correct, and an excellent case study is incredibly hard to perform (which of course somewhat explains the method’s less than stellar reputation) (Swanborn, 2010, p. 43; Yin, 2014, p. 23). In light of the above, this study makes an effort to gather all relevant information, seek those alternatives that challenge the underlying assumptions, and also, present the findings in a well composed and engaging way.

As pointed out above, some theory development as part of the design phase is highly desirable when performing a case study. The theoretical propositions do not need to be well-articulated or complex, but should present some vague ideas about what is reality and loosely describe why certain relevant acts, events and structures occur (Swanborn, 2010, p. 76; Yin, 2014, pp. 37–38). An already existent theory may be tested in order to confirm or refute a hypothesis, or be extant, and serve to describe, explain or illustrate a phenomenon. Correspondingly, a study

may also be theory-generating, either purposely, or resulting as a by-product. Regardless of the form it takes, a theoretical starting point will usually help make a grounded choice out of all the possible variables, provide a frame for the interpretation of the results, in addition to making it easier to reach the desired analytic generalizations (Swanborn, 2010; Yin, 2014).

During the initial design phase of this study, theories and hypotheses based on key issues from existing literature were consulted. The very first were taken from Gomez' (2015) article on the BRIC countries' (Brazil, Russia, India and China) response to AIDS, upon which a model was crafted. As will be described more in detail in Chapter 2.3.2, the model stipulated a set of presumed causal links between Russia's political leadership, donations to HIV/AIDS aid and domestic HIV/AIDS policy outcomes. The model proved to be a very useful tool throughout the research process. Initially, it provided a theoretical basis on which this thesis' research questions could be formulated, and contributed with strong guidance on what data to collect. During later stages of the research process, the model's proposed causal links enabled comparison between theoretically stipulated events and empirically observed events, which helped define a domain to which the study's findings could be generalized. It can therefore be interpreted as laying out the groundwork for reaching analytic generalizations in this study.

This study adopted a single-case design with embedded units of analysis. This research design seemed suitable for several reasons. Firstly, a major rationale for choosing a single-case study instead of a multiple-case study, which is often considered more robust, is when the case is *critical*, that is, critical to the study's theoretical propositions. The single-case design can thus be successfully used to confirm, challenge or extend the original theoretical framework, and can also provide a better understanding of the circumstances in which the propositions will or will not hold (Yin, 2014, p. 51; Bryman, 2016, p. 62). As noted above, a theoretical model specifying a set of circumstances within which its propositions were believed to be true was developed prior to data collection. This made it possible to assess whether the propositions appeared to be correct, or whether some alternative set of explanations seemed more relevant.

Secondly, another major rationale for choosing to apply a single-case study is when the case is *longitudinal*, i.e. the same single case is studied at two or more different points in time (Yin, 2014, p. 53). As this thesis examines the Russian regime's re-orientation, moving from modernization toward cultural conservatism, the case is by default longitudinal. The single-case is a potent research design for the study of developments, changes and trends following a "before and after"-logic. Considering this study hypothesizes that a policy shift occurred in

Russia in 2012, and that it seeks to investigate developments connected to this shift affecting the regime's ability to respond to HIV, the single-case study was further confirmed as an appropriate design. Thirdly, the fact that subunits could be identified and included made it possible to perform a more comprehensive and robust analysis (Yin, 2014, p. 55). An embedded design is also usually more powerful in avoiding what Yin calls unsuspected slippage.² Lastly, a general concern about case study research is that it may require enormous resources and time, often particularly true for multiple-case designs. By applying a single-case design to this thesis, the research will hopefully not end up restrained by external factors.

Single-case designs can undoubtedly produce successful case studies, but certain potential vulnerabilities should be addressed. A main concern is that a case may turn out to be something else than what it was believed to be at the outset of the study (Yin, 2014, p. 53). In order to minimize chances of misrepresentation and increase the access needed to collect the relevant data, a thorough examination of Russia's HIV epidemic had been conducted before choosing to apply this design. In order to narrow the scope of information relevant to the thesis, tentative research questions were formulated early on. A flexible outline was also drafted at an early stage, providing structure and overview. With the purpose of strengthening the insights into the chosen single case, two embedded units of analysis were included. Although an embedded design of this kind can help focus the study and make the analysis more extensive, the larger holistic aspect must not be lost, as the original phenomenon of interest then may end up being the context, and not the study's main target (Yin, 2014, pp. 55–56). Staying aware of the dynamic between this thesis' two analytical levels, i.e. the primary unit and the embedded units, has remained a focus throughout the research period.

Measures taken to increase the thesis' trustworthiness

Four criteria, or tests, are commonly used to judge the quality of a research design. The tests are valid also in the context of case study research (Swanborn, 2010, p. 36; Yin, 2014, p. 45), and have been integrated in this research process.

The first test can be defined as *construct validity*, that is, to identify the correct operational measures for the concepts being studied. As different concepts call for the usage of different sources, a main tactic to increase construct validity is to use multiple sources of evidence

² Unsuspected slippage occurs when the entire nature of the case study shifts during the course of the study. Consequently, the implemented design may no longer be appropriate to answer the research questions posed. The largest criticism of case studies is based on this kind of unwanted shift (Yin, 2014, p. 55).

(Yin, 2014, pp. 45–46). For the purposes of the present thesis, employing multiple sources of evidence made it possible to address a broad range of historical and behavioral issues related to the case, and even more importantly, to *triangulate* the data.³ However, it is essential to understand that using multiple sources of evidence does not automatically increase construct validity. If sources are analyzed separately to produce isolated findings and conclusions, no data triangulation, and hence increased construct validity, has taken place (Yin, 2014, p. 121). Moreover, one should also be aware that using multiple sources of evidence imposes a relatively heavy burden on the researcher, as data collection will generally be both time and resource consuming, and require the researcher to master several different data collection techniques. Another tactic to increase construct validity that has been used in this study is to establish a *chain of evidence*, i.e. to make the study's steps between posed questions to the finished report traceable (Yin, 2014, p. 47). The chain of evidence will be further discussed in the section on reliability, as its maintenance was also a main tactic to increase the reliability.

The second test commonly used is *internal validity* (Swanborn, 2010, p. 36; Yin, 2014, p. 45, Bryman, 2016, p. 41). Internal validity mainly concerns the question of causality and is primarily relevant in explanatory case studies like this one, i.e. studies trying to explain how and why a given event has led to another event. For instance, if one suggests that Putin's shift in 2012 has hampered Russian cooperation with the global HIV/AIDS community, how can one be sure that the relation between the variables is causal? How can one confirm that correlations do not result from another causal factor? Because not all events covered in a case study can be directly observed, the researcher has to make certain inferences on basis of the collected evidence. However, the process of doing so calls for careful evaluation. One should at all costs avoid jumping to premature conclusions, but rather continuously strive to evaluate the correctness of inferences made, review eventual convergence between the evidence, and attempt to address all possible rival explanations, particularly if they challenge the underlying assumptions of the study (Yin, 2014, p. 47). With the purpose of increasing a study's internal validity, specific techniques can be applied during the analytic phase. The technique applied in this thesis, explanation building, will be presented and further discussed in Chapter 2.2.2.

The third test, *external validity*, concerns the question of whether or not a study's findings can be generalized beyond the specific research context, regardless of the research method applied

³ Data triangulation occurs when the researcher collects information from several sources, and then combines them in order to corroborate the same findings. This convergence of evidence is likely to help strengthen the construct validity and result in more convincing findings (Yin, 2014, pp. 119–121).

(Yin, 2014, p. 48; Bryman, 2016, p. 42). As noted in the part on general concerns about case study research, the aim of a case study is not to make statistical generalizations, but analytical generalizations through expanding and generalizing theories. In this regard, the form of the research questions posed is highly important. For instance, if there are no questions seeking to explain how or why something occurred, it may be difficult to reach analytical generalizations at all, and the case study may not be the appropriate method (Yin, 2014, p. 48). To avoid a situation where the entire research design had to be altered, this thesis' original research questions were posed prior to applying case study as the research method. Moreover, as using theory is a main tactic to increase external validity in single-case studies, relevant theoretical propositions were identified at an early stage and continuously reviewed throughout the study.

The last test, *reliability*, is concerned with whether the findings and conclusions of a study can be reproduced by others, if he or she follows the same procedures as the original researcher (Yin, 2014, p. 48; Bryman, 2016, p. 41). Thus, the goal of this test is not to replicate a study's results by doing a second study, but to minimize potential errors and biases within the existent case. In order to make this study as repeatable as possible, a case study protocol⁴ was kept throughout the process, providing guidance and overview. As mentioned in the section on construct validity, a chain of evidence was also maintained, with the aim of making it possible for an outsider to trace the steps back and forth from initial research questions to conclusions. Maintaining this chain of evidence entailed storing all original evidence and collected data in a case study database, and citing the employed data adequately, so that an external observer could easily access the specific sources used to reach the study's findings (Yin, 2014, p. 127).

2.2.1 Selection of the primary and the embedded units of analysis

When selecting a primary unit of analysis for a case study, one should have some prior knowledge of the case, so that a grounded and informed choice can be made. This will help avoid a scenario where the selected primary unit of analysis would have to be replaced during the research process, because it for example turned out to represent something else than what it was believed to represent. The primary unit of analysis may be identified at an early stage, or it may be selected after screening several candidates (Yin, 2014, p. 95). In this study, the identity of the case was clear early on. Through working on another essay on the HIV epidemic in Russia, a substantial share of information had been obtained, and the potential of

⁴ A case study protocol may be defined as a guide of how data should be collected, or as a representation of the researcher's "mental agenda". It should include 1) an overview of the study, 2) data collection procedures, 3) data collection questions, and 4) a tentative outline (Yin, 2014, p. 240, pp. 84–93).

examining the epidemic more in-depth and connecting the epidemiological situation to the changing political environment seemed evident.⁵ As a significant amount of data already had been collected, the availability of sources had been established as pretty good. This increased the confidence in the HIV epidemic as being a qualified case candidate for this thesis.

However, other circumstantial factors also contributed to perceiving the HIV epidemic as a potent case. Firstly, the spread of HIV is possibly the biggest public health challenge Russia currently faces. Thus, when examining how the political environment affects Russia's public health situation, the political leadership's response to a major health crisis like HIV seemed important. Secondly, because significant epidemiological changes in the spread of HIV have taken place in Russia over the last 20 years, the epidemic appeared to be a suitable case for examining the correspondence between different regime orientations and public health outcomes. Thirdly, the public controversy and conflict HIV repeatedly provokes in the Russian society provides favorable conditions for examining collisions between conservatism and modernization, and how this dynamic influences Russian health care policy. Lastly, the epidemic also entails a highly interesting geopolitical dimension. Because HIV has generated massive global attention and cooperation for more than two decades, a study of Russia's response to the infection is also a study of the country's relations with the global community.

Another public health challenge that could possibly have been chosen as the primary unit of analysis in this thesis is tuberculosis (TB). TB share many of the characteristics that make HIV a potent case; it is an infectious disease that is widespread in Russia, key populations are disproportionally affected, an efficient response from the Russian government is absent, and it is a global health challenge that has stimulated extensive international cooperation, which Russia has contributed financially to (The Global Fund, 2017a). However, certain features pointed to HIV as being a more relevant primary unit of analysis. Firstly, although people with TB in Russia report stigmatization, TB seems to create less open ideological conflict than HIV.⁶ The two infections are also closely linked in Russia, and developing TB disease⁷ is

⁵ As a part of my master's degree, I spent the spring of 2017 working as an intern at the Royal Norwegian Consulate General in St. Petersburg. During my internship, I followed the epidemic closely and met with both state institutions and NGOs working on HIV/AIDS issues. The severity of the situation, combined with the minor media attention the epidemic usually is granted in both Russian and Western media, motivated me to write an essay on HIV as part of my internship, which again inspired me to focus on the epidemic in this thesis.

⁶ This might be due to TB's un-stigmatized transmission modes. TB spreads through the air, while HIV transmits via certain bodily fluids, i.e. blood, semen and vaginal fluids (WHO, 2017b). HIV is also linked to homosexuality, further increasing its controversy in Russia.

often a consequence of already being HIV-positive. The regime's managing of HIV could thus be expected to influence the TB situation. Although HIV and TB will not be treated as one and the same epidemic in this thesis,⁸ it is worth noting that the infections frequently overlap.

With the purpose of strengthening the insights into the chosen single case, two embedded units of analysis were included in this study. As this thesis seeks to examine how Russia's response to HIV is shaped by, respectively, modernization and neo-patrimonialism, subunits illustrating this conflict were of special interest. Moreover, cases providing insight into why and how the Russian approach to HIV is as ineffective as available data show that it is were searched for. During the data collection process it became apparent that embedded units could be identified. As the inclusion of such subunits is likely to produce a more robust single-case analysis (Yin, 2014, p. 55), two subunits were selected and will be briefly presented below.

The first embedded unit of analysis included in this thesis is a long standing conflict over sex education and HIV prevention in Cheliabinsk. Back in 2014, a regional state-run youth center had all its educational activities suspended after parents had complained about the center distributing free anonymous HIV tests, condoms and educational brochures to students on the World AIDS day. The center was allowed to resume its educational activities in 2016, but a new scandal erupted in 2017, when its lesson "Basic HIV Knowledge for 10th and 11th Graders" became subject to scrutiny. An expert committee, consisting of representatives from the conservative "All-Russian Parental Resistance Group" (RVS), was appointed to perform the examination on behalf of Roskomnadzor, and a report ruling the lesson to violate Federal Law (FZ) 436 was published shortly after on the agency's webpage (Roskomnadzor, 2017b).

For more than two decades, Cheliabinsk has had major problems with HIV transmission. By the end of 2017, roughly 1.2% of the population was living with HIV, and the virus is, like in all of Russia, increasingly spread through sexual contact. In 2016, more than 50 000 Russians contracted HIV through sex (Federal'nyi Tsentri SPID, 2016, pp. 1–3). Despite these figures and pressure from the global community to introduce sex education in Russia, resistance remains vivid, in all probability linked to Putin's conservative shift in 2012 and his inclusion of morality, tradition and history as legitimate principles of policy crafting. Educating people on HIV and how it spreads is a basic strategy to prevent the spread of HIV in societies, and

⁷ A person can live with latent TB (he or she is infected but is not sick), and develop TB disease if the immune system weakens. Because HIV weakens the immune system, HIV-positive are at 20-30 times increased risk of TB disease (WHO, 2017c, p. 46). Around 10% of the 115 000 Russians diagnosed with TB in 2015 had HIV.

⁸ Please note that some researchers name the situation in Russia a dual HIV/TB epidemic.

the conflict in Cheliabinsk will be used to illustrate how the regime's current focus, rhetoric and priorities impact the formation of a viable domestic response to HIV in Russia.

This thesis' second embedded unit of analysis is from Ekaterinburg, Sverdlovsk Oblast'. For almost two decades, the region has been severely affected by HIV, and Ekaterinburg currently presents the highest HIV prevalence in Russia with every 50th citizen officially registered as living with HIV. In November 2016, local health authorities declared the situation an epidemic (Rossiia 24, 2016). Seven months later, two of Ekaterinburg's independent NGOs working on HIV prevention had been forced to register as foreign agents, while an Orthodox project offering care to people "dying from AIDS and other incurable diseases" received half a million rubles from the Presidential Fund (Miniust, 2017b; Fond presidentskykh grantov, 2018a). Of the 28 projects supported by the fund in Sverdlovsk Oblast' this round, the ROC's palliative care project was the only one involved in any kind of HIV/AIDS-related work.

This subunit is highly interesting for several reasons. While Russian contributions to global HIV/AIDS cooperation were substantial during the 2000s, they were significantly reduced during Putin's third term. Concurrently, the sums made available to civil society through state sponsored competitions were multiplied. A domestic redistribution of money thus seems to have taken place, i.e. money previously used in international aid has gradually been channeled into Russian projects. However, the magnified state financing of civil society should not be interpreted as an overall increased sponsoring of NGOs in Russia, but rather as a tool for the regime to mobilize actors who are either loyal and/or useful, and to demobilize those who do not meet the same criteria. In this regard, the situation specifically for HIV/AIDS NGOs changed in 2017. While HIV/AIDS civil society traditionally has received minimal state support, various HIV/AIDS projects started to receive state grants last year, first seven projects in August 2017, and an additional 16 projects in November 2017. In light of this development, the situation in Sverdlovsk will be used to exemplify, and also preface a broader discussion on, current patterns of mobilization and demobilization within the existing Russian landscape of HIV/AIDS NGOs.

2.2.2 Methods of data collection and analysis

With some important premises for this thesis' selection of the primary and embedded units of analysis presented, the present section will proceed to provide an overview of the methods used to collect, structure and analyze the data employed in this study.

Data collection

As discussed in Chapter 2.2, a high quality case study should always rely on data collected from multiple sources of evidence. However, it is important to be aware that no single source of evidence has complete advantage over all the others, and that not all sources of evidence are relevant to all case studies (Yin, 2014, p. 118). In order to achieve an overview of which sources of evidence were relevant and available to this study, and to identify how information from these sources could be obtained, *the first phase* of the data collection process consisted of establishing a tentative data collection plan. The plan was not crafted, nor used, as a fixed scheme throughout the study, but it served as a useful starting point for how to organize and structure the data collection process. It included the following main objectives:

- 1) Identify which sources of evidence (documents, interviews, observation, videotapes etc.) could be used in order to answer the thesis statement and the research questions
- 2) Collect objective and accurate epidemiological HIV data globally and from Russia
- 3) Collect documentation on the Russian government's efforts to stop the spread of HIV, e.g. official state strategies and funding granted their implementation
- 4) Collect information on Russian cooperation with the international health community
- 5) Identify possible sources of information available for tracing attitudes in the Russian society toward HIV and people living with HIV
- 6) Search for potential embedded units of analysis
- 7) Identify possible limitations of the data available and reflect upon challenges that may appear during the data collection process

Prior to collecting data, certain boundaries were defined. Because the case study does not have any clear cut-off point, as many other methods do, the plentitude of information and sources can be overwhelming and cause the researcher to lose sight of a study's initial inquiry (Yin, 2014). In order to meet this concern, five criteria were set: 1) the centrality of the information must constantly be reviewed, 2) when available, primary sources should be used, 3) Evidence should be accessed in its original language, 4) two or more sources of evidence must be collected for each of the main objectives posed, and 5) this evidence should include attempts at examining major rival explanations. With regard to the plan's first objective, emphasis was placed on considering all sources of evidence equally relevant before collecting enough data to make a conscious choice. The purpose was to avoid the selection of sources being guided by other factors, such as prior familiarity with certain data collection procedures.

The second phase of the data collection process consisted of working systematically through the data collection plan. It became clear that documentation and archival records⁹ were relevant sources of evidence, and that a considerable amount of data from these sources could be obtained online. Most of this thesis' third chapter was interpreted as being adequately covered by a combination of documentation and archival records, which could be triangulated in order to corroborate the findings.¹⁰ Another important realization was that entirely correct Russian HIV data do not exist. International health agencies, e.g. UNAIDS and WHO do not collect their own Russian HIV data, but either rely on data from the Russian Federal AIDS Center, or leave the section on Russia blank. In light of this, the center's online database was chosen to be the primary source of Russian epidemiological data.¹¹ Moreover, it became clear that attitudes in the population toward HIV could probably best be identified by producing survey data with a substantial sample size,¹² but that doing so was outside this thesis' scope both time and resource wise. Thus, the relevant data needed to be obtained through a third party. I was very lucky to be given access to survey data collected by the Norwegian Institute for Urban and Regional Research (NIBR).¹³ Lastly, while documentation and archival records could in large part be used to identify and examine the embedded units of analysis, it became clear that interviews could be included as an additional source of evidence in the fifth chapter.

The third phase of the data collection process can be described as "snowballing". This refers to the well-known interview technique where the researcher makes initial contact with certain participants relevant to the research topic, and then uses these participants to identify other actors who share experiences or characteristics relevant to the research (Bryman, 2016, p. 188, p. 415). However, in this thesis, snowballing refers to the process where data collected from certain sources of evidence was used to identify other sources or specific documents. The documentation employed frequently included references to events, names and other

⁹ Understood here as defined by Yin (2014, p. 109): Archival records include statistical data produced by governments, service records, organizational records, maps, charts and survey data produced by others.

¹⁰ A more elaborate discussion on this thesis' approach to the documents collected will be provided below.

¹¹ The Federal AIDS Center, subordinated Rospotrebnadzor, is in charge of HIV surveillance in Russia. Due to low data quality and inefficient surveillance systems of testing and surveillance, the data include around half of HIV-positive in Russia (Levi et al., 2016, p. 5). The center is, however, known as a relatively autonomous institution, which for many years has criticized the state's HIV response. With the center's data limitations considered, it nevertheless seemed reasonable to use its estimates as the main source of Russian HIV data.

¹² The larger the sample size, the greater is usually the precision. However, with a sample size of around 1000 respondents the sharp increases in precision usually become less pronounced (Bryman, 2016, pp. 183–184).

¹³ The NIBR survey was part of a larger Norwegian-Russian project on the governance of HIV/AIDS prevention in North-West Russia. Data were collected through a cross-sectional study based on telephone interviews of respondents aged 18 and above in Arkhangelsk and St. Petersburg (Aasland, Grønningsæter et al., 2011).

documents, and thus provided useful suggestions on where to “look next”. To give an example of how this was exercised in practice; a news article or previous done research could for example refer to a specific speech held by a Russian government official where the HIV epidemic was commented on, which again presented the opportunity to search directly for the document in question. While being defined here as the third phase in the data collection process, it should be noted that this practice at times overlapped with the second phase.

This thesis’ considerable reliance on electronic sources requires some attention. While electronic archives provided valuable access to a broad range of different sources of evidence and clearly simplified the process of retrieving data, care had to be exercised. In order not to get lost in the abundance of material and spend excessive time and resources on information that turned out to be irrelevant, the criteria posed in the section on preparations to data collection were sought to be followed. Also, the accuracy of the information had to be cross-checked with other material in order to identify possible biases, misconceptions or other shortcomings. Social media sites such as VKontakte and YouTube were approached especially carefully, as claims about authorship or times may be misleading. For example, YouTube was efficient in searching for Russian TV shows debating HIV, but clips were always traced back to their primary sources and then re-viewed in order to confirm authorship, content, place and time.

The interviews with representatives from NGOs were carried out by using both synchronous (real-time), and asynchronous (non-real-time) online interview methods. During the last years, online communication has become an increasingly important tool for conducting qualitative interviews (Hooley, 2012; Janghorban et al., 2014; Iacono, 2016). While face-to-face interviews can be limited by time, distance or budget, online methods allow the researcher to interview people worldwide in a way that is both efficient and affordable (Iacono et al., 2016, p. 1). VoIP (Voice over Internet Protocol), e.g. Skype, can be especially successfully used, as it enables users to send verbal (voice) and non-verbal (video) cues in real-time, providing an authenticity level similar to face-to-face interviews (Sullivan, 2012). Asynchronous interviews, most commonly conducted via e-mail, do not give the same opportunities for real-time interaction and non-verbal cues, but it is a quick, convenient and inexpensive method with its own advantages that can generate high-quality data¹⁴ (Meho, 2006, p. 1293).

¹⁴ E-mail interviewing allows participants to take their time in answering questions, and also to stay in control of the flow of the interview. The rate of transcription errors and interruptions that may occur during a real-time interview, are also eliminated. In comparison with synchronous interview methods, responses are also usually more thought out before they are provided, and thus more focused on the asked questions (Meho, 2006, p. 1292).

The process of recruiting interviewees was conducted online, mainly via e-mail, but also via the social networking sites Facebook and VKontakte. Eighteen Russian NGOs working on various HIV/AIDS issues from seven federal subjects were contacted, selected on basis of their relevance to this thesis' second embedded unit of analysis, and their believed potential to contribute with diverse experiences. Recruitment proved to be slightly challenging, possibly linked to the tough pressure many HIV/AIDS NGOs currently are under (HRRCenter, 2018), and also due to potential negative consequences of giving interviews, as one NGO declining to participate pointed out (e-mail correspondence with the NGOs leader, April 17 2018). Recruiting participants by e-mail can also be challenging due to factors such as non-delivery, changed e-mail addresses, or not all potential participants reading their invitations (Meho, 2006), factors that of course also may have been present in this study's recruitment process.

Four representatives from NGOs agreed to be interviewed.¹⁵ All were informed about the research and gave their consent to participate before answering any questions. In order to reduce participants' eventual concerns about any negative consequences of being interviewed, and also as a means to encourage them to talk openly about their experiences, all interviewees were assured full anonymity. Respondents were also given the choice to be interviewed over telephone, Skype or e-mail. To enable interviewees with this choice was deemed important, as it gives participants a degree of control over the research process and encourages a more equal relationship between the researcher and the researched (Hanna, 2012). Two participants preferred e-mail, and the remaining two chose Skype interviews. In the e-mail interviews, four open-ended questions were initially sent to the participants, and follow-up questions used to elaborate aspects in the interviewees' answers. The Skype interviews were semi-structured in nature, which allowed for a flexible interview process focused on what the respondents viewed as important and relevant to talk about (Bryman, 2016, p. 468). An interview guide including a predetermined set of open questions was used,¹⁶ and questions sometimes asked slightly different than what was outlined in the guide, in an effort to follow the interviewees' responses and focuses. Follow-up probes and pauses were carefully used, with the purpose of obtaining in-depth answers. Consent to record the Skype interviews were in both cases collected, and the interviews were recorded using the program MP3 Skype Recorder before being transcribed. All four interviews were conducted in Russian, before translated to English.

¹⁵ Project number Norwegian Centre for Research Data (NSD): 60472. Due to initial challenges with recruiting participants, interviews were conducted relatively late into the research process, in April 2018.

¹⁶ Prior to being interviewed, participants were given the possibility to inspect the interview guide's questions. For more information on the interviewees and the interview guide, please see Attachment 1 and 2.

Structuring and analyzing the data collected

As an initial part of the data collection process, a case study database was established. The purpose of this was to have a separate and orderly compilation of all observations made and data obtained. Computer files, articles and other documents retrieved online were converted to PDF files and stored together in an electronic database, sorted after which research question the content addressed. Non-electronic data, such as handwritten notes, questions, tables, calculations and tentative connections were saved in a physical folder sorted after entry date, even if their relation and relevance were not properly understood at the time of observation. Creating and maintaining a database of this kind is not only useful to structure the collected data, but also helps to increase a study's reliability (Yin, 2014, pp. 123–124). The (highly motivated) outsider is given the possibility to inspect the full array of data, not only the data included in the written report, which contributes to making the study repeatable (Yin, 2014).

An additional way of structuring the collected evidence was to use the previously mentioned tentative outline actively during the data collection process. The outline included a full overview of the thesis' planned chapters and sections with separate headings. As the data collection proceeded, the obtained information was not only stored in the database, but could also be put into the respective chapters and sections. The sequences of headings and titles were at times rearranged, a process which also helped yield initial analytic insights.

The process of analyzing case study evidence can be challenging, as no fixed techniques for how to do so exist. However, a beneficial starting point is to have an analytic strategy (Yin, 2014, p. 133). One strategy employed in this study was to return to the database, and to “play around” with the collected data and observations. In this regard, the physical folder proved to be particularly useful. The fact that it functioned as a chronological archive made it possible to revisit and to trace developments in previously made observations and reflections about the case. The purpose of this exercise was to detect potential patterns and concepts that could help produce analytic insights. Another strategy used was to rely on the theoretical propositions posed at the onset of the study. These had already yielded some loose analytic conceptions and priorities, which helped organize and guide the analytic process. Moreover, potential rival explanations identified during the data collection process had to be attended to. Considering those alternatives that seriously challenge the underlying assumptions of a study will enable the researcher to place stronger confidence in the findings (Yin, 2014, pp. 141–142).

Certain specific techniques can also be applied during the analytic phase. One that has been used in this thesis is explanation building or process tracing, i.e. to stipulate a presumed set of causal links about a phenomenon or “how” or “why” something happened (Gerring, 2007, p. 173; Yin, 2014, p. 147). The aim is to analyze the collected data by building an explanation about the case, and the technique can be very useful in studies like the present one, where the proposed causal links are complex and difficult to measure through any precise quantitative procedure (Yin, 2014, p. 147). Although the different bits and pieces of collected evidence may be relevant to a central hypothesis, they cannot be reduced to statistically comparable dataset observations. Instead, multiple types of evidence must be employed to verify the single inferences, and causal links will be gradually built by carefully piecing the evidence together, a process that likely includes several feedback loops (Gerring, 2007, pp. 172–173). To give an example, this thesis’ initial theoretical model proposed that the Russian regime’s ambitions of being a strong donor in global HIV/AIDS aid had distracted it from ensuring domestic programs the necessary support.¹⁷ Thus, the next step was to compare findings from the collected data to this proposition, go back and alter the model in accordance with any new insights, compare other details against this revision, edit the proposition again, and so forth.

However, using explanation building as an analytic technique requires considerable analytic insight and sensitivity from the researcher, and certain potential pitfalls need to be addressed. Because the process takes time and includes circular revisions, one may, unintentionally, slowly drift away from the original topic of interest. Furthermore, an unintended selective bias may slide into the process and produce a set of causal links that neglects key data (Yin, 2014, p. 150). Hence, the original purpose of this study needed to be constantly reviewed, and the earlier mentioned potential rival explanations had to be attended to. To try to make sure that no loose ends are left, and to seriously consider alternative interpretations does not only help avoid a situation where a study incorrectly concludes with causality, i.e. internal validity is low, but is also a main tool to increase a study’s overall quality, as the analysis will be less prone to alternative interpretations based on the evidence in the study’s database (Yin, 2014).

Lastly, some complementary remarks on how the textual material employed in this thesis was approached seem to be in place. Traditionally, document¹⁸ analysis has been divided into two

¹⁷ This model was based on Gomez’ article on the BRIC countries response to AIDS (2015) and will be presented and further described in Chapter 2.3.

¹⁸ The term “document” here refers to all types of written material, not to be confused with the previously used term “documentation “. In the following, the terms texts, material and documents will be used interchangeably.

main approaches, the former quantitative and the latter qualitative (Bryman, 2014). While quantitative techniques could be used in the analysis of within-case evidence in this thesis, e.g. SPSS to analyze survey data, this study's proposed causal links were too intricate to be measured in any precise quantitative manner. For this reason, the process of analyzing the material predominantly followed the principles of qualitative document analysis (QDA). QDA can be defined as "a systematic procedure for reviewing or evaluating documents" (Bowen, 2009, p. 27). The underlying presumption is that one interpretation of a certain text is just one of many possible, and that findings do not result from analyzing documents separately, but from seeking convergence and corroboration through the use of various documents, i.e. data triangulation (Bowen, 2009, p. 28). A common criticism of QDA is that it relies too heavily on the researcher's subjective non-verifiable intuition, and that readers are left with no choice but to trust that a study's interpretations of the data are accurate (Wesley, 2014, p. 143). This criticism can largely be met by adhering to the four quality tests of research designs. In this regard, providing a thorough description of this thesis' data collection process in addition to maintaining a chain of evidence were considered to be especially important steps.

Certain additional quality criteria should also be assessed when analyzing documents. The first is *authenticity*, that is, to establish whether the evidence is genuine and of unquestionable origin (Bowen, 2009; Wesley, 2014; Bryman, 2016) While certain texts employed in this thesis, e.g. official state strategies obtained from the Russian government's online databases could be considered relatively authentic, authenticity was more difficult to establish when using sources such as online newspapers and social media. Material without clear authorship makes it hard to determine whether the author is in fact in a position to provide an accurate version of the topic in question (Bryman, 2016, p. 555). In this study, two main tactics used to increase the authenticity of documents have been 1) to try to locate the original sources of epidemiological data, speeches, legislation, financial disbursements, news articles etc., and 2) to access all documents in their original language. The aim was to make the research less prone to misconceptions produced by others. However, misconceptions and mistranslations on my behalf may of course occur, and cause an incorrect presentation of the material. In order to meet these concerns, data have always been sought to be cross-checked, and native Russian speakers have been consulted when in doubt regarding a translation.

A second criterion can be referred to as *credibility*, that is, to establish whether a document is free from error and distortion or may reflect some bias (Bryman, 2016, p. 546). The original purpose of the document, the reason for why it was produced, and its target audience needs to

be reviewed (Bowen, 2009, p. 33). The fact that a majority of the documents employed in this thesis were produced for a specific purpose and a particular audience other than this study thus had to be taken into account. Moreover, texts are commonly revised and altered before published in final form, and should not be interpreted as literal recordings of events that have taken place (even though they are presented to be exactly that). Potential issues of reporting bias also needed to be attended to, as any author of a given document may have had a bias (Yin, 2014, p. 106). However, documents that seem to reveal a bias can also be of particular interest precisely because of the bias they reflect (Bryman, 2016, p. 553). For example, a 2017 statement made by Health Minister Veronika Skvortsova about how increased HIV testing coverage had resulted in Russian transmission rates being nearly halved seemed significant, as it was contradicted by official epidemiological data, and therefore could be interpreted to reveal an intention of downplaying the severity of the Russian epidemic (Minzdrav, 2017).

A third criterion that should be assessed, *representativeness*, refers to whether the documents selected are in fact representative of the totality of relevant material (Bowen, 2009; Bryman, 2014). In order to assess the representativeness of the documents used in this thesis, its typicality was reviewed. If evidence appeared untypical, understood as arguing perspectives or presenting information deviating from the majority of the collected evidence, the material was not dismissed, but the extent of its untypicality rather attempted to be determined. The purpose of this was to avoid an intentional selective bias creeping into the research process, which in turn could jeopardize the overall quality of this study. To only include material that corresponded with the majority of the data collected would not have made it possible to place strong confidence in the findings. It should also be noted that issues of representativeness may not only originate from an intentional selective bias, but also be caused by an unintentional selective bias, for example problems related to accessibility, and produce an incomplete data collection (Yin, 2014). As this cannot be directly controlled by the researcher, the only reasonable way to meet this concern is to let the research be based on open sources.

A final criterion that should be assessed when analyzing documents can be referred to as *meaning*. This relates to whether the material is clear and comprehensible, and may require considerable awareness of contextual factors depending on the nature of the evidence (Bryman, 2016, pp. 552–555). For instance, while governmental HIV strategies could be seen as relatively clear and comprehensible, documents of a more quantitative nature, such as epidemiological data or financial disbursements, clearly benefited from being evaluated against other sources of information in order to elicit meaning useful to this study. However,

the process of doing so required awareness, in the sense that one's contributions to the construction of meaning should be recognized. Moreover, one should strive to be objective and seek to represent the material employed fairly and also be sensitive by responding to even subtle cues of the meaning various documents convey (Bowen, 2009, pp. 31–32).

2.3 Theoretical framework

This section begins with a short discussion on the role and limitations of the theory employed in this study, before a theoretical foundation for the interpretation of Russian regime dynamics will be provided in Chapter 2.3.1. The initial theoretical model developed as part of this study's design phase will then be discussed in Chapter 2.3.2, before an adapted theoretical framework, resulting from the initial propositions coupled with additional propositions and concepts emerging from this study's findings will be presented in Chapter 2.3.3.

The theoretical propositions consulted during the design phase of this study proved to be very valuable throughout the research process. The model crafted upon Gomez' article on the BRIC countries' response to HIV, presented in Figure 3, provided a theoretical basis upon which this thesis' research questions could be formulated. The form of the initial questions posed directly influenced the decision to apply case study as the research method in this thesis, and also helped define a domain to which the findings could be generalized, i.e. the process of addressing external validity was initiated. The theoretical framework also contributed with strong guidance on what data to collect, and later, how to structure and analyze the data. The model's proposed causal links also enabled comparison between theoretically predicted events and empirically observed events, which in turn facilitated usage of the explanation building technique employed during the analytic phase.

While the theoretical propositions posed at the onset of the study could in part be used to describe the Russian approach during Putin's first two presidencies (2000–2004 and 2004–2008) and Medvedev's presidency (2008–2012), it became clear that the model needed some adjustments in order to properly illustrate the course that was laid out during Putin's third term. This realization necessitated the introduction of additional theoretical propositions that could, among other things, help explain the consequences of different regime types on the development of policies. Thus, theories on Eurasian regime dynamics (Hale, 2015), Russian neo-patrimonialism and Putin's turn to cultural conservatism (Robinson, 2017), authoritarian modernization and policy reforms (Gel'man and Starodoubtsev, 2016) and neo-patrimonial

governance and reform processes (Gel'man, 2016) were also included. The additional theoretical propositions were incorporated into the explanation building process and reviewed together with empirical insights resulting from the collected data, in conclusion producing the adapted theoretical framework which will be presented in Chapter 2.3.3.1 and 2.3.3.2.

As pointed out above, this thesis to a great extent employs already developed theoretical propositions. Its theoretical premise can thus be seen as theory consuming. However, as an expansion of the initial theoretical framework will be introduced in Chapter 2.3.3.1 and 2.3.3.2, its theoretical premise may also be interpreted as theory generating.

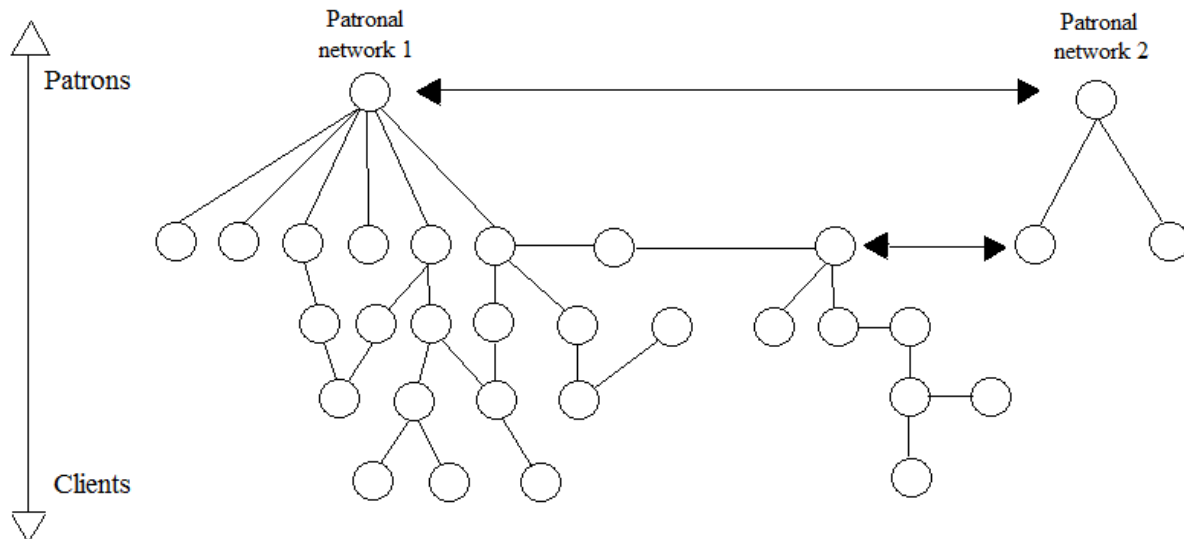
2.3.1 Russian regime dynamics

Henry Hale argues that making sense of post-Soviet regime change requires to replace a theory of the ideal with a theory of the real, and to part with the assumption that regime types are best identified in snapshots rather than dynamic patterns. While traditional research on post-Soviet political systems tend to reflect an underlying conception of how politics are supposed to work, and focuses on topics such as elections, constitutional design, public policy making or parties, “the way things really work” is often contained within another political aspect, what Hale refers to as the “patronalistic dimension of politics” (Hale, 2015, pp. 7–9):

Patronalism refers to a social equilibrium in which individuals organize their political and economic pursuits primarily around the personalized exchange of concrete rewards and punishments, and not primarily around abstract, impersonal principles such as ideological belief or categorizations that include many people one has not actually met in person. [...] [In highly patronalistic societies] everyday politics and power struggles revolve around extended networks connecting people through actual personal acquaintance (Hale, 2015, p. 20).

Thus, Hale proposes an understanding of politics in patronal societies as revolving chiefly around personalized relationships, joining extended networks of *patrons*, the most powerful people in these relationships, and *clients*, people who are subordinate to the patrons (Hale, 2015, p. 21). The networks of patrons and clients can be highly complex and involve combinations of connections between individuals with ties to multiple actors in the same network, and contact between individuals belonging to different networks:

Figure 1: Example of a patronal network



Source: Hale (2015, p. 21).

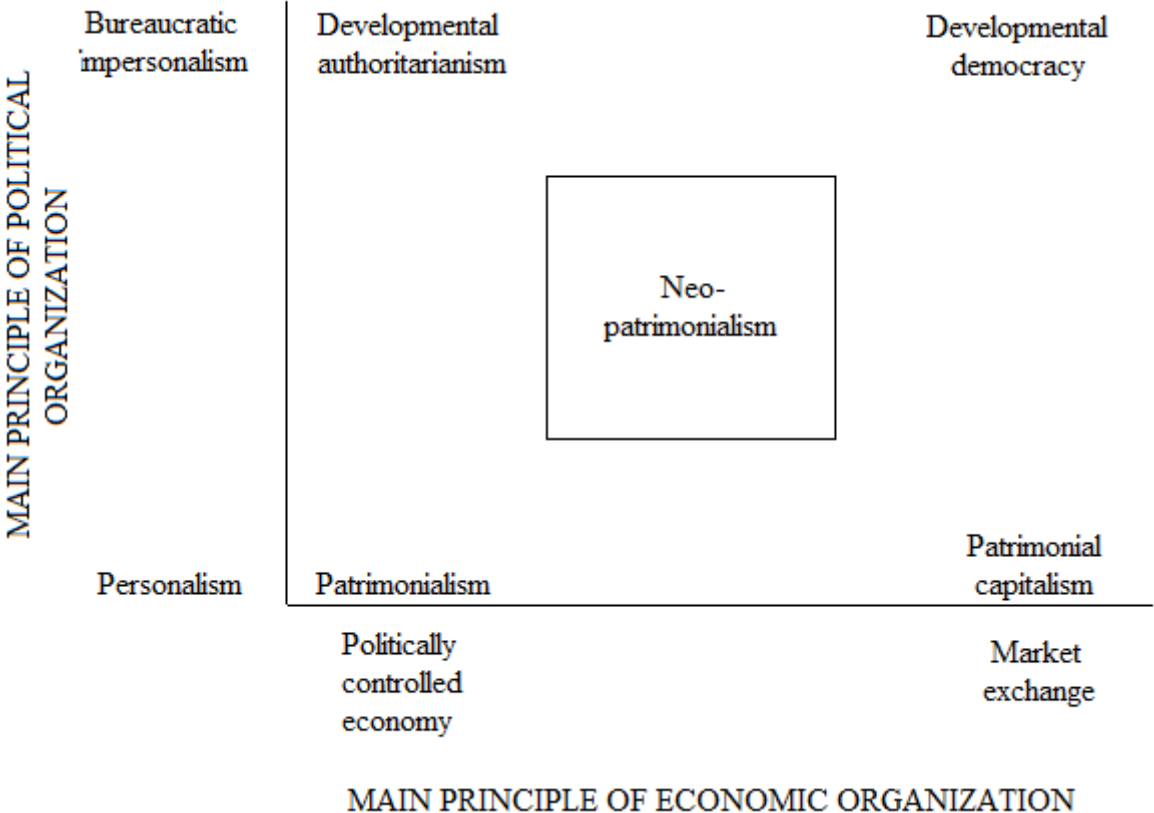
According to Hale, the logic of collective action within a patronal network can be explained by the involved actors' expectations. Clients carry out the patron's orders to punish and reward because they expect others to do so. Individual clients are unlikely to attempt to challenge the leadership without expecting others to join them, as disobedience can bring punishment or the loss of access to resources. A patronal network is therefore strong when its clients believe it is strong (Hale, 2015, pp. 34–36). This dynamic produces a vicious cycle, whereby individuals who would try to act on principle usually only succeeds in impoverishing and marginalizing oneself and one's family, in sum achieving nothing. Power becomes a type of self-fulfilling prophecy, where people who are expected to become powerful (regardless of reason) can become powerful as a result of these expectations (Hale, 2015, p. 61).

Hale's concept of patronalism, and his understanding of Russia's political development as taking place in a dynamic space where personalized power networks and informal practices play a major part, is largely shared by other scholars, although other terms are used to describe it. Alena Ledeneva refers to Russia's system of governance as *sistema*, and defines it as a space where "formal rules and informal norms are combined in a way that is non-transparent for outsiders but recognized by insiders of the public administration of Russia" (2013, p. 278). She argues that while the practices of this system, e.g. the widespread use of personal networks to obtain goods and services, also was very prevalent in Soviet society, the networks have reoriented themselves in the post-Soviet sphere to adjust to the new reality, in which access to money is key. Because the networks based on personal acquaintances are so

intertwined, and informal power an attribute to any formal status, Ledeneva argues that every leader who aims to modernize Russia will face the obstacle of this system (2013, pp. 10–14).

Neil Robinson applies the term *neo-patrimonialism* to the Russian system of governance, and describes it as a space where “predominantly personalist politics exist alongside and are interwoven with larger administrative systems that have some features and functions of a modern bureaucratic system” (2017, p. 350). Thus, what unites neo-patrimonial polities is not a common institutional design, but rather the opposition between a highly personalist regime, which holds rules on access to power, and an impersonalist state, which provides formal structures and holds impersonal rules for accessing power. Regime members use the patronal networks to gain access to power and resources, but cannot be certain that their arrangements are maintained, since the state may intrude at any time to fulfill its functions (Robinson, 2017, p. 351). This mix of personalized and formal institutions with both relational capital and impersonal market exchange as power tools complicates the consolidation of a stable regime, and a high level of uncertainty about the future will generally prevail in neo-patrimonial polities (Robinson, 2017). Due to its lack of a common organizational form, Robinson argues that neo-patrimonialism is best perceived as a space between four other distinct forms of rule:

Figure 2: The neo-patrimonial space



Source: Robinson (2017, p. 352).

Competing interests will constantly seek to push the polity toward one of the four corners in Figure 2, and dynamic movement occurs as the system tries to deal with pressures for change (Robinson, 2017, pp. 352–353). The pressure may be *exogenous*, i.e., if an external actor exert pressure on policies in a neo-patrimonial system, or *endogenous*, if the pressure comes from within the polity itself, for example as a result of social discontent or elite conflict. Stability in a neo-patrimonial system requires that no pressure gains too much leverage, causing the polity to move too far toward one of the corners. Political leaders will maneuver within the space and combine elements of various positions, with the purpose of reducing current uncertainty, and ultimately, securing their power in a longer perspective (Robinson, 2017, p. 353).

Robinson argues that Russia's political development since the dissolution of the USSR has been driven by a series of crises over the management of neo-patrimonial instability (2017, p. 353). After the dissolution of the USSR, there were aspirations of Russia transitioning to the democratic developmental state, but Russia did not have the necessary preexisting conditions or capacity to do so. The bureaucracy could not constrain particularistic interests by ignoring societal and elite demands for resources, and the state did not have the capacity to control the reactions to changes in resource allocation that a marketization would produce. Nevertheless, social pressure to provide welfare and security remained high throughout the 1990s. This presented a challenge for the strained Russian economy, and Russia struggled to balance regime stability with this type of state building pressures (Robinson, 2017, pp. 354–355).

As a result, Russia left the 1990s with a weakened state capacity, where regional elites largely structured local political systems to their own advantage. During his first presidency, Putin took action against oligarchs and regional leaders, and made considerable efforts to strengthen the state's coercive capacity (Taylor, 2011, p. 288; Robinson, 2017, p. 355). But, rather than resulting in a parting with neo-patrimonialism, this enhanced his personal powers and pushed Russia further toward patrimonialism. Propositions and plans that could have moved Russia closer to a developmental state were not fully supported by Putin, and not implemented to any great extent. State development once again had to succumb to regime strength, but because of Russia's economic growth, state building pressures could be more successfully responded to than in the 1990s. The maintenance of state functionality, however, did not result from state policy or better financial management, but was rather a spillover from an oil-fuelled economy and a closer bureaucratic management of the economy (Robinson, 2017, pp. 355–356)

During Putin's first two presidencies, the state did not develop the capacity to control elites or society, and particularistic interests preceded state needs and functionality, as long as their loyalty was not a concern. A repressive approach was pursued toward those challenging the Putin administration, justified by "serving the larger, universal needs of Russia", and the employment of the judicial system to fulfill this task (Robinson, 2017, p. 357). Putin's way of maneuvering Russia within the neo-patrimonial space meant greater stability compared to the 1990s, but overall, there was no real improvement in governance during his two presidencies (Taylor, 2011, pp. 292–293). Formal and informal elements of the system, political undercurrents aiming at pushing Russia toward one of the four corners in Figure 2, and latent social discontent all had to be balanced to achieve regime stability (Robinson, 2017, p. 357).

The problem of replacing state functionality with regime strength became potent again after 2008. There two main reasons for this: 1) the tandem arrangement of Putin as prime minister and Medvedev as president highlighted the contrast between formal and informal power. Medvedev inherited only the formal powers of the presidency, while the real informal power remained with Putin, still in charge of regime politics and the maintenance of regime stability (Robinson, 2017, p. 357). Thus, although Medvedev had some leeway, especially with regard to setting out a policy agenda, he was not in a position to alter the political system in a way that could have pushed Russia out of the neo-patrimonial space altogether, and 2) the financial crisis that hit Russia in the fall of 2008 accentuated the state's limited ability to build a modern economy, constrained by the informal politics of the regime (Robinson, 2017, p. 357).

However, these developments changed how modernization was discussed Russia (Robinson, 2017, p. 358). While modernization earlier primarily had been understood as diversification of the economy and a more directed role for the state in the economy, Medvedev connected the experience of the economic crisis to the need for institutional change, and a move toward a more developed democracy. His think tank, the Institute for Contemporary Development (INSOR), proposed three conditions for a modernization in line with this understanding: 1) to improve democracy, 2) to improve Russia's human capital, and 3) make business and "citizen activism" independent of bureaucratic interference (INSOR, 2010, pp. 10-12). However, Medvedev's plans never gained much support from within the political system, and Putin stayed largely above the debate. It might have been because he did not support his successor's proposals, or because he wanted to see how much support his plans gained before committing. Either way, his quietude augmented the general sense that there was no consensus on change, and that supporting Medvedev's plans would entail significant risks and potentially have

negative consequences at an individual level. Thus, even though the economy recovered in 2010-11, the weak response from Putin and the political system to Medvedev's plans left little room for him to make a successful move toward democracy (Robinson, 2017, pp. 358–359).

Putin's re-election in 2012 restored his complete political dominance of the Russian political system, and it was clear that his return was accompanied by a clear shift in priorities. Instead of adopting Medvedev's modernization plans and developing it into his own political project, as he hypothetically could have done, Putin took what Robinson describes as "a cultural turn":

The 'cultural turn' shifted the ground of what counted as success in state building from issues of functionality towards vague and indeterminate goals based on a cultural rather than an administrative conception of the state. This cultural conception of the state enables a rejection of political alternatives that might pose some solution to Russia's place in neo-patrimonial space (Robinson, 2017, p. 360).

The basis for thinking about the Russian state within this context is that Russia is unique as a civilization (Robinson, 2017, p. 360). This is of course to some extent true, as all countries have their own experiences, histories and geographies, but Putin claims that Russia is different because of the character of its civilization and the extent to which it has preserved this civilization in recent times. A close alignment between Russia's ability to exist as a state and as a civilization follows from this logic. The strength of the state is not connected to its functionality, but rather to how strong its civilizational identity is. Religion is important, with Russian Orthodoxy joined by other religions present in Russia on basis of their common concern for the protection of traditional values. Thus, other faiths have no room or need to develop state-bearing cultures of their own, as their moral concerns already are addressed within the larger Russian-Orthodox faith (Robinson, 2017, pp. 360–361). Following this rhetoric, Russia's state functionality can no longer be measured merely according to material terms, but must be evaluated also according to spiritual ones (Robinson, 2017, p. 364).

Putin's new value-based approach also contains an important global aspect. A main part of the rhetoric consists of stressing how globalization has led to other "state-civilizations" debasing, or worse, completely abandoning the traditional values they once had, and how this global trend continue to pose a threat to true Russian culture, morality and stability (Hale, 2015, p. 287; Robinson, 2017, p. 361). As the erosion of traditional values is especially advanced in the West, Russia cannot comply with their forms of democracy, but should instead proceed at its own path (Robinson, 2017). Putin explained this himself during the 2013 Valdai Forum:

Another serious challenge to Russia's identity is related to events occurring in the world. Here, there are both foreign policy and moral aspects. We can see how many of the Euro-Atlantic countries are actually rejecting their roots, including Christian values, which constitute the basis of Western civilization. They are denying moral principles and any traditional identities: national, cultural, religious and even sexual. Policies equating large families with same-sex partnerships, and the belief in God with belief in Satan, are being implemented (Zavrazhin 2013).

While this conservative shift has been relatively popular with a majority of the population, it has also been divisive. However, the protests in 2011-12 that had surrounded the presidential elections illustrated that the groups that likely would not approve of the new rhetoric already were quite alienated from the regime, which again implied that adopting the new conservative themes maybe was not all that damaging to the regime. As will be discussed more in detail in Chapter 3.3.2, legislation painting those opposing the new rhetoric as advocates of Western liberal and moral degeneracy was introduced shortly after Putin's re-election, reflecting his shift and more hostile attitude toward the West (Shevtsova, 2015, p. 30; Hale, 2015, p. 287).

By focusing on culture, moral values and history, Putin avoids bringing the organization of the state into question, and political agency to any group interested in pushing Russia toward any of the four corners is efficiently limited. Russia thus remains stuck in the neo-patrimonial space, and the result of Putin's cultural turn is a revitalization of his charisma, rather than improved governance (Robinson, 2017, pp. 363–364). The replacement of realism with the idea that Russia protects a unique civilization, and the substitution of state functionality with regime strength, is not very fertile. Given Russia's degree of socioeconomic development, the quality of governance is remarkably low. While neo-patrimonialism in Russia may be stabilized for now, assisted by Putin's portrayal of himself as a great leader who protects tradition and ancient lands, longer-term prospects are not good (Robinson, 2017, p. 364).

2.3.2 Gomez' analytical framework

In his article on the BRIC nations' responses to HIV, Eduardo Gomez (2015) examines¹⁹ the way in which the four countries have differed in their approaches toward HIV. Gomez' article introduces the concept of *historical policy backlash*, and proposes an analytical framework for interpreting how a country's legacy in foreign health aid can shape its domestic HIV response.

¹⁹ Gomez' article is a comparative study of the four BRIC countries. This thesis is a single-case study focused on Russia's HIV epidemic. Thus, while presenting, and drawing on, Gomez' theoretical propositions, the present study is not a comparative study.

While all the BRIC countries initially were slow to respond to HIV, Gomez argues that Brazil eventually did better than her counterparts. Brazil's success was in large part due to efforts made in the following three areas: 1) the ongoing construction of federal public HIV/AIDS programs, 2) the ongoing funding for prevention policies and access to ART, and 3) the creation of conditional fiscal transfer programs and partnerships with HIV/AIDS NGOs (Gomez, 2015, p. 316). The sustenance of the above measures were possible because of the Brazilian government's presidential electoral incentives to respond to HIV, its strategic usage of domestic investments in HIV as a means to boost its global reputation, the government's willingness to include civil society in the national policy agenda, and, a focus on a domestic response rather than ambitions of asserting leadership in global aid (Gomez, 2015).

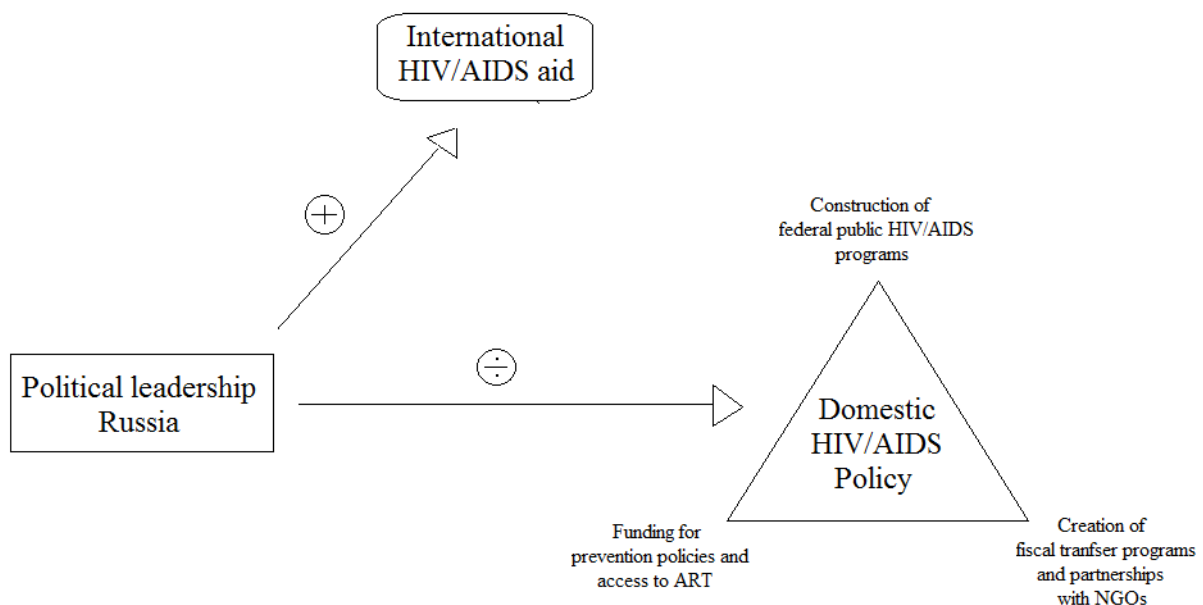
In contrast to Brazil, Russia's political institutions have never provided the incentives needed to invest in HIV/AIDS policy (Gomez, 2015, p. 316). As will be further discussed in Chapter 3.3.2, Russian NGOs have also been poorly included in the national policy agenda. Furthermore, as will be examined in Chapter 3.1, the Russian regime has not been devoted to scaling up domestic HIV/AIDS investments. And, while global health agencies, e.g. UNAIDS and WHO, have criticized the Russian response (or the lack thereof) for almost two decades, the political leadership has not responded to these pressures by using HIV as a tool to increase its global reputation, like Brazil arguably did. On the contrary, Gomez maintains that Russia's political leaders in recent years have prioritized to exhibit leadership in foreign aid, and that this foreign policy ambition has distracted the government from ensuring domestic HIV/AIDS programs the necessary financial and political support (2015, p. 316).

Gomez proposes an understanding of the dynamic between investments in domestic versus foreign aid as being affected by a country's historical policy traditions. He refers to this as the challenge of *historical policy backlash* (Gomez, 2015, p. 318). This backlash occurs when a country with long traditions of assuming leadership in foreign health aid suddenly experience a decline in its ability to sustain the donations. Once the financial situation improves, the country's legacy of being a donor rather than a recipient of health aid will create incentives for the government to restore its former leadership role and status. However, this commitment frequently seems to go at the expense of investments in domestic health policy. In contrast, governments without histories of being strong donors in foreign aid will not in the same way be bound by their legacies, and are more likely to focus on building an efficient domestic response to emerging public health challenges like HIV (Gomez, 2015, pp. 318–319).

In his article, Gomez argues that Russia has experienced a historical policy backlash in relation to HIV (2015, p. 324). The USSR had been a major donor in global health aid, providing financial support, medical personnel and technologies to both multilateral health agencies and directly to other socialist countries. After the USSR dissolution, Russia’s ability to sustain the donations declined (Twigg, 2010). Russia’s improved economy around the turn of the millennium then stimulated the authorities to restore the foreign health legacy inherited from the USSR. Between 2001 and 2007, Russia donated USD 115.7 million to the Global Fund, the world’s biggest financier of HIV/AIDS programs, (The Global Fund, 2017b) while overlooking necessary domestic investments in HIV.²⁰ The choice to channel efforts toward the global community can be interpreted as a means to recover Russia’s image as a super power, and also as a tool to strengthen Russia’s geopolitical influence (Gomez, 2015, p. 316).

Figure 3 is based on Gomez’ propositions and aims to illustrate how a historical policy backlash has affected the dynamic between foreign versus domestic HIV efforts in Russia:

Figure 3: Model based on Gomez' analytical framework, Russia and HIV/AIDS



Source: Gomez (2015). Model prepared by the author

Because of the historical policy backlash Russia experienced, Russian investments in HIV/AIDS has been concentrated toward the international community, which is marked + in Figure 3. This global focus has affected the political leadership’s efforts to invest in domestic

²⁰ The federal program “Urgent preventive measures to prevent the spread of HIV in the Russian Federation” (2002-2006) had a RUB 2.8 billion budget, but was grossly underfunded and insufficiently implemented.

HIV/AIDS policy negatively, which is marked ÷ in Figure 3. As a result, the three policy areas Gomez argues were vital to Brazil's success have been neglected, explaining why the Russian government has not been able to curb the spread of HIV domestically.

Gomez' propositions proved to be very useful during the explanation building process of this thesis. The collected evidence, potential rival explanations and additional propositions could all be systematically reviewed against the model in Figure 3. This process yielded some important insights. First, Gomez' article makes no explicit distinction between Putin's first two presidencies (2000–2008), Medvedev's presidency (2008–2012) and Putin's third term (2012–2018). This thesis argues that significant changes have occurred, in particular between Medvedev's presidency and Putin's third term, and that a historical policy backlash cannot fully explain the current Russian policy course. Second, Gomez' framework does not address the relationship between the global community and the Russian HIV/AIDS policy triangle. Examples are multi-lateral partnerships between Russian and global actors, financial support from foreign donors to Russian NGOs, or ART distributed to Russians via Global Fund grants. Arguably, this dynamic has played a major role in the absence of a viable domestic response to HIV in Russia, and should be included in a comprehensive theoretical framework.

2.3.3 Adapted theoretical framework: Two models

In light of the above, the present section will introduce an adapted theoretical framework that 1) reflects the contrasting approaches to HIV and the global community that exist between Medvedev's presidency (2008–2012) and Putin's third presidency (2012–2018), and 2) addresses the relationship between the global community and the Russian HIV/AIDS policy triangle. This framework has resulted from Gomez' propositions coupled together with the propositions presented in Chapter 2.3.1, and additional insights from this study's collected data. Because the discrepancies between Medvedev's presidency and Putin's third term are interpreted as being especially vast, these two presidencies will be at the center of attention in the following. For the same reason, the framework consists of two models; Chapter 2.3.3.1 addresses Medvedev's presidency, while Chapter 2.3.3.2 addresses Putin's third term.

2.3.3.1 Medvedev – pushing toward modernization

This thesis interprets Gomez' propositions of Russia experiencing a historical policy backlash in relation to HIV/AIDS as able to partly explain the course followed during Medvedev's presidency. Despite the financial crisis that hit Russia in 2008, the regime sustained, and

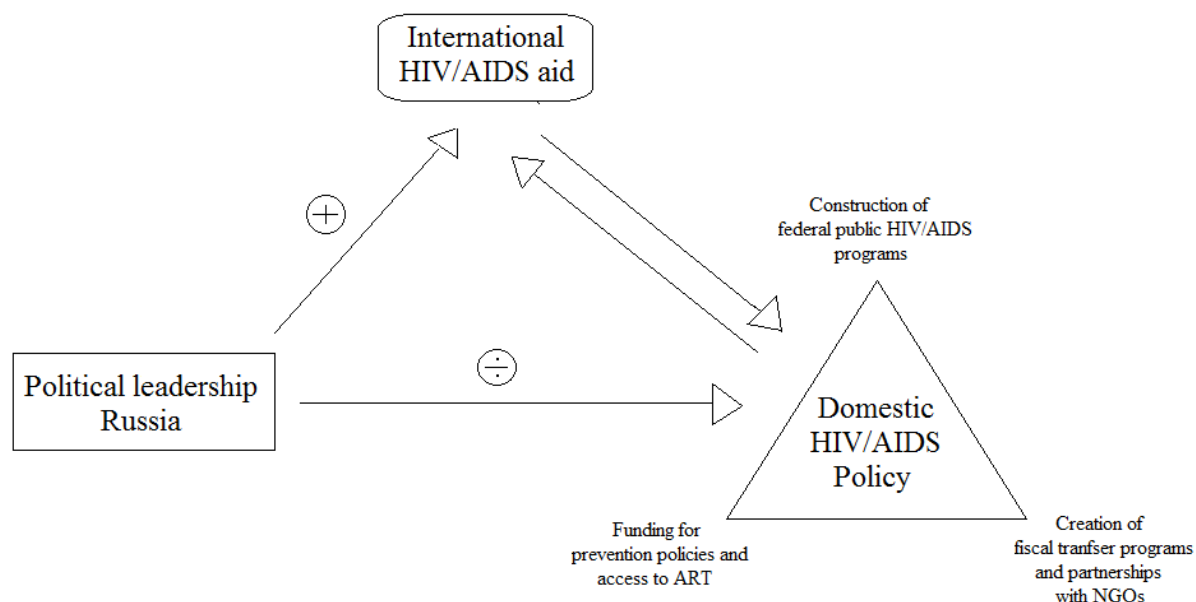
scaled up, its donations to foreign HIV/AIDS aid during his time in office. Between 2008 and 2010, Russia donated USD 141.3 million to the Global Fund, an amount exceeding all prior and later Russian contributions (The Global Fund, 2017b). In 2010, an additional USD 60 million pledge was made (The Global Fund, 2010). Less sizeable sums were also allocated to other global HIV programs, e.g. USD 2.95 million to UNAIDS (UNAIDS, 2010; UNAIDS, 2013a; UNAIDS, 2013b), while no new domestic programs were implemented. Hence, the weighty donations to global cooperation combined with the lack of a domestic effort seem to substantiate Gomez' propositions of Russia experiencing a historical policy backlash.

However, while increased donations to global HIV/AIDS aid during Medvedev's presidency may reveal that Russia experienced a historical policy backlash, in the sense that Medvedev used donations to strengthen Russia's image as a super power and as a global partner, it is less evident that these ambitions were solely responsible for the lack of a viable domestic response to HIV. As discussed in Chapter 2.3.1, Medvedev argued for institutional changes and a move toward a developed democracy in order to modernize Russia. However, he had inherited only the formal powers of the presidency, and, although having some leeway in setting out a policy agenda, he still had to face the constraints of Putin's vast informal power and the patronal networks that permeate Russia's political system (Ledeneva, 2013; Hale, 2015; Robinson, 2017). Without support from Putin and informal parts of the political system, he was not able to pursue his plans of modernization or to push Russia out of the neo-patrimonial space. In this light, it is unlikely that he could have used his position as president to ensure the domestic HIV/AIDS policy triangle sufficient support, even if he had made HIV a top personal priority.

However, civil society was allowed to operate with a degree of independence during his presidency, and NGOs involved in HIV prevention and treatment could receive support from sources other than the regime. Arguably, this resulted in a (limited) capacity to respond to HIV, despite the lack of direct engagement from the political leadership. Hence, Medvedev's openness toward the global community and his relatively liberal approach toward Russian civil society were arguably the most important HIV/AIDS policies he administered. An additional external factor able to assist the domestic HIV/AIDS policy triangle during Medvedev's presidency was Russia's World Bank classification as a middle-income country. This meant that Russia was eligible for grants from the Global Fund. Between 2008 and 2012, three grants were active in Russia, contributing with support to numerous HIV/AIDS NGOs.

Figure 4 presents an adapted theoretical framework, illustrating Medvedev’s presidency. Gomez’ theoretical propositions are retained, while arrows illustrating the dynamic between the global community and the Russian domestic HIV/AIDS policy triangle have been added:

Figure 4: Adaptation of Gomez’ framework, illustrating the period 2008–2012



Source: Gomez (2015). Model prepared by the author

During Medvedev’s presidency, Russia made significant donations to international HIV/AIDS aid, marked + in Figure 4. While a historical policy backlash seems to have occurred, in the shape of a means for Medvedev to convey the message that Russia was a partner of the global community, this thesis does not interpret a historical policy backlash as being the sole factor for the Medvedev administration’s negligence of the domestic HIV/AIDS policy triangle. Russian regime dynamics and the low quality of governance likely also contributed. Thus, the ÷ in Figure 4 illustrates both of the two above components (and not only a historical policy backlash, as it did in Figure 3). Reciprocal arrows have been added to the model in Figure 4, aiming to illustrate how the permitted interaction between the global HIV/AIDS community and the domestic HIV/AIDS policy triangle became essential during Medvedev’s presidency.

2.3.3.2 Putin – neo-patrimonialism preserved through cultural conservatism

As discussed in Chapter 2.3.1, Putin’s third term was marked by a restoration of his complete dominance of the political system, and accompanied by a distinct rhetorical shift. Instead of adopting Medvedev’s modernization plans and his predecessor’s interest in building relationships with the global community, Putin chose to pursue a rhetoric according to which

Russia is portrayed as a lonely defendant of tradition and culture in a world characterized by increasing (Western) moral degeneracy. Putin's new cultural conception of the state enables a rejection of political alternatives that could have pushed Russia out of the neo-patrimonial space altogether, and has strengthened his patrimonial grip on society (Robinson, 2017). Resulting from this cultural conservative shift is not only a stricter supervision with domestic actors, but also a more restrained Russian relationship with the international community.

Arguably, the shift in 2012 has hampered both global HIV cooperation and Russia's ability to build a domestic HIV response. Putin's re-election was followed by a total cut in Russian donations to the Global Fund. While having contributed with USD 317 million up until then, Russia was not found on the list of donor governments at the 4th (2013) or 5th (2016) Global Fund replenishment pledges conferences (The Global Fund, 2013; The Global Fund, 2016b). As Russia had previously been a leading donor,²¹ the withdrawal had a direct negative impact on international HIV/AIDS cooperation in financial terms. Its impact was felt also in more geopolitical terms, in the sense that it underlined the generally increased Russian hostility toward the global community. Russia has largely receded²² from being a participant in global HIV/AIDS cooperation, and Gomez' concept of historical policy backlash, when applied to HIV and Russia, is in practice probably no longer applicable.

However, a decrease in Russian donations to global HIV/AIDS aid was not the only change following Putin's return to presidency in 2012. Legislation aiming at reducing interaction between global actors and Russian NGOs has been introduced, resulting in less possibility for the HIV/AIDS policy triangle to receive structural and financial support from non-Russian sources.²³ Global agencies providing weighty financial support to Russian HIV/AIDS civil society, e.g. USAID (U.S. Agency for International Development) and UNICEF (United Nations Children's Fund) have been forced to leave the country, and many Russian NGOs have had their scope and impact severely limited by new legislation.²⁴ As such, the domestic situation is also drastically changed compared to Medvedev's presidency. Thus, what provided a (limited) capacity to respond to HIV before 2012, i.e. interaction with the global

²¹ Between 2002 and 2012, Russia was the 12th biggest country donor to the fund (The Global Fund, 2017b).

²² It should be noted that Russia has sustained its donations to UNAIDS, and has thus not completely withdrawn from being a donor in global HIV/AIDS cooperation. However, these donations constitute only a fraction of the previous total donations. Between 2008 and 2012, a yearly average of USD 40.3 million was spent on global HIV/AIDS aid in Russia, reduced to USD 5.5 million yearly between 2012 and 2016 (86.4% decrease) (The Global Fund, 2017b; UNAIDS, 2018; WHO, 2018). Please see Chapter 3.4.2 for further details.

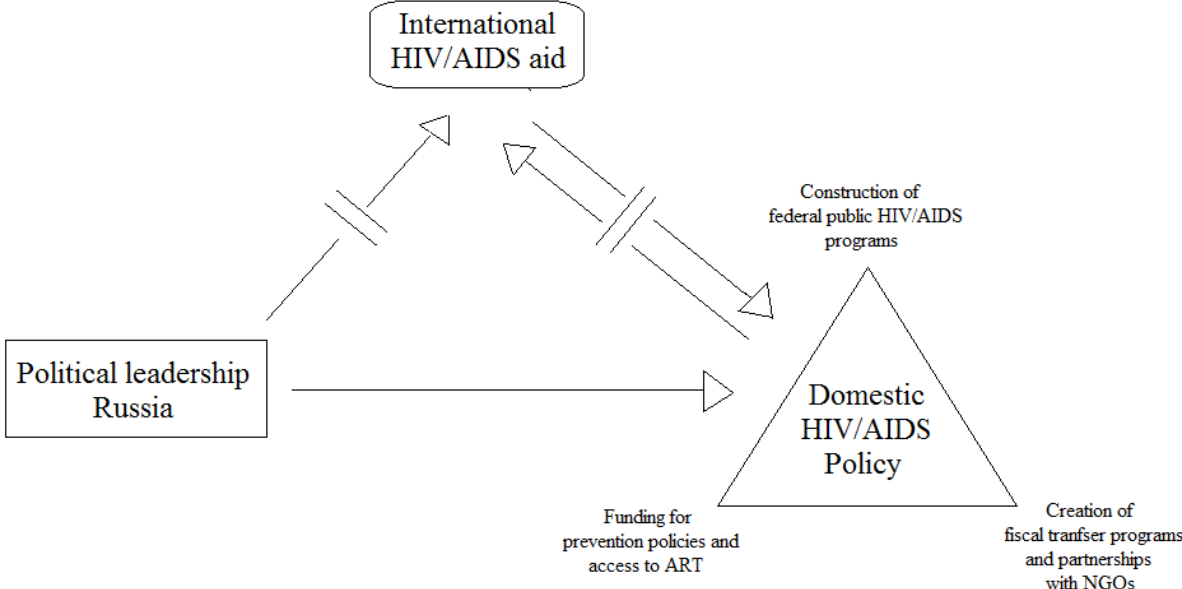
²³ This legislation as well as its implications will be discussed in detail in Chapter 3.3.2.

²⁴ Currently, six organizations working on HIV/AIDS are listed as "Foreign Agents" (Miniust, 2018b).

community and a relatively liberal approach to civil society, is no longer effective. Further decreasing the Russian capacity during Putin’s third term was Russia’s 2013 World Bank classification as a high-income country, causing the Global Fund to withdraw from Russia.²⁵

Figure 5 presents an adapted theoretical framework, illustrating Putin’s third presidency. The conservative shift has brought a situation where Russia’s political leadership essentially is the domestic HIV/AIDS policy triangle’s only source of support:

Figure 5: Adaptation of Gomez’ framework, illustrating the period 2012–2018



Source: Gomez (2015). Model prepared by the author

The model in Figure 5 illustrates the new reality established during Putin’s third presidency. The regime has significantly reduced donations to foreign HIV/AIDS aid, and also practically blocked the former cooperation between the global community and Russia’s domestic HIV/AIDS policy triangle, resulting in a situation where the triangle’s only source of support essentially is the Russian political leadership. Arguably, this is not a fortunate situation. The current conservative Russian climate and the hostile rhetoric toward the global community leave little expectations of Russia complying with its recommendations, e.g. decriminalizing OST or introducing state sponsored country-wide harm reduction initiatives. Although a 2016 approval of Russia’s first state HIV strategy in fifteen years can be interpreted as the regime scaling up its investment in domestic HIV/AIDS policy, the prospects of this strategy achieving notable results within the current neo-patrimonial framework are less evident.

²⁵ The fund returned in 2015 with a small grant (USD 10 million). Please see Chapter 3.4.1 for further details.

3 The context of the Russian HIV epidemic

Since the 1990s, the number of people living with HIV in Russia has increased dramatically, and Russia now faces a generalized HIV epidemic.²⁶ At present, Eastern Europe and Central Asia is the only region²⁷ in the world where the number of new infections is rising, and Russia accounted for more than 80% of new positive tests here in 2016 (UNAIDS, 2017a, pp. 4–5). Other parts of the world severely affected by HIV have been able to reduce virus spread over the last 10–15 years, mainly through broad coverage of harm reduction and prevention programs. However, in Russia, such initiatives remain highly controversial and are repeatedly met with vivid resistance. Further complicating the situation are major problems with the organization of HIV care, and the crackdown on NGOs and their foreign sponsors after 2012.

The current epidemic did not appear unannounced. Both medical researchers and the international health community have emphasized the severity of the situation in Russia over the last 20 years. In 2002, a report from the US National Intelligence Committee stated that:

Driven by widespread drug use, inadequate healthcare infrastructure, and the government's limited capability to respond, the number of HIV positive people [in Russia] probably will rise to 5 to 8 million by 2010. This condition would reflect an adult prevalence rate of around 6 to 11 percent, exacerbating Russia's population decline (NIC, 2002, p. 12).

Although available epidemiological data look less disheartening than the predictions above,²⁸ there is no doubt about the fact that Russian authorities never have succeeded in curbing the spread of HIV. The present chapter will therefore examine the context in which the Russian epidemic has evolved. As infectious diseases do not take international borders into account, it is impossible to give a comprehensive portrayal of the Russian situation without taking the global dimension into account, and the chapter will begin from the perspective of the global history of HIV. Chapter 3.2 then provides an overview of the specifically Russian history, including an update on current epidemiological trends, before Chapter 3.3 reviews the government's domestic HIV response. In order to provide a more thorough understanding of the institutional environment in which HIV policies are to be implemented, a review of the

²⁶ A generalized HIV epidemic is defined as when HIV is firmly established in the general population, and the prevalence exceeds 1% among pregnant women (WHO, 2013, p. 15). In Russia, 1.2% of the population aged 15–49 years are HIV-positive, and the prevalence among pregnant women has consistently exceeded 1% since 2002 (Federal'nyi Tsentr SPID, 2013, p. 7; Federal'nyi Tsentr SPID, 2015, p. 6; Federal'nyi Tsentr SPID, 2017, p. 3)

²⁷ Please note that UNAIDS defines Eastern Europe and Central Asia as constituting one and the same region.

²⁸ 589 581 Russians had been diagnosed with HIV by the end of 2010 (Federal'niy Tsentr SPID, 2010).

Russian health care system is included here. A section on Russian HIV/AIDS civil society and their current legal constraints then follows, as well as a presentation of domestic stakeholders lobbying against viable changes in Russia's HIV response, before the third section of this chapter closes with an analysis of eventual prospects of curbing the epidemic within the current neo-patrimonial framework. Chapter 3.4 then shifts back to the global perspective, and discusses Russian cooperation with the international health community more in detail. A thorough examination of Russia's role as both a donor and a recipient of HIV/AIDS aid will be provided here, before Chapter 3.5 addresses the social context of the Russian epidemic.

3.1 The history of HIV: A global overview

It is widely believed that HIV originated in Kinshasa, the Democratic Republic of Congo, around 1920 when the virus crossed species from chimpanzees to humans. However, HIV was unknown until the 1980s, and we do not know how many people were affected prior to that or whether or not they developed AIDS. After recurrent incidents of highly aggressive cancers, rare lung infections and severe immune deficiencies in several US cities in 1981, it was understood that the conditions could have a common cause (Aids.gov, 2015). The term AIDS was first used in 1982 by the Centers for Disease Control and Prevention (CDC), describing it as “a disease at least moderately predictive of a defect in cell mediated immunity, occurring in a person with no known case for diminished resistance to that disease” (CDC, 1982).

Prior to 1983, AIDS was mainly reported among men who have sex with men. Consequently, it was believed to be a “gay” disease. However, in January 1983 the CDC reported that female partners of men with AIDS also had been diagnosed, and this suggested the disease could be passed on also via heterosexual contact. Later that year, researchers at the Pasteur Institute in France discovered a new retrovirus, Lymphadenopathy-Associated virus (LAV), which they believed caused AIDS (Barré-Sinoussi et al., 1983). This was a big breakthrough, as detecting the virus made it possible to understand transmission patterns and develop recommendations to prevent further spread. By September 1983, all major transmission routes were identified, and transmission by casual contact, food, water, air or surfaces ruled out (CDC, 1983).

In 1984, researchers from the U.S. National Cancer Institute announced they had found the virus that caused AIDS, the retrovirus HTLV-III (Marx, 1984). This virus and the LAV discovered in France proved to be identical, and two years later the International Committee on the Taxonomy of Viruses officially renamed the HTLV-III/LAV with a virus group name;

HIV (Case, 1986). The first antiretroviral drug to treat HIV, the Zidovudine, also known as AZT, was approved in 1987 by the U.S. Food and Drug administration (DHHS, 1987). Later the same year, AIDS became the first illness to be debated in the United Nations (UN) General Assembly, demonstrating its severity and global impact. WHO launched its first global initiative in 1987 called “the Special Program on AIDS”.²⁹ Within two years, it was the biggest WHO program with a budget of USD 80 million (WHO, 1997, pp. 1–2).

In January 1996, UNAIDS was established, to advocate for global action and to strengthen the way in which UN was responding to HIV and AIDS. By then, almost 6 million people had died from AIDS, and an estimated 30 million people were living with HIV (UNAIDS, 1996). The majority of those affected lived in developing countries (93%), with the largest number of infected found in sub-Saharan Africa, comprising 68% of the global total (UNAIDS, 1996). HIV-positive faced stigma from the very beginning. Many of those affected already belonged to marginalized groups, e.g. men who have sex with men and drug users. Subsequently, HIV was frequently connected to sexual promiscuity or to behaving in an “unnatural fashion”. The response from both governments and the global environment was slow, while the epidemic escalated to devastating levels, fueled by ignorance and fear (Knight, 2008, pp. 8–9).

The 2000s brought some improvements. Pharmaceutical companies began producing generic ART, and several big manufacturers agreed to further reduce prices for low-income countries. In November 2001, the WTO presented the DOHA Declaration, which affirmed developing countries’ rights to buy and produce generic medication to fight public health crises like HIV (WTO, 2001). The Global Fund to Fight AIDS, Tuberculosis and Malaria was created the year after, at the initiative of the UN General Assembly (UN, 2001). During the last half of the 2000s, AIDS-related deaths finally started to decline. AIDS caused 1.9 million yearly deaths in 2005, a number that was reduced to 1.5 million in 2010 (UNAIDS, 2017a, pp. 1–2).

In 2014, UNAIDS set the “90–90–90 targets”, ambitious goals aiming to diagnose 90% of HIV-positive, provide ART to 90% of those diagnosed, and achieve viral suppression for 90% of those on ART. Achieving these targets by 2020 will enable us to end the global epidemic by 2030 (UNAIDS, 2014, p. 1). However, major challenges remain with prevention, and HIV continues to vary considerably between regions and populations. Sub-Saharan Africa remains most severely affected. However, the incidence in Eastern and Southern Africa was reduced by 29% from 2010 to 2016, and the number of AIDS-related deaths fell by 42%. At the same

²⁹ The program was renamed “the Global Program on AIDS” (GPA) in 1988.

time, Eastern Europe and Central Asia present highly alarming numbers. New infections here rose by 60% between 2010 and 2016, and deaths increased 27% (UNAIDS, 2017a, pp. 2–5).

In total, an estimated 76.1 million people have been infected with HIV since the first outbreaks in 1981. Of these, around 35 million have died from AIDS-related illnesses. Globally, approximately 36.7 million people were living with HIV in the end of 2016, which amounts to roughly 0.8% of all adults in the world aged 15-49 years (UNAIDS, 2017b, p. 1).

3.2 The Russian history of HIV

Compared to most countries affected by HIV, the USSR encountered the virus rather late, linked to the Cold War and the strict control placed on USSR citizens' movement and contact with foreigners (Field, 2004, p. 117). However, a Russian man had contracted HIV already in 1981, while working in Eastern Africa. After developing an unknown illness, he was brought to Moscow for treatment in 1982. As nothing was known of HIV in the USSR at the time, his HIV-positive status was not discovered. He was instead diagnosed with mononucleosis, and discharged in 1983 after prolonged treatment. Considering the man was not aware he had HIV, he unintentionally passed the virus on to several of his sexual partners, both men and women, over the next years (Medvedev, 1990b, p. 932). Because he did not receive treatment, his health continued to decline, and the man was diagnosed with Kaposi's sarcoma³⁰ in 1985, and AIDS in 1987. Many of his sexual partners were also diagnosed with HIV that year, in addition to other USSR citizens diagnosed in two mass screenings (Medvedev, 1990a, p. 860).

In 1995, only 1090 people had tested positive for HIV in Russia³¹ (Federal'nyi Tsentri SPID, 1995), a time when other parts of the world already faced an advanced virus spread. The main transmission route in Russia during these early years (1987–1995) was sex, with homo- and heterosexual contact each accounting for around 40% of cases. A significant number of new infections were also acquired in health facilities, and blood transfusions caused nearly 20% of cases in 1987. Some mother-to-child (vertical) transmission was also observed (Pokrovskii et al., 2017, p. 74). During the last half of the 1990s, transmission patterns underwent radical changes. The most significant development was that HIV started to spread among injecting drug users. From officially causing 6% of new infections in 1995, the share had risen to 84%

³⁰ Kaposi's sarcoma is a cancer usually seen in people with advanced HIV or AIDS (Abbas and Lichtman, 2009)

³¹ The probable inaccuracy of this estimate must be addressed. HIV surveillance in the 1990s mainly consisted of ineffective mass screenings, where 90% of those screened belonged to categories of the population least likely to be HIV-positive (Kalichman et al., 2000). Consequently, very few HIV-positive tests were detected.

the year after, and injecting drug use was responsible for 95.5% of new infections in 2000 (Federal'nyi Tsentri SPID, 2008, pp. 13–14). Sharing needles is one of the most efficient ways of transmitting HIV, and the cumulative number of people diagnosed with HIV consequently rose from 1090 to 89 808 (+8139%) between 1995 and 2000 (Federal'nyi Tsentri SPID, 2000).

The spread of HIV among injecting drug users occurred at a time when drug abuse overall increased in Russia,³² a trend likely related to the financial, political and social instability that shook post-Soviet Russia in the 1990s. The number of patients in drug treatment rose from 64 896 in 1995 to 269 064 in 2000 (Rosstat, 2005), and UNDCP estimated that 0.9% of the Russian population were abusing drugs by the end of 1999, the bulk injecting opiates (2000, p. 185). As the Soviet state dissolved, borders had opened and trafficking routes from Afghanistan through easily permeable former Soviet Central Asian borders blossomed. Trafficking on the so-called northern route (from Afghanistan via Central-Asia to Russia) became one of the main trafficking flows of heroin in the world, supplying the growing number of opiate addicted Russians with cheap products (UNDCP, 2000, p. 58).

Injecting drug use continued to be a main transmission route in Russia during the 2000s. More men than women injected drugs, and 79% of all new positive tests in 2000 belonged to men. However, a steady increase in heterosexual transmission was observed from around that time, a development entailing an increased share of women acquiring HIV. In correspondence with the increased heterosexual transmission, the share of new cases acquired through injecting drug use declined. Russians testing positive for HIV also gradually got older. In 2000, 87% of those newly infected were 15–30 years, a share reduced to 42% in 2010. The biggest rise in new infections was seen among people aged 30–40 years (Pokrovskii et al., 2017, pp. 72–74).

3.2.1 Current epidemiological situation in Russia

By the end of 2017, roughly 1.2 million Russians have tested positive for HIV. The highest HIV prevalence is currently found among men aged 35–39, where a striking 3.3% are living with HIV. In 2017, around 32 000 HIV-positive Russians died. Tuberculosis was the leading cause of death, and the mean age at death 38 years (Federal'niy Tsentri SPID, 2017, pp. 1–5).

It is estimated that around half of all HIV positive Russians are aware of their status, far away from achieving UNAIDS' targets (Levi et al., 2016, p. 5). This is very unfortunate, as people infect others without knowledge of their own HIV-positivity. They also miss out on receiving

³² Between 1992 and 2000, the incidence of drug addiction in Russia rose from 3.5 to 50.7 (Rosstat, 2010).

treatment and care. Treatment coverage in Russia is also far from UNAIDS' targets. In 2017, 35.5% of all Russians registered as living with HIV received ART (Federal'nyi Tsentri SPID, 2017). Low treatment coverage is another concern, as those untreated are at much higher risk of passing on HIV, than people receiving treatment. ART also significantly improves the length and the quality of HIV-positive's lives (WHO, 2017a). Among those on ART, the share exhibiting a suppressed viral load (82.5%) is actually not bad (UNAIDS, 2016, p. 178).

The epidemic is shifting from primarily affecting key populations, to increasingly affect the general population. In 2017, 53.5% reported heterosexual contact as the route of transmission, while 43.6% had contracted the virus through injecting drug use. Roughly 2% of cases were acquired via homosexual contact (Federal'nyi Tsentri SPID, 2017, p. 3).³³ The heterosexual turn has affected the gender distribution, with an increased share of women infected (roughly 40% in 2016). It has also exposed a broader age range to HIV, as sexual activity is not in the same way as injecting drug use concentrated within a certain age group. Consequently, around 75% of those diagnosed in 2016 were above 30 years old. However, it is important to note that many Russians are diagnosed late, i.e. they are younger when they contract HIV than what official data show. In 2016, 40% of newly diagnosed Russians had CD4 cell counts below 350/mm³, signaling they had been HIV-positive for years (ECDC, 2016, p. 17).³⁴

In 2017, the Russian HIV incidence was 71.1 (per 100 000 inhabitants). Kemerovo Oblast' presented the highest number (203.0), and the other top 5 spots were occupied by Irkutsk (160.7), Sverdlovsk (157.2) Cheliabinsk (154.0) and Novosibirsk (142.8). The prevalence was 643 (per 100 000), i.e. 0.64% of all Russians were HIV-positive. Eleven federal subjects had more than 1% of the population living with HIV: Sverdlovsk (1741.4), Irkutsk (1729.6), Kemerovo (1700.5), Samara (1466.8), and Orenburg (1289.5) oblasts, Khanty-Mansiisk Autonomous Okrug (1244.0), Leningrad (1190.0), Cheliabinsk (1174.4), Tiumen (1161.2), and Novosibirsk (1118.8) oblasts, and Perm Krai (1043.3) (Federal'nyi Tsentri SPID, 2017, pp. 1–2). The figures above show that a few regions carry the main burden of the epidemic.

³³ It is reason to believe that the actual share is slightly higher. A decrease in women getting infected from 2013 is observed, indicating that men who have sex with men may report heterosexual contact as the transmission route instead of disclosing their homosexuality (Pokrovskii et al., 2017, pp. 72–73). Arguably, this is related to the tougher official rhetoric toward homosexuality in Russia seen during Putin's third term.

³⁴ HIV infects immune cells, mainly CD4 T-lymphocytes, and causes their progressive destruction. HIV-positive will therefore experience a gradual CD4 cell loss. A blood sample can measure CD4 counts, and be used to determine how far HIV has progressed. Counts below 200/mm³ are usually defined as AIDS. A normal CD4 count of a healthy immune system is usually 1000–1500 cells/mm³ (Abbas and Lichtman, 2009, pp. 231–235).

3.3 Government response to HIV in Russia

As previously noted, the USSR remained relatively untouched by HIV during the first half of the 1980s, and state monitoring was therefore not initiated until 1986. Two mandatory mass screenings of selected groups were then performed, the first one in Moscow in 1986 and the second in several big cities across the USSR in 1987. Of over 90 000 people tested, 246 tests came back positive. A majority (86%) of those testing positive were African students, 11% Soviet citizens, and the remaining 3% other foreign students. All USSR citizens identified belonged to key populations similar to those in the West, i.e. sex workers, drug users and men who have sex with men. It seemed there was no pressing danger to the general population, and the Soviet Ministry of Health expected to be able to curb the virus spread by pursuing a repressive approach toward those affected. This included deportation of all HIV-positive foreigners and isolation of USSR citizens in a hospital in Moscow (Medvedev, 1990a, p. 860).

In 1987, a new decree introduced compulsory HIV testing for all foreigners staying more than three months in the USSR, in addition to citizens who had visited Africa. Criminal liability for transmitting HIV or putting others knowingly at risk was also introduced, making it possible to legally isolate HIV-positive from the general population (Medvedev, 1990a, p. 861). No informational campaigns were conducted, and HIV was rarely mentioned in Soviet media. If so, it was usually presented as an infection of “the West”, and not something USSR citizens needed worry about (Pape, 2012, p. 72). It was also speculated that AIDS was caused by US biological weapons experiments, a conspiracy theory that had been campaigned by KGB in foreign media for years (Qui, 2017). After HIV outbreaks among newborns in USSR hospitals in 1988–1989, mandatory screening of pregnant women was introduced. An AIDS commission was also created, and it was announced that funding would be allocated to produce condoms and disposable syringes. Regional AIDS treatment centers were planned, and doctors willing to work with HIV promised salary supplements to compensate for the risk. At the same time, articles on HIV/AIDS started to disappear from USSR medical journals, illustrating the strict censorship imposed to reduce knowledge, reporting and discussion in the medical community (Medvedev, 1990b, pp. 933–934).

The Soviet narrative above is important, as it shaped Russia’s HIV response after 1991 (Pape, 2014). The mass screenings were maintained, absorbing resources while producing minimal public health benefit. A massive 90% of those screened belonged to population groups least likely to be HIV-positive, and very few positive tests were detected (Twigg and Skolnik,

2005). The screenings also likely lead to prejudice and stigma, as the names of those infected were put in a central registry (Kalichman et al., 2000). In 1993, the first federal HIV program was introduced, and the second followed three years later. However, minimal funding was allocated to the programs, making their impact negligible (Bobrik and Twigg, 2006, p. 26).

In 1995, a new law brought all HIV/AIDS activity under federal jurisdiction and guaranteed free treatment and care to HIV-positive. In an attempt to bring the increased transmission among injecting drug users under control, a new law on “Narcotic and Addictive Substances” was adopted in 1998, making all drug consumption not prescribed by a physician illegal. OST was simultaneously criminalized, in sharp opposition to recommendations from agencies like UNAIDS and WHO. The law had several unfortunate consequences, e.g. it was frequently used to terminate needle exchange programs, and health workers reported reluctance to teach drug users how to inject safely in fear of prosecution (Twigg and Skolnik, 2005, pp. 12–15).

First in the beginning of the 2000s, state officials recognized that HIV potentially could pose a threat to Russia, and more substantial programs were introduced. The federal program “Prevention and Fight against Diseases of a Social Nature” was implemented between 2002 and 2006, in which a sub-program called “Urgent preventive measures to prevent the spread of HIV in the Russian Federation” (shortened “Anti-HIV/AIDS”) was included. The stated goals in the resolution from the Russian Ministry of Health (Minzdrav) were comprehensive:

The main objectives of this sub-program [...] are to stabilize the epidemiological situation of HIV/AIDS, and to prevent a mass spread of HIV, especially among young people. Its implementation will include: modernization of the AIDS centers, [...] establishment of a permanent system that can inform the public about HIV prevention, creation and broadcasting of thematic programs on HIV/AIDS through state TV and radio channels, [...] introduction of anonymous consultations, [...] development of a single, unified reporting system [...], improvement of diagnosis and treatment among incarcerated people, provision of social protection to HIV-positive people and their families through the creation of psychological and social support offices in the AIDS centers [...] (Minzdrav, 2001, pp. 8–9).

The document proposed a RUB 2.8 billion budget for the implementation of these measures, of which roughly one-fourth was to be provided from the federal budget, and the rest from the respective federal subjects’ budgets (Minzdrav, 2001, pp. 42–43). However, the program was grossly underfunded and its stated goals never achieved. This was reflected in transmission rates, which more than doubled between 2002 and 2006 (Federal’nyi Tsentr SPID, n.d.).

While Minzdrav seemed to take HIV relatively seriously in 2001, Russia's unfolding epidemic was not mentioned publicly by the president until a year into the new sub-program. Putin broke the silence during a state of the nation address, in which he addressed Russia's demographic decline and commented on how AIDS contributed to the negative trend:

Over the last years, the mortality rate [in Russia] has continued to grow. In three years, it has increased by 10 percent. Meanwhile, life expectancy has continued to decline. [...] The spread of so-called “new” epidemics, including drug addiction and AIDS, is only making the situation worse (Putin, 2003).

The president did not, however, present any specific strategies or plans on how to get these epidemics under control. He also left out any remarks on how the implementation of the “Anti-HIV/AIDS” sub-program was proceeding. Instead, Putin spoke about the importance of Russia transitioning to an insurance-based health care system, and emphasized the potential and importance of legal immigration contributing to more positive demographic trends.

Although drug addiction was referred to as a “new” epidemic by the president in his speech, key populations were still neglected, and the “Anti-HIV/AIDS” resolution from the health ministry did not even mention drug users (Minzdrav, 2001). Thus, their only support came from another neglected part of society, i.e., civil society. Of the about 300 HIV/AIDS NGOs active in Russia in 2005, the majority received foreign support (Pape, 2014). Conservative parts of civil society were also involved, e.g. pro-life organizations, ROC and the Communist Party (CPRF), all sharply opposed to harm reduction. Their achievements included a reduction in public spending on family planning programs, the cancellation of a UNESCO sex education project in Russian schools, and the termination of an anti-AIDS campaign in Moscow organized by Doctors Without Borders (MSF) (Twigg and Skolnik, 2005, p. 19).

A possible policy shift was signaled in April 2006, when Putin called for an assembly of the Presidium of the State Council, an advisory body to the Russian Head of State. In his opening speech, “Opening Remarks at State Council Presidium Meeting on Urgent Measures to Combat the Spread of HIV-AIDS in the Russian Federation”, Putin expressed his concerns:

So far, the situation in Russia is what we call a concentrated epidemic, it is concentrated among certain risk groups. However, specialists have begun observing a dangerous trend, where the infection spreads outside these groups. Such an alarming situation requires an appropriate response, we need action instead of contemplation, and all parts of Russian society

must get involved. Of course, people directly responsible for working with HIV should set the tone, but it is necessary to also include politicians, teachers, cultural figures and representatives from mass media in this work. Our common task is to promote a healthy way of life and raise awareness of the importance of moral values (Putin, 2006).

Putin also noted that RUB 3.1 billion (approximately USD 175 million) had been allocated to prevention, diagnosis and treatment of HIV, AIDS and viral hepatitis that year, an amount exceeding all former budgets, demonstrating the government's newfound commitment. However, although referring to "risk groups", Putin seemed predominantly occupied with the fact that HIV had now started to affect "normal" Russians, not only less desirable parts of society. Moreover, his emphasis on promoting "a healthy way of life" and "moral values" did not exactly signal that key populations would get the necessary support. Nevertheless, some improvement was seen from his 2003 speech, as he addressed the need for the development of an efficient long-term strategy, accentuated the possibility of Russia learning from other countries' experiences, and called for improved coordination between different state bodies:

Our first task is to develop a long-term strategy to combat this epidemic and overcome its consequences. The five-year sub-program "Anti-AIDS/HIV" ends this year. [...] Our second task is to organize accurate and objective monitoring of the epidemic. [...] we need to establish a system that meets common international standards. A comprehensive data base enabling us to really assess the causes of this illness and the efficiency of preventive medical and social measures is needed, in order to respond adequately to HIV and, of course, we should also take the experience of other countries into account. Another topic to be discussed today is the coordination of activities between federal ministries and agencies (Putin, 2006).

Although the need to establish an accurate HIV monitoring system was evident, the Federal AIDS Center had at this point been publishing detailed epidemiological data for more than a decade. Thus, general transmission patterns were well understood. Moreover, evidence on the efficiency of various prevention strategies was easily available from other countries. While acknowledging that Russia could learn from the global community, Putin did not seem very concerned about complying with their recommendations. Despite Russia's adoption of the UN universal access targets' assessment in 2006, which states that "National Governments, where needed, should remove legal, regulatory or other barriers that block access to effective HIV-prevention interventions and commodities such as condoms and harm reduction" (UN, 2006,

p. 12), OST³⁵ was not decriminalized, and harm reduction remained highly controversial. Putin noted that the legislation needed revision, but focused on tougher criminal liability for intentionally passing on HIV rather than improving the situation for those already infected:

Another issue we must work on together is improving the legislation related to the fight against AIDS. The law on HIV prevention that was passed in 1995 provides quite wide-reaching guarantees for the rights of people affected by AIDS. However, it does not fully take into account the responsibility issue for the deliberate spread of HIV [...] (Putin, 2006).

In his closing remarks, the president stressed the importance of informational campaigns, and the need to include non-governmental actors. This time he also included civil society:

We need to persistently and consistently inform people about how dangerous HIV is, and how great the risk of contracting the infection is today. [...] Many projects and programs of this kind are already being implemented in Russia. However, they are not united by a common strategy. [...] we need to involve the business community, political parties and civil society organizations more actively [...] (Putin, 2006).

Three months after Putin's speech, Russia hosted a G8 summit as part of their G8 presidency. Here, infectious diseases were for the first time made a top priority, on Russia's initiative (Kirton et al., 2014, p. 155). One of the documents adopted, "Fight against infectious diseases", included a joint HIV/AIDS statement calling for increased cooperation between governments, civil society, those affected and private partners, better access to prevention and treatment for key populations, and higher public awareness (G8, 2006). After the summit and Putin's Presidium of the State Council speech, HIV gained somewhat momentum in Russia, and an AIDS commission was created, consisting of representatives from federal agencies and ministries, parliamentarians, and civil society delegates. Its main task was to coordinate federal and regional bodies in the implementation of a new national HIV policy (Twigg, 2012, pp. 4–5). Political awareness of HIV in Russia remained high over the next years, interpreted by many observers as a step toward a more viable Russian response to HIV (Pape, 2014).

In May 2009, then President Medvedev approved the "National Security Strategy of the Russian Federation until 2020". Compared to the one it replaced, "National Security Concept" (2000), the new strategy presented a less hostile attitude toward Western actors, e.g. EU and

³⁵ The use of OST in preventing the spread of HIV is supported by strong evidence. OST results in fewer unsafe injections, which again reduces HIV transmission. OST also increases chances of receiving ART (and thus viral suppression), which improves HIV-positive's life and prevents onward transmission (Gowing et al., 2013).

the US, and placed a greater emphasis on the significance of Russian citizens' life quality in a security perspective. Thus, the concept of national security was expanded from the need to protect Russia from perceived internal and external threats, to also include personal protection for its citizens. Among the goals in the section on life quality are poverty reduction, increased food safety, improved access to medicines and health care, reduction in organized crime and drug use, and protection of human rights. According to the strategy, this would facilitate a population stabilization, which in turn could result in an improved demographic situation (Sovet Bezopasnosti, 2009, pp. 16–18). The strategy also has its own section on health care:

The strategic national security goals in the sphere of public health are as follows: to increase life expectancy, reduce disability and mortality; improve disease prevention and the provision of high-quality primary health care and high-tech medical assistance; improve the standards of medical assistance, and ensure quality control, efficiency and safety of medicines. Among the main threats to national security in the sphere of health is the emergence of large-scale epidemics and pandemics, the massive spread of HIV, tuberculosis, drug addiction and alcoholism, in addition to increased access to psychoactive and psychotropic substances (Sovet Bezopasnosti, 2009, pp. 24–25).

However, the section is rather general and does not present any plans of how to approach HIV or Russia's many other health challenges. Civil society seems somewhat randomly included, and it remains unclear how its cooperation with national security forces should work:

In order to counteract threats to health care and the health of our nation, national security forces in cooperation with civil society institutions will ensure the effectiveness of state-legal regulation in the following areas: standardization, licensing, certification of medical services, accreditation of medical and pharmaceutical institutions, provision of state guarantees in medical care and modernization of the compulsory medical insurance system and definition of common evaluation criteria for the assessment of health care institutions both at the municipal level and in the federal subjects of the Russian Federation (Sovet Bezopasnosti Rossiiskoi Federatsii, 2009, pp. 25–26).

Despite the concerns raised above, the security strategy's focus on health, social problems and Russian citizens' well-being must be considered an innovation.³⁶ This “security through social

³⁶ Under section III: “Threats to the National Security of Russia” in the 2000 Security Concept it is stated that “the crisis of the health care and the social protection systems, and the increase in alcohol consumption and drug addiction are threats to the nation's physical health”. Thus, although health and social challenges received some attention, it is not as explicitly and thoroughly presented as a security issue, as in the 2009 strategy.

development” logic can be interpreted in several ways. Because the document declares improvement of the demographic situation a priority, increased efforts to provide decent health care and social support to citizens seems logical, as it would be expected to help turn around the demographic decline, which itself presents a threat to national security. However, Medvedev’s aim to present Russia as a partner in the league of modern super powers may also have contributed. Health issues, and especially HIV, had for nearly a decade been recognized as security issues by the international community (Sjöstedt, 2008, p. 16). While Putin was willing to accept this norm abroad and donated substantial amounts to global HIV cooperation,³⁷ less effort was made to accept that the same norm would apply also to Russia (Sjöstedt, 2008, p. 22).³⁸ In this regard, the strategy’s focus on health and HIV signals a shift. It may be understood as reflecting the identity construction proposed by Medvedev, in which Russia was presented as a partner of the global community rather than an opponent.

However, a coherent Russian effort was still missing. As Putin correctly pointed out in 2006, a main barrier remained the lack of cooperation between different state institutions. At a press conference in 2010, Vadim Pokrovskii, head of Russia’s Federal AIDS Center, said he was not aware that the AIDS Commission created in 2006 had held one single meeting. He also criticized the lack of coordination and cooperation, and recent cuts in expenditures on HIV prevention. In 2009, the Federal Program to fight AIDS and the National Priority Program “Health” received USD 12.8 million, but the funding was completely cut for 2010 (Alekseev, 2010), probably related to the global economic crisis, constraining the regime’s ability to run social programs (Pape, 2014, p. 87). Anyhow, the increased interest in HIV that had been seen from the mid-2000s definitely seemed to have slowed down in the 2010s (Pape, 2014, p. 75).

In October 2016, the first new national HIV policy in fifteen years, the “State Strategy to Combat the Spread of HIV in Russia through 2020 and beyond” was signed by then Prime Minister Medvedev. Its main goal is to “decrease the number of new HIV cases and reduce AIDS mortality”. The following key tasks are stated: 1) increase awareness and knowledge of HIV, 2) ensure an integrated approach of both medical and social support to HIV-positive, 3) develop and implement technologies for social rehabilitation and support to HIV-positive, 4) improve legislation affecting HIV prevention, 5) employ science in HIV prevention and

³⁷ Between 2000 and 2007, Russia donated a total of USD 115.7 million to the Global Fund to Fight AIDS, Tuberculosis and Malaria, and USD 3.5 million to UNAIDS (The Global Fund, 2017b; UNAIDS, 2018).

³⁸ It should be noted that Putin’s 2006 speech on HIV also has been interpreted as a securitization move (Sjöstedt, 2008), although he did not explicitly call the infection a threat to national security (Putin, 2006).

treatment, 6) improve epidemiological surveillance, and 7) improve the coordination between health facilities providing HIV services (Pravitel'stvo Rossiiskoi Federatsii, 2016, pp. 5–1).

However, experts have criticized the strategy for not including recent WHO treatment guidelines, for having an incomplete section on key populations, and for not containing any specific plans on how to achieve the main objective or implement the key tasks (Clark, 2016). In contrast to UNAIDS' "90–90–90" targets, the strategy also sets a less ambitious target of providing ART to 56% of those diagnosed, and does not include any information on how it should be financed (Pravitel'stvo Rossiiskoi Federatsii, 2016). In November 2016, the Russian news agency RBK reported that a draft from Minzdrav proposed a RUB 70 billion budget (USD 1.2 billion), and that an additional USD 300 million also was suggested to be allocated. However, the Ministry of Finance (Minfin) rejected this requested funding, reportedly on basis of a lack of federal funds (Zvezdina, 2016). Without sufficient funding, the strategy's impact will likely be insignificant, and Minfin's decision reflects a lack of willingness and ability to seriously respond to the epidemic (Zardiashvili, 2017).

A month after the new strategy was approved by Medvedev, a new national HIV prevention campaign called #STOPHIVAIDS was launched by his wife Svetlana. The campaign is organized by the "Foundation for Social and Cultural Initiatives", where Svetlana is president. The campaign is part of the 2016 state strategy and will be implemented with the participation of Russian ministries and agencies. During the event, Medvedeva herself commented that:

The main objective of this action is to inform the population about HIV prevention, methods of timely diagnostics and the infection's irreversible consequences once it develops, and to create conscious and responsible behavior among young people [...] Particular attention is paid to informational work among high-school pupils, students, military personnel and young people in prison (Minzdrav, 2016b).

Public events, film screenings, free anonymous express HIV testing and social media events are arranged during special #STOPHIVAIDS-weeks. Thus far, four weeks have been organized, the most recent in November/December 2017. In a speech held at the 3rd all-Russian forum for specialists on HIV and AIDS, connected to this fourth #STOPHIVAIDS week, the Russian Health Minister Veronika Skvortsova talked about how Russia had been able to reduce the spread of HIV, and stressed the importance of increased testing coverage:

[...] for the first time in recent years our common measures to combat the spread of HIV and reduce AIDS mortality have started to bring real results. [...] Although there has been an annual increase in the number of new infections since 2006, on average yearly by 10–12 percent, the measures taken have made it possible to reduce the rate of new cases by nearly two times. This is a result of the increased testing coverage [...] (Minzdrav, 2017)

Russia indeed screened a lot of people in 2016, but a scarce 0.3% of the tests came back positive, demonstrating the inefficiency of the current surveillance system.³⁹ Furthermore, Skvortsova's claims about the rates of new infections being nearly halved are contradicted by data from the Federal AIDS Center.⁴⁰ The Health Minister's statements efficiently summarize what seem to be main deficiencies in the state HIV response; efforts are not made toward those most in need and HIV policies are crafted without a realistic assessment of the situation.

3.3.1 The Russian health care system and the organization of HIV care

Russia inherited its health care infrastructure and institutions from the system established in the USSR, and the Soviet legacy has informed much of the Russian discourse and practices (Popovich et al., 2011, p. xvi). This is true both for the organization of the health system in general, and the care offered to HIV-positive. In light of the above, a brief overview of USSR policies and HIV care is included below, before a review of the current system follows.

Article 42 in the Soviet constitution guaranteed citizens the right to “free, qualified medical care provided by state health institutions” (USSR, 1977). The system itself, based upon what is known as the Semashko model,⁴¹ was in many ways equitable, but also proved to be full of flaws. One of its main deficiencies was the policy of constant expansion, combined with no system of quality management (Tkatchenko et al., 2000, p. 165). Success was measured in numbers, rather than the outcomes achieved. This approach generated several expensive mass screening campaigns and an unusual high number of hospital beds and physicians per capita.⁴²

³⁹ In 2016, a total of 32 855 597 people were tested for HIV in Russia. Of these, 103 438 tests were HIV-positive. Only 4.7% of those tested belonged to key populations (Federal'nyi Tsentri SPID, 2016, p. 4).

⁴⁰ Between 01.01.2016 and 01.01.2017, 106 140 Russians tested positive for HIV, that is, a 10.5% increase.

⁴¹ The Semashko model proposed a centrally planned and administered system, in which the state assumed full responsibility for health care. All personnel were state employees, and private practice prohibited. Care was delivered through a complex network of service providers, ranging from local nurse posts and health centers, to district polyclinics and hospitals, regional polyclinics and hospitals and, on top, country-wide polyclinics, hospitals and “centers of excellence”, all connected by a referral system. Coordination between institutions and levels was usually poor, which frequently led to a duplication of services and inefficient treatment (WHO, 1998).

⁴² In 1990, there were 4.1 physicians per 1000 people (world average 1.3) and 13 hospital beds per 1000 people (world average 3.7) in the USSR (The World Bank, 2018f; The World Bank, 2018g).

However, doctors were overall poorly qualified, and the indiscriminate use of inpatient care required enormous resources (Popovich et al., 2011, p. 15). Assessments of actual needs and health promotion approaches were largely ignored. Gross underfunding, inefficient spending mechanisms and a widespread use of informal networks⁴³ to obtain quality services further aggravated the organizational deficiencies pointed out above (Younger, 2016, p. 1087). Consequently, the quality of even basic services was remarkably uneven, and the system was overall highly inefficient (Tkatchenko et al., 2000; Bobrik and Twigg, 2008; Younger, 2016).

When the first cases of HIV were detected in the USSR in the last half of the 1980s, Minzdrav created a centralized system of separate AIDS centers, which (only) provided surveillance. HIV-positive Soviet citizens were, as mentioned, isolated in a Moscow hospital. A network of specialized laboratories was also created, prepared to perform mass scale testing. In line with the Semashko model's hierarchical system of separate institutions with little coordination in between them, no overarching program to coordinate HIV activities in the USSR was set up, and the new AIDS centers never integrated into primary health care (Sharma et al., 2008). As a result, health professionals remained untrained and uninformed about HIV, and the system's ability to reach the general population was undermined (Bobrik and Twigg, 2006, pp. 16–17).

After the dissolution of the USSR, the need to reform how health care was financed became evident. In order to secure a steady financial flow, a model based on regional governance was introduced, funded by a hybrid public-private mix of sources⁴⁴ (Popovich et al., 2011, p. xiii). Former problems with underfunding were thought to be addressed through the dependence on other sources than solely Minzdrav's budget (Burger et al., 1998, pp. 755–756). However, while funding had been scarce in the USSR, newly independent Russia was practically ribbed of resources. In 1995, only 5.4% of Russia's GDP was spent on health, a share that had not increased by 2000 (The World Bank, 2018a). It was common for hospitals to require patients to bring food, linens and medication, and health care facilities often lacked equipment and medicines (Bobrik and Twigg, 2006). Confusion remained over how the new system should work, and the degree of success in the federal subjects varied. As a result, parallel systems of health care were created, and the role of informal payments⁴⁵ was expanded and strengthened (Burger et al., 1998; Tkatchenko et al., 2000). The separation of HIV care was upheld.

⁴³ The USSR was penetrated by informal networks, where people used personal acquaintances in order to obtain different goods and services, such as food, health care, education and consumer goods (Ledeneva, 2013, p. 9)

⁴⁴ Russia passed a new law on health financing in 1993, which introduced compulsory medical insurance. A 3.6% wage bill tax was set, to be paid by all employers and employees (Popovich et al., 2011, pp.16–17).

Currently, a mix of government revenues, payroll contributions and out-of-pocket payments finances Russian health care. The range of benefits covered is quite comprehensive, but the system has consistently been undermined by a lack of resources and informal payments. Table 1 below presents an overview of health expenditure and mortality rates from Russian and other selected Upper Middle (UM) and High Income (HI) countries:

Table 1: Health expenditure, % of GDP and mortality rate, selected UM/HI countries:

Country	Total % of GDP (2014) spent on health (public/private)	Mortality rate (2014) per 1,000 male/female adults
Algeria (UM)	7.2% (5.2/2.0)	109/86
Brazil (UM)	8.3% (3.8/4.5)	196/96
Colombia (UM)	7.2% (5.4/1.8)	193/89
Korea (HI)	7.4% (4.0/3.2)	92/38
New Zealand (HI)	11.0% (9.1/1.9)	81/53
Russia (HI/UM)⁴⁵	7.1% (3.7/3.4)	322/120
Samoa (UM)	7.2% (6.5/0.7)	144/71
Slovenia (HI)	9.2% (6.6/2.6)	95/44
Uruguay (HI)	8.6% (6.1/2.5)	137/77
Upper Middle average	6.2% (3.4/2.8)	142/85
High Income average	12.3% (7.7/4.6)	109/60
World average	9.9% (6.0/3.9)	179/120

Source: The World Bank (2018b, 2018c, 2018d, 2018e). Table prepared by the author.

As Table 1 shows, Russia spent 7.1% of its GDP on health in 2014, a relatively low figure considering the country's economic development. Russia also relies quite heavily on private expenditure in comparison with other UM and HI countries. The replacement of public health expenditure with private out-of-pocket payments since 1991 has contributed to a less equitable distribution of health resources between populations and regions. Rural populations' access to medical services is lower than that for people living in big cities, and wealthier people more frequently seek health care than poorer layers of the population (Popovich et al.,

⁴⁵ Russia was classified as UM 2004–2001, HI 2012–2014 and UM again from 2015 (The World Bank, n.d.).

2011, pp. xx–xxi). Russia also registers significantly higher mortality rates than countries with similar health expenditures, and the mortality rates have actually worsened since the USSR collapse (316/116 in 1990). All of these features point to the current system’s inefficiency.

Outpatient prescription drugs are generally not included in Russia’s health care package, but people living with HIV are guaranteed free treatment by law. However, Russians on average wait three years from being diagnosed with HIV until they start treatment, and only one-third of patients received ART in 2017 (Fernando and Allan, 2014; Federal’nyi Tsent SPID, 2017). A combination of factors is responsible for this. Firstly, while hospitals and clinics are scattered throughout Russia, the AIDS centers, where ART can be obtained, are fewer and usually only located in big cities. Patients outside of urban areas thus often find it difficult to access them (Fernando and Allan, 2014). Some larger cities have several offices, but most federal subjects only have one center. For example, Zabaikal’skii Krai has a population of 1.1 million and covers an area that is bigger than Norway and Denmark combined (431 500 sq. km.), but has only one AIDS center and no HIV/AIDS NGOs⁴⁶ (Minzdravsotsrazvitiia, n.d.). Secondly, certain groups in the HIV-positive population are excluded from treatment, even if they manage to access an AIDS center. This includes people without a local registration stamp, a *propiska*, and those who do not have low enough CD4 cell counts⁴⁷ (Federal’nyi Tsent SPID, 2014, p. 47). Thirdly, there are big challenges related to the supply and distribution of ART. Russian authorities have never initiated domestic production of ART, and its cost is considerably higher in Russia than in most other countries.⁴⁸ Russia’s reliance on internationally produced ART combined with the deteriorating economic situation from 2014 efficiently created an acute country-wide shortage in 2017, when AIDS centers all over Russia announced they did not have any medication left in stock (Rykova, 2017; Boronov, 2017; Filimonov, 2017c). Problems with corruption have also been reported (Pape, 2014).

Access to treatment for HIV-positive cannot by any means be considered universal in Russia today (Sarang et al., 2013; Pape, 2014; Levi et al., 2016). Many HIV-positive Russians are affected also by other diseases, such as hepatitis and TB, but do not receive the integrated treatment they need because of the system’s institutional isolation of HIV care. Whether or not a person will receive treatment also depends upon several factors outside their control,

⁴⁶ In the absence of a functional state system, the lack of NGOs is arguably a core problem (see Chapter 3.2.2).

⁴⁷ According to Russian guidelines, ART should be initiated at counts below 350 per mm³. According to WHO, all HIV-positive adults should receive ART, regardless of their clinical stage and cell count (WHO, 2016b, p. 74)

⁴⁸ Price of ART, per person/year (2015): USD 2687 in Russia, USD 110 in Ukraine (UNAIDS, 2016, p. 178).

such as the economic strength of the region they reside in, their CD4 cell count, the coverage of NGOs in their local environments, and the knowledge, training and individual willingness of the staff at their regional AIDS centers. Thus, the need for a large-scale reform of both the Russian health care system in general and the HIV care system is evident.

3.3.2 HIV/AIDS civil society and legislation interfering with their work

The first Russian NGOs working on HIV/AIDS were established during the early 1990s. With HIV transmission rates rapidly escalating in the late 1990s, more organizations popped up. A majority of prevention programs have been offered by NGOs, and civil society should as such be recognized as a key player in Russia’s HIV response (Pape, 2014; King, 2017, p. 125). Although socially oriented NGOs traditionally have had both better access to state funding and a less antagonistic relationship with Russian authorities than other NGOs, those working on HIV/AIDS have received little support (Gomez, 2015). The global community has therefore played a major role in the development and preservation of the sector (Pape, 2014)

It is difficult to establish the precise number of non-governmental HIV/AIDS actors active in Russia, as this number also would include associations that are not legally registered, i.e. local initiative groups (Pape, 2014, p. 120). However, a database developed by the Russian Federal Research Institute for Health Organization and Informatics lists 149 NGOs operating in 47 different federal subjects.⁴⁹ Thus, according to this database, almost half of all federal subjects do not have any HIV/AIDS NGOs. In the absence of a viable state response, this is arguably a core problem. The location of listed NGOs essentially follows the geographical distribution of HIV. NGOs are registered in almost all regions with very high disease burdens, indicating that groups have emerged from an evident need for increased services in heavily affected areas:

Table 2: Overview of federal subjects’ HIV transmission rates, including NGOs:

Federal subject	Prevalence (2017)	Incidence (2017)	HIV/AIDS NGOs
Sverdlovsk Oblast ⁷	1741.4 (1)	157.2 (3)	3
Irkutsk Oblast ⁷	1729.6 (2)	160.7 (2)	5
Kemerovo Oblast ⁷	1700.5 (3)	203.0 (1)	5
Samara Oblast ⁷	1466.8 (4)	105.0 (13)	6

⁴⁹ It should be noted that NGOs are frequently forced into liquidation, and that this database seems to lag behind the most recent developments. However, although not entirely accurate, it will in the following be used, as it is interpreted as providing a useful overview of still relevant patterns.

Orenburg Oblast'	1289.5 (5)	114.7 (10)	8
Khanty-Mansiisk Autonomous Okrug	1244.0 (6)	109.2 (12)	0
Leningrad Oblast'	1190.0 (7)	n.d.	1
Cheliabinsk Oblast'	1174.4 (8)	154.0 (4)	4
Tiumen Oblast'	1161.2 (9)	138.7 (7)	0
Novosibirsk Oblast'	1118.8 (10)	142.8 (5)	2
Mean Russian Federation	643.0	71.1	1.77

Source: Federal'nyi Tsentri SPID, 2017; Minzdravsotsrazvitiia, n.d. Prepared by the author.

While most of the NGOs are registered as regional organizations, several take part in country-wide and/or global networks and associations. “The National Forum for NGOs working in the sphere of HIV/AIDS” is in this regard the biggest association, gathering 86 NGOs from all over Russia, while the “All-Russian Association of people living with HIV” and ESVERO⁵⁰ each counts more than 60 member NGOs. “E.V.A.”, an association protecting women affected by HIV, unites 78 activists, specialists and NGOs from 27 regions, and the Moscow-based network La Sky gathers 14 groups working with men who have sex with men. A majority of the NGOs have one or more key groups they target. Two thirds of NGOs in the database lists injecting drug users and/or youth as their targets, while 52% focuses on sex workers. Roughly 30% targets children, and 20% men who have sex with men (Minzdravsotsrazvitiia, n.d.).

Ever since Putin was first elected president in 2000, he has pursued a strategy of mobilizing certain civil society actors while demobilizing others. These policies were enacted to secure control over NGOs in Russia (Gilbert, 2016, pp. 1554–1556). In 2006, the NGO law⁵¹ was passed, providing authorities with wide-reaching scrutiny over organizations' internal financial statements, activities and documents. NGOs were required to complete new registration papers with detailed information about each member and donor, and to report all foreign donations and account for how money received were spent. Several amendments have been made to the law since its introduction, but most of the provisions remain intact (Crotty et al., 2014, p. 1254). During Medvedev's presidency, the law was not significantly altered, and his administration generally followed the policy course laid out by Putin (Gilbert, 2016).

⁵⁰ ESVERO (previously known as the Russian Harm Reduction Network), was named a foreign agent in June 2016, and forced to liquidate in October 2017 (Miniust, 2018b; Rusprofile, 2018; Bol'tskaia, 2018).

⁵¹ FZ 18 (2006): “On Introducing Amendments into Certain Legislative Acts of the Russian Federation”.

After Putin's cultural conservative turn in 2012, a wave of legislation has placed severe restrictions on civil society and sharply reduced NGOs' possibilities for cooperation with non-Russian actors. In 2012, legislation requiring NGOs that receive foreign funding, and that are involved in the highly diffusely defined term "political activity", to register as foreign agents was introduced (Flikke, 2016).⁵² NGOs not willing to register voluntarily can be punished with liquidation, registered against their will (from 2014), fined or prosecuted. Organizations in the registry also have to regularly submit detailed financial reports, and mark all their material with a disclosure that information is being given by a foreign agent (Crotty et al., 2014). Several international bodies have criticized the law for undermining civil society and violating the constitutional provisions on freedom of association. Many NGOs have chosen to reorganize or close instead of accepting the highly stigmatized label. The national registry established on basis of the law currently counts 76 NGOs, of which six are working with HIV/AIDS (Miniust, 2018b). Two LGBT NGOs are also listed as foreign agents. Even if HIV and/or AIDS is not their primary concern, such organizations are an important part of a comprehensive HIV response, as they spread information on sexual health and aim to decrease homophobia and negative attitudes toward sexual minorities (WHO, 2016a, p. 99).

In 2013, the situation for Russian HIV/AIDS civil society further deteriorated, as the «anti-propaganda» legislation was passed.⁵³ This amendment regulates distribution of information interfering with «traditional Russian family values», and has, among other things, been used to limit education on HIV prevention, drug use and safe sex. An example can be taken from a school in Arkhangelsk, where a group of parents in 2017 protested against HIV lessons, which they believed violated FZ 436 on basis of being "gay propaganda". The reason was that the teacher had mentioned that HIV transmits via homosexual contact (Rogozhin, 2017). Another example, which will be examined in Chapter 4.3, is from Cheliabinsk, where a Roskomnadzor report last year ruled a HIV prevention lesson to violate FZ 436. According to the report's authors, the lesson could cause irreparable damage and was aimed at "destroying childhoods" (Roskomnadzor, 2017a, pp. 14-16). The 2013 amendment has also provided a legal basis for the already widespread stigmatization of homosexual people in Russia (Kuzina, 2017).

In 2015, yet another NGO-limiting component was added to the Russian penal code, this time

⁵² FZ 121 (2012): "On amendments to legislative acts of the Russian Federation regarding the regulation of the activities of non-profit organizations performing the functions of a foreign agent."

⁵³ "For the Purpose of Protecting Children from Information Advocating for a Denial of Traditional Family Values" is a 2013 amendment to FZ 436 (2010).

the authorities' right to declare organizations "unwanted" in Russia.⁵⁴ Both Russian and non-Russian groups regarded as threats to national security can be placed in this registry. NGOs listed as unwanted are obliged to disband immediately and are not allowed to work in Russia or support Russian NGOs financially. Their employees may face criminal and administrative penalties if activities are upheld, while Russians who maintain ties with them may receive up to six years in prison (Human Rights Watch, 2016). In 2017, Andrei Rylkov Foundation, a Moscow-based NGO offering harm reduction services to injecting drug users, was fined 50 000 rubles for having an old, but active, link to an unwanted NGO on their homepage (Andrei Rylkov Foundation, 2017). The law has been criticized by both Russian and foreign institutions, for violating the Russian constitution (Ombudsman RF, 2015), for discrediting civil society participants in opposition to the regime (Nienaber et al., 2015), and calling it a "crackdown on independent voices" (Harf, 2015). At present, fourteen NGOs are declared unwanted (Miniust, 2018c), of which two, the Open Society Foundations (OSF) and the Open Society Institute Assistance Foundation (OSIAF), were involved in HIV work in Russia.

3.3.3 Domestic partners supporting the status quo

An enthusiastic bloc of actors sharply opposes any liberalization of HIV policy in Russia. Among these are the ROC, leading politicians and state institutions such as health minister Veronika Skvortsova and the Ministry she leads — and other state agencies, e.g. Rospotrebnadzor and Roskomnadzor, state health care commissions and research institutions. Another group is the growing number of AIDS denialists, people who do not believe HIV is real, but a campaign created to make money on people's panic and fear⁵⁵ (VKontakte, n.d.). The present chapter will examine how some of the most notable groups contribute to inaction.

The ROC is an active participant in Russia's HIV response. Faith-based groups and local parishes offer services to HIV-positive all over Russia, which often include palliative care and drug rehabilitation. As ROC provides valuable support to many HIV-positive who otherwise would be left without any assistance, the church should be considered a resource in Russia's HIV response. However, its rejection of harm reduction and understanding of the epidemic as a problem of morality also make it one of the biggest contributors to inertia (Zigon, 2009, p. 79; Pape, 2014, pp. 98–99). ROC has its own HIV declaration, adopted by the Russian Holy Synod in 2005, which functions as a guideline for how the epidemic should be approached by

⁵⁴ Addition: "On amendments of some legislative acts of the Russian Federation" (Federal'nyi Zakon, 2015).

⁵⁵ AIDS denialists gather online. Russia's biggest AIDS denialist community on the social media platform VKontakte, called "HIV AIDS – The biggest hoax of the 20th century", currently counts 17 703 members.

ROC institutions (Russkaia Pravoslavnaia Tserkov', 2005). The church considers it one of its “duties to God and the people” to give a “spiritual and moral assessment” of the situation:

The original cause and source of the rapid spread of the epidemic is the unprecedented expansion of sin and lawlessness in society, in addition to the loss of fundamental spiritual values, moral principles and guidelines. All of these destructive processes testify to the serious spiritual-moral diseases tormenting society, which, if they continue their course, may lead to a larger catastrophe (Russkaia Pravoslavnaia Tserkov', 2005).

However, HIV-positive should not be excluded from ROC, but rather be met by “compassion, mercy and sacrificial love”. The church is not opposed to treatment, and the declaration emphasizes the importance of social support and prayer in combination with ART. With that being said, the section on HIV prevention, in which family values, chastity, and how to resist the “dangers of the modern world” are key elements, does not exactly follow international recommendations. Sex education is also rejected, as it advocates for a way of life that is “incompatible with Christian morality” (Russkaia Pravoslavnaia Tserkov', 2005).

Among the issues stirring up major discussion is Russia’s legal ban on OST. Despite several complaints to the European Court of Human Rights (ECHR) from Russian drug users (Nekhezin, 2014), and pressure from international health agencies to decriminalize OST (WHO, 2016a, p. 87; UNAIDS, 2016, p. 50), Russia rules the treatment to be “incompatible with national traditions, laws and cultural values”⁵⁶ (Anisimov, 2016). Health Minister Veronika Skvortsova shared her thoughts on OST in an interview with the UN in 2016:

The fact is that harm reduction only is a noble strategy at first glance. In reality, it [methadone] protects the surrounding people from the drug user, but actually kills the drug user himself. If we take a look at the percentage of overdoses and deaths on such substitution therapy, it actually exceeds numbers resulting from heroin use. It turns out that we sacrifice people in trouble and make them drug users, instead of helping them (Novosti OON, 2016).

It is not known where Skvortsova got her numbers, as available research and recent Russian experience contradict her statements. Within eight months after Russia’s 2014 annexation of Crimea, at least 10% of the peninsula’s 800 patients on OST had died, after the treatment became illegal overnight (Hurley, 2015). Even so, Minzdrav and other state institutions continue the war on harm reduction. In 2016, Roszdravnadzor banned the popular condom

⁵⁶ This statement was made by Russia’s deputy Minister of Health, Sergei Kraevoi, in relation to the Russian delegation’s no to OST in the UN General Assembly, May 2016.

brand Durex in Russia after it had failed to “register correctly”. Gennadii Onishenko, State Duma deputy, doctor and ex-chief of Rospotrebnadzor, noted that “Condoms do not have any relation to health. This [import ban] will simply force Russians to be more strict and selective when choosing partners and, perhaps, it can contribute to solving the demographic problems” (Liss, 2016). Moreover, a report by the Putin-founded Institute of Strategic Research (RISI) expressed concerns about what a less conservative approach to HIV might do to Russia:

Over the years, [...] two completely opposite preventive approaches [to HIV] have emerged: one liberal and the other conservative. This [Western liberal approach] is likely to exacerbate the problem, rather than to provide an adequate solution. It includes showing sexual material to children and adolescents, and places a premature emphasis on sexuality (including non-traditional forms). [...] That is why many experts and representatives from the parental community reasonably believe this approach will lead to the corruption of the younger generation, the destruction of the family as an institution, and a worsening of the demographic situation [in Russia] (Guzenkova et al., 2016, p. 47).

According to the report, the best ways to prevent HIV is premarital sexual abstinence and a “moral life” (Guzenkova et al., 2016, p. 51). The report also discredits global cooperation:

The Moscow model is built on international HIV experience and achievements, and it incorporates cultural, historical, psychological and social characteristics [...]. However, this model exists in a tough and competitive environment, where international structures offering global cooperation on the HIV epidemic are among the opponents. Their work is characterized by pronounced neoliberal ideological content, principles of unification, insensitivity to national characteristics, and an assertion of the rights of risk groups (drug addicts, prostitutes and LGBT) to the detriment of the rights of the majority (Guzenkova et al., 2016, p. 58).

It should be noted that none of the report’s authors are medical experts, and that RISI mainly focuses on “issues of national security”, and “counteracting the falsification of history” (RISI, n.d.). The report was prepared on request from Moscow City authorities. At the presentation of RISI’s report, Liudmila Stebenkova, chairwoman of the Moscow City Duma Health Care Commission, said that she was tired of “all sorts of insinuations in the press that we [Russia] allegedly have a huge number of HIV-infected people”, and that she was not against condoms but that she did not believe in their “effectiveness against HIV” (Chernykh, 2016). Opinions presented in RISI’s report, and statements like those from Stebenkova, can be interpreted as signals of how the Russian regime exploits HIV to distance Russia from the West, by limiting Western influence on how Russia should respond to the epidemic (Colborne, 2016, p. 299).

As Stebenkova correctly noted, the Russian press participates in the HIV discourse. Because information on HIV in Russia traditionally has been scarce, the media's portrayal of the virus has had an enormous impact on the societal discourse (Pape, 2014, p. 96). While many media outlets criticize the current approach and acknowledge that an HIV epidemic is unfolding, others publish inaccurate assessments and provide their readers with dubious prevention recommendations. Shortly after the RISI report was published, an article called "Strong family – the best protection against AIDS" was published in the newspaper *Komsomolskaia Pravda*. Clearly inspired by the RISI report, the author describes Russian HIV estimates as "exaggerated", repeats the highly questionable advices presented by RISI, and also notes that:

It is becoming increasingly evident that the discussion of HIV/AIDS in Russia has taken on a highly political character, and that it has become part of the information war against Russia, which is clearly in the interests of global structures such as UNAIDS (Frolov, 2016).

Furthermore, a movement taking the regime's ignorance one step further, *AIDS denialism*, has steadily been gaining ground in Russia. Some denialists reject the existence of HIV, while others believe the virus is real, but that it is harmless and do not cause AIDS. The idea is grounded in a myriad of conspiracy theories and medical mistrust, and those following this course aim to undermine HIV prevention, testing and treatment (Kalichman, 2014). One well-known Russian AIDS denialist is the physician Olga Kovekh, in certain circles also known as "Doctor Death" (Merzlikin, 2017b). In 2014, Kovekh made an expert appearance on the health program "Doktor I" on the channel TV Tsentr,⁵⁷ where she tried to convince viewers with a plausible explanation of how Western scientists initially invented HIV to make money:

In the Herpes virus family, there is a third category, called Gamma Herpes viruses, a category of lymphotropic viruses. It was exactly this type of Herpes virus the scientists examined. [...] And they just decided to name it the human immunodeficiency virus (Tv Tsentr, 2014).

According to Kovekh, HIV is a US created conspiracy invented to earn money, control the world's population, kill Russians, and facilitate money laundering through AIDS centers. She has also suggested that Russian authorities are involved in the plot, and Medvedev has been named a possible co-conspirator, since his wife Svetlana is involved in state HIV projects (Merzlikin, 2017b). Opinions put forward by denialists such as Kovekh may seem absurd, but the fact that a state TV show raises the question of whether or not HIV exists and broadcasts a lengthy discussion in which a physician rejecting basic medical facts is included as an expert

⁵⁷ TV Tsentr is a state-run Russian TV station, owned by the Moscow City Administration.

is highly concerning. Considering a majority of Russians use TV as their main informational source, this is even more alarming (Inglehart et al., 2014). Myths and misconceptions are fueled by disinformation, which can cause people to not seek or adhere to treatment. A recent example can be taken from St. Petersburg, where a ten year old girl died of AIDS because her parents refused treatment. The Russian-Orthodox couple did not trust modern medicine, and believed AIDS was “invented by pharmaceutical companies” (Merzlikin, 2017a).

The growing impact of AIDS denialism in Russia should not be interpreted as a coincidence, but rather be understood as a trend facilitated by the Russian system itself (Pape, 2014, p. 102). The lack of information and the low quality of services offered to HIV-positive make Russians prone to the denialists’ messages. A study examining interaction between members in Russia’s biggest AIDS denialist group on VKontakte confirms this, and concludes that:

Contrary to the widespread public health depiction of AIDS denialists as totally irrational, our study suggests that some of those who become AIDS denialists have sufficiently reasonable grounds to suspect that “something is wrong” with scientific theory, because their personal experience contradicts the unitary picture of AIDS disease progression. Odd and inexplicable practices of some AIDS centers only fuel these people’s suspicions (Meylakhs et al 2014, p. 1)

3.3.4 The neo-patrimonial space: Prospects of curbing the epidemic

As examined in Chapter 3.1, Russia has had four official state HIV strategies, signed in 1993, 1996, 2001 and 2016, but none of them have been able to achieve any significant results. The programs have generally suffered from sound underfunding,⁵⁸ but sufficient funding does not automatically produce viable results. It is nevertheless essential that increased investments in health are accompanied by reforms able to improve the efficiency of the services provided (The World Bank, 2008, p. 9). In Russia, implementation of reforms is a complicated process.

All state agencies and institutions involved in HIV prevention and care in Russia exist alongside, and are interwoven with, the highly personalist regime (Robinson, 2017). The president controls the decision-making process through far-reaching authorities over the prime minister, the cabinet of ministers, the government, advisory bodies and different directorates, and even though the state apparatus is divided into several formal institutions,

⁵⁸ Russia has no coordinated system for collecting data on HIV related expenditures. However, the first program had a USD 20 million budget, of which 40% was allocated (Bobrik and Twigg, 2006). The second program had a USD 4 million budget, and the third USD 96 million. The exact sums spent here are unclear, but both programs were underfunded (WHO, 2005). The fourth program has a budget of USD 1.2 billion (allocated sum unclear).

their autonomy is both limited and conditional. The political leadership is also the sole mastermind of reforms and plans (Gel'man, 2016, pp. 459–462). Negotiations tend to be focused on personal, rather than social achievements, and the patronal networks that permeate all levels of policy making thus exert a distorting influence on the directions and effects of policy changes (Gel'man, 2016, p. 436). Successful implementation of reforms will therefore require a combination of conditions being present. First, the president must consider a given reform a top political priority. Second, the team of reformers has to be able to keep major interest groups at bay. Third, the reform must implement policy changes quickly, and fourth, it must bring immediate positive results (Gel'man and Starodubtsev, 2016, p. 114). This complexity contributes to a status quo bias in several policy areas, such as HIV and AIDS.

With regard to the first condition, the most efficient policy-making strategy would probably be an appeal by reformers to the president, who consider the reform a personal priority, and shows open support to the project (Gel'man, 2016, p. 463). Putin expressed interest to discuss HIV in the mid-2000s, but has never made any real commitment to strengthen the domestic HIV response. There were expectations that Medvedev would focus on HIV during his presidency, as he had shown interest in the topic, but he did not manage to make any notable changes, anyhow constrained by the purely formal powers he inherited. Minzdrav has been given a leading role in handling the epidemic, but no Russian health ministers in the 2000s or 2010s had any known experience of working on HIV, or seemed to have a personal interest in the subject. Minzdrav has traditionally also had a weak power structure, consistent with the health sector's low priority in Russia. Arguably, this has not improved the habitat for policy-making. Without any interest from those positioned to propose and implement reforms, and without commitment from Putin, it is unsurprising that state strategies have been fruitless.

What concerns the second condition, strong interest groups lobbying against liberal changes in the Russian approach to HIV are currently not being held at bay. On the contrary, they are often included in the regime's response. The ROC is in this regard probably the most substantial group, but as discussed in Chapter 3.3.3, a number of other groups, influential politicians and AIDS denialists have also shown clear resistance to the implementation of HIV preventive measures (Pape, 2014).⁵⁹ The current Russian regime relies on a strong conservative base to maintain its political dominance and power, and to place HIV prevention on top of the political agenda would probably interrupt these powerful connections. Thus, it

⁵⁹ Chapter 4 and 5 will examine in detail how two such groups are included in the regime's response: 1) RVS, granted authority to make legal evaluations on behalf of Roskomnadzor, and 2) ROC, financially mobilized.

seems to be a higher political priority for the president to maintain the relationship with the conservative groups, than to make sure that HIV strategies are being adequately implemented. This dynamic is arguably highly counterproductive when it comes to curbing the epidemic.

The third requirement, quick implementation of policy changes, presents a major challenge in Russia. Authoritarianism allows the government to distance itself from the impact of political parties or public pressure, and it could be assumed that reformation in such a system would proceed quite smoothly, since the regime is able to operate outside democratic regulations. However, successful implementation of policy reforms in authoritarian systems is in fact quite rare, as policy making frequently turns into a complex and inefficient series of bargains and provisional agreements, where personal achievements are the main currency (Gel'man and Stardodubstev, 2016, p. 99; Gel'man, 2016, p. 463). Thus, reforms often get lost in a web of competing interests within the power apparatus, before they ultimately end up as distorted and decomposed versions of what they initially were, and Russia's neo-patrimonial system of governance is a highly inefficient instrument for reform implementation (Gel'man, 2016).

The fourth condition, to produce immediate positive results, is in general a very difficult task to achieve when working with HIV. A vaccine against HIV could present a solution to this challenge, as it would be a cost-efficient one-time intervention (UNAIDS, 2017b). However, no vaccines or other easy-fix solutions exist, and a long-term commitment to both prevention and treatment is required. According to UNAIDS, success in halting the epidemic rapidly relies on focusing on the locations and populations where risk is greatest, in addition to holding people responsible for results (2014b, p. 18). Russia has shown little willingness to focus on key populations, and AIDS centers generally suffer from underfunding (Pape, 2014). Both factors undermine Russia's ability to achieve immediate positive results. Moreover, people are currently not being held responsible for results. Taking these aspects into consideration, it does not seem any easier to achieve this fourth task, than the three above.

3.4 Russian cooperation with the global health community

This section will provide a thorough examination of Russia's role both as a donor, and as a recipient of HIV/AIDS aid. Because the Global Fund is the world's largest financier of programs in countries affected by HIV, and also has been the most notable donor to, and receiver of, Russian HIV/AIDS aid, it will mainly be subject to discussion in the following.

3.4.1 Russia as a receiver of international HIV/AIDS aid

Prior to 2012, Russia regularly received financial contributions from international donors to strengthen its domestic HIV response. The Global Fund has been the biggest sponsor, but also other agencies, such as USAID, UNICEF, UNDP (United Nations Development Programme), OSF, and MSF have contributed. Funding has also flowed directly from foreign private donors and organizations to Russian NGOs. However, the Russian regime's post 2012 crackdown on civil society and foreign involvement has resulted in both less foreign funding being channeled into the Russian domestic HIV/AIDS policy triangle, and in the expulsion of several global agencies working on HIV and AIDS from Russia.

In September 2012, the Russian Ministry of Foreign Affairs (MID) expelled USAID, because the agency did not “respond to the stated goals of development and humanitarian cooperation”, and for allegedly attempting to influence political processes in Russia through distribution of grants (Anisimov, 2012a). At the time of expulsion, USAID had spent USD 2.7 billion on projects in Russia, the bulk on civil society assistance and democracy development. USAID was one of the international agencies most actively involved in HIV prevention, care and treatment in Russia, collaborating with institutions such as UNAIDS and the Global Fund, in addition to Russian NGOs and regional and national authorities (USAID, 2012).

UNICEF left Russia only a few months later, after MID in October 2012 had requested the fund to withdraw by the end of the year. In contrast to USAID, however, UNICEF was not accused of meddling in Russian politics, but the demand was, according to a spokesperson from the MID, connected to Russia transitioning from being a recipient to a donor in foreign aid. MID added that there was “nothing special about the situation”, as Russia already back in 2009 had announced they would scale down UN presence in Russia (Anisimov, 2012b; Raibman, 2012). UNICEF had been working in Russia since 1997, active in improving health care and children's rights. Between 2008 and 2012, the fund spent USD 45.8 million on HIV/AIDS issues, children's rights and youth development in Russia (Makedonov, 2012).

The Global Fund withdrew from Russia the year after USAID and UNICEF. The official reason was the classification Russia received from the World Bank in July 2013 as a high income country.⁶⁰ Since 2004, the fund had been the biggest sponsor of HIV/AIDS programs in Russia, particularly programs targeting key populations. A major consequence of the fund's

⁶⁰ In order to ensure available resources are allocated to countries most in need, the fund operates with eligibility criteria, determined by income classification and official disease burden classification (Global Fund, 2017a).

exit was leaving 30 projects serving 27 000 injecting drug users without financial support (UNAIDS, 2016, p. 178). Due to Russia's discontinuation of grant supported activities, one grant was eventually extended and an additional grant approved on basis of the NGO rule⁶¹ and Grace Period criteria⁶² (The Global Fund, 2014, p. 8; The Global Fund, 2015a, p. 26).

In November 2015, OSIAF and OSF, both George Soros foundations, became the newest additions to the list of "undesirable" organizations in Russia, on basis of being "threats to Russia's constitutional order and national security" (Miniust, 2018c). Both organizations are vocal advocates of harm reduction, and had at that point been supporting Russian NGOs involved in HIV/AIDS work through grants, in addition to previously having operated several needle-exchange programs in the region (OSI, n.d.). Following the "undesirable organization" announcement, the OSF commented that they were "dismayed by the decision" (OSF, 2015).

3.4.4.1 Grants from the Global Fund to fight AIDS, Tuberculosis and Malaria

The Global Fund is organized as a global public-private partnership between governments, civil society, the private sector, technical partners and people affected by the three diseases. The fund does not implement programs, but supports local projects through grants intended to add to a country's existing investments in health. Russia has received four HIV/AIDS grants worth a total of USD 257 million. All projects financed by the grants have been run by NGOs.

The first grant, "Stimulating an effective national response to HIV/AIDS in the Russian Federation" was signed in 2004. GLOBUS, a consortium of five NGOs led by the Open Health Institute, one of Russia's largest HIV/AIDS NGOs, was the principal recipient, and several Russian and foreign NGOs appointed sub-recipients (The Global Fund, 2015a, p. 36). The program's objectives included HIV prevention and community outreach work targeting key populations, and also social support to HIV-positive (The Global Fund, 2015a, pp. 12–17). After extensions due to Russia's discontinuation of activities supported by the grant, it was closed in 2015. A total of USD 119.1 million had then been disbursed. The grant received an A1 performance rating, meaning it exceeded expectations (The Global Fund, 2015a, p. 1).

The second grant, "Promoting a Strategic Response to HIV/AIDS Treatment and Care for Vulnerable Populations in the Russian Federation", was signed in 2005. The Russian Health

⁶¹ For HIV/AIDS only, upper middle income countries are able to access funding if they meet certain conditions, for example if the requested services are not being provided due to political barriers (The Global Fund, n.d.a.).

⁶² Countries with an existing HIV grant under the NGO rule that become ineligible due to changes in income level are given a grace-period (one period); such countries must continue to meet the conditions of the NGO rule.

Care Foundation⁶³ was approved its principal recipient, and 57 sub-recipients also received funding (The Global Fund, 2015b, p. 46). The program's main objective was to reduce HIV-related morbidity and mortality by expanding access to HIV prevention, treatment and care, with a particular focus on poor and marginalized groups (The Global Fund, 2015b, p.7). The grant was financially closed in 2011. A total of USD 136.8 million had then been disbursed. There were some initial issues, e.g. the number of regions where treatment was provided was downscaled (The Global Fund, 2015b, pp. 46–47), but this grant also received an A1 rating.

Grant number three, “Scaling up access to HIV prevention and treatment by strengthening HIV services for injecting drug users in the Russian Federation” was signed in 2006. Its principal recipient was ESVERO, a (then) harm reduction network consisting of 24 NGOs and 15 individual members providing low-threshold services for injecting drug users, also involved in advocacy work and policy development (Pape, 2014, p. 213). When the grant was closed in 2014, EUR 14.5 million had been disbursed. Due to previous significant foreign currency exchange rate losses, this was made a EURO denominated grant in order to ensure better stability (The Global Fund, 2016a, p.45). ESVERO had some issues regarding financial management and governance, including the withdrawal of one sub-recipient. Nevertheless, the grant received an overall A2 grant performance rating, meaning expectations were met.

The fourth grant, “Improving access to HIV prevention, treatment, and care services for key populations in Russia” was signed in 2015, almost a decade after the third grant. It was, as previously noted, approved on basis of the NGO rule. The principal recipient was once again the Open Health Institute. The program's main goal is to assist development of a national legal, methodological and financial base to provide broad coverage of HIV services among key populations (The Global Fund, 2017c). Stated program objectives include the removal of legal barriers to treatment, the strengthening of HIV prevention among key populations in the national HIV strategy, and in the Russian health care system in general. The grant was worth USD 10.4 million, and closed in December 2017. No performance rating is yet available.

3.4.2 Russia as a donor in international HIV/AIDS aid

After the dissolution of the USSR, Russia lacked both the financial base and the political determination to participate in global health aid, and the country was a recipient rather than a donor for more than a decade. However, with a strengthened economy in the 2000s, in large

⁶³ The Russian Health Care Foundation was founded with support from Russian authorities, and its status as an entirely independent NGO, or as government affiliated (GONGO), is hard to determine (Pape, 2014, p. 212).

part due to revenues from sales of oil and natural gas, Russia started to engage in foreign aid, including HIV/AIDS aid (Twigg, 2012; The Global Fund, 2017b; UNAIDS, 2018).

Between 2001 and 2007, Russia donated USD 115.7 million to the Global Fund (The Global Fund, 2017b). Most of this funding was provided after 2006, when Russia terminated its recipient status and announced it would compensate the Global Fund for the grants previously received (grant number one and two, see above). During the same period, Russia also donated USD 3.5 million to UNAIDS, with 65% of this sum being core funding, i.e. un-earmarked funding used at the sole discretion of UNAIDS and its governing board (UNAIDS, 2018).

The policy of channeling HIV/AIDS investments into the international community while neglecting domestic efforts was continued during Medvedev's presidency (2008–2012). Between 2008 and 2010, Russia donated USD 141.3 million to the Global Fund, and an additional USD 60 million pledge was made in 2010 (The Global Fund, 2017b). Russia also contributed with USD 5 million to UNAIDS during this period (UNAIDS, 2018), while no new strategies or programs were implemented at home. Thus, as discussed in Chapter 2.3, Russia's political leadership may have experienced a historical policy backlash prior to 2012, both during Putin's two first terms and during Medvedev's presidency, which caused the regime to invest in foreign HIV/AIDS aid at the expense of domestic efforts (Gomez, 2015).

As examined in Chapter 2.3.3, this was about to change with Putin's return to presidency in 2012. While Russia's total ODA was increased more than four times during his third presidential term, from USD 289.8 million in 2012 to USD 1300.5 million in 2016 (OECD, 2018), the same cannot be said about the Russian donations to global HIV/AIDS cooperation. After having paid the USD 60 million that was pledged to the Global Fund in 2010, Russia completely withdrew from being a donor to the fund. Contributions to UNAIDS and WHO have been upheld, but they constitute only a fraction of the amounts previously granted the Global Fund, and the bulk is non-core funding.⁶⁴ In 2016, Russia's ODA included only 0.7% spent on HIV/AIDS aid, a significant decrease from 18% (2000–2008) and 12% (2008–2012).

3.5 HIV and Russian society

As earlier noted, HIV started to spread rapidly in Russia during the last half of the 1990s. Circumstantial features of this period, such as political and social instability, accessible drugs,

⁶⁴ Between 2012 and 2016, Russia donated USD 29.3 million to UNAIDS and WHO. Of this, 90% was non-core i.e. money earmarked specific locations, programs and activities by Russia (UNAIDS, 2018; WHO, 2018).

and rising unemployment rates certainly contributed to Russia being a risk environment.⁶⁵ However, this risk environment cannot alone explain how some hundred cases of HIV turned into an uncontrolled epidemic, and neither can the previously discussed flaws in the health care system or the regime's lack of investment in domestic HIV/AIDS policies alone. In order to understand how the current epidemic evolved, it is necessary to also include the social context of HIV (Pape, 2014, p. 88). While every country has its own social context, certain societal reactions affecting the spread of the virus are universal. Among the foremost global barriers to HIV prevention, treatment and support are HIV-related stigma and discrimination⁶⁶ (UNAIDS, 2017c). Chapter 3.5.1 will therefore present an overview of their mechanisms and effects, before Chapter 3.5.2 proceeds to discuss the specifically Russian social HIV context.

3.5.1 HIV-related stigma and discrimination

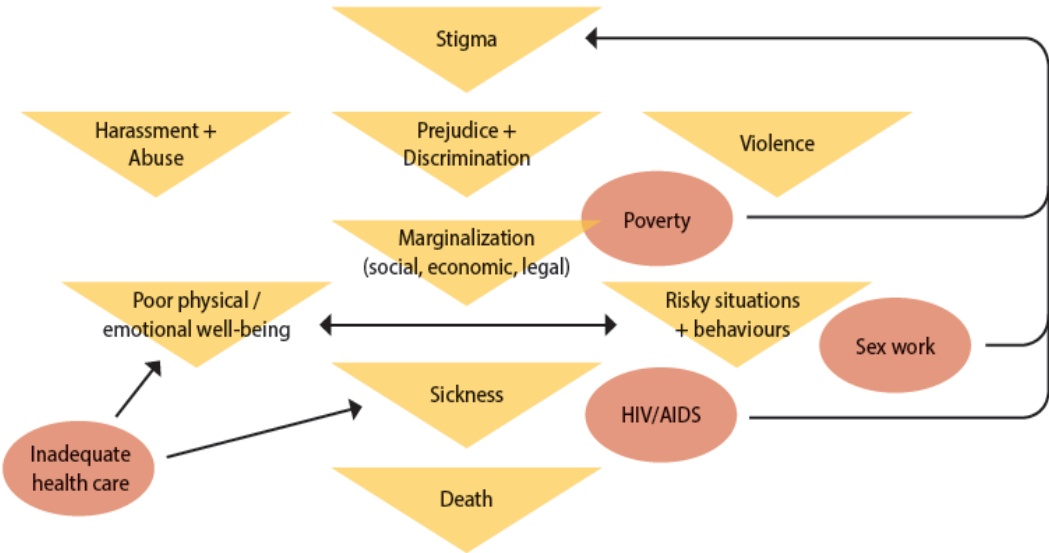
Ever since the first cases of AIDS were detected, people living with HIV have been subject to stigma and discrimination. The stigma likely originated from fear, as little was initially known of the virus, and the fact that many of those affected belonged to marginalized groups in society. Consequently, HIV was commonly regarded as being self-inflicted, connected to behaving unnaturally or immorally, or as affecting only a certain type of people (Pollak, 1992; Knight, 2008). Although transmission routes were settled 35 years ago, HIV's incurability continues to provoke fear in people, including in those with correct and comprehensive knowledge. Fear can again create irrational behavioral reactions, two of the most common being stigma and discrimination. The possibility of death seems to remind people about their own mortality and engenders a "distancing-stigmatizing" response (Carlisle, 2001, p. 119). Because of the unpleasant response tends to HIV provoke, it has long been common for people to conceal their HIV-positivity. As long as a person is asymptomatic this is fairly easy; the virus itself is not visible from the outside. To pass as normal is central to avoid stigma and discrimination, but concealment may have severe negative effects on the affected individual's life quality (Goffman, 1963). To live in a constant fear of discovery, be reluctant to seek appropriate health care, and experience loneliness and a lack of social support are common among people who hide their HIV-positive status (Carlisle, 2001, pp. 121-122).

⁶⁵ A risk environment is defined as an environment that "comprises risk factors exogenous to the individual". Research on HIV prevention highlights four types of such influence: 1) physical, 2) social, 3) economic, and 4) policy (micro and macro). The micro-risk environment involves an individual's personal decisions in addition to influence of community level norms and practices. The macro-risk environment captures structural factors, such as laws, military actions, economic conditions and wider cultural beliefs (Rhodes and Simic, 2005, p. 220).

⁶⁶ Please see Chapter 2.1 for a definition of HIV-related stigma and discrimination.

Despite decades of awareness-raising, irrational fears of HIV and negative attitudes toward HIV-positive are still widespread. People living with HIV report unpleasant reactions from all parts of society, e.g. police, health officials, colleagues and people in their local communities (UNAIDS, 2017c). In Russia, there have been reports of psychological and physical abuse, threats, forced abortions, refusal of necessary medical care, and health care confidentiality issues (Levada Center, 2010, p. 8; Pape, 2014, p. 94; UNAIDS, 2017c, pp. 5–6). Those belonging to key populations are extra vulnerable to experiencing stigma and discrimination, and are often subject to “double stigmatization”, that is, they face stigma in more than one way (Carlisle, 2001, p. 120). HIV-negative belonging to key populations are also commonly marginalized from society and services they need to stay healthy, which can lead to risky situations and result in sickness and/or death, also known as the “stigma-sickness slope”:

Figure 6: The stigma-sickness slope



Source: UNDP, 2012, p. 13.

3.5.2 Attitudes and awareness in the Russian population

Because the degree of controversy that surrounds the topics HIV intrinsically touches upon, such as homosexuality, drug use, gender identity and commercial sex varies greatly in societies, the social contexts of HIV are diverse (UNAIDS, 2017c). In Russia, the degree of controversy is substantial, and disagreement over HIV prevention and how the epidemic should be approached has for more than two decades formed barriers to building an efficient HIV response in the country. In many ways, Russian HIV/AIDS politics can be understood as

“a battle of opinions”, where prejudice, lack of information, controversy and stigma prevent the adoption of necessary prevention programs (Pape, 2014, p. 90). In this regard, a central question is not only how this social context influences knowledge levels and awareness of HIV in society, but also whether the regime’s HIV/AIDS policies actually reflect positions and opinions that exist in the Russian population.

In light of the above, the present chapter will proceed to take a closer look at attitudes toward, and awareness of, HIV in the Russian population. In order to do so properly, survey data collected by NIBR will be analyzed.⁶⁷ This section will thus address this thesis’ third research question, and also provide a relevant contextual background for this study’s first embedded unit of analysis, a dispute over sex education, which will be further discussed in Chapter 4.

Data and methods of the NIBR survey

The data were collected through a population-based cross-sectional study based on telephone interviews in Arkhangelsk (1028 respondents) and St. Petersburg (1005 respondents) in 2010. Respondents were aged 18–90 years, 57% women and 43% men. At the time of questioning, the HIV prevalence was 8 per 100 000 inhabitants in Arkhangelsk, and 48 in St. Petersburg. Interviews were performed by two professional Russian public opinion agencies frequently working in the two cities. In order to ensure representativeness, quota systems were applied to the population selection. The survey consisted of twelve main questions, randomized to avoid habituation and acquiescence (Aasland, Grønningsæter et al., 2011).

Analysis

NIBR’s survey yielded some interesting insights. Firstly, what Carlisle (2001, p. 119) refers to as a “distancing-stigmatizing” response seems to be widespread. While a majority (91.3%) agreed with the statement “People living with HIV should have the same opportunities for participation in school, education and working life as everyone else”, answers reflecting irrational fears were also apparent. For example, almost 50% said they would never let an HIV-positive person watch their child, and 20% tended to think they would not allow for this to happen. Seventy percent thought HIV-positive should be obliged to inform their workplace,

⁶⁷ The NIBR survey was conducted in 2010. A main concern was therefore that attitudes and awareness may have changed since then, resulting in the detected patterns presented in this chapter not reflecting the current situation entirely accurately. As the survey was part of a larger Norwegian-Russian project on HIV governance in North-West Russia, another concern was that findings inaccurately reflect the entire Russian population. To meet these concerns, and as a means to increase the reliability and validity of detected patterns, data from the most recent World Values Survey (WVS) wave 6 (2010–2014, Russia 2011) are included in the analysis.

and that employers should be able to change their work tasks to protect colleagues. These are situations in which there is practically zero risk of transmission. Similar attitudes were also reflected in the WVS, where 54.3% said they would not like to have an HIV-positive person as their neighbor (Inglehart et al., 2014). The answers may reflect low knowledge levels, and/or show how HIV provokes irrational fears of death, including in those properly informed. Regardless of the underlying reasons, such feelings fuel stigma and discrimination.

Secondly, certain groups in society, e.g. homosexual people, drug users and immigrants, were evidently subject to marginalization. In the NIBR survey, almost 50% said they supported criminalization of homosexual practices, and 66.2% of those asked in the WVS would not like to have a homosexual person as their neighbor. This share is, as we can see, even higher than the share opposed to having an HIV-positive neighbor. Similarly, 93.2% would not like to have a person using drugs as their neighbor, and 32.2% said the same about immigrants (Inglehart et al., 2014). Pape (2014, p. 95) emphasizes that the Russian society's strong reaction to those who are different is a main characteristic of the mechanisms and effects of HIV-related stigma and discrimination in Russia. People who are both different and HIV-positive therefore frequently fall victim to double stigmatization, while those HIV-negative can be pushed into HIV-positivity, as illustrated in Figure 6 (Carlisle, 2001; UNDP, 2012).

Thirdly, although most of the respondents assessed their own knowledge of HIV as good, either "very good" (16.6%) or "fairly good" (57.7%), their answers, as pointed out above, could not confirm this. For example, while 61% knew that injecting drug use placed people at increased risks of contracting HIV, only 24.5% thought anyone (i.e. the general population) was at risk. Considering heterosexual transmission caused nearly 40% of all new infections in Russia in 2010, and more than 60% of cases among women (Federal'nyi Tsentri SPID, 2011), this indicates a lack of awareness and knowledge. In this regard, media seems to play a key role. Respondents most frequently reported having received information about HIV from TV/radio (81.5%), and printed mass media (70.5%), also the leading informational sources in the WVS. Although people indicated relatively moderate levels of trust in the media, information from other sources is largely absent, and the media's portrayal of HIV therefore continues to have a major impact on perceptions and knowledge in the Russian society⁶⁸ (Pape, 2014, pp. 95–96). In contrast, only 18.6% had ever received information about HIV in school, 9.9% from a doctor, 3.4% from a regional AIDS center, and 1.6% from an NGO.

⁶⁸ Please see Chapter 3.3.3 for more information on Russian media and its portrayal of HIV and AIDS.

Fourthly, respondents seemed to be slightly more liberal than the regime's official HIV policies. When asked about which prevention activities they supported, the two most frequently supported initiatives were mass media campaigns (either fully or mostly supported by 92.9%), and sex education in schools (92.8%). Free distribution of condoms was also broadly approved of (supported by 83.5%), in addition to needle-exchange programs (72.4%). Even OST, which is criminalized and may result in 20 years in prison if prescribed, was supported by a majority (63.2%). Overall, respondents were not impressed with the way in which authorities, the health sector and civil society work together to prevent the spread of infectious diseases in Russia. Only 14.3% assessed their joint efforts as very good, and only 9.3% fully agreed that the treatment and care offered to HIV-positive in their cities was of good quality. More than 90% were positive about the government spending resources on HIV.

So, what do these findings communicate? First, both prejudices and misinformation appear to be relatively widespread. In all probability, this affects perceptions of HIV and people living with HIV negatively, and also contributes to further virus transmission in Russia. With that being said, the NIBR survey showed that a vast majority of respondents were positive about the government spending resources on HIV, and that they welcomed initiatives that are not provided by the regime. The survey thus reveals what appears to be a dissonance between what the regime offers, and what people want. In this regard, a particular potential seems to lie in the introduction of informational campaigns and sex education, the two initiatives most frequently supported. Respondents reported especially high levels of trust in HIV information provided by educational institutions, and the introduction of lessons on sexual health and HIV prevention in schools therefore seems to hold a particular potential.

Following Robinson's (2017, pp. 352–353) propositions of pressure and movement within the neo-patrimonial space, social discontent can, if the pressure it exerts on the regime is strong enough, force the political leadership to make policy changes in order to secure regime stability. However, discontent requires awareness, and the survey indicates that knowledge levels in society about the severity of the HIV situation in Russia are insufficient to provoke a broad public uprising against the regime's prevention policies. Putin, on his part, has not used his third term to attend to potential latent pressures for a liberalization of HIV policies. On the contrary, his cultural turn has been used to distance Russia further away from conventional HIV prevention, and to include conservative domestic actors in policy crafting and implementation. In order to give an example of how this can play out, the next chapter will proceed to present a recent conflict over sex education in Cheliabinsk.

4 The first embedded unit of analysis: To war against sex education in Cheliabinsk

With the purpose of illustrating how Putin's turn to cultural conservatism and his inclusion of actors supporting this rhetoric serves to push Russia further away from building a viable domestic HIV response, this fourth chapter will proceed to present this thesis' first embedded unit of analysis, a dispute over sex education in Cheliabinsk. The most basic way to prevent HIV transmission in a society is to provide citizens with information about the virus and how it spreads, and sex education is therefore a principal HIV prevention strategy that should be included in all national HIV responses. As shown in the NIBR survey in Chapter 3.5, it was also the prevention initiative most broadly supported and trusted by respondents. In order to be an efficient prevention policy, however, it is crucial that such programs receive sufficient political and financial support. Thus, this first embedded unit of analysis will investigate a topic inherent in two of the domestic HIV/AIDS policy triangle's⁶⁹ three corners: 1) the ongoing construction of federal public HIV/AIDS programs, and 2) the ongoing funding for prevention policies and access to ART. The situation in Cheliabinsk will be used to illustrate how the regime prioritizes to nurture relations with conservative actors, valuable for Putin to maintain his political dominance and power, at the expense of fighting HIV.

For contextualization purposes, Chapter 4.1 will start with a presentation of the HIV situation in Cheliabinsk. Chapter 4.2 then proceeds to present the history of sexual education and HIV prevention programs in Russia, before an overview of programs available in Cheliabinsk Oblast' will be provided. Chapter 4.3 will proceed to discuss the relevant dispute over the HIV prevention lesson offered by the Cheliabinsk-based youth center Compass, before the report from Roskomnadzor, which ruled the lesson to be in violation with FZ 436, will be examined more in detail in Chapter 4.4. Chapter 4.5 leaves room for comments and reflections.

4.1 Cheliabinsk and HIV

Cheliabinsk Oblast' is situated in the Southern Urals, spread out on both sides of the Ural Mountains. The oblast' is home to 3.5 million people, of whom 1.1 million reside in its administrative center, Cheliabinsk city. The subject borders Sverdlovsk Oblast' to the north

⁶⁹ Please see Figure 3, Chapter 2.3.2.

and Kazakhstan to the south. For more than two decades, Cheliabinsk has had major problems with HIV transmission, linked to its location along the Northern heroin trafficking route.⁷⁰

The spread of HIV in Cheliabinsk largely followed national epidemiological patterns. That is, the prevalence remained low throughout the 1990s, and the majority of those testing positive for HIV were infected via injecting drugs.⁷¹ And then, once HIV had been firmly established among people injecting drugs, incidence rates exploded. Between 2000 and 2002, the number of HIV-positive inhabitants in the oblast' increased by 2389%, placing Cheliabinsk among the top ten HIV-affected Russian regions (Federal'nyi Tsent SPID, 2000). However, the incidence of drug abuse and the HIV prevalence among injecting drug users never reached the proportions seen in surrounding Ural subjects, i.e. Sverdlovsk.⁷² Consequently, in terms of transmission rates, Cheliabinsk was surpassed by a number of other federal subjects during the 2000s, before regaining its top ten spot during the 2010s, mainly due to a rapid spread of HIV through sexual contact (Federal'nyi Tsent SPID, 2009; Federal'nyi Tsent SPID, 2016).

Already in 2007, around 60% of new cases were acquired through sex, a share that had risen to 70% in 2011 (Cheliabinskii Tsent SPIDa, 2014). Currently, heterosexual contact is still responsible for the majority of new positive tests (54%), but a rise in HIV among injecting drug users over the last years has resulted in an increased number of cases being acquired also this way. Between 2012 and 2016, the HIV prevalence among injecting drug users rose by a devastating 557%, likely connected to the crackdown on HIV/AIDS NGOs offering harm reduction services during Putin's third presidency.⁷³ The oblast's incidence rate has increased by 90% since 2012, placing it fifth in the country, illustrating the major current challenges with HIV prevention (Federal'nyi Tsent SPID, 2013; Federal'nyi Tsent SPID, 2016)

In addition to the three HIV/AIDS NGOs, the oblast' has one regional AIDS center, where ART can be obtained by those with a local registration stamp. Among the region's roughly 38 000 registered HIV-positive inhabitants, less than 25% received ART in 2016 (TSMSCH, 2017; Rospotrebnadzor, 2017b). HIV testing, on the other hand, is offered at more than 20 places throughout the subject, and a substantial 31% of the population underwent testing in 2016 (Minzdrav, n.d; Rospotrebnadzor, 2017c). However, roughly one-third of those

⁷⁰ For more information on this route, please see Map 1, Chapter 5.1.

⁷¹ In 1996, all cases were acquired via drug use, reduced to 87% in 1998 (Cheliabinskii Tsent SPIDa, 2014).

⁷² In 2008, the incidence of drug use was 24 in Cheliabinsk, and 51 in Sverdlovsk (per 100 000) (Rosstat, 2010). In 2010, 8.5% of IDUs in Cheliabinsk had HIV (14.6% in Sverdlovsk) (Minzdrav, 2013, pp. 107–108).

⁷³ While Cheliabinsk had nine NGOs listed as active in 2008, only three of them are currently active, none of which offer needle exchange programs (Minzdravsotsrazvitiia, n.d.).

diagnosed with HIV in 2015 had an advanced infection, meaning they had been HIV-positive for years at the time of diagnosis (Gorodskaja Mezhdedomstvennaia Kommissiia, 2016, p. 6).

At present, roughly 1.5% of the population in Cheliabinsk city is registered as HIV-positive (Rospotrebnadzor, 2017b). While HIV used to primarily affect those incarcerated or unemployed, the share of newly infected belonging to the region's work force has more than doubled over the last ten years. HIV is increasingly affecting people aged 30–39 years, who are socially well off, have permanent sexual partners and do not use drugs (Rospotrebnadzor, 2017b). There has also been a significant rise in women in childbearing age testing positive for HIV, and the incidence of women diagnosed during pregnancies is more than double the national average.⁷⁴ These developments are highly concerning, and Cheliabinsk may experience a significant negative impact on its financial and demographic growth in the near future, if the epidemiological developments observed over the last six years continue.

4.2 Sex education and HIV prevention in Russian schools

In order to provide a comprehensive understanding of the environment in which sex education and HIV prevention programs (such as Compass' lesson) exist in Russia, a brief historical overview will be presented below, before current conditions will be discussed more in detail.

In Czarist Russia, the religious influence on society was strong, and sexual matters excluded from the public. At the beginning of the 20th century, however, Russian literature, ballet and art started to include notable erotic elements. Following the Communist revolution, attitudes in society toward sex and the family as an institution became increasingly liberal, and sexual education was even introduced in some schools (Kon, 1995). However, Stalin's rise to power in 1922 was accompanied by conservatism and a more repressive approach toward citizen's individual freedoms, entailing a reversal of previous sex education initiatives, in addition to criminalization of certain issues linked to sexuality, such as homosexuality (1934) and abortion (1936). However, hygiene was important, portrayed as a main path leading to moral purity, and was therefore taught in schools (Rivkin-Fish, 1999). After Stalin's death, sexuality became more openly discussed in society, and texts on "sexual hygiene" appeared. Here, biological mechanisms such as fertilization and the menstrual cycle were described, but sex itself was excluded. In the 1980s, certain country-wide educational programs were introduced, including the course "Hygienic and Sexual Education" for 8th graders in 1983, and "Ethics

⁷⁴ In 2014, the incidence of HIV among pregnant women in Cheliabinsk Oblast' was 273.1 per 100 000 (Russian average 133.8) (Federal'nyi Tsentr SPID, 2014, p. 7).

and Psychology of Family Life” for 9th and 10th graders the year after (Rivkin-Fish, 1999). However, sexuality was avoided, and the focus was on love, family and proper contact between the genders (Shapiro, 2001; Dudkina, 2017). To sum up, sex education was never taught in any systematic way in Soviet schools.

During the early 1990s, Russia underwent a sexual revolution. Sex started to appear in media and films with sexually explicit language and erotic scenes were broadcasted on popular TV channels. This sudden exposure to sex shocked a society unaccustomed to any discourse on such matters (Rivkin-Fish, 1999, p. 805). As a result, sexuality began to polarize and politicize, and opposition to the existence of a public discourse on sexuality in Russia was strong throughout the 1990s. Conservative parts of society, e.g. the ROC, professionals and parental communities vividly opposed sex education, portraying it as an invasion from the West, where “Western cultural evils”, e.g. homosexuality and depopulation would pollute and threaten Russian traditions and values (Kon, 1997, pp. 399–400 in Rivkin-Fish, 1999, p. 806).

The disagreement over sex education and a healthcare system ribbed of resources resulted in a rampant spread of sexually transmitted diseases (STDs), heavy abortion rates and the world’s lowest fertility rate during the 1990s (Gevorgyan et al., 2011). This situation was clearly unfortunate, and experts argued that Russia needed sex education (Kon, 2005, in Meylaks, 2011). Subsequently, various projects were initiated, supported by NGOs, UN agencies and bilateral donors. The UN-assisted “In-school Sex Education for Teenagers in Russia”, which included topics such as anatomy, sociocultural aspects and sexual behavior, was among the most substantial. It was planned to be implemented throughout Russian schools, but cancelled shortly after its creation due to public resistance (Shapiro, 2001; Gevorgyan et al., 2011). Other initiatives, such as the state project “Family planning”⁷⁵ were also stopped, and systematic sex education has not been attempted introduced in schools since (Dudkina, 2017).

Resulting from generations devoid of sex education is a Russian society broadly uneducated about HIV. For instance, a study among science teachers in 2006 revealed that only 11% knew it is impossible to get infected through sharing plates, cutlery or glasses. Moreover, 85% thought HIV could be acquired simply by having an HIV-positive colleague, and 86% thought the virus may transmit through kissing (Avina and O’Connell, 2006, pp. 10–11). Similarly, a study among final year nursing students showed that only 70% knew that HIV cannot transmit through casual contact. Moreover, 28% were unsure, or believed all homosexuals have HIV,

⁷⁵ “Family planning” was part of the presidential program “Children of Russia” (1991–1995).

and only 50% knew there is no cure for AIDS (Suominen et al., 2015, pp. 5–7). The fact that professionals are unaware of basic facts illustrates how misinformation penetrates the society, a situation that is likely to fuel prejudice, discrimination and further virus transmission.

The arguments against sex educations vary, from how issues of sexuality do not belong in the public sphere, to how youth will learn what they need to know at some point anyway (Dudkina, 2017; Kochetova, 2017). Other common arguments include how educating youth only awakes an excessive interest in sex that stimulates them to be sexually active, (Shapiro, 2001; Roskomnadzor, 2017a) and that sex education is incompatible with Russian tradition and morality (Todorov, 2014). Moreover, arguments about how sexual education may harm children’s psychological and moral health, their ability to love and their mental development, (Roskomnadzor, 2017a) or that it is a “Western imposition” aimed at destroying Russian society, moral and tradition, have also been put forth (Shapiro, 2001, p. 93; Korobatov, 2014).

Because no unified system of sex education exists in Russia, schoolchildren are educated only on the occasion of individual teachers being dedicated to the topic,⁷⁶ or in the event of other groups carrying out in-school trainings. Although sex education is not criminalized, a basis for its legal prosecution has increasingly been granted in recent years.⁷⁷⁷⁸ This offensive is in line with Putin’s cultural turn and its rhetoric, in which Russia is portrayed as a lonely defendant of tradition and morality in a world characterized by (Western) moral degeneracy. When the state Duma approved the UN Convention on Children’s Rights in 2014, which affirms youths’ right to sexual education, Russia’s then Ombudsman for Children’s Rights, Pavel Astakhov, stressed that no consensus had been reached with his European colleagues: “They ask me: When will you introduce sex education? I answer: Never” (Todorov, 2014).

4.2.1 Programs available in Cheliabinsk Oblast’

Cheliabinsk’s oldest NGO educating youth about HIV is the research center “There is an Opinion”, established in 2000. The center aims to reduce the spread of drug addiction, HIV

⁷⁶ A study from 2006 carried out among Russian science teachers, showed that only 10% of the respondents had ever taught sex education (Avina and O’Connell, 2006, p. 10).

⁷⁷ FZ 436 (2010) has increasingly been used to stop HIV prevention among youth, with the argument that sex education violates the law. The 2013 amendment "For the Purpose of Protecting Children from Information Advocating for a Denial of Traditional Family Values", has provided opponents with further legal legroom, as explaining how HIV transmits via homosexual contact now is punishable by fines. Teachers should not teach about safe sex and contraceptives, but promote abstinence and marriage as the best forms of protection (Roskomnadzor, 2017a; Rogozhin, 2017). An example from Cheliabinsk will be examined in Chapter 4.2.3.

⁷⁸ Starting in 2016, FZ 121(2012) has been utilized to name NGOs engaged in HIV prevention among youth, i.e. educational initiatives and condom distribution, foreign agents (Kuzina. 2017).

and other socially significant diseases through seminars, socio-psychological support and outreach work. The center targets various population groups, such as youth, men who have sex with men, sex workers, health care personnel and representatives from other NGOs. The center does not currently run any sex education projects, but more than 3000 teenagers in and around Cheliabinsk have attended their trainings. There is an Opinion cooperates with both domestic and foreign actors, i.e. the Cheliabinsk City Administration, the regional AIDS Center and the US-based Aids Healthcare Foundation (Est' Mnenie, n.d.). Collaboration with the Ministry of Justice in Cheliabinsk was also recently initiated, and in this regard the center expressed their satisfaction with the ministry's "openness and willingness to work together, despite the fact that this structure usually monitors and controls NGOs" (Est' Mnenie, 2017).

One of the center's main achievements was the establishment of the youth center "Compass" in 2006, co-founded with the Department for Youth Affairs in Cheliabinsk, which also heads the center. Compass' main objectives are to prevent the spread of socially significant diseases among youth, and to provide support to those affected by HIV and/or drug use. The center offers a variety of activities, such as trainings, outreach work and consultations. Every year, around 1000 schoolchildren from 8th to 11th grade undergo their in-school seminars on sexual health, HIV and drug prevention, co-organized with Cheliabinsk's educational administration. Similar courses for teachers and parents are also available (Kompas, n.d.). Compass' HIV prevention trainings provide direct and comprehensive information about the virus and how it transmits (Kompas, 2008). However, this approach is highly unpopular with conservative segments of the parental community, who for years has fought to terminate the lessons.

Another HIV prevention initiative targeting youth in Cheliabinsk is organized by "Family Plus", an NGO registered in 2016 that offers support to families and children in difficult life situations (Sem'ia Plius, n.d.). Their program called "The Route of Life Safety" received a presidential grant worth half a million rubles in 2017. The program aims to train teachers, psychologists and social workers to become educators of a spiritually-morally oriented HIV prevention program developed by experts from the ROC, and also to arrange quarterly HIV prevention weeks in local schools (Sem'ia Plius, 2017a). The program intends to be a spiritual counterpart to "one-sided programs purely focused on informing adolescents and teaching them about so-called safe sex", and will instead, "promote the ability to resist evil and develop spiritual and moral potential in the younger generation" (Lad'ia, n.d.). Family Plus notes the following about the project on their website:

The Russian state has lost its official ideology, and the society has lost its spiritual and moral ideals. The spiritual and moral aspects of the current educational system have been reduced to a minimum. Education based on the traditions of our national culture is replaced by liberal democratic values. These values exert a decisive influence on the system of moral standards of children, youth and even the society as a whole. [...] Levels of youth criminality and drug use are increasing, and the spread of socially dangerous diseases growing. In this regard, spiritual and moral education of the younger generation is extremely important (Sem'ia Plius, 2018).

4.3 The dispute over Compass' HIV prevention lesson

Between 2008 and 2014, Compass ran the program “Basic HIV Knowledge for 10th and 11th Graders” in a majority of Cheliabinsk schools. However, in 2014, the center had all of its educational activities suspended, after parents had complained about Compass' activities on the World AIDS Day, when employees had distributed an informational HIV leaflet, free condoms and offered free HIV express testing to students. Conservative parents demanded an immediate termination of all the center's HIV prevention activities, and Compass was allowed to resume their lessons only in 2016 (Zhukova, 2017; Tsybul'skii, 2017; Kolerov, 2017).

In 2017, furious parents once again united to stop the center's lessons, and this time they were joined by Roskomnadzor. An expert committee consisting of representatives from the “All-Russian Parental Resistance Group” (RVS)⁷⁹ examined “Basic HIV Knowledge for 10th and 11th Graders” on behalf of Roskomnadzor, upon which the federal agency published a report ruling the lesson to be in violation with FZ 436 (Roskomnadzor, 2017a). According to article 19 in the relevant law, Roskomnadzor must issue an order to cease illicit activities within 15 days following this type of ruling (Federal'nyi Zakon, 2010). However, Compass was not even aware of their program being subject to scrutiny, and sent a request to the regional Roskomnadzor department asking for possible consequences of the report (Kompas, 2017a; Kompas, 2017b). Roskomnadzor replied that since Compass' lesson was not registered as a mass media outlet, it could not be prohibited by their agency after all, and forwarded the letter to the regional Ministry of Education and Science (Minobnauki) (Roskomnadzor, 2017b).

Compass later received a letter from Minobnauki, confirming that “Basic HIV Knowledge for 10th and 11th Graders” cannot be prohibited by FZ 436 by their agency either, since it is not registered as a mass media outlet. The letter also stated that the ministry recommended continuation of the program, provided that some adjustments, such as updating the literature

⁷⁹ RVS is an NGO that arose from the community of protestors against the Russian juvenile law projects in 2012.

used, were made (Minobnauki, 2017). In July 2017, Compass received yet another letter, this time from Rospotrebnadzor, affirming that any legal judgments of the program were outside their scope as well (Rospotrebnadzor, 2017a). Thus, “Basic HIV Knowledge for 10th and 11th Graders” is not ruled to be in violation with FZ 436 after all, and the center is free to continue their trainings. Following the conflict, Compass published a statement in which they questioned the objectivity of the relevant report and asked for a legal evaluation of the relation between Roskomnadzor and the expert committee from RVS (Kompas, 2017a).

4.4 The Roskomnadzor report: HIV education violates FZ 436

The Roskomnadzor report is a 37 page long document authored by six representatives from the “All-Russian Parental Resistance Group” (RVS); three teachers, two psychologists and one geographer, all certified by Roskomnadzor to perform examinations. RVS is an NGO that “unites people who are seriously concerned about the state’s policy toward children and the family”, and defines itself as a “family protection organization” (RVS, 2013). Patriotic upbringing and improvement of Russia’s “degraded educational system” are among its main priorities. Besides performing examinations on behalf of Roskomnadzor, RVS has members serving on the Federation Council’s Scientific Expert Council on Legislative Changes to the Family Code, where one of its big achievements was the 2017 deletion of amendments to the criminal code’s article 116 (beating and other violent acts), which would criminalize parents slapping their children. In RVS’ opinion, the proposed amendments were absurd, as “More than 90% of Russians consider light physical punishment of children a norm” (RVS, 2013).

The examination of “Basic HIV Knowledge for 10th and 11th Graders” was conducted on basis of an appeal by a Russian citizen concerned about the content of the program, and the possibility of the lesson violating FZ 436. The inspection had the following three main objectives: 1) To determine whether or not the lesson included information that is prohibited to distribute among children, 2) To evaluate whether or not the lesson corresponded to the age of the youth, and 3) To decide if the program contained information harmful to the development and/or the health of the children (Roskomnadzor, 2017a, pp. 1–2).

The report sets off with a rather lengthy section in which a myriad of international agencies, NGOs and multilateral partnerships⁸⁰ advocating for sexual education are criticized for their

⁸⁰ Among those named are UNAIDS, UNICEF, UNPFA (United Nations Population Fund), WHO, USAID, OSI, MSF, IPPF (International Planned Parenthood Federation), PSI (Population Services International) and the international health care organization Project HOPE (Roskomnadzor, 2017a, pp. 4-6).

involvement in Russia, and portrayed as actors aiming to destroy Russian tradition and culture. Russian civil society are not exempt from critique, and domestic NGOs supporting sex education are described as for years having “destroyed traditional values and tried to introduce new behavioral norms”⁸¹ (Roskomnadzor, 2017a, pp. 4–7). The authors then move on to describe how sex education and family planning corrupt the younger generation:

The purpose of the above organizations [organizations supporting sex education] and their programs is to teach children about different types of ‘safe’ sex, and thus, ruin their innocence and reduce the sacrament of love to a simple animal instinct, which further blocks the normal reproduction of the population within the family. [...] Family planning centers have taken root under the label of protecting the health of children and youth, combating AIDS and STDs, protecting motherhood and childhood, preventing drug addiction, and so forth. [...] however, when informing children and adolescents about HIV transmission and prevention, sexual education, i.e. corruption of the youth, inevitably occurs (Roskomnadzor, 2017a, pp. 6–7).

The report then proceeds to discuss the relevance and impact of Compass’ HIV prevention program, and the general fruitfulness of raising awareness about HIV among youth:

[...] despite the trainings and events conducted by the center [Compass], the HIV situation in the city of Cheliabinsk only worsens. It can therefore be concluded that the prevention of socially significant diseases carried out by this center’s specialists is not only ineffective, but also has the opposite effect, that is, it increases the incidence of HIV. In conclusion, to raise awareness of HIV-related issues among youth and students is either plainly unproductive or actually leads to an increase in the number of people infected (Roskomnadzor, 2017, p. 8).

The above claims are unsubstantiated by any epidemiological data or research, and it is not known how the authors reached their conclusions. It is undoubtedly true that the number of people living with HIV in Cheliabinsk has increased rapidly over the last years, but to conclude that a lesson carried out among a few hundred schoolchildren yearly is co-responsible for this situation cannot be considered plausible. Already in 2007, a year prior to the creation of “Basic HIV Knowledge for 10th and 11th Graders”, around 60% of new HIV cases in Cheliabinsk were acquired via sex (Cheliabinskii Tsentri SPIDA, 2014). Cheliabinsk has also experienced a significant age rise in people testing positive for HIV over the last years, with people aged 30–39 years currently accounting for the bulk of new infections (Rosspotrebnadzor, 2017b), a population segment not exactly targeted by Compass’ lessons.

⁸¹ This quote belongs to Leonid Reshetnikov, RISI director (Roskomnadzor, 2017a, p. 7).

A thorough analysis of the content in “Basic HIV Knowledge for 10th and 11th Graders” then follows. The experts note that the program is “overloaded with negative content” and criticize the “categorical tone” of the provided information. The lesson is also criticized for not encouraging critical thinking, and for not stimulating the schoolchildren’s “cognitive activity.” Also, Compass’ lecturer apparently delivered a number of controversial statements that should be removed, for example that condoms protect against STDs (Roskomnadzor, 2017a, p. 11). The following conclusions about the program’s content are finally presented:

After analyzing this program [Basic HIV Knowledge for 10th and 11th Graders], it is determined that it contains information that is harmful to the health and development of children, which is prohibited by Federal Law No. 436-FZ “On Protection of Children from Information Harmful to Their Health and Development”. A number of criteria provided by the relevant law are present, including the denial of family values, the exploitation of interest in premarital and extramarital sex and the establishment of a foundation for early sexual activity (Roskomnadzor, 2017a, p. 12).

The next part of the report is dedicated to assessing the program’s possible impact on the mental health of the schoolchildren. It starts off relatively lively:

The lecturer, being an adult, an authority, a teacher, who is requisitioned to inform children about moral values, instead destroys the already existing concepts of morality in them. The position ‘If one has a desire, then why should one resist that desire?’ does not in any way contribute to the creation and strengthening of family ties. It destroys family values. In addition, it triggers teenagers to be promiscuous and is corrupt (Roskomnadzor, 2017a, p. 13).

The authors then proceed to warn how the program provokes experiences that can lead to anxiety, fear, depression and neurotic actions, and inflict “irreparable damage to adolescent personalities” (Roskomnadzor, 2017a, p. 14). It is also concluded that the program can cause “all sorts of sexual perversions”, e.g. homosexuality, abolition of parents’ authority, formation of anti-family attitudes, stimulation of early sexual onset, impoverishment of adolescents’ inner world, influence their ability to love, and “hinder the ability to form long-lasting and deep relationships, essential elements in building a normal psyche.” According to the report, the lesson is overall aimed at “destroying childhoods” (Roskomnadzor, 2017a, pp. 16–20).

4.5 Comments

Schools are optimal settings for HIV prevention, as they provide an already established infrastructure where large numbers of uninfected parts of the population can be equipped with consistent and timely information on how to protect themselves and others. Curriculum based

sex education programs have also proved to delay initiation of sexual activity among youth, decrease their number of partners, reduce their risk taking, and increase condom use. Employing sex education as an HIV prevention strategy is also very cost-efficient (The World Bank, 2002, p. xvii; UNESCO, 2018, pp. 28–29). However, as examined in this chapter, the Russian educational system provides youth with little opportunities to access such information in schools. While sex education never has been a part of the Russian curriculum, it appears that Putin’s cultural conservative turn has further reduced Russian schoolchildren’s chances of receiving sexual education, in all probability presenting a barrier to curbing the epidemic.⁸²

In this regard, the regime’s increased use of anti-Western rhetoric after 2012 seem to be a main factor. Global agencies advocating for youths’ right to sex education, e.g. UNICEF and USAID, have been forced to leave Russia. The regime’s increased efforts to discredit conventional HIV prevention, its emphasis on how the “Moscow model” is fundamentally different from Western HIV prevention methods, and the little interest Putin has shown in using HIV as a tool to increase Russia’s global reputation, leave little hope of Russia complying with international pressure to introduce sex education. Another main barrier is arguably the new legislation, especially FZ 436 with its 2013 amendment, which prohibits distribution of information about “non-traditional sexual forms”, and FZ 121 (2012). The former law places severe restrictions on what type of information educators can provide schoolchildren with, and is likely to further decrease individual teachers’ motivation to bring HIV prevention into their classrooms. The latter has forced a number of NGOs to liquidate, reorganize or downscale, a situation that has impacted their ability to provide HIV prevention and sex education initiatives to youth in their local environments (Kuzina, 2017).

While the dispute above did not result in any prosecution of Compass’ lesson, it shows how the conservative power base the regime currently relies on is granted access to state structures. This dynamic has also been illustrated by other events in this thesis, e.g. the RISI report (Chapter 3.3.3), the inclusion of AIDS denialists as experts on state-run TV (Chapter 3.3.3), or the distribution of the presidential grant to a ROC-run abstinence oriented HIV prevention program for youth (Chapter 4.2.1). In the specific context of sex education, the NIBR survey analyzed in Chapter 3.5 showed that sex education was broadly supported. In light of this, the regime’s prioritization appears to be even more erroneous. Having a population devoid of correct and comprehensive information will, in all probability, only fuel HIV transmission.

⁸² It should be noted that several blogs, webpages and YouTube-channels targeting youth with information on sexual health have appeared in Russia. For examples, please see www.sexprosvet.me or <http://nikonova.online/>

5 The second embedded unit of analysis: Mobilization of Russian HIV/AIDS NGOs

This chapter will take a closer look at HIV/AIDS civil society and the way in which Russian authorities employ state funding in combination with the existing legislation to include, or exclude, NGOs from the domestic HIV response. As examined in Chapter 3.3.2, ever since Putin was first elected president in 2000, he has pursued a strategy of mobilizing certain civil society actors while demobilizing others, enacted to secure the control over NGOs in Russia (Gilbert, 2016, pp. 1554–1556). Because legislation, especially FZ 121 from 2012, has limited the inflow of foreign funding to Russian NGOs, state sponsoring of civil society has become an increasingly important mobilization tool for the regime during his third presidency. This second subunit will thus proceed to address the third corner of the domestic HIV/AIDS policy triangle, i.e. the creation of fiscal transfer programs and partnerships with NGOs. As outlined in Chapter 2.3.2, the inclusion of civil society has been one of the main reasons behind other BRIC countries' success in curbing their domestic HIV epidemics (Gomez, 2015). In Russia, however, NGOs have traditionally been poorly included in the state's response. In this regard, an interesting development took place in 2017, when HIV/AIDS projects started to receive state grants, first seven projects in August, and an additional 16 projects in November.

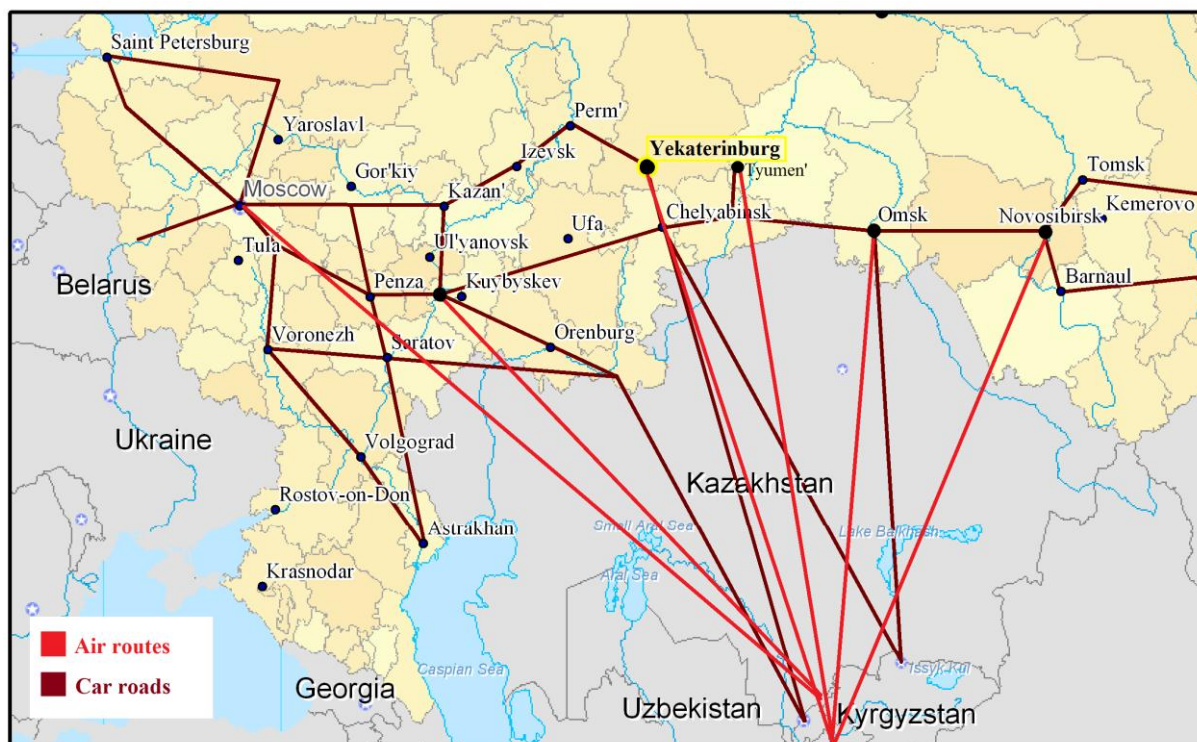
In light of the above, the present chapter will provide a thorough examination of the Russian regime's methods of mobilizing HIV/AIDS civil society, by using Sverdlovsk Oblast', the Russian federal subject most severely affected by HIV, as a second subunit. Chapter 5.1 will start with a presentation of the epidemiological situation in Sverdlovsk Oblast' before Chapter 5.2 proceeds to address the system of presidential grants in Russia. Chapter 5.3 will then present an overview of HIV/AIDS projects receiving presidential grants in Sverdlovsk Oblast' in 2017, before Chapter 5.3.1 provides an overview of the remaining HIV/AIDS NGOs in the oblast'. Chapter 5.4 then shifts back to the country-wide perspective, and discusses national patterns of mobilization and demobilization. Findings from interviews with representatives from HIV/AIDS NGOs will also be included here. Chapter 5.5 leaves room for comments.

5.1 Ekaterinburg, Sverdlovsk Oblast' and HIV

Sverdlovsk Oblast' is located in the Ural Federal district, and home to around 4.3 million people. Roughly 1.5 million of them reside in Ekaterinburg, the oblast's administrative center and Russia's fourth-largest city. Due to Ekaterinburg's location along the Northern trafficking

route,⁸³ heroin became cheap and accessible during the 1990s, resulting in a large share of the population injecting drugs.⁸⁴ During the early 2000s, HIV started to spread among injecting drug users in the area, causing transmission rates to explode. Between 2000 and 2005, the number of HIV-positive in the oblast' increased by a devastating 8771%. Map 1 illustrates how Ekaterinburg's location made it both a destination and transit point for heroin trafficking:

Map 1: Drug Trafficking Routes from Central Asia to Russia: Air routes and car roads



Source: UNODC, 2008, pp. 18-19.

The drug abuse peak from the 2000s has slowed down, and the popularity of injecting drugs has also decreased.⁸⁵ The spread of HIV, however, has not been proportionally reduced, and the area persistently registers HIV incidence and prevalence rates double to triple the national average. This is mainly caused by two reasons. First, the spread of HIV among injecting drug users was never successfully curbed. Combined with a large number of people injecting drugs

⁸³ The Northern route runs from northern Afghanistan via Central Asia to Russia and Western Europe. The route developed in the 1990s, after the USSR collapse had made borders permeable. Trafficking on this route mainly occurs by road (70–75%) and the rest by air or train (UNODC, 2012). Yearly, approximately 95 tons of heroin is smuggled on the route, with 1-6% of this quantity reaching Western European markets (UNODC, 2010, p. 45).

⁸⁴ In 2000, the incidence of drug abuse in Sverdlovsk was 75.0 (Russian average 50.7) (Rosstat, 2010).

⁸⁵ In 2011, 92% of drug users in Sverdlovsk injected drugs, reduced to 49% in 2016 (Minzdrav, 2013, p. 106; Minzdrav, 2017, p. 121). As HIV is spread through needle sharing, but not via other forms of drug use, e.g. tablets, snorting, smoking, a reduction in injecting drug use should reduce HIV transmission among drug users.

in the area, transmission was fuelled. Second, the failed efforts to treat drug users resulted in the virus spreading outside this group, and HIV is now widespread in all population groups.⁸⁶

Despite nearly two decades of biproblems with drug abuse and HIV transmission, Sverdlovsk Oblast' does not have any state drug rehabilitation facilities, and only one governmental health center offering free treatment for drug addiction.⁸⁷ In 2016, there were 0.23 psychiatrists per 100 000 inhabitants qualified to treat drug addiction, well below the national 0.35 average (Minzdrav, 2017, pp. 40–43). In the absence of a state effort, several private programs have been set up. The most well-known is the “City Without Drugs” foundation, led by Ekaterinburg's mayor Evgenii Roizman. Here, controversial tough-love treatment of heroin addiction is practiced, and Roizman has stated that he is convinced HIV-positive drug users can be permanently cured from HIV once they stop using heroin (Roizman, 2012).

The oblast' has one AIDS center, located in Ekaterinburg. Thus, people residing north in the subject may have to travel up to 600 kilometers to access HIV treatment. One hospital and five polyclinics offer testing. Three HIV/AIDS NGOs are active, of which two are registered as foreign agents. In line with the general stratified organization of health care in Russia, there is little institutional cooperation between HIV and drug treatment. For instance, a person testing positive for HIV upon admission into drug treatment will have to personally visit the regional AIDS center after being discharged from drug rehabilitation in order to receive HIV services. Given the immense prevalence of HIV among injecting drug users in the oblast' (42%), it seems evident that the area could benefit from coupling HIV and drug treatment.

Roughly 1.7% of the population in Sverdlovsk Oblast' is currently living with HIV, and in Ekaterinburg the share is 2% (Federal'nyi Tsentri SPID, 2017). In 2016, city health authorities declared the situation an epidemic (Rossiia 24, 2016). However, this statement was later withdrawn, when the spokeswoman, Tatiana Savinova, first deputy chief of the local health ministry, said that the word epidemic “does not mean anything” and that “nothing was announced” (Morozov, 2016). Regardless of the authorities' preferred choice of words, both Sverdlovsk Oblast' and Ekaterinburg definitely satisfy WHO's epidemic criteria.⁸⁸ Without viable changes in the HIV response, prospects for economic and demographic development

⁸⁶ In 2017, 55% of new HIV cases were acquired via sex, and 41% through injecting drug use. People aged 20–39 accounted for 69% of cases, i.e. nearly 1/3 belonged to other age groups (Sverdlovskii Tsentri SPID, 2017).

⁸⁷ Treatment is not free for those without a local registration stamp, or those who wish to remain anonymous.

⁸⁸ A generalized HIV epidemic is defined as when HIV is firmly established in the general population, and the prevalence consistently exceeds 1% among pregnant women (WHO, 2013, p. 15). In Sverdlovsk Oblast', 1.7% of the general population and 2% of all pregnant women are HIV-positive (Sverdlovskii Tsentri SPID, 2017).

look bleak. HIV increasingly affects women in childbearing age, and 2% of pregnant women are HIV-positive. In 2017, newborns accounted for 1.7% of all cases, more than double the national average, demonstrating the inadequate support system, even among those routinely screened.⁸⁹ The epidemic's heterosexual turn has led to an increased share of HIV-positive being otherwise healthy, i.e. they constitute the area's work force. In 2015, roughly 60% of those testing positive in Ekaterinburg held jobs (Sverdlovskii Tsentri SPID, 2015). If this trend continues, it is likely that the city's ability to cover its demand for labor will be impacted.

5.2 Presidential grants in Russia

Since 2006, the regime has held yearly competitions where NGOs can apply for state funding, so-called presidential grants. Prior to 2017, funding was distributed through various grant operators,⁹⁰ with the Public Chamber (PC) as the main coordinator. The PC was established in 2005, after Putin called for the formation of a body that could serve as a “platform for wide dialogue” between civil society and the state (Putin, 2004; Federal'nyi Zakon, 2005). Its creation was part of Putin's effort to redefine relations between state and society following color revolutions in other former Soviet states (Richter, 2009, p. 17). Public participation in policy matters could here be advocated for, while any autonomous activity capable of being a basis for organized opposition could concurrently be restricted. A majority of PC members were appointed either directly or indirectly by the president,⁹¹ which let the regime present a model of the public sphere that efficiently excluded oppositional voices (Richter, 2009).

In 2017, the previous arrangement was abandoned, and a new single organizer established, the “Fund for Presidential Grants for the Development of Civil Society”, in short “the Presidential Fund” (Filimonov, 2017b). Initially, only socially oriented NGOs (SO NGOs) were eligible for grants (Richter, 2009, p. 8), but this criterion has been discarded, and all NGOs registered in Russia except those listed as “unwanted” can apply, also foreign agents (Filimonov, 2015). As long as formal application requirements are met, all projects in theory have the same opportunity to receive grants. With that being said, SO NGOs have been granted the bulk of the funding, and supported projects have focused on health, youth, civil society development,

⁸⁹ After outbreaks of HIV among newborn babies in Russian hospitals in 1988–1989, mandatory screening of all pregnant women was initiated. For more details on governmental HIV screening, please see Chapter 3.3.

⁹⁰ The grant operators had different areas of expertise, i.e. the “Russian Union for Youth” distributed grants to projects targeting youth. In 2016, there were nine operators (Obshchestvennaia Palata, 2018).

⁹¹ Until 2013, the PC had 126 members: one-third appointed by the president, this group selected another third; and the last third was selected in the federal districts. Since 2013, the PC has had 168 members: 40 appointed by the president, 85 from regional PC's, and 43 representatives from NGOs (Obshchestvennaia Palata, 2013).

disadvantaged groups in society, culture and education (Henderson, 2011). SO NGOs assist the state in its role as a service provider, and, as long as they stay within the regime's prescribed boundaries, their beneficial contribution to society has been rewarded with access to state funding (Bindman, 2015). The Presidential Fund notes the following on their website:

[The Presidential Fund] provides comprehensive support to NGOs established to achieve social, charitable, cultural, educational and scientific goals, with the purpose of protecting the health of [Russian] citizens, develop physical culture and sports, meet spiritual and other non-material needs citizens may have, protect the rights and legitimate interests of citizens and organizations, provide legal assistance, in addition to other purposes aimed at achieving public good [...] (Fond presidentskykh grantov, 2018c).

In 2017, socially oriented projects were granted 85% of the total funding. Projects providing social protection and/or services received 15% of the total sum available, while educational projects and health projects followed closely behind with 12% each (Fond presidentskykh grantov, 2018b). What has changed, however, is the number of applications and the amounts distributed. In 2013, the PC received 7308 applications, a number that had more than doubled in 2017. While grants worth RUB 473 million were distributed in 2006, this had risen to RUB 1.5 billion in 2012, and in 2017, the disbursements reached an all-time high of RUB 6.7 billion (Obshchestvennaia Palata, 2016, p. 54; Filimonov, 2017a). Putin has announced that RUB 8 billion will be distributed in 2018 (Putin, 2018; Fond presidentskykh grantov, 2018c).

This rise in number of applications to, and amounts distributed through, the presidential grants are not particularly surprising. As discussed in Chapter 3.3.2, a main consequence of FZ 121 is that Russian NGOs no longer can receive funding from foreign donors without risking being listed as foreign agents. Thus, state grants are many NGOs' sole option for risk-free funding, and those previously relying on foreign donors are increasingly applying for state funding, or alternatively, using crowdsourcing as a way to survive financially. Arguably, the sums allocated to the presidential grants have been increased to give the impression that the removed foreign support has been replaced by the regime. During a meeting of the Council for Civil Society and Human Rights in 2017, Putin himself commented on the situation:

The registry of foreign agents has been almost halved [...] Of course, this would not have been possible to achieve without the NGOs themselves revising their positions. As you know, an NGO must either stop engaging in political activity or refuse to receive money from abroad in order to be removed from the registry. And NGOs are quite actively opting for the latter path.

Because very favorable conditions have been put in place, they do not have to look abroad to find money for their political activities, but can receive this funding in Russia. Within the framework of the presidential grants, more than 22 billion rubles have been distributed over the last five years, and the annual amounts allocated have increased sevenfold (Putin, 2017).

While there is no doubt about the regime's massive increase in sums made available to NGOs, the distributions have been criticized for being biased and for lacking transparency (Crotty et al., 2014, pp. 1256–1257). NGOs that are useful to the regime, either by assisting the state in its role as a service provider, or as advocates for the current rhetoric (i.e. patriotic youth groups), are financially mobilized, while those not fitting into the regime's visions are being denied access to funding, i.e. demobilized (Crotty et al., 2014; Bindman, 2015; Gilbert, 2016). The policy of bringing civil society under greater oversight and making NGOs dependent on the state was initiated already with the creation of the PC and the introduction of the 2006 NGO law (Richter, 2009). Within this context, the crackdown on foreign interference and NGOs' autonomy merely seem like necessary steps to secure state control over civil society.

5.3 Sverdlovsk: Presidential grants to HIV/AIDS projects

Two HIV/AIDS projects received presidential grants in 2017 in Sverdlovsk Oblast'. The first project allocated funding, "Service for Palliative Care", is organized by the Russian-Orthodox Eparchy in Ekaterinburg and was bestowed RUB 479 433 in the first competition. The project intends to create an outreach service providing care and spiritual support to people suffering from incurable conditions such as AIDS, cancer, progressive neurological diseases and cardiac failure (Fond presidentskykh grantov, 2018d). Through the Eparchy's service, relatives of terminally ill patients will be given the possibility to borrow medical equipment for free, so that their loved ones can be cared for at home during the last stage of their lives:

This project is unique because it provides families [of terminally ill patients] with essential equipment (hospital beds, anti-bedsore mattresses, oxygen concentrators, germicidal lamps, washing equipment, etc.) that is not provided by the social services. [...] Time will be spent on each other, instead of through running down doctors' offices. The family will learn to survive a tragedy together. To soothe the patient's pain is the greatest and most important thing that must be done for him (Fond presidentskykh grantov, 2018d).

The project was the only grant-winner in the first competition involved in any kind of HIV or AIDS-related work. As discussed in Chapter 3.3.3, the ROC contributes with support to many HIV-positive Russians that would otherwise be left without any social assistance, and ROC

must therefore be considered a resource in Russia's response to HIV. However, the Presidential Fund's choice to support palliative care at the expense of HIV prevention and treatment appears to be an unfruitful priority. Sverdlovsk Oblast' has both a large share of the population infected with HIV and major problems with further virus spread. Inadequate prevention and treatment coverage annually causes hundreds of easily avoidable deaths, and the prevalence of HIV among injecting drug users has almost tripled since 2010 (Federal'nyi Tsentr SPID, 2011; Minzdrav, 2017, p. 122). Arguably, the area could benefit from employing NGOs targeting drug users and those involved in HIV prevention, in the fight against HIV.

In this sense, the second project involved in HIV/AIDS work granted support appears to be a more beneficial priority. The project, called "Together: Plus and minus", is organized by the Ekaterinburg-based NGO "New Life", and offers support to HIV-discordant couples (couples where one is HIV-positive and the other is HIV-negative). The project won a grant worth RUB 2 998 970 in the second competition. According to the NGOs' webpage, the aim of the project is to provide discordant couples with information on how to stay healthy, and how to have healthy children. As New Life explains, not all discordant couples in Sverdlovsk Oblast' receive the necessary help and support. The regional AIDS center does not have enough capacity, and HIV-negative may be unwilling to register because they are afraid about the center disclosing their information. Resulting from this is a situation where people living with HIV frequently infect their HIV-negative partners (Novaia Zhizn', 2018).

5.3.1 Other HIV/AIDS NGOs in Sverdlovsk Oblast'

While the projects above were granted state support, the two remaining HIV/AIDS NGOs in the oblast' have been forced to register as foreign agents, as both had received foreign funding and allegedly were involved in political activity. The first was The Era of Health, which had received funding via AIDS Healthcare Foundation and the Global Fund.⁹² Miniust categorized its political activity simply as "HIV prevention among the population in Sverdlovsk Oblast'", while the goal of this activity was to "influence the development and implementation of state policies, formation of state bodies, local self-government bodies, their decisions and actions" (Miniust, 2018b). At the time of inclusion in the registry, The Era of Health ran various HIV programs, such as peer consultations (consultations led by HIV-positive) and harm reduction programs (Sverdlovskii Tsentz SPID, 2016; Sverdlovskii Tsentz SPID, 2014).

⁹² The Era of Health was one of the sub-recipients of the grant aimed at harm reduction among injecting drug users allocated to ESVERO by the Global Fund (2006–2014). Please see Chapter 3.4.1.1 for more details.

The second NGO placed in the registry was “New Time”, an NGO that has been working in Sverdlovsk Oblast’ since 1999. New Time offers HIV prevention among injecting drug users, and also provides support to HIV-positive women, children and people in prisons (Novoe Vremia, 2018a). After Ekaterinburg’s epidemic gained country-wide attention in 2016, its leader, Marina Khalidova, criticized the Russian HIV response in the German publication *Der Spiegel*, and said that she thought the real number of HIV-positive in the region was triple the official estimates (Hebel, 2016). She also gave an interview to the media platform *Open Democracy*, where she said that “We will never cope with HIV without opioid substitution therapy” (Magkoeva, 2016). Seven months later, New Time had been forced to register as a foreign agent. The NGO had received money from a German protestant development agency, and the Ministry of Justice presented a long list of political activities, including “prevention of socially significant diseases in Sverdlovsk” and “formation of public views” (Miniust, 2018b).

Arguably, the situation in Sverdlovsk eminently illustrates how the Russian regime’s rhetoric and priorities promotes an inefficient HIV response. The oblast’ has topped Russian HIV and drug use statistics for nearly two decades, but the creation of institutions, initiation of cooperation, and development of policies able to improve the epidemiological situation have never been prioritized. And then, to make matters even worse, NGOs offering harm reduction and evidence-based prevention have been demobilized after Putin’s cultural turn in 2012.

5.4 National patterns of mobilization and demobilization

The situation in Sverdlovsk Oblast’ is not unique. This section will thus shift back to a country-wide perspective, and discuss more in detail how the regime uses specific strategies to create a national scene of HIV/AIDS NGOs in line with its current rhetoric and priorities.

5.4.1 Financial mobilization/demobilization

As previously noted, Putin has during his third presidency (2012–2018) created a situation in which state grants are many Russian NGOs’ sole option for funding that does not entail a risk of legal prosecution. The Presidential Fund’s allocation of grants is therefore considered to be a primary mobilization/demobilization strategy in this thesis.

In 2017, 23 HIV/AIDS projects⁹³ received presidential grants. By examining these projects, it was possible to identify certain patterns. Firstly, the Presidential Fund seems to prioritize

⁹³ This categorization is based on the applications, available from the Presidential Fund’s open database. Several of the NGOs are also involved in activities other than what is stated as the grant-winning projects’ main focuses.

projects targeting those already HIV-positive (70% of supported projects) at the expense of HIV prevention. In addition to receiving grants more often, projects in the former category also received higher amounts per project (on average +10%) than the latter group. Secondly, the population groups targeted also appeared to influence the distributions. Youth was the most popular group (27%), followed by women/children/families and drug users⁹⁴ (both 17%), and incarcerated people (13%). Thirdly, prevention projects were very unvaried. Five of seven projects targeted youth, and all of them had applications referring to how the projects would “change behaviors” by promoting “healthy lifestyles” and/or “moral and spiritual values.” Fourthly, the projects’ activities also seemed to affect the fund’s selection. A majority of supported projects offered social support or counseling (70%), and more than half of all projects were also involved in informational or educational work. Twenty two percent had an explicit religious affiliation. Certain factors also seemed to influence the size of the fund’s allocations. Applications mentioning a connection to, or cooperation with, Russian authorities received sums 42% above average, and projects targeting women/children/families amounts 41% above average. In contrast, palliative care projects received sums 33% below average, and educational projects amounts 23% below average (Fond presidentskykh grantov, 2018a).

A project coordinator from a grant-winning project talked about how the creation of the fund had simplified the process of receiving grants, and explained why their project had succeeded:

There used to be a lot of rumors going around about how everything was very corrupt, and not transparent [in the PC and the different grant operators]. It was extremely difficult to receive grants, and impossible to understand which criteria their assessments relied on. Of course, it is still not easy, but the criteria have become clearer, and it is easier to understand how we should write our applications. [...] The problem that our NGO deals with is relevant, and I believe the Fund’s experts understood this. But, to focus on a relevant problem is not enough, the quality of the application itself is very important, it must be very detailed, everything should be properly described, especially the budget section (Interview 010102, 2018).

A project manager from another grant-winning project also stressed the importance of having an application that is both high-quality and focused on the state’s priorities:

I think the success in receiving a presidential grant depends on the quality of the application and the project’s stated tasks. For instance, we wrote our application in accordance with the state HIV strategy, where our target group is listed as a key group (Interview 010201, 2018).

⁹⁴ None of these projects offers harm reduction services to people injecting drugs.

In contrast to the two organizations above, an NGO that is currently placed in the registry of foreign agents had a very different experience with applying for state funding:

Judging from previous experience, our chances of obtaining state funding are very small. We have applied for presidential grants several times, but our applications have never been supported. The last time we applied was in February, so we are waiting for a decision, but I am not surprised if it is negative. We have never received state funding (Interview 020101, 2018).

5.4.2 Legal mobilization/demobilization

While some NGOs work without having legal restrictions imposed on their work (legally mobilized), others are severely hindered by the current legislation (legally demobilized). In this regard, FZ 121 (2012) and FZ 436 (2010), in particular its 2013 amendment, appear to be especially noteworthy. Thus, this second mobilization/demobilization strategy has also primarily been used after Putin's cultural turn in 2012. With regard FZ 121, the term "political activity" and what it includes in terms of HIV/AIDS requires some attention. In 2016, Putin signed a law stating that "Political activity does not include activities in the field of science, culture, art, health, prevention and protection of public health" (Federal'nyi Zakon, 2016).

Despite this legal affirmation of health activities not being political, HIV/AIDS NGOs are frequently forced to register as foreign agents. In February 2016, the Omsk-based NGO "Sibal't" was the first to be placed in the registry, after it had distributed a brochure called "LGBT. Human Rights in Russia", which contained criticism of the 2013 amendment to FZ 436 (Sibal't, 2016). Miniust concluded that Sibal't by this had tried to influence public opinions and state decisions (Miniust, 2018b). Two months later, the Global Fund supported Saratov-based NGO "Sotsium", member of the Russian harm reduction network ESVERO,⁹⁵ was named a foreign agent. Sotsium distributed needles and condoms to injecting drug users, and had been conducting opinion polls, which the Prosecutor's office considered political (Chernykh, 2016b). In its request, the office relied on an expert opinion stating that "NGOs like Sotsium and ESVERO destroy our traditions and our national values", and that their harm reduction services should be regarded as "part of a hybrid war against Russia" (Lykov, 2016).

Following these two initial rulings, a large number of HIV/AIDS NGOs was forced into the registry. In June 2016, ESVERO and Andrei Rylkov Foundation were listed, both providing harm reduction services to injecting drug users and vocal advocates for decriminalization of

⁹⁵ ESVERO and Sotsium are now both liquidated. Sotsium was a sub-recipient of the third Global Fund grant.

OST (ARF, 2018). By the end of 2016, an additional four NGOs had been named foreign agents, “Panatsea” from Penza Oblast’, which distributed needles and condoms to key populations,⁹⁶ the previously discussed Ekaterinburg-based The Era of Health, a medical association from Samara Oblast’ that had been advocating for country-wide harm reduction services to injecting drug users, and “Project April”, also from Samara Oblast’, involved in HIV education and harm reduction. One of its employees had also filed a complaint to the EHCR in 2014 on basis of Russia’s ban on OST (Assotsiatsiia Meditsinskikh Rabotnikov, 2014; Nikitina and Petunin, 2016; Kuzina, 2017; Miniust, 2018b). The trend continued in 2017, when the previously discussed New Time from Ekaterinburg was registered, in addition to “Choice” from Altai Krai,⁹⁷ which had programs on HIV prevention, peer consultations and testing, and had received support from the Global Fund via ESVERO (Abdurakhmanov, n.d).

The examination of HIV/AIDS NGOs named foreign agents shows that the regime has led an especially harsh offensive against NGOs offering harm reduction and/or advocating for LGBT rights. In light of Putin’s conservative shift and the regime’s current rhetoric, it is unsurprising that NGOs assisting drug users and sexual minorities are attacked. It is however, a formidable challenge to curb the spread of HIV in Russia. FZ 121 is directly responsible for liquidating three of Russia’s biggest harm reduction NGOs, which is likely to facilitate virus spread among injecting drug users, in turn fueling spread to their sexual partners. In Ekaterinburg, for example, the prevalence of HIV among injecting drug users increased from 26.4% in 2012, to 57.2% in 2017 (Federal’nyi Tsentri SPID, 2017). A representative from an NGO placed in the registry of foreign agents talked about how this affects the diversity of HIV/AIDS NGOs:

[...] there is no sustained support of HIV/AIDS NGOS at the state level, especially not for those involved in HIV prevention among key populations. Sporadic funding is available, but not to everyone, and sustainability for HIV prevention activities is not ensured [...] NGOs offering HIV prevention in Russia to groups such as drug users, sex workers and men who have sex with men can be counted on the fingers, fewer every year (Interview 020101, 2018).

FZ 121 has efficiently reduced the sum of foreign funding being channeled into Russian NGOs,⁹⁸ a situation not only affecting organizations registered as foreign agents. A manager from a 2017 grant-winning project explained how this situation restricted their work, despite the NGO being a presidential grant recipient:

⁹⁶ Panatsea announced its liquidation shortly after Miniust’s decision.

⁹⁷ Choice was later excluded from the registry.

⁹⁸ Despite the risk receiving foreign funding now entails, all of the NGOs I talked to still accept foreign funding.

In 2016, the turnover of our organization was 35 million rubles a year, now it is 20 million rubles a year. The funding from international donors has dropped, and many of our projects are closed. For example, in 2015, we had 18 peer consultants [...] and now we only have 3, who are paid by the presidential grant we received (Interview 010201, 2018).

FZ 121 has also resulted in NGOs spending excessive time and resources on staying out of the registry, absorbing resources from their main work. The leader of an NGO that had received Global Fund funding explained how the constant fear puts their NGOs under great strain:

Right now, I am very concerned about the law on foreign agents, because over the last couple of years we have only had international funding. I am afraid that they [Miniust] will name us a foreign agent. I have just met with them, they intimidated us, threatened to close us down [...] I had brought our documents, and I thought that we had given them everything they needed, but then they asked for more boxes of documents, so we spent the whole weekend copying, and tomorrow I will bring it to them. [...] Our NGO used to be able to provide more services to people, but we spend more and more time on legal protection (Interview 030103, 2018).

Other legal barriers were also mentioned by interviewees. One project manager said that:

HIV testing can only be performed by medical specialists or NGOs licensed to do so, it even applies to express testing, and all recommendations say that pre-test counseling should also be performed by physicians. And this applies not only to tests on capillary blood, but also to saliva. In our opinion, this makes it difficult to run prevention projects, because we cannot test people, so we have to do this in partnership with health facilities (Interview 010201, 2018).

A leader of another NGO pointed to how the AIDS center's requirements interfered with their work, and how, in her opinion, Russia's legal ban on OST fuels the epidemic:

We have big problems with the AIDS centers. A large number of the people we work with are not from this city. So, we have to prepare documents and register them [in our federal subject], but often they do not even have passports, which you obviously need, and our clients, mostly drug users, commonly have problems with documents. [...] In countries in the post-Soviet sphere, take for example, Armenia, they treat everyone, even those without documents. And, I am not sure, but maybe, like 95% of these countries also offer opioid substitution therapy. I do not like our policy [in Russia]. It helps spread the epidemic (Interview 030103, 2018).

5.5 Comments

This thesis' collected evidence supports that HIV/AIDS NGOs that are either 1) supportive of the regime ideologically, i.e., groups that can serve as advocates for the cultural conservative

rhetoric that has been pursued after 2012, or 2) beneficial to the regime as service providers, but not interfere with the regime's current priorities, are being mobilized. This mobilization appears to mainly occur through the allocation of state grants (financial), and by not imposing legal restrictions on the NGOs' work (legal). NGOs that do not offer anything the authorities regard as useful are being demobilized, either financially (denied state funding) and/or legally (having their work restricted by legislation). With regard to the situation in Sverdlovsk Oblast', the above propositions seem to fit relatively well. ROC, the recipient of the first grant, is a vocal supporter of the regime's cultural conservative rhetoric. The second grant-winner, New Life's discordant couple project, is oriented toward (heteronormative) families and demographic growth, and is thus a useful service provider in health, while not interfering with current priorities. The two foreign agents, Era of Health and New Time, mainly provide harm reduction. New Time's leader has also criticized the Russian HIV response to Western media. Consequently, both of the NGOs have been legally and financially demobilized.

The Presidential Fund's newfound interest in supporting HIV/AIDS projects in 2017 may reflect a governmental awareness about the inefficiency of the approach to HIV led during Putin's third term, which has prompted the regime to invest financially in (selected) projects. Projects targeting families, women and children, e.g. New Life's project, are in this regard "safe" options; they do not propagate views contradicting the current rhetoric, and they do not disturb the regime's relationship with actors supporting the 2012 shift. Sponsoring HIV/AIDS projects may also be a way for Putin to exhibit how he takes action against the epidemic, and includes civil society. As examined in Chapter 3.3, both the 2009 security strategy and the 2016 HIV strategy emphasize how civil society should be employed in the state's response.

The result of the regime's mobilization/demobilization policies seems to be a landscape of HIV/AIDS NGOs that is both decreasingly diverse, and decreasingly capable of assisting the state in reducing the spread of HIV. Projects targeting marginalized groups, e.g. injecting drug users and sexual minorities, are among those suffering most from the regime's priorities, but as Chapter 5.4 showed; other NGOs are also negatively affected, even those being mobilized. The current situation has also created an environment in which NGOs may avoid certain activities, e.g. harm reduction, in fear of being demobilized, further reducing the diversity of services offered. This is a highly unfortunate development, as it is unlikely that the epidemic can be curbed without including all population groups. Many HIV/AIDS NGOs now also spend excessive time and resources on bureaucracy, staying out of the foreign agent registry, and on obtaining funding, reducing their capacity to assist the state in the fight against HIV.

6 Conclusions and reflections

The aim of this thesis has been to examine how Russian health care policy is shaped by the diverging forces of modernization and neo-patrimonialism, with a particular focus on possible consequences of this dynamic for the prevention and spread of HIV in Russia today. This aim was pursued by answering the three research questions presented in Chapter 1, which are: 1) How, and to what extent, does Russia's political leadership make use of anti-Western rhetoric to cover up problems related to the HIV epidemic in Russia?, 2) Which parts of Russia's current NGO legislation appear to be especially limiting for organizations working on health-related topics, hereunder in particular HIV and AIDS? How is this likely affecting the response to HIV in Russia?, and 3) To what degree does the Russian population seem to be updated on HIV issues and the epidemic that is currently unfolding in Russia, and how is this likely to affect the further spread of HIV?

The first research question has been pursued through reviewing a combination of contextual background (Chapter 3) and collected empirical data (Chapter 4 and Chapter 5). As this thesis interprets "anti-Western rhetoric" not only to involve direct statements made by representatives from the political leadership, such as the president(s), the health minister, and other relevant state officials, but also to entail the various policies that have been implemented and pursued, an effort has been made to map all actions that can shed light on how the Russian regime utilizes anti-Western rhetoric to conceal its inability to curb the spread of HIV. This thesis found that this has been done mainly in three ways; to openly discredit "Western" methods, recommendations and societal values, to include AIDS denialists in the public discourse, and to introduce laws limiting cooperation between foreign and Russian NGOs. The findings were explained with reference to the initial theoretical framework, which was presented in Chapter 2.3.1, and the additional theoretical framework developed as part of this thesis. The additional framework was introduced because the initial model was interpreted as not reflecting the contrasting approaches to HIV that arguably exist between Medvedev's presidency and Putin's third term properly, and as not addressing the relationship between the global community and the domestic Russian HIV/AIDS policy triangle. This adapted framework consisted of two models, which were presented and discussed in Chapter 2.3.3.

The second research question has been approached through exploring the history of HIV/AIDS civil society in Russia, in addition to examining the relevant legislation (Chapter 3). This contextual background was then complemented by a thorough investigation of the

current legal situation and its implications, illustrated by using Sverdlovsk Oblast' as an embedded unit of analysis (Chapter 5). As highly interesting developments in the financial mobilization of Russian HIV/AIDS NGOs took place during the period of writing this thesis, national patterns of mobilization and demobilization were also analyzed in Chapter 5. This analysis was built on both collected empirical data about the regime's financial contributions to NGOs and on interviews with representatives from relevant NGOs. The chapter concluded that significant changes in the regime's approach toward HIV/AIDS civil society have taken place after 2012, mainly through the introduction of FZ 121 and the 2013 amendment to FZ 436, and, in the prolongation of FZ 121, the state sponsoring of HIV/AIDS NGOs. The findings were explained with reference to the theoretical propositions presented in Chapter 2.

In order to answer the third research question properly, survey data collected by NIBR, supplemented by data from the most recent WVS, were analyzed in Chapter 3. This third chapter also set out to explain possible consequences of having a society broadly uneducated about HIV, and presented an already developed model for understanding how stigma and marginalization in societies can impact the spread of HIV. Findings from this analysis also provided a useful contextual background for this thesis' first embedded unit of analysis, a conflict over sexual education and HIV prevention lessons in Cheliabinsk (Chapter 4). Sex education in schools was broadly supported and trusted by respondents in the NIBR survey, and the analysis revealed what appeared to be a dissonance between what people want in terms on HIV prevention, and what the regime offers. This finding was discussed with reference to theoretical propositions of regime dynamics and pressure on neo-patrimonial polities presented in Chapter 2. The conflict in Cheliabinsk also prefaced a broader discussion on how the regime's current reliance on a strong conservative base to maintain its political dominance and power affects its ability to build a viable domestic HIV response.

The first finding in this study is that Putin's cultural turn in 2012 appears to have affected Russia's ability to respond to HIV negatively. While the policy course pursued during Putin's two first presidencies (2000-2004 and 2004-2008) and during Medvedev's presidency (2008-2012) allowed for interaction between the Russian domestic HIV/AIDS policy triangle and the global community (see Chapter 2), which provided a (limited) capacity to respond to HIV, Putin's third term (2012-2018) has not offered the same opportunities. Thus, Russia's more hostile rhetoric toward the international community has not only created a tenser geopolitical climate, but arguably also impacted Russia's ability to limit the spread of HIV domestically. This thesis' collected evidence supports that three specific developments in particular have

reduced Russia's capacity to respond to HIV. Firstly, the introduction of FZ 121 in 2012, including its 2015 addition, has resulted in a situation where Russian HIV/AIDS NGOs have been pressured to scale down, reorganize or liquidate, and global agencies working on HIV/AIDS issues in Russia have been forced to leave the country. Secondly, Putin's post 2012 cultural conception of the state, which efficiently limits agency to any group interested in pushing Russia out of the neo-patrimonial space, has also arguably contributed to inaction. Neo-patrimonialism provides highly unfavorable conditions for successful implementation of reforms, and its stabilization is thus expected to contribute to inaction. Lastly, the value-based conservative rhetoric Putin's 2012 shift was accompanied by apparently includes increased access to state structures, policy crafting and funding for actors opposing conventional HIV prevention, expected to further worsen the epidemiological situation.

The second observation is that the regime to a great extent utilizes anti-Western rhetoric in order to cover up domestic problems related to the spread of HIV. The collected evidence supports that this has predominantly been done after 2012, and in three main ways. Firstly, Russian government officials and state institutions have on several occasions presented Western societies, laws and recommendations as a collective moral deterioration, intended to destroy Russian history, tradition and values. For instance, Putin, in his 2013 Valdai Forum speech stated that Western countries are "rejecting their roots, including Christian values which constitute the basis of Western civilization", that such countries are "denying moral principles and any traditional identities" and that Western policies "are equating large families with same-sex partnerships, and the belief in God with belief in Satan" (Zavrazhin, 2013). Global and Western HIV prevention recommendations have also repeatedly been dismissed on basis of being "incompatible with Russian traditions, laws and cultural values"⁹⁹, that they "kill people",¹⁰⁰ that they "exacerbate the problem, rather than provide an adequate solution"¹⁰¹, or "destroy Russian tradition and culture"¹⁰². Secondly, the regime's inclusion of denialist voices the public discourse is also regarded as a part of the anti-Western rhetoric, as AIDS denialism, through its understanding of HIV being a virus fabricated by the US undermines Western actors (Pape, 2014, p. 101). Thirdly, the crackdown on foreign involvement in Russia, most notably through the introduction of FZ 121 and its 2015 amendment, is also interpreted as constituting an important part of this rhetoric.

⁹⁹ This statement was made by Sergei Kraevoi, deputy Minister of Health in Russia in 2015 (Anisimov, 2016).

¹⁰⁰ The Russian Health Minister, Veronika Skvortsova, commenting on OST (Novosti OON, 2016).

¹⁰¹ RISI's report, discussing the "Western liberal approach" to HIV (Guzenkova, et al., 2016).

¹⁰² A statement from the Roskomnadzor report prepared by representatives from RVS (Roskomnadzor, 2017a).

The third observation is that two parts of the current legislation appears to be especially limiting for NGOs working on HIV and AIDS in Russia. The first one is the law on foreign agents (FZ 121) from 2012, and the second is the 2013 amendment to the law on protecting children from information that is harmful to their health and development (FZ 436). Collected evidence from Sverdlovsk Oblast', Russian authorities' registries of foreign agents and organizations declared "unwanted" in Russia, collected information about HIV/AIDS NGOs that have been forced to close, and information obtained through interviews with representatives from Russian HIV/AIDS NGOs support this observation. However, another interesting observation was that interviewees also mentioned other legal issues restricting their work. Examples are that HIV testing, including on saliva, only can be legally performed by doctors, which makes it difficult for NGOs to run prevention programs (Interview 010201, 2018), or that the requirement of presenting documents in order to access services at the regional AIDS centers practically excludes injecting drug users from treatment and care (Interview 030103, 2018). Thus, while free medical and social support to HIV-positive has been a legal right in Russia since 1995, this right is restricted through other legal mechanisms.

The fourth observation is that the Russian population appears to be inadequately informed about HIV, especially about how widespread the infection is in the general population. This is likely to contribute to stigma, discrimination and further virus transmission. However, the analysis of the survey data Chapter 3.5 also showed how a majority of respondents thought the authorities were doing an inadequate job with HIV/AIDS prevention, care and treatment, how state spending on HIV and AIDS was broadly supported, and also how the "liberal methods" that the regime rules to be incompatible with Russian tradition, laws and moral values were broadly supported. Thus, a dissonance between what the regime offers, and what people want, seemed evident. In this regard, it should be noted that Putin at present is somewhat restricted by the conservative base he relies on to maintain his political dominance and power, in the sense that its representatives oppose any liberalization of HIV policy, and they expect their opinions to be heard at a state level. How this can play out was explored in Chapter 4, illustrated by using the embedded unit of analysis from Cheliabinsk.

So, what are the implications of these observations? As long as Russia remains stuck in the neo-patrimonial space, prospects for building a viable HIV response look bleak. As discussed in Chapter 3.3.4, the patronal networks that permeate all levels of policy making exert a distorting influence on the directions and effects of policy changes, and neo-patrimonialism greatly complicates the implementation of reforms. A modernized Russia, in the form that

Medvedev proposed, i.e. institutional changes and a move toward developmental democracy, could have provided better conditions for reforms able to improve Russia's HIV response, or at least have moderated the policy of denial. But, Medvedev, constrained by Putin's informal powers never achieved his plans, which now have been abandoned. As pointed out in Chapter 3.5, regime stability may be threatened if its inability to curb the spread of HIV provokes sufficient social discontent. However, discontent requires awareness, and without increased awareness in society about the severity of Russia's HIV problems, the emergence of social pressure able to challenge regime stability seems unlikely. Putin's efforts to conceal Russia's HIV challenges with anti-Western and pro-civilizational rhetoric thus seem to have paid off for now. Even so, regime strength cannot make the epidemic disappear.

At present, the only hope for building a viable response to HIV in Russia seems to be Putin devoting himself to the task. A policy change may result from social discontent threatening regime stability, or because he, for some other reason, becomes sufficiently concerned about the epidemic to ensure that sustainable changes are made. However, thus far, no indications of this becoming a reality have been given. Neo-patrimonialism has been stabilized in Russia during Putin's third term, which complicates the implementation of reforms (see Chapter 3), and the post 2012 cultural conception of the state limits political agency to anyone interested in pushing Russia out of this space (see Chapter 2). The introduction of "liberal" changes in Russia's response, e.g. decriminalization of OST, introduction of harm reduction services and incorporation of sex education into the school curriculum is likely necessary to curb the current epidemic, but would in all probability disrupt Putin's relationship with, and reliance on, influential conservative institutions such as ROC. These are alliances he has shown no intentions of breaking. Thus, although the approval of the first domestic strategy in 15 years and the allocation of presidential grants to more than 20 HIV/AIDS projects in 2017 may indicate that the regime recognizes Russia's severe challenges with HIV, these events should not be interpreted as automatically resulting in any epidemiological improvements.

This thesis has provided a thorough examination of the Russian HIV epidemic within its real-world context, and has contributed both empirically and theoretically to the field of Russian regime dynamics and its effects on the development of health care policies. Empirically, the study has provided new research that can help shed light on the above dynamic and its consequences, an issue that has received relatively scarce attention by existing literature and research. Theoretically, this study has contributed with an analytical framework for the interpretation of how two different pressures on neo-patrimonial Russia, i.e. modernization

and cultural conservatism, has influenced the country's ability to curb the spread of HIV. In this regard, the research has hopefully contributed to a broader understanding of how a polity stuck in the neo-patrimonial space can influence the public health of its citizens. The findings may also be relevant when applied to other polities with a power structure of a similar kind.

While the global community's pressure on Russia seemed to have a degree of impact on the regime's focus and priorities prior to 2012, illustrated by events such as Russia's pioneering role in making the fight against HIV a G8 priority in 2006, or the weighty Russian donations to international HIV/AIDS cooperation during Putin's two first presidencies and Medvedev's presidency, a similar effect has not been seen after 2012. Russia has pulled further away from the global community, and by this, also its methods and recommendations. The regime's behaviors, such as the crackdown on civil society and foreign involvement in Russia, or the increased resistance to evidence-based HIV prevention, may seem irrational, but can also be interpreted as rational and necessary acts for the regime to preserve a Russia that is strong and capable of handling its own business, without foreign, and especially Western, interference. Within this context, it seems to be particularly important to maintain dialogue with Russian HIV/AIDS civil society, which still to a great extent, relies on foreign support. This also applies to global agencies, e.g. the Global Fund, where Russia, with its current upper middle income classification, should be eligible for additional HIV/AIDS grants under the NGO rule.

This study has mainly focused on neo-patrimonialism as a form of rule and its consequences on the development of HIV policies in Russia. Multiple-case studies, or other types of comparative studies, may broaden our understanding of the Russian challenges, and identify measures that can possibly be successfully introduced within Russia's current political framework. In this regard, one might look to sub-Saharan Africa, where neo-patrimonial governance is prevalent in a number of polities, and HIV incidence rates and AIDS related deaths, which have been enormous public health challenges, have been successfully reduced over the last decade (UNAIDS, 2017a, pp. 2–3). Further research may also focus more isolated and in-depth on the Russian epidemic. Here, it could arguably be advantageous to link research on neo-patrimonialism and HIV to other relevant Russian public health challenges, such as TB, hepatitis or drug addiction. An ambition should be to ensure that people in Russia receive not only the HIV services they need and deserve, but, for a large number of Russians affected by HIV, also the integrated treatments their conditions require.

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Attachment 1 – Table of Interviewees

First two numbers—main services offered by the organizations:

- 01 – Counseling and social support
- 02 – Harm reduction
- 03 – Information and education

Second two numbers—regional versus country-wide.

- 01 – Regional NGO
- 02 – Country-wide association

Third two numbers—interview format:

- 01 – E-mail
- 02 – Skype with video
- 03 – Skype without video

Interviews

Number	Date conducted
010201	April 11, 2018
010102	April 14, 2018
030103	April 16, 2018
020101	April 24, 2018

Attachment 2 – Interview Guide

*Interview guide for Skype interviews:*¹⁰³

- 1) Вы можете мне, пожалуйста, немного рассказать о вашей организации? [Could you please tell me a bit about your organization?]
- 2) Как Вы оцениваете возможности вашей организации работать независимо и автономно? [How do you assess your organization's possibilities to work independently and autonomously?]
- 3) Изменились ли условия деятельности вашей НКО за последние годы? Если да, то каким образом? [Have the conditions of your NGO's activities changed in recent years? If so, then how?]
- 4) Как ваша организация оценивает свой доступ к государственному финансированию и к другим источникам финансирования? [How does your organization consider its access to state funding and other sources of funding?]
- 5) В действующем законодательстве, существуют ли какие-либо законы, которые накладывают ограничения на работу вашей организации? Если да, то какие? [Under the current legislation, are there any laws that impose restrictions on the work of your organization? If so, which ones?]
- 6) По Вашему мнению, какова в целом нынешняя ситуация для ВИЧ-сервисных НКО в России? [How would you characterize the overall situation for NGOs working with HIV in Russia today?]

¹⁰³ During the e-mails interviews, questions 3–6 were initially sent to respondents, and follow-up questions used to elaborate and clarify aspects of the interviewees' answers.