Non-Invasive Pre-Natal Testing: Controversies and Ethics in Norway

Domitille Ménager

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Abstract

This dissertation explores the current controversy surrounding the implementation of Non-Invasive Prenatal Testing (NIPT) in Norway and how the associated debate articulates itself between various participants: the scientific community, the medical personnel, political parties, medias and individuals who have voiced their concerns. The implementation would be either as secondary method to the current Combined Ultrasound and Blood sample, or replacing this method as a primary testing method for the detection of chromosomal anomalies such as the trisomies 13, 18 and 21.

Each participating side argue with either scientific facts, religious or cultural values, some appeal to the more humanistic dimension of the test. The controversy is being studied through a Science and Technology Studies perspective, making use of the Actor Network Theory methodology while using a narrative and semantic approach towards the analysis of official statements from three national institutions: The Directorate for Health, the Biotechnological Council and the Ministry for Health and Care Services.

Acknowledgments

My motivation for this subject came from a very engaged position into the theme. I have a mother, I have a sister, I have friends who have or will in their life at one point be pregnant, and one day, will have the possibility to choose a reproductive technology such as NIPT. I had the chance to grow up in a house where I had access to medical knowledge through books, I spent hours reading the *Larousse Médical* while questioning my mother about various part of the body and their functions. As I turned to academics, I also wanted to write about scientific and social contemporary issues, being able to spread a knowledge that all should have access to because learning makes us better as a specie.

Although this is not the Academy Awards, there is a sense of accomplishment in finishing a superior academical degree, and I owe a debt of gratitude to my parents, Chantal and Serge for supporting me, guiding my brain through education, encouraging me to go back to university. Along the path of academical work, I have come to meet smart, patient and dedicated individuals whose methodologies, advices and pure intellect were a symbol of what modern university can mean for those who want to learn and improve: Susanna Maria Solli at the University of Oslo whose encouragements through my Bachelor encouraged me to pursue a Masters' education, Kristina Ask at NTNU for being the most inspiring geek-gamer-academic teacher one could dream to have in a lifetime and Daniel Giguet for being my professor of philosophy when I was a student in high school, who showed me that believing in your brain and being stubborn to get through a text, even the ones who you disagree with can lead to amazing experiences. And finally, my thesis'counsellor, Tone Druglitrø whose help has been incomparable. You have been so patient towards me and a puzzle solver whenever I wrote myself in circles and helped me throughout the writing for all these months.

And last but not least, thank you, Magnus, for being there with an objective mind, a calm scientific oriented reflection to answer my questions, calming my worries, soothing my fears, showing me how to navigate the technicalities of various software and accepting that I do not type this thesis using LaTeX, despite how pretty it would have looked. You have been the support that I needed to be where I am today.

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I – Introduction

When Non-Invasive Pre-Natal Testing also called NIPT came to be introduced in Norway, it was first reviewed by the Biotechnology Council who recommended its use in the detection of trisomies and gender based chromosomes diseases. NIPT is called non-invasive because it consists of a blood sample drawn from the pregnant woman and has no risk of spontaneous abortions as opposed to other traditional pre-natal testing. However, the implementation of NIPT in Norway was not and is not without its problems. It is riddled with controversy which seems to be the case when reproductive technologies are being debated. There are often moral and cultural values issues arising out of reproductive technologies debate due to their expected impact on society and people's life. In the implementation of NIPT, the controversy has caused these issues and other associated values to be put forward in the debate, and it has been very clear that this is a difficult and challenging area of medicine.

In this dissertation, I intend to trace how the controversy of NIPT has unfolded in the Norwegian context. I will specifically concentrate on the role played by the Directorate of Health because of its advising function in matters of technology and health in the Norwegian society. One of the main issues arising out of the controversy is whether non-conforming humans to set standards will be eliminated before birth by using technologies such as NIPT. This is one of the arguments made by the people opposing the implementation of NIPT in Norway, such as political party members of KrF and activists of the organisation Menneskeverdig, for example. Another side of the debate will enhance the fact that this is a safer medical practice than the traditional use of amniocentesis or placenta biopsy which carry a risk for spontaneous abortion, that is the position of the Biotechnology Council and Directorate for Health. For some of the participants of the controversy who are opposed to the implementation of NIPT, is it because NIPT as a reproductive technology forms a stepping stone to a eugenic society due to its implication that non-standard looking human beings are imperfect? And if everything is to be determined and screened in advance for engineering "normal" human beings, are women the future "incubators" for producing these human beings because of their reproductive role, does it mean that we are headed towards a reductionist perspective in society towards the women' role in terms of science and technology? On the other hand of the controversy, most scientists tend to agree that NIPT as a reproductive technology is a tool that will enable medical personnel to provide better help and care to

pregnant women and their families, due to its non-invasive nature, removing altogether the risk of miscarriage.

I argue in this dissertation that neither a reductionist nor an optimistic perspective on the role of reproductive technologies form adequate explanations for the work that NIPT contribute on the issues of reproduction, choice and practices of normality. I intend to show that NIPT, in similar but also crucially different ways than other reproductive technologies, is a complex phenomenon as it is. To approach the controversy and phenomenon of NIPT, I will mainly draw upon theoretical and analytical resources from the Science and Technology Studies as this field of academics provide the means to study and understand how both Science and Technology work in society and on bodies, and how science and technology contribute to shape life as we know it. The Science and Technology Studies perspective allows to study how new technologies and their implementations impact society and individuals, by providing an insight which encompasses the scientific facts but also to identify agendas, arguments and how a controversy is constructed. I will focus on key documents and texts that have taken part in framing the issue at stake, as well as been important in "taming" the controversy and ultimately implementing NIPT as part of prenatal care routine testing in Norway. As such, my narrative strategy is to describe what NIPT is by following actors in and by texts.

1.2 Problematisation and actualisation

The controversy around NIPT puts into light the rationale around the normalisation of the definition of a human being and its role's definition into society from a social and cultural frame perspective, being a wide ethical issue. The Biotechnological Law states that in its chapter about Foetal Diagnosis (Article §4) that:

> "Fetal diagnosis refers to the examination of fetal cells, fetuses or from a pregnant woman for the purpose of obtaining information on the genetic characteristics of the fetus or for detecting or excluding disease or developmental defects in the fetus. Ultrasound examinations in general pregnancy care are not considered as fetal diagnosis in accordance with the first paragraph […]." (Bioteknologiloven §4-1. Definisjon)

Currently, the Norwegian government recommends the use of NIPT in the early detection of trisomy from the 10th week of pregnancy but it is not a systematic medical procedure and it is

also reserved to specific patients. As of today, the medical procedure to determine presence of trisomy in the foetus is offered to pregnant women from the age of 38 years old and over. This procedure consists of what is called KUB/CUB (Combined Ultrasound and Blood sample) from the 12th week. If the results of the KUB show signs of trisomic chromosomes, the pregnant woman will be directed to take a secondary test to either confirm or reject the risk of trisomy. The secondary test is either an amniocentesis or a placenta biopsy.
Another side of the controversy is set onto the economical and safety dimension of NITP. The Biotechnological council stated that is in fact cheaper and safer to perform this procedure instead of the traditional amniocentesis (where amniotic fluid is being drawn from the amniotic sac contained in the womb of a pregnant woman). The latter procedure is expensive, invasive and can lead to miscarriage (very low risk: 0,5 to 1%, but still present) (Helsedirektoratet 23.01.2017). There are many aspects to that controversy, heated debates have ensued from both medical personnel but also non-health care related individuals.

After official statements were issued by the Biotechnological Council and the Directorate for Health, newspapers articles focused on the debate of NIPT and NIPD (Non-Invasive Prenatal Diagnosis). One article from NRK (Hellesnes 2017) presented the NIPT controversy and put it under political scrutiny to show how it includes more than the medical field related personal and pregnant women as patients. This is a controversy that is at the heart of society because half the population of the world are women, and to this extent, reproduction and its associated themes have an impact on all individuals. Another article, this time on TV2 (Talsnes, Hallgren and Godal 2016) gives an account of Norwegian pregnant women who had to travel abroad to have access to NIPT, how much money they had to spend on travelling and buying the laboratory services from a private clinic. The article also exposes the emotional fear of the women and the implications that the knowledge provided by NIPT would provide to ease their mind. Finally, the article puts the accent on how these women are being forced to seek medical care from other countries such as Sweden or Denmark due to the Norwegian authorities not having approved NIPT.

This dissertation hopes to see how the controversy articulates itself around the questions being raised as well as the implications for the individuals directly concerned. It would benefit the understanding of the controversy by establishing how NIPT can be interpreted as a social phenomenon. That is to say how is NIPT used in its worth and how the roles of the objects are

impacted by it in the Norwegian society, and to extent, how this influences the Norwegian logic around the notions of reproduction and the female body narrative.

II – Prenatal Testing

> *"A lack of awareness of the indications for prenatal genetic studies by both physician and public has probably constituted another major reason for the tardiness. Additional hesitations have focused on some inadequate, unproven, or absent facilities for prenatal genetic studies, while antipathy to abortion has been a factor in other communities."* (Milunsky as cited in Woo 2002)

2.1 History of Prenatal Testing

There are records of amniotic fluids being extracted during the third trimester of pregnancy through the process of transabdominal amniocentesis as early as the 1880's, and amniotic fluid being used to determine the presence of genetic disease was presented in the reports of Fuchs and Riis in 1956. This opened the door to new possibilities of medical technologies such as the determination of foetal sex, it led to John Edwards who approached the possibility of "antenatal detection of hereditary disorders" (Woo 2002). In other words, the presence of possible genetical anomalies in foetuses due to inherited traits from the parents. Milunsky (as cited in Woo 2002) also points that the reports from Bevis in 1950's exposed how to manage the rhesus of isoimmunised patients.

These burgeoning technologies present a common purpose, being able to identify and manage possible genetical disorders that could cause harm for the foetuses and to an extent, the parents, notably death from birth complications. Another similar trait from these prenatal technologies is that they are invasive. For instance, the first fetoscopy consisted of introducing a very long needle through the cervix to retrieve foetal tissue sampling (Woo 2002). In Scandinavia, the premises of Choronic Villius Sampling were performed in 1968, the reports of success were high quite high at the time, however, the technology was considered unsafe due to its complications such as bleeding, infection and failed culture of the samples and eventually, the mid-trimester amniocentesis was chosen instead due to its increasing safety (Woo 2002).

2.2 Reproductive Technologies

The development of NIPT as a reproductive technology for prenatal testing demarks itself from other previously used prenatal methods due to its non-invasive nature, as it does not require the insertion of a needle or other perforating instrument through the womb of the pregnant woman to obtain biological sampling for testing. The fact that NIPT is non-invasive constitutes a revolutionary process because it removes the risk of miscarriage which always was a constant risk with other testing methods, low risk but nonetheless existing.

Traditional prenatal testing includes test such as amniocentesis, chorionic villus sampling (placenta biopsy) or cordocentesis (percutaneous umbilical blood sampling); which pose a risk of miscarriage. These tests are performed during different stages of the pregnancy. For instance, cordocentesis is being performed after the 18th week of pregnancy, it also can be used to effectuate blood transfusions or medication delivery to the foetus. It is a test which is usually aimed for detecting conditions such as foetal anaemia (Mayo Clinic 2015). However, it remains a rather rare prenatal procedure as opposed to amniocentesis or CVS which are the norm. There is an underlying sociological dimension to reproductive genetics, as a concept, as it is anchored into a social and cultural process (Ettorre 1999) that we understand as a standard medical norm, we do not question, it comes as an obvious rite-of-passage for the pregnant individual.

According to Rothman (1994: 127), the knowledge of sex for the parents and relatives acts in two ways. Firstly, the foetus is being specified reinforcing a pre-determined projected identity onto the future child. Secondly, the assignment of sex can be blended into a framed genderisation of the foetus, attributing images of personality that are more intended towards gender rather than sex due to the contextual cultural representation of gender in society. For the future parents, this knowledge allows them to define in advance their progeny, individualising it, which can lead to influence the medical decisions they will take during prenatal care.

Furthermore, Rothman questions if this knowledge impacts the reaction of women towards the foetus. This knowledge creates a shift from an abstract foetus to a baby, making it “real” according to the women interviewed by Rothman, some even claiming to have been buying gender type items that they would not have done otherwise (1994: 126). Rothman explains the

differentiation that is being made between gender and sex already in 1994, which is still a highly debated point of view more than twenty years later:

> *"The knowledge makes a difference, the knowledge changes things, because with sex comes gender. Gender is the social identity, our different expectations for boys and for girls, for sons and daughters. Gender goes beyond the Y and Y chromosomes, beyond genitalia, to our ideas about the kind of person the foetus will become" (1994: 119).*

She points out that knowledge changes our social and cultural perception about the child to be born, and that this perception is already being exerted on the prenatal level. Alongside some of the associated perspective to gender, there are also personal expectations from the parents to be about the sex of their child, and which type of social construct of gender role to conform to. Pre-natal testing encompasses various tests that are being performed from a stage of pre-pregnancy throughout the entire duration of the pregnancy and up till birth. In the case of Non-invasive prenatal testing, the test which consists of a regular blood sample can be taken as early as week 10 of the pregnancy.

The Biotechnology Council acts as a source of information on the scientific facts related to NIPT and its effects onto patients. However, this counselling role has for intent to remain as a neutral as possible and not account for politics or religious external sources that could influence their decision.

Among the various reproductive technologies and prenatal testing, CUB – Combined Ultrasound and Blood (or KUB in Norwegian), is a screening test based on the combination assessment of early ultrasound and blood sample.

It is important to understand how NIPT works to better grasp the scientific perspective in the controversy. The foetus in the womb releases a small amount of cell free DNA into the bloodstream of the mother, and this is what the laboratory technicians will look for into the blood sample. NIPT is recommended in these specific cases: if the triple test or first trimester screening indicates an increased risk for any of the three trisomies, advanced maternal ages (from 38 years old and over), anxiety for invasive procedures (placenta biopsy or amniocentesis, for example). There are a few contraindications to the use of NIPT such as foetal anomalies on ultrasound, known genetic anomalies that cannot be diagnosed through the means of NIPT, a triplet pregnancy or a vanished twin.

2.2.1 Foetal Cell-Free DNA

NIPT as a technological tool to detect chromosomal anomalies relies on a biological phenomenon, cell-free DNA. The maternal plasma is derived from the placenta which is located in the same sack as the foetus, being nourished through the umbilical cord. According to the studies being summarized by Bianchi and Edlow (as cited in Swanson, Sehnert and Bhatt 2013), the majority of foetal cell-free DNA is contained in the maternal plasma "with minor contributions from the foetal hematopoietic system and the foetus itself". The hematopoietic system of the foetus like a grown adult has for function to form blood cellular components, which are derived from hematopoietic stem cells.

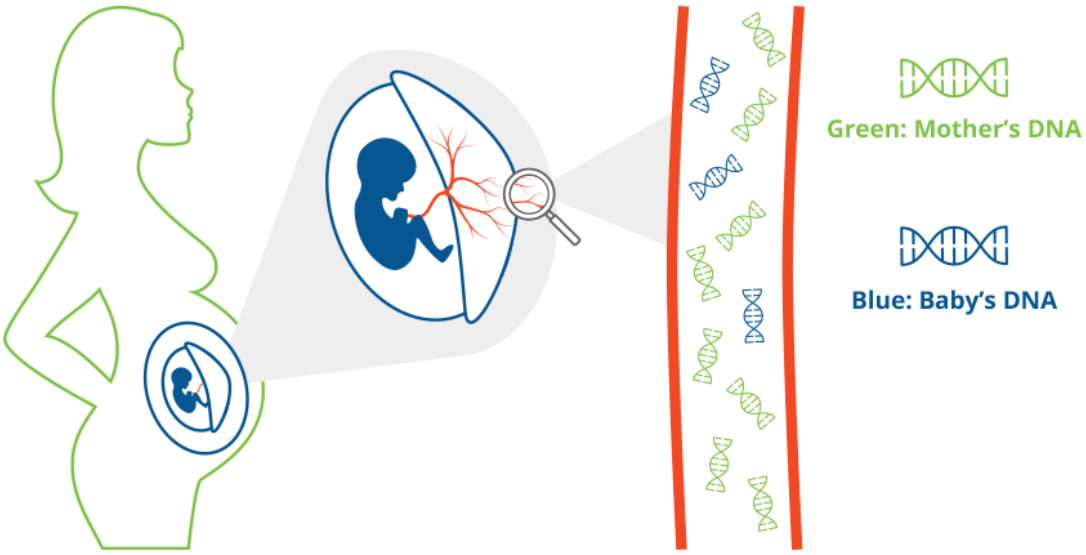

Fig. 1: *Non-Invasive Prenatal Testing Principle – Foetal cell-free DNA retrieval*

From the 7th week of pregnancy, this foetal cell-free DNA can be detected in the maternal circulation, the foetal fraction is 10% in average in pregnant individuals, although it may vary. One of the studies reviewed by Bianchi and Edlow was theorizing that the foetal cell-free DNA has "an average half-life of 16.3 minutes", the variation being from 4 to 30 minutes, however, after a few hours of post-partum, the levels are undetectable. All of the properties mentioned above suggest that foetal cell-free DNA is "an ideal candidate for NIPT" (Swanson, Sehnert and Bhatt 2013).

2.3 Trisomies

The term of trisomy refers to three copies of a chromosome instead of the regular pair. The most known type of trisomy is Down, also called trisomy 21, it was established as a medical diagnosis in 1959 by Jerome Lejeune. It was then the first time that a clinical disorder was related to a chromosomal abnormality from an etiological standpoint. The following year, two more types of trisomy were attributed to be the cause of Edwards and Patau syndrome, trisomy 18 and trisomy 13. The clinical significance of these findings prompted more research which established these chromosomal anomalies. An incorrect number of chromosomes is called "aneuploidy", and it is estimated that 10 to 30% of fertilised eggs present a case of aneuploidy. Furthermore, one-third of all miscarriages are due to aneuploidy, and one in every 300 liveborn. The leading genetic known cause of miscarriage and congenital birth defects is due to aneuploidy (Swanson, Sehnert and Bhatt 2013).

The diagnosis for chromosomal anomalies is traditionally done during the prenatal testing phase, although it might happen after birth. Like other type of chromosomal detection, a karyotype (the amount and looks of an individual's chromosomes pairs) of the chromosomes is being analysed. During that phase, each chromosome is being isolated, stained and examined under a microscope. Each standard human being body possesses 46 chromosomes divided in 23 pairs. The extra chromosome present on a pair is the trisomy.

2.4.1 Trisomy 13 – Patau

Patau syndrome is the third most common of the trisomy but is also the most severe of them. Miscarriages happen in an occurrence of 15 to 20% of all clinically recognized pregnancies, and from these, 50% are due to chromosomal anomalies. During prenatal testing, trisomies 13 and 18 are easier to detect due to major malformations that can be noticed during an ultra-sonographic procedure (Witters, Van Robays, Willekes, Coumans, Peeters, Gyselaers and Fryns 2011). Some of the first mention of the trisomy 13 was made as early as 1657 by Thomas Bartolin, but it is in 1960 that it was discovered a cytogenetical level by Klaus Patau, giving it its namesake.

The foetal loss in trisomy 13 is extremely high, about 97%, resulting in a birth incidence of 1 for 5000. After birth, nearly all infants affected by trisomy 13 die within 4 months. The Patau

syndrome manifests itself in the following signs, the foetus is smaller than it should at a given gestational stage, it has central nervous system anomalies, the median facial traits have defects (cyclopia (single median eye), nose, mouth/palate cleft, etc) and urogenital malformations. Infants affected by trisomy 13 suffer from organ failures and malfunctions, about 80% have heart malformations. In addition, the hands may also present polydactyly (more than the standard 5 fingers on each hand) with small hyperconvex nails (Witters et al. 2011).

2.4.2 Trisomy 18 – Edwards

During the cell division phase of the foetal conception, an error occurs, this is called a meiotic disjunction. This disjunction results in an extra chromosome being produced and it hinders the normal development part of the foetus in such a way that it is life-threatening, even at a prenatal stage.

According to the Trisomy 18 Foundation, 1 in every 2500 pregnancy is touched by Edwards syndrome, and 1 in every 6000 live births. The amount of total births is greater due to the high mortality risk of this syndrome, the important numbers of still births in the second and third trimester of pregnancy being the main cause. The United States National Library of Medicine accounts that this syndrome is 3 times more frequent in female foetus than male. Trisomy 18 is the second most common trisomy, when the foetus has 47 chromosomes instead of the standard 46 in the affect cells (Trisomy 18 Foundation), the third most common is Patau syndrome.

At the prenatal stage, an examination can be performed, the presence of an unusual large uterus and extra amniotic fluid is one of the many signs, a small placenta at birth is another sign. The new-born can have a non-standard fingerprint patterns, X-rays on the infant may present a short breast bone. Eventually other signs may arise such as congenital heart disease, polycystic kidney, umbilical hernia, a hole, split or cleft in the iris of the eye. There are no determined or specific treatments for trisomy 18 since each case is specific to the individual.

The mortality rate is alarming as half of the new-born children do not live past the first week, 9 out of 10 children will die by the first year of their lives. Some might survive to the age of 10 and above, however, with severe medical and developmental complications. The symptoms of trisomy 18 may be observed as an infant with microcephaly, clenched hands, mental delay, poorly developed fingernails, micrognathia; these are just examples, research is

still on-going as the physical and mental ramifications this condition has onto the human body (Witters et al. 2011).

2.4.3 Trisomy 21 – Down

Trisomy 21 or Down's syndrome was first described by John Langdon Down in 1866, the birth rate is of 1 for 700 live births. The main part of infants born with trisomy 21 (approximately 95%) is due to a maternal non-disjunction during meiotic division of the gestational stage (Witters et al. 2011).

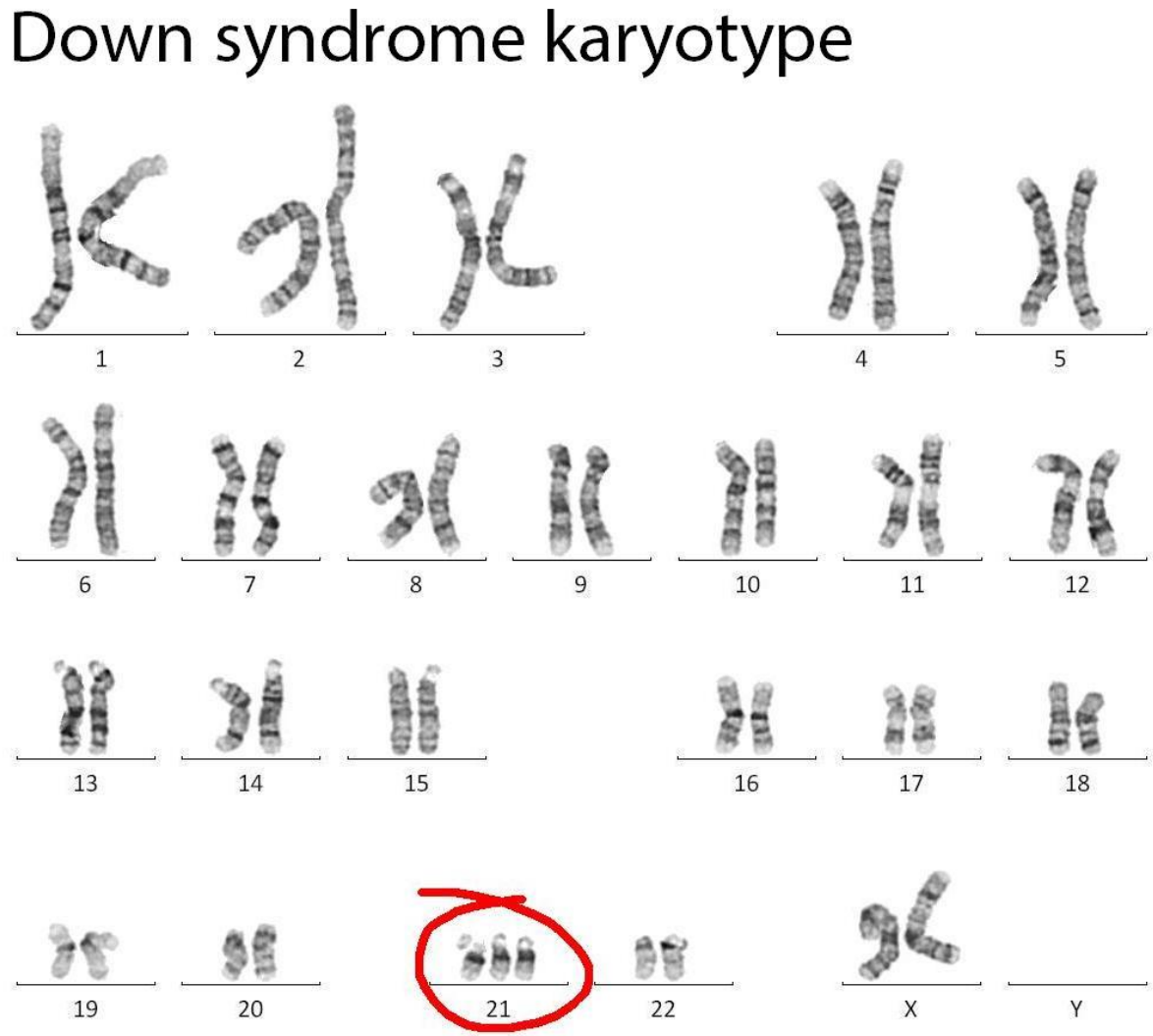

Fig. 2: *Presence of a third chromosome onto the pair 21 – Down's Syndrome*

The signs (or phenotypes) presented by the infant at birth are easily recognisable: facial dysmorphism (the skull is flattened), enlarged tongue, small white spots in the iris. There are

also varying malformations or complications that can appear such as cardiac malformations, genital and imperforate anus, and later in life, leukaemia. Syndactyly is also a phenotype where the second and third toe are attached to each other, as opposed to clinodactyly of the fifth finger where there is a lateral deviation of the finger or toe.

Traditional prenatal testing such as ultrasounds are not as effective to detect trisomy 21 as they are for trisomy 13 and 18; a nuchal translucency is then recommended as to determine the thickness and biochemistry of the measurements. This test is performed during the first trimester of pregnancy. This testing is crucial to not only detect possible chromosomal anomalies but also to uncover possible pathological complications in the pregnancy: pre-eclampsia, preterm birth, intrauterine death, placenta issues (Spencer and Nicolaides as cited in Witters et al. 2011).

The medical approach and explanations of the various trisomies are there to expand the ramifications and possibilities that NIPT present, not only to detect the trisomies that have a chance at survival but also the ones which have a high mortality rate. Furthermore, these genetical abnormalities contribute to the social definition of the "standard" human body; what differs become the stigma, the non-normality. These social physical stigmas are being integrated into the controversy as an underlying issue of the technology, as to create a gap in the possibility of an accepting and tolerant society based on the richness of differences.
From that perspective, it becomes reasonable to question whether the reproductive technologies that we consider as beneficial for the quality of the human life is as non-invasive as it is presented.
If from a medical standpoint, it is non-invasive because the risk of miscarriage has been removed, can the same thing be said from a social and cultural standpoint?

NIPT is a test that will provide results on a genetical level that goes far beyond what the test is originally intended for. The parents and their medical practitioner will know about the risks associated to the pregnancy. However, the laboratory technicians will have access to the entire genetical mapping of an individual, ranging from eye colour to possible associated diseases, predictable height and weight. Laboratories do not communicate this data further and are ethically bound to destroy both results and sample once the testing is done, according to regulations.

However, this begs the questions as to how far this testing can be pushed should the national laws are modified to accommodate a larger freedom to access and ownership of this sensitive information. There is a form of objectification of the patient through the technology. When the test ceases to be a medical instrument, but rather the process into which a de-individualisation happens. This is true to most prenatal testing which was relying on invasive procedures as they render non-visible body aspects to a public setting, whereas NIPT does not categorize as traditional invasive procedure. However, it acts on a different level of visual agency in the private sphere. The private sphere defines a social setting where the woman stops being an individual that is being interacted into a face-to-face social context to being dressed in a patient gown and being examined with medical tools, where she becomes an object of study and observation, redefining her identity (Cussins 1996). The objectification also happens through the administrative process upon which the identity of the patient is limited to the medical information specific to the individual, which asks the question: how much of our bodies do we truly own in matters of information?

III – Theoretical Approach

3.1 Controversies in Science and Technology Studies

> *"The study of controversies in modern technoscience -- with its porous boundaries between science, technology, politics, the media and the citizenry -- also calls for the analyst to broaden the array of analytical tools employed."* (Pinch and Leuenberger 2006)

A controversy, alike a debate, may seem to be two sides opposing each other in the way they are framed, however, they are usually more than just two sides in a controversy (Jasanoff as cited in Sismondo 2015: 123). One way to study a controversy is to approach it symmetrically, STS provides the advantage of a rational analysis in controversies, which helps being thorough, as sometimes, a side tend to be dismissed or forgotten (Sismondo 2015: 121). On the other hand, if controversies may appear symmetrical on the surface, they are rarely neutral. If one observes the mechanisms that provide closure, controversies studies provide insight into positions that are not so conventional, because they help less orthodox arguments being put into light (Sismondo 2015: 133).

Scientific knowledge and technological artefacts become visible during a controversy through the analysis of the processes that lead to them (Sismondo 2015: 125). While being involved in a controversy, the actors or participants show their positions by making claims, they present their strategies, but they also expose the weaknesses and resources of their opponents. That is the reason why STS researchers can use a large selection of information during times of active controversy as opposed of studying a controversy which has been resolved.

The processes detailing how the controversy is developing relate the data being used, the articles being cited, the argumentations from the various parts, the terminology being used; this constitutes how scientific writing can contribute to affect the controversy. However, it is important to consider that scientific articles being used can contain "criticism of assumptions, studies, experiments or arguments made by opponents in the controversy" (Sismondo 2015: 128). The aforementioned criticism can appear to be mild or diplomatic, sometimes more aggressive depending on how it is wielded, the criticism even technical is meant to convince. Therefore, a well-thought consideration of the terminology and vocabulary being used in controversy is based on the chosen discourse because the modalities are added or removed from scientific claims to make them "more or less fact-like" according to Trevor Pinch (Pinch and Leuenberger 2006).

One of the advantages provided by Science and Technologies Studies is the large array of activities based on the science and technology it analyses. In the same methods that STS use for examining controversies, it can extend these methods to domains outside of traditional scientific areas such a media, policy organizations, citizens' action group or courtrooms (Pinch and Leuenberger 2006). And these domains can also serve as an extension platform to controversies which were first restricted to the scientific field originally.

Kristin Asdal (2011: 212) writes that: "*Politics is also about a series of technical devices and practices that in various ways help to control, interact and create controversy. And when we get persuaded and try to persuade others, then it happens in connection with the issues, the realities, politics and management, as well as other actors, getting involved and engaging*."

3.2 Actor-Network Theory

Asdal (2011: 221) notes that the Actor Network Theory is not about following actors, or studying which social networks they are sharing or using. The basis of the theory rather lies in an ambition to investigate what enables and implements action. The Actor-Network Theory methodology was originally a claim that every actor is already a network in itself: a variety of devices, tools, technologies allow for certain types of action and movement.
It is crucial to determine who are the actors present in that controversy as to establish the limitations, but also the ramifications of the controversy itself for NIPT and the issue of reproductive technologies. This sociological approach is slightly different from other traditional theories because it accounts for non-human items, such as script or objects who have a function. It first identifies the actors within the networks but also analyses the frames and relations.

This theoretical methodology allows for the identification of the relations and interactions between the actors within the various networks: the patients being pregnant women, the medical staff being doctors, nurses, laboratory technicians, NIPT being the blood test and the items associated to it such as the laboratory machines, printers and the cost, and finally, the state as a representation of the institutionalised medicine, the state itself being divided into subcategories of actors who contribute to the controversy by exerting political influence. It is the actors who build networks, according to Sismondo (2015: 83), "laboratories give scientists and engineers power that other people do not have, for "it is in the laboratories that most new sources of power are generated". That statement is true when the controversy originates while new technology is being developed but as soon as the technology is being considered to have moral implications in the public domain, new actors enter the arena and bolster new opinions.

However, knowing from where the controversy originates gives a sense of visibility for the chronological pattern of how, when and where it stretches to encompass various domains. In addition to form a map of actors, it enables the researcher to establish how and by which means an argument or object is being promoted and how to promote an object in such a way that is has an effect. In the case of NIPT, we can imagine that there are various and different actors who make a claim as to be able to "talk for" this object, being able to interpret its meaning as well as the work NIPT is doing in transforming pregnant bodies and reproductive technologies.

The conceptual tools associated to the analysis of a controversy can be articulated in various manners, but in this specific case, the actors are not necessarily singled out as a person. The confrontations resulting from the controversy can establish a visual mapping on how the various parties articulate themselves, showing how they try to exert influence and gain cognitive or social authority (Martin and Richards 1995). The conflicting versions of these contributions to the controversy are constantly redefining the object and its significance. Quite often there are overlaps between the versions or conflicting versions which are allowed to exist side by side.

There is an undeniable political dimension to this controversy which expresses itself in the agenda of the actors. According to Nikolas Rose (2001), the political authorities have inextricably intertwined themselves within the management and policies that surround reproductive technologies. They attempt to regiment the "vital processes of human existence" as this is an extension of the individuals composing society. This policing covers not only the reproduction field but other areas such as parental and familial relations, general health, as well as birth and death. Rose even accentuates that "biopolitics was inextricably bound up with the rise of the life sciences, the human sciences, clinical medicine."

3.3 Feminist Perspective

According to Cussins (1996: 578), one must consider some of the problematics associated with women' status towards reproductive technologies, specifically from a reductionist point of view. This point of view articulates itself on the understanding of the individual as a human body, and how that human body becomes an object.

Cussins points out that the accent is being put on the difficulty of defining the agency without presupposing the unitary human subject, in other words, how do we understand and account for the agency without the human factor influencing said agency. Elizabeth Ettorre (1999) explores how experts in reproductive genetics are seen as "storytellers" and how reproductive genetics as a medical field has demonstrated the disparity in the treatment of men and women when it comes to reproduction. Furthermore, Shildrik (as cited in Ettorre 1999) accentuates the biological function of conception and gestation as being typically feminine in its nature, due to the internal factor. Only the female body is an active participant of that gestation while the male body can only witness the progression and birth; in principle, this means that beyond

the involved genetical of two donors, one of them remains involved in the pregnancy process, while the other donor is unwillingly removed from the natural process.

Reproductive technologies are the applied instruments upon which reproductive genetics articulate itself, it is a human achievement in modern medicine where as a specie we attempt to control “nature”.

A problematic that can arise from this controversy is better explained if seen from a feministic approach about the role that the female body plays in reproductive technologies. One side of the argumentation uses a form of scientific reductionism to consider the female body as no more than an object being scripted in the technological design. The body is therefore seen as detached from a will or consciousness and inscribes itself in a scientific and technological medical process. The advantage of feminist scholars of technoscience is that they try to find a balance of critical politics in the use of science and technology and in their development, and how they are put into place in “scientific, technological or medical practice for different women” (Cussins 1996: 577).

If the body is more than an object rendered to the service of science and technological, a middle path needs to be found between patients and medical staff in the first place. For emotional reasons, medical personal such as doctors tend to detach themselves by dehumanizing their patients, allowing them to adopt what is considered a “professional behavior”.

However, it is not just the medical trained personal who exercise this type of practice. It is also a type of practice found in patients, who tend to reduce their individuality into a list of symptoms and associated ailments. That reducing practice can be observed as the patient become its own expert witness on how to translate what is wrong to the doctor on how to find a solution. Cussins writes that the “behind-the-scene ontology of the body can no longer reconcile the long-term self-narrative with the physical body” (1996: 584).

There is a self-narrative of emotion and physical sensation that is interpreted and translated from common language to medical jargon. In the practical case of the woman as a patient, there is a dualistic nature, the desire to have a successful pregnancy resulting in a healthy child, and the body presenting a risk of malfunction, negating the woman’s desire. In a way, the individual is reduced to a sum of body parts and problems thus visiting the clinic allows to make a correlation of cause and consequence between the internal and the external world which find their middle ground in the body as an object (Cussins 1996: 582). The body is then

seen as visible, manipulable, moldable, prepared for tests which are the way to frame the problem contained by the body, the diagnoses and treatments becoming the consequence. This reasoning encompasses a train of reflective thinking on how one's body is being considered and handled.

However, Cussins (1996: 576) notes that "the liberal feminist' discourse of the increased choice offered by reproductive technologies is a significant and largely favorable feminist reaction to them". Cussins defines a process of objectification of the female patient as an individual to an object. The medical field in its composition from instruments to personal information, employees and administrative resources create a long line of steps upon which the patient gets subjected to, a form of choreography as the body is being examined and articulated.

There is a correlation between how the body is being treated generally not as belonging to an individual with an identity but rather the materialistic projection of an abstract.

The abstract is that the body is a tool, an object that can be inspected, detailed and tested and analysed, made for diagnosis and results; it is detached from having any type of emotions or other attributes than physical. It constitutes a projection of an individual, the individual is not being treated medically, the body is. And this is, in this strange schism that Cussins' notion of the objectification takes its whole meaning; there are different narrative about the body and the pregnant body forming its own narrative, an 'ontological choreography'. The same idea goes towards the use of NIPT as a tool, an object, the instrument upon which the objectification goes through.

Furthermore, if NIPT is not an isolated object but rather a part of a process, it becomes an object of conflict because of the actors around it, and in turn, NIPT as a test becomes an actor itself due to a desire of appropriation of the technology and what the other participants want it to represent.

Cussins (1996) presents excerpts of interviews conducted with patients who went through IVF (In Vitro Fertilisation) which resulted in either successful or failed pregnancies. The patients seem to present a common narrative pattern in how they explain the process (test, procedures and treatments) they went through. They identify their desires and needs but also failures as their own, and yet they describe their own bodies as if it was an external item gravitating around them but not a part of them, as if the mind and the body were disassociated.

However, the choices of words were opposed whether the results of the IVF procedures were positive or negative. A contradiction of terms, an incompatibility appears as if the patient was referring to two distinctive beings. The context itself with its consequences towards the desired result influence the patient's self-narrative. According to Cussins (1996), the "context of the self has moved and the nature of the account helps to fix the identity of the patient at the time she is speaking."

3.4 Ethical Issues

> *"The philosophical status' – indeed the very ontology – of human beings is being reshaped through the decisions of entrepreneurs as to where to invest their capital and which lines of biomedical research and development to pursue."*
>
> (Nikolas Rose 2001: 20)

There is a social trend that is accepted as a norm that reproductive technologies are a difficult subject. For some families, it is a relief to be able to determine that they can produce a healthy child, for some, it can also come as a devastating news if the outcome of the testing is negative. The underlying issue is the meaning the results have for the patient, but in this context, the patient is no longer an individual, it is the whole family who becomes the patient and the consequences it may mean for them. In a way, the patient becomes the representative symbol for the genetical potential of the family, which can then be turned into a stigma towards the outside core of the family. A whole new vocabulary opens itself, cementing a genetics problematic that affects the family on a personal level: risk, affected offspring, viability, defective genes, carrier status, with other acronyms and names which belong to the reproductive technologies semantics (Ettorre 1999). There is a gap of medical jargon understanding between the medical experts and the families concerned in reproductive genetics, the terms "carrier status" and "risk" may mean a "family with genetical issues" to the experts, while it might carry an entirely different meaning to the family (Parson and Atkinson as cited in Ettorre 1999).

But taking part in reproductivity also means that the network around the individual trying to become or that is pregnant broadens extensively. It is also very much a social and political

body. Medical experts are key to making the "pregnant body" public in that respect. Medical experts propose for instance that all pregnant women should take part in prenatal diagnosis and screened for genetic disorders. To some part of the population, it is a positive idea because it may mean we will be able to remove a variety of serious diseases that are life threatening.

The ethical question is to determine which ones will be categorised as serious and life-threatening. If the possibility to eventually eliminate diseases such as cystic fibrosis or Huntington's disease rise, it will be seen as progress, but what if social diseases start to be integrated into this? Not all countries share the same standards of social and cultural values, their norms are not all the same. Some of the ethical issues rise, what of the other social behaviour or conditions that are considered as negative by the social consensus such alcoholism, schizophrenia, bipolarity, and to some extent, homosexuality?

Ettorre (1999) asks if "a hierarchy of social diseases" will be put into place as a basis for discrimination? The purpose being to eliminate all types of behaviour and physical types which do not fit a frame of standard human being based on a normative social and cultural frame. And this is these types of unwanted behaviour and physical types are being categorized as "social diseases".

Nikolas Rose (2012) explains that early in the 20th century, many organizations and a certain number of individuals in many countries started to provide reproductive advices, focusing on the choice of marital partners or would-be parents and if these individuals have family history related to specific types of diseases thought to be 'hereditary'. These people would be then advised to not marry or not have children, in extreme cases, they were offered a termination of pregnancy, even in locations where abortion was illegal. For Nikolas Rose, the genetical type of advising that was provided in prenatal care during the first half of the 20th century constitute a form of explicitly eugenic tool.

Deeply anchored within the debate is the discourse of a normalisation of the 'human being' as understood and defined by cultural norms. However, since they evolve and change as society progresses alongside medicine, what is now accepted was not a few generations back in terms of physical appearance or mental disabilities. This also serves to question how much we account as to how this normalisation process functions. The changing mentality on how disabilities are being perceived serves as an anthropological and social indicator to what is considered "normal". Ettorre in addition to Cussins accentuate the need for a deeper

understanding and interpretation of the normalisation narrative that is made about the human being as a standard with a set of required physical and mental traits.
It makes one wonder whereas mankind uses technological for the improvement of the quality of life or for the engineering of the future human beings.

IV – Research and Method

4.1 Document Choice and Description

The point of departure for this dissertation is the official statement from the Directorate for Health published on January 23rd, 2017 where they recommend the use of NIPT for determining the presence of trisomy 13, 18 and 21. This document has in fact turned out to be a key document for this analysis, despite being quite short and concise. The reason for it becoming a key document relies on the fact that it presents a turning point for the controversy of NIPT, as I will also explain in depth in the following analysis. For now, it is necessary to point out that the statement considers NIPT as a non-invasive prenatal technology and based on a rapport from the Centre for Knowledge, the Directorate for Health comments on the possible scenarios and findings.

In addition, I will use other official statements from the Norwegian authorities about the use of NIPT. To support my discussion, I have also taken upon reading and collecting medical journals accounting for the procedure of NIPT performed in other countries and the studies that were conducted. These studies allow other countries who are considering implementing this test in prenatal care to have an idea but also a possibility to apply these results to their own demographics. They can adapt and learn from these studies and see what they might learn from it, to adapt the technology and wait until new developments are made on the medical field or instead, simply reject the test, preferring to continue the use of traditional invasive prenatal testing.

The main part of this controversy is happening on a public domain, it is displayed for all. The internet constitutes a main source of information with various rapports about NIPT from medical journals to newspapers articles and social and economic perspectives and how this is

a political appropriated debate to personal blogs where individuals wish to express their opinions.

The rapport from the Directorate for Health refers to the RAPID-study (Reliable Accurate Prenatal non-Invasive Detection) that was conducted in Great Britain in collaboration with the National Genetics and Genomics Education Centre (NHS). The study was performed in the health services to help them determine if NIPT should be introduced as a secondary test after CUB in the public medical domain (hospital, health centres). Over 40 500 pregnant women participated in the study. The study was designed as follows: all pregnant women were given the option of doing a CUB test the ones with a risk of foetal trisomy lower than 1:1000 received "standard" pregnancy care, the ones with a risk higher than 1:150 could choose between invasive testing and NIPT, the ones with a risk of trisomy between 1:151 and 1:1000 were given the option of NIPT.

If the ultrasound demonstrated a nuchal translucency superior to 3.5mm, the pregnant woman was given the option of invasive testing and pregnancy care in concordance with the local hospital's routines in case of high risk pregnancy. A nuchal translucency is a prenatal test which occurs during the first trimester of pregnancy, it consists of a sonographic scan in the nappe of the neck of the foetus to determine the amount of liquid accumulating there. This test has for function to detect cardiovascular anomalies, it also can help determine pregnancy dating and the viability of the foetus.

The analysis used in the study were developed and conducted by the Great Ormond Street Hospital laboratory, which is also the institution who was responsible for the RAPID-study. The results of the study emphasise the choices taken by the pregnant women when cases of trisomies were presented, from further testing to the type of pregnancy care. It is important to note that the results being showed by the Directorate of Health from the study only mention trisomy 21, "Down Syndrome", but does not include other chromosomal anomalies or Patau and Edwards trisomies.

This is symptomatic of reflecting a trend in contemporary society where the most well-known trisomy is Down's Syndrome, due to its higher chance of survivability compared to the other trisomies. For morale reasons, pictures of deformed foetuses are not being published in

newspapers but they are available in medical journals and reviews which described the various pathologies associated to chromosomal anomalies.

Those journals describe how NITP is being used, the difference between non-invasive and invasive procedures, the risks involved; which will help for the credibility and reliability aspect of my argumentation through the discussion part of this dissertation.

4.2 Data Gathering

NIPT as a reproductive technology has gathered a lot of publicity over the last few years internationally. It is figured prominently into medical journals, collaborative projects but also newspapers, blogs and social media platforms. The medical articles tend to focus on studies that have been performed with pregnant women at different stages of pregnancies over a set period of time.

The research for this dissertation was very interesting. There is a profusion of articles concerning NIPT but the challenge was sorting out the sources and finding the relevant articles in a STS oriented thesis. I was primarily interested into finding documents and other information that could show how this controversy has been debated publicly, and not behind closed doors. Firstly, I chose a document that I thought was a representative source for the use of NIPT in Norway: an official statement from the Biotechnology Council recommending the use of NIPT for the detection of trisomies and gender based chromosome diseases. This recommendation was destined to the Health Department.

To complement this statement, I then chose a document published the previous month from the Directorate for Health and then another month later, from the Government itself. In the lapse of three months, I could see how the recommendation was discussed, how the numbers of participants into the debate increased and started to figure prominently in newspapers as well, bringing this controversy into light and then how the suggestion from the Biotechnological Council and Directorate for Health became an official statement on the Government official website.

It was very helpful to explain what I was writing about to my classmates and relatives, either from their feedback on the vocabulary being used, their opinions or personal experiences.

Everyone provided insight. One highlight was the medical jargon that I was using to explain the theme, which I came to realise might have seem simple to me because I was writing about it, but not to someone who might not be well versed in medicine. This new issue meant that I would require extra sources to justify and explain the documents at hand. I was interested in seeing how the reproductive technologies in the public health sector were implemented in society: the routines of these technologies and how they impacted the body but also the conceptions about life. What came to light after my research through medical journals and newspapers were how these health technologies were partially or completely overlapping many areas: ethics, efficiency, justice, gender, economic, the levels of understanding for the individual and collective.

In addition of the main document that was going to be used for analysis and the supporting official documents from the government and the Biotechnological Council, a serious and reliable scientific source of medical data was required to explain and inform the thesis on the state of NIPT in western countries. The medical journals informed about the technology behind NIPT, the type of chromosomal anomalies that can be detected, what are those anomalies, how is NIPT shaping our understanding as individual but also as citizen, how it can redefine our perspective about reproductive technologies but also reproduction generally. These medical journals were stating what had been discovered through research and scientific method which would be a good way to explain but they did not make the claim for a positive of negative claim upon non-invasive prenatal testing. Therefore, an extra source of data was required, a more qualitative information type was required: newspapers and websites which gathered different options providing a sample of different opinions. It was relevant to see what non-scientific professionals were expressing and how they formulated their interpretations of traditional prenatal testing and how they would think that NIPT would fit in that frame.
For the mapping of the controversy, it was necessary to establish how each side were participating, what their arguments were and how they formulated it, and through which expressive platform (public statements, social media, newspapers interviews).

4.3 Ethical Perspective

Due to its very private nature, NIPT exposes informants in a way that can be emotionally difficult. My original idea was to interview three different women at different stages of reproductive life: one that had given birth, one that was pregnant and another who wanted children in the future. These were women who would at some point be faced with reproductive technologies, which choice would they take and the reasoning behind that specific choice.

At first, the idea was interesting but I grew rapidly concerned about the respect for their privacy and the emotional distress this could cause. By respect for their privacy, I do not mean the anonymity that is due to protect the identity of an informant, but rather the personal space invasion that these types of questions represent. More specifically, a pregnant woman is already sensitive due to the hormonal changes in her body; probing with questions about genetical anomalies, ethical choices and the possible outcome of her pregnancy was highly unwelcomed.

Therefore, I chose a method which would rely on an official narrative by analysing documents by delving into the information provided to the public. In that perspective, there is an intention to present the data from an equal standpoint with the patients and their families, but also to insist on the fact that this controversy is public and is not debated behind closed doors.

4.4 Document Analysis

4.4.1 Analysis Methodology

The rapport includes how many people were involved in studies where different types of prenatal testing were performed, the statistical results, how NIPT is being practiced in other countries, the financial costs of these prenatal reproductive technologies and the health directorate comments on each of the categories.

The constructivist interpretive methodology allows to approach the NIPT controversy as a source of informational material towards the social interactions between key actors and audiences. Alike the Vanstone, Yacoub, Winsor, Giacomini and Nisker (2015) study where they analyzed a series of documents (brochures, catalogues, adverts) about NIPT strategies and which audiences they were directed to. This study helped me how to codify and then sort out the key words to determine the interactions built around the controversy and how they

were expressed. The study's focus point was looking at the words being used, the formulations as well as graphic representations. The professional statements of medical experts serve as an authoritative modality based for other pro-testing parties to rely their opinions on and other constructs to be found in, the same principles are being derived through media coverages, individual opinions and political statements transcriptions.

How do these documents contribute to give clarity to the controversy by analyzing their content considering the current debates?

4.4.2 Analysis Process

I was first interested into looking at the vocabulary used to define NIPT and the chosen terminology around this reproductive technology. Secondly, I also wanted to see how I could be able to answer some of the questions associated to the controversy by codifying the semantics used by the content in the text. By codifying, we can see how the various terms inscribe themselves into a specific context attached to the controversy. The advantage of an inductive method was that it would keep the research grounded, as well as providing a constant comparison between elements. The other advantage was that it allows for an open mind, preventing the researcher to form a preconceived result before the end of the analysis. I used a type of codifying methodology that I had learnt during my bachelor's studies, where triangulation is used through the data to cross check information and conclusions to see if corroboration is obtainable. The triangulation makes use of multiple factors, data, methods and theories to study phenomena, understand them, analyze and then interpret them.

If each document is an actor, it should also mean it has a function (its role) and a purpose, its agenda – can it be thought of as a single entity within the controversy?

The first reasoning was to take the main document from the Directorate of Health consider it as the medium upon which they were presenting their argumentation for NIPT, as a positive side-taking action in the controversy. The second reasoning was to consider the document as an actor by itself with an agenda which went further than its semiotics attachment to the Directorate of Health. The third stage was decomposing the document by sections and paragraphs, then distinguishing the words which belonged to a theme, as to codify the entire document. However, by experience and methodology reading from previous academic work, I

knew that a page of codes should be the limit, not more, least the dissertation would lose significance and the discussion would extrapolate beyond the investigated problematic.

Once the entire document was codified, the themes categorized, a counting of recurring key-words was done as to establish where the accentuation was put: reproductive technologies, finances (cost of establishing and maintenance of equipment and tests), technical competencies, patients, medical personal, law and regulations, institutions, medical practices, prenatal care; were the themes that recurred the most throughout the documents. The second phase was to associate the two other documents: one from the Biotechnological Council and the other from the Ministry for Health and Care Services into the list of codes. The point was to see where the themes were overlapping and how they differed when they did.

Was the narrative of the document on the same register?

Was the focus of the document to inform the possible non-medical professionals such as patients about the development of this new prenatal testing technology?

Or on the other hand, was it a statement as to declare and pave the way for more public and social frame of action towards the controversy?

4.5 Credibility, Validity and Reliability

The documents being used in the main analysis are official statements from the Directorate for Health, the Norwegian Government and the Biotechnological Council of Norway, available and free for all to access of their distinctive websites. Furthermore, the studies that provided the data about NIPT and other reproductive technologies are either peer reviewed scholarly articles or medical journals found through the University of Oslo library's searching engine. The other sources of documentation were newspapers articles or organisations' internet blogs that I have quoted verbatim as to prove and maintain a desire of transparency to either support or illustrate the argumentation.

4.6 Critique of the Method

Choosing the appropriate type of method for analysing a controversy that reaches within a very intimate sphere of the family life and therefore society was difficult. However, as I settled for a document analysis, I was interested in seeing how each side of the controversy was expressing itself as a representation of a larger entity: state, medical field, political party – almost all except the most concerned side of the actors, the patients. Although it might seem a little sterile or detached to use document analysis to process the information and reactions within the controversy, it also allowed me to remain somewhat objective.

Objectivity in a controversy is a crucial position to be able to gather data and retrace a chronology of events without omitting facts. This chronology enables the researcher to obtain a sense of transparency through agendas and how one new piece of information can impact others. The succession of events allows to create a schema where elements and actors are linked throughout the controversy, eventually, this forms a map. This map also helps to form an illustration of a symmetrical presentation of the controversy where the disagreements can be justified in their legitimacy, therefore, proving a case of heterodoxy (Sismondo 2015: 132). Furthermore, Sismondo points out that the advantage of a symmetrical presentation "highlights the resolution of debates as local and practical achievements" (2015: 133), that is to be placed into a set context so that the local culture can be understood correctly.

V – Discussion

To shed some clarity over the controversy, it is important to place some chronological markers on how the elements evolved on a timeline. The debate around the implementation of NIPT in Norway was made when a letter from the hospital in Northern Norway was sent to the Directorate for Health to approve non-invasive prenatal testing as a mean to determine the presence of trisomy 13,18 and 21 as a foetal diagnosis method. It took many meetings and the contribution of the Biotechnology Council before a statement was made on a public forum.

It was the Biotechnological Council which formally approved NIPT for the detection of these trisomies, encouraging the Directorate of Health and the Norwegian government to follow suit. However, shortly after their statement, the statement reached the media who used it for their headlines, therefore implicating the public opinion and political parties.

The rapport from the Directorate of Health first makes a mention of the written correspondence between the Ministry of Health and Care Services, the Biotechnological Council and their own researchers. The rapport states what the current prenatal care and its requirements are as of the dated document, 23.01.2017, then they proceed to give their primary advice about NIPT: they recommend the use of NIPT to detect trisomies as it is in accordance to the Biotechnological Law §4-2, and that this method should be accepted as a safer alternative to placenta biopsy or amniocentesis when the results of the CUB show a high risk of trisomy for the foetus (on an estimation of 1:250 or higher). Aligned to the Great Britain's RAPID study, CUB shall remain the primary prenatal test for pregnant individuals who are 38 years old or older at the due date or for whichever other medical reasons present a high risk of chromosomal anomalies, such as trisomy. NIPT will then replace as a secondary test the other invasive prenatal testing alternative, removing the risk of miscarriage.

The rapport presents then its main arguments to support their advice towards the practice of NIPT; high sensitivity and high accuracy in the detection of trisomy in the foetus, the test bears no risk of spontaneous abortion which is a much safer alternative than traditional invasive prenatal testing. The systematisation of NIPT as a secondary test will significantly reduce the amount of invasive testing and therefore reduce the amount of spontaneous abortions. According to the Directorate for Heath, ideally, the NIPT would be incorporated into the existing prenatal care package of CUB and NIPT as a secondary test, which would not cause too many drastic changes.

However, the rapport further mentions that the establishment of NIPT as a regular practice in prenatal testing would require an adjustment of the technical facilities and qualified medical personnel to enable its systematisation. Despite this recommendation, the Directorate of Health recommends that pregnant women should be allowed to choose between the tests but should be carefully informed of the differences, and in case of very high risk, a more invasive test should be precautioned; the concerned fields are more adapt at determining this course of action when this is put into place.

The rapport mentions the importance of having the shortest possible delay between the CUB's result and the required NIPT testing. It is not mentioned in the document right below this recommendation but it is later explained.

	Chorionic Villus Sampling	Amniocentesis
Benefits	• Able to examine baby's chromosomes • Diagnostic (provides yes or no answer) • Can be used to test for other genetic conditions	
Limitations	• Invasive procedure • Risk for miscarriage	
Timing	10-13 weeks*	15-22 weeks*
Miscarriage Risk	1/100 – 1/200*	1/200 – 1/500*

Fig.3 : *Both CVS and Amniocentesis are part of the current prenatal care package in Norway.*

First, there is the urgency of determining the possible chromosomal anomaly and which test should be performed next as to predict the outcome of the pregnancy.

Second, the emotional distress caused to the pregnant woman is negative and constitutes an unnecessary worry that is unhealthy.

Third, prenatal testing is very time dependent; some must be performed early on, some later, it relies on the development of the foetus: some tissues or cells only forming from a certain stage and having limited timespan.

The next point of interest in the recommendations being made which put into the light the sensitive nature of the information as data. NIPT as a reproductive technology is based on genome sequencing which means that a wide range of genetical information about the foetus

is being generated, information that covers more than what the test is required to do: to determine chromosomal anomalies.

Therefore, the Directorate for Health advocates for a complete deletion or full anonymity of the results once the results are obtained and a confirming answer has been established through the means of a placenta biopsy or amniocentesis.

In a general way, the gathering of health data, especially on a collective manner, as census of health population from random or representative samples tend to be visualised by using geopolitical maps, which is in the case in European comparative and policy oriented research (Bauer 2008). The way that health data is being recorded and archived forms a type of monitoring which becomes an objectification tool, because it renders visible the trends onto various perspectives: spatial, temporal and other projections, as it is usually performed in European health surveillance practices.

5.1 Mediatisation of the Controversy

This is a point which is not raised by the media in the various news articles that were related to NIPT or other prenatal testing topics. The media have prominently had headlines focusing on how NIPT is a new way to detect trisomies, specifically trisomy 21, Dawn's Syndrome. The individual with Dawn's Syndrome are more visible in nowadays society and with the help of modern technological progress in medicine, their life expectancy has significantly increased. Having a child with trisomy 21 is still a challenge (in health and practicality) but it is no longer a social stigma as it used to be. Dawn's Syndrome awareness has been active in western countries which has contributed to the acceptance of the physical and mental differences presented by individuals with Dawn's.

There is however, a recurring pattern in the various media: the way that NIPT is being presented suggest that the test will be administrated to all, without discern for age or personal choices. One of the reason that could explain why the media chose this approach to present the NIPT controversy as a medical scientific community versus the public type of debate, is based on one basic truth, mortality rate. Children with Down's Syndrome have a higher chance of survival and eventually lead semi-professional life and know family life as a

growing child as opposed to other children with trisomy with 13 or 18. Therefore, the media relate the news in a way that the public can relate to, to something that is familiar.

It is reasonable to think that information concerning our bodies should be confidential but not blocked from us, we should decide what happens to our bodies and minds and therefore, have access to the medical knowledge that concerns us. If one follows the reasoning than the pregnant woman as a patient should be informed of the condition and status of the foetus that she carries. However, on the other hand and according to the literature, the foetus is counted as a separate entity which would mean that no one should have access to this data. This is a standpoint which is particularly difficult to the pregnant woman and family. From a pregnant woman perspective, the foetus is growing inside her womb, inside her body, she can feel the changes and how it affects her physically, the foetus is a part of her. If the pregnancy was desired, the status of the foetus as being detached from her is confounding, it remains a very abstract concept, it can then be a challenge for the medical personnel to fully explain the test without withholding information from the patients. It is in this perspective that all sensitive data which is out of the chromosomal anomaly for trisomy detection shall be either deleted or anonymised according to the Directorate of Health.

The association "Menneskeverd" (Human's Worth) is presenting an article on their website about how NIPT as a new reproductive technology is a debatable choice as a "safe" foetal diagnosis method. In the interview mentioned by the article, Ingrid Marie Hardang, doctor in medical biochemistry at Akershus Hospital, says that *"The main argument to use NIPT blood test is that it is a safer form of foetal diagnosis because it gives less false positives and therefore, less patients will need to have amniocentesis*". This should be ground for a better quality of life for patients in prenatal care, however, Hardang preconises caution as some countries have made use of NIPT for sex selection in the foetus (Våge 11.10.2016).

The mediatisation of the controversy also relies on the engagement of the public opinion. If this was not a sensitive topic, it would not get so much attention and publicity. It is a sensitive topic and people do feel concerned and wish to have a say into what happens to their bodies and their offspring. Living in a welfare system in Norway, the population health is being thoroughly recorded and tracked through a monitoring that people participate into, because it is our health, we consider it an important matter, but at the same time, we entrust it into an electronic system or software that we are not very well informed about. We trust the

representatives of the system in the form of physicians and nurses, but we are somehow oblivious of what lies beyond what we can see. Bauer (2008) notes that "observational systems to record data – "monitoring" – and visualizations of the epistemic object "population health" play a crucial role". Bauer continues her argumentation explaining that this type of monitoring considers the 'health population' as an entity which is then later divided into layers that help categorise the population – "which is the object of surveillance technologies and becomes the rationale and the target of governance" (Bauer 2008).

5.2 Political Implications

One other aspect on the controversy appearing in Norwegian society is how political parties have appropriated this technological controversy making it public domain as a social debate and argue their perspective in opposing each other. Asdal (2011: 211) argues that politics is not just about speech and persuasion, in the form of direct interaction between people. Politics is about interests and values, about ideas and technologies and how these inscribe themselves into society.

The interactions between people are being defined by the context into which they present themselves and as such, politics is inherent part of life. To that extent, political parties being the representation of citizens sharing common ideas and ideologies implicate themselves into the public debate of what their members are concerned about.

Most notably, during 2016, where the Biotechnology Council had advocated the use of NIPT as a mean to detect chromosome based anomalies or diseases such as the trisomies or even Duschenne's disease. One of the prominent voices of the opposition in the NIPT implementation is Olaug Bollestad (KrF) who is also a member of Norwegian Parliament. In an article written by NRK on the 17.02.2017, she is saying that "this blood sample testing is a hunt for what society considers as imperfect".

Meanwhile on the other spectrum of the political scale, the parliament representative Ingvild Kjerkol from the Labour Party argues that while the Minister of Health and Care Services, Bent Høie is waiting to make an official statement from the government side, "there are women who do not get this alternative which would be better and gentler for them". Bollestad writes that "women nowadays get the NIPT option instead of the usual amniocentesis or placenta biopsy" according to the Labour Party political meaning. Ingvild Kjerkol adds that

"this is easier for women and there are less risks of spontaneous abortions, especially in the cases where there is nothing wrong with the foetus".

According to DagensMedisin magazine (21.04.2016), there is a large financial downside to the practice of NIPT, the journalist Målfrid Bordvik writes "the obvious disadvantage is the price. The Centre for Knowledge has established many different scenarios. In the first alternative, the NIPT is used in addition of today's CUB. The cost will be approximately 196.000 Norwegian Kroner extra for each case of detected chromosomal anomaly". Then Bordvik considers the second option where he mentions that if NIPT was to replace the current CUB test, we will detect more cases of trisomies, but "this is also the more expensive alternative. If this method is being used by all who have access to prenatal diagnosis, it will cost 4.4 million Norwegian Krone for each detected case, when compared to the best alternative".

The article then focuses on the ethical concerns of this prenatal testing method, quoting the rapport from the Centre for Knowledge, "the introduction of NIPT as a primary test will eventually force a new assessment of why and how as a society and health service, we wish to organise the foetal diagnosis offer in Norway". The article quotes Lene Juvet who is the senior researcher on this rapport, she states that:

> *"The fact that this test is simpler and less people will require invasive testing can lead to younger patients wishing for this type of prenatal testing. We do not know, says Juvet, who also points out that the Centre for Knowledge does not give any recommendations in its rapport to the Directorate of Health."*

The article refers to another document chosen for this dissertation, and it is partly because of the strong correlation between these documents that they represent the main source of public and official information on the controversy. "The Directorate of Health states that they will obtain a statement from the Biotechnological Council and involve the professional communities in this work. If the Directorate of Health approves the project, the "Deciding-Forum" for new methods will determine if the method is to be used in Norwegian hospitals". Along the recommendation given by the Directorate of Health a mention of the required infrastructure for the systematic practice of NIPT, one or maximum two laboratories in Norway should oversee and treat the results from the test before it can be proposed as an

alternative to the target group, pregnant women who present a risk of foetal chromosomal anomalies.
However, they suggest the possibility that the analysis might be conducted in laboratory in another country while the test is not fully established in Norway, assuming the Norwegian scientific community has access to the data which is necessary to evaluate the method: for the positive results or the inconclusive, false positive, etc. The financial dimension of the debate puts into light the question of how the funding for the test implementation and how it will be put to practice.
The rapport from the Directorate of Health is clear about the financial estimate that this process will require: material, laboratories, salaries; however, it carefully avoids how this budget will come to be created and from where the funds will be provided.
Kristin Asdal (2011: 212) writes that: "Politics is also about a series of technical devices and practices that in various ways help to control, interact and create controversy. And when we get persuaded and try to persuade others, then it happens in connection with the issues, the realities, politics and management, as well as other actors, getting involved and engaging."
The financial aspect of the controversy suggests a dimension that goes beyond the primarily concern about the well-being of patients in prenatal care, that this care has a cost and that its impact upon the people due to a welfare state. And due to the state implication, this suggests that a political agenda is at work.

What type of funding has the Norwegian government allotted to this? Will this be reflected in possible taxes? Furthermore, if this supposed to be a state sponsored project, would not the political parties involved in the current government have a reason to either advance or halt the implementation of NIPT, due to a political agenda that relies on the political opinion of their voters?
The rationale for political interest in the 'health of the population' (Rose 2012), is not presented as a consequence of a stereotypical unfit population anymore, which would be the result of a struggle within various nations. It is rather now framed and reasoned in economic terms: absence from work related to poor health, evaluation of an increasing insurance to apply preventive medicine cost – an accentuation is being put onto the importance of reducing inequalities in health between individual furthering a large social and economic gap in social strata. Cussins (1996) provides an insight by commenting that the "interaction between insurance coverage and cost of each procedures serves as a continuous function on the

possible treatment options for most patients. The practitioners are generally referred to simply as sources of authority."

If the term 'public' points out an open forum of discussion for debate, the term 'population' creates a link between social statistics and social policy into the field of life sciences (Bauer 2008). And as such, the term of 'population health' is considered as an entity by the life sciences. The term of 'population' encompasses population ecology, physical anthropology and population genetics, therefore connection social sciences and demography into one common field of study. In this perspective, it is interesting to see how the idea of 'health population' is being used an umbrella term to accommodate a form of health surveillance done upon the population as to shape a community perspective upon knowledge understanding. The 'population health' becomes an object of study to a central government state-statistics rendering the 'population body' as a mean to envision how to configurate how health and disease narrative are being negotiated.

There is an undeniable meddling of the government politics into our private lives and as such, a new ethical vision about life is taking shape. A pattern of interventions, a need to act upon what is under human control seems to appear, as if something needed labour to gain a sense of worth. According to Nikolas Rose (2012), "the human vital order has become so thoroughly imbued with artifice that even the natural has to be produced by a labour on the self"; he points out examples such as natural food, natural childbirth and other elements of our daily lives that were originally natural and which are not the result of a laboured effort. He further argues that the choice to not act or intervene in living process is in itself a form of intervention.

On the other hand, Cussins (1996) points out that some of the ethical concerns being usually raised are being met with the liberal principle of *'volenti non fit iniuria'* (a willing party cannot cause injury) by ethics committees as a mean to protect the clinic and physicians. The principle relying on the idea that if the patient is being informed of the risks and benefits of various procedures and treatments. Cussins notes that "this informational ethic is particularly salient in medical sub-disciplines, like infertility medicine, which are marked by a high proportion of experimental procedures".

5.3 Eugenics: Towards the Perfect Human Being?

The Oxford Dictionary defines Eugenics as “The science of improving a population by controlled breeding to increase the occurrence of desirable heritable characteristics” (Oxford Dictionary 2017). In this context, it would be the “normalisation” of a cultural and social norm definition of what is considered being a “human being” in matter of physical appearance and mental properties. If the definition from the Oxford Dictionary stands then the “desirable heritable characteristics” is the recurrence of “normal” human beings, and the individuals who do not fit the standard criterion are therefore considered “abnormal”.

People expressing a fear of a future eugenics society are voicing their concern of the possible eradication of individuals suffering from genetical diseases. According to them, NIPT is the mean that would be used to determine whether these foetuses will live or not, depending on the results from the blood sample test. Wendell (as cited in Ettorre 1999) argues that reproductive genetics within the Western countries is a powerful strategy, a mean to shape our modern conception of what is a standard body and what are disabilities, how we understand and project a common census of the “perfect” body.

The chronicler Eivor Andersen Oftestad writes in her column (24.08.2016) for NRK about the possibilities but also the worries that accompany NIPT as a prenatal testing, “but where is the limit? Is it acceptable to check the child’s gender because one already has many boys and wishes the next child to be a girl?”. Oftestad is a researcher and the author of the book “We make children. Reproduction throughout 500 years”, she ponders the symbolical path that we, as a society, are heading towards to by redesigning our understanding of the human being through medical technology.
However, she suggests that we are perhaps tackling this new technological progress in a symptomatic consumerism manner, redefining our moral values in the western society. Almost to a degree of science fiction, like the movie “Gattaca”, where perfect human beings are designed by selecting chosen genetics and are bio-engineered to conform to their parents’ expectations who are merely following social norms.

Onto the topic of eugenics where a society of “sorting out” its individuals based on selected criteria of physical and mental abilities, Oftestad mentions Askel Braanen Sterri who argues that “the human life’s worth must be anchored in the individual’s characteristics”. Sterri

quotes a sentence from Karl Ove Knausgårds from an essay on the Nazism' human vision, "Who cares for the inviolability of human life understood at a non-individual size, human life as a collective life, like all?".
Oftestad draws a comparison between the eugenics of a time where massive euthanasia was used as mean to regulate the desirable from the non-desirable individuals in society. However, the term of "eugenics" is quite often associated with a strong negative connotation, as explained by this clinical geneticist interviewed by Ettorre (1999). The geneticist explains that not all eugenics are meant to be associated with mass murder, but as a mean to improve the quality of the human race, that the prenatal testing is a mean to achieve this.

Another researcher interviewed in the study underlines that "abortion for disabling handicaps for serious disorders that cause disability is acceptable, however, disagreeable that may be". Another side of this argument, which is not to improve the quality of human race by removing undesirable genetical traits, what if this type of reproductive technologies could allow us to spare the emotional distress that miscarriages and physical malformation with a high mortality rate to some families?

On this reflection, Rose (2012) writes that a form of Foucault's panopticon adapted to the surveillance of life can be observed in the prenatal care given to pregnant women by midwives and gynaecologists. The early times of reproductive advices were based on genetics which had for purpose the identification of members who had epidemiological factors, medical family histories and probabilities. Rose argues that "so did the eugenic programmes of sterilization of "the feeble minded", psychiatric patients and sexual offenders in the early 20th century". Foucault saw the original 'panopticon', which was a model of control and surveillance for prison, into another perspective which could be applied to domains of the public life, such as 'population health' as well as a "machine for social experimentation" (Bauer 2008).
The Biotechnological Council expressed itself in non-unanimous ways: a majority of the members of the Council were in agreement that if a prenatal test should be institutionalised, it should be ensured that this is a method with the most reliable accuracy. The main goal of the Biotechnological Council being to reduce the amount of invasive testing to prevent miscarriages. They also preconised that this knowledge of prenatal testing will prevent distress in patients, which is another argument in favour of NIPT. Another option to this main opinion is the limited knowledge from the test that should be provided to the patients as to not

alarm them unnecessarily, the accent being put into humanizing the patient, giving an individual dimension to a rather delicate situation.

However, two members of the Council expressed a more reserved position encouraging to wait for a revision of the Biotechnological Law due to the scientific significance of NIPT, seeing is as a "ground-breaking" technology and will open new possibilities and that we should see how society will be influenced by this and how to organise health care and services. They recognised that NIPT is a safer practice than the traditional invasive methods of testing.

When members from the Bioreference Group who are scientists specially in foetal medicine and genetics, they come to an agreement that pregnant women wish to protect their pregnancies, pregnant women as patients should have the possibility to make an informed choice towards what happens to their bodies and pregnancies, it is not ethically acceptable to only have prenatal testing that is invasive to detect trisomy when there is another, safer way which is NIPT. It seems that despite a few variations of opinions in the representation of the scientific community, cohesion can be found with a desire to serve patients with care and dignity.

Ten members of the Bioreference Group speak in support of NIPT and suggest an implementation of NIPT in the current prenatal care as a testing method. This suggestion is mostly supported by the scientists specialised in foetus medicine. In a starting phase, CUB will be performed as a primary test to the pregnant women who filled the age criterion. The ultrasound will take place in the 12^{th} week of pregnancy, then women presenting a risk of 1:250 after the ultrasound examination can either choose between NIPT and an invasive detection test. The following-up evaluation should be monitored by specialised medical personnel and centre for foetal medicine. The idea is to avoid invasive testing whenever possible, the guidance and informative meeting towards the patients should take place in their local hospital before they are being examined through any of the prenatal procedures. The need for building specialised infrastructures and forming medical personnel for this type of prenatal testing as technicians and experts should also be encouraged.

However, the scientists who are oriented towards genetics medicine recommends NIPT to be used as a primary test for the pregnant women who satisfy the required conditions, followed by an ultrasound in the 10^{th} week. This comment was followed with more feedback from the Bioreference Group, the week into which the ultrasound is being performed should be

changed due to the development of crucial elements inside the foetus for the determination of the pregnancy's dating, the numbers of foetuses in case of multiple pregnancies (which happen quite often if ovulation enhancers were used as they tend to stimulate the production of more than one follicle in the ovaries), early death of the foetus or lack of foetal development, specifically lack of brain.

These are considerations that are being presented and interpreted by the scientific community but also readily available to the public domain via internet for free, yet, the media seem to sift through the information and relating only the facts that might provoke a stronger reaction to possible patients. On the other hand, the blending from political parties into a cause that is inherently humane but mainly an individual case is equally puzzling.

According to Nikolas Rose (2012), the arguments above suggests that the vision of biological ethics would rank human life as equally worth, but in practicality, we can see through various perspectives and techniques, that on the contrary, the biological lives of human beings are all more or less subjected to judgements from one actor or another.

VI – Conclusion

6.1 Implications

Reproductive genetics play an important in contemporary culture and there is a definitive need for substantive and empirical work on its impact upon society, to study the "social construction of this biological phenomenon" according to Lippmann (as cited in Ettorre 1999). Rothman through her work on reproductive technologies and how they impact the life of patients concludes that "genetics isn't just a science: it is a way of thinking – an ideology for our time" (Ettorre 1999). She argues that scientists produce culture as they "are not detached observers of nature", they make decisions that are significant to them and they shape the society to which they belong. Rothman has worked extensively on the controversy of amniocentesis: the risk of miscarriage, the emotional and psychological consequences of it to which she terms as "tentative pregnancies" (1994). The term refers that despite our modern understanding of reproduction and pregnancy as biological phenomena, there are still a part of

uncertainty that we cannot determine and that yet, we are attempting to control from the near conception stage.

The controversy is still on-going and new data is being published and released, increasing new information to be processed, yet the controversy is touching a difficult area of negotiation between the scientific and non-scientific community because arguments are based on completely different standing ground: religion, ethics, human care, human quality of life, politics.

As Nikolas Rose argues (2012), the definition of the human vital order has changed over time from what used to be natural to artificial, a new value being constituted by the fruit of a labour, it is produced. And for some of the participants in the controversy who advised for a gentler approach to reproductive technologies or "letting nature run its course", this is the human involvement factor manipulating on what they think is either unnecessary or forcing a human agenda on a natural biological process. On the other hand, the more enthusiastic side of the controversy is advising to take advantage of this technology, especially if it can spare emotional and psychological distress and pain on families afflicted with chromosomal anomalies. That advice is more specifically addressed to families with a foetus afflicted with trisomy 13 and 18 where the mortality is extremely high, not trisomy 21.

6.2 Suggestions for Further Research

After reading the official statements and arguments from various sides of the controversy, it would seem adequate to create a committee composed of individuals with various backgrounds who possess a deep understanding of the human conditions, science and technology, social and cultural change. They could evaluate and consider ethical questions about scientific progress and how these impact society and change our understanding; their decisions would work as a representative vote for the population. A systematic right to information for all patients according to their medical status and required care, a method of non-invasive prenatal testing that is there for pregnant women to choose, that ultimately the choice of what happens to the pregnancy remains the individual's decision. A more open and less controversial oriented debate which is based on the human experience beyond the cultural and religious prerogatives to take place where improvement in the human quality of life is at the centre.

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